Direct Support Professionals and Adults with Developmental Disabilities: A Study of the Role Direct Support Professionals have in the Health Behaviors of their Clients with Developmental Disabilities

Dissertation

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Abstract

**Introduction:** People with developmental disabilities use tobacco, lead sedentary lifestyles, consume poor diets, as well as have higher rates of chronic conditions such as diabetes and heart disease when compared to members of the general population. Direct support professionals (paid caregivers) play a large social role in the lives of their clients with developmental disabilities. Because direct support professionals play such a large social role in the lives of their clients with developmental disabilities, they have the potential to influence the health behaviors of their clients; however, this potential influence has not yet been explored in the literature. The purpose of this study was to better understand the role that direct support professionals have in promoting the health of their clients with developmental disabilities, and to assess the relationship between the health behaviors of direct support professionals and their clients.

**Methods:** A mixed methods approach was used. Six qualitative focus groups (n=48) were conducted with key members of the developmental disability community to better understand the perceptions of the role of direct support professionals in the health promotion efforts of their clients. Using the findings from the qualitative study, a survey was developed to assess the health behaviors of direct support professionals and their clients. A total of 398 direct support professionals completed this online survey. Descriptive statistics were calculated for the prevalence of smoking, dietary and physical activity behaviors of direct support professionals and their clients. Chi-square tests and
Pearson/Spearman correlations were used to examine the relationship between the health behaviors of direct support professionals and their clients with developmental disabilities.

**Results:** Findings from this study suggest that direct support professionals experience several barriers when trying to promote the health of their clients with developmental disabilities, with one of the main barriers being fear over violating the rights of their clients. In addition, this study suggests that there is no association between the current smoking status of direct support professionals and their clients with developmental disabilities ($\chi^2=0.300, p=0.584$); however, small yet significant associations were found between the dietary and physical activity behaviors ($r=0.127-0.333, p<0.05$) of direct support professionals and their clients with developmental disabilities.

**Discussion:** This study was the first to examine the role of direct support professionals in the health promotion efforts of their clients by using both qualitative and quantitative methods. In order to reduce the fear experienced by direct support professionals about violating the rights of their clients, service coordinators should consider including a health promotion section in their clients’ Individualized Service Plans (ISPs). Disability service organizations that employ direct support professionals should also consider offering health promotion trainings and educational opportunities for both direct support professionals and their clients with developmental disabilities. In addition to assessing the influence of direct support professionals, future research on this topic should consider addressing the social influence of family/guardians and roommates on the smoking, dietary and physical activity behaviors of people with developmental disabilities.
Dedicated to my mom.
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Table of Contents

Abstract......................................................................................................................... ii

Acknowledgments....................................................................................................... v

Vita............................................................................................................................... vii

List of Tables ............................................................................................................... xi

Chapter 1: Background and Significance...................................................................... 1

Chapter 2: Overview of Research Design & Methods .................................................. 30

Chapter 3: The Perceived Role of Direct Support Professionals in the Health Promotion Efforts of their Clients with Developmental Disabilities (Manuscript #1) ........50

Chapter 4: Smoking Behaviors of Adults with Developmental Disabilities and their Direct Support Professional Providers (Manuscript #2)........................................ 77

Chapter 5: Dietary and Physical Activity Behaviors of Adults with Developmental Disabilities and their Direct Support Professional Providers (Manuscript #3).......... 96

Chapter 6: Conclusion................................................................................................ 120

References.................................................................................................................... 128

APPENDIX A: Focus Group Consent Form................................................................. 143

APPENDIX B: Focus Group Capacity Screener....................................................... 147

APPENDIX C: Focus Group Demographic Form...................................................... 149

APPENDIX D: Focus Group Recruitment Flyer......................................................... 151

APPENDIX E: Survey Recruitment E-mail................................................................. 153
APPENDIX F: Survey Online Consent .........................................................155
APPENDIX G: Survey Disqualification Page .............................................158
APPENDIX H: Survey Instrument ..............................................................160
APPENDIX I: Survey Gift Card Documentation.......................................176
List of Tables

Table 1. Focus group question guide.................................................................56
Table 2. Demographic characteristics of individuals who participated in the
focus groups........................................................................................................58
Table 3. Perceptions of health for people with developmental disabilities..............59
Table 4. Perceived role of direct support professionals in the health promotion
efforts of their clients..........................................................................................60
Table 5. Individual-level barriers of clients..........................................................62
Table 6. Individual-level barriers of direct support professionals..........................65
Table 7. Interpersonal-level barriers between clients and direct support professionals...66
Table 8. Organizational-level barriers....................................................................67
Table 9. Strategies for overcoming barriers to health promotion............................69
Table 10. Demographic characteristics of direct support professionals and clients with
developmental disabilities..............................................................................86
Table 11. Facilitation of client smoking behaviors by direct support professionals among
clients who were reported to be current smokers (n=24).....................................89
Table 12. Direct support professionals’ perceptions about health promotion
for clients.............................................................................................................90
Table 13. Prevalence of health behaviors, and correlations between direct support
professionals’ and clients’ with developmental disabilities behaviors...............109
Table 14. Direct support professionals’ use of behavior change strategies and
dietary behaviors of clients with developmental disabilities…………………………110
Table 15. Direct support professionals use of behavior change strategies and physical
activity behaviors of clients with developmental disabilities…………………………113
Table 16. Client preference for physical activity/healthy diet associated with direct
support professionals’ perceived difficulty of helping client perform
healthy behaviors ………………………………………………………………………………115
Chapter 1: Background and Significance

A. Adults with developmental disabilities

A.1. Description of the population

The federal definition of the term developmental disability was established in the Developmental Disabilities Assistance and Bill of Rights Act Amendment of 2000 and defines a developmental disability as a, “severe, chronic disability of an individual 5 years of age or older that: 1) is attributable to a mental and/or physical impairment; 2) occurs before the age of 22; 3) is likely to continue indefinitely; 4) results in functional limitations of three or more of the following: (i) self-care (ii) receptive and expressive language (iii) learning (iv) mobility (v) self-direction (vi) capacity for independent living and (vii) economic self-sufficiency.” The Developmental Disabilities Assistance and Bill of Rights Act Amendment of 2000 also states that individuals with developmental disabilities have a need for, “a combination and sequence of special, interdisciplinary, or generic services, individualized supports or other forms of assistance that are of lifelong or extended in duration and are individually planned and coordinated.” The term developmental disability is an “umbrella” term that includes many other developmental conditions such as: attention deficit hyperactivity disorder, autism, epilepsy, cerebral palsy, Down syndrome, intellectual disability, learning disability, deafness and blindness (Boyle et al., 2011). Oftentimes, even in the literature, the terms developmental disability and intellectual disability are used interchangeably even though there is a distinct
difference. An intellectual disability is defined as, “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior as expressed by conceptual, social and practical adaptive skills that originates by the age 18” (Schalock et al., 2010, p1). Intellectual disability was once broken down into four levels that was determined by IQ score—mild (IQ 50-55 to 70), moderate (IQ 35-40 to 50-55), severe (20-25 to 35-40) and profound (IQ below 20-25), but now the levels of intellectual disability have been removed from the classification system in the newest edition of the Diagnostic and Statistical Manual of Mental Disorders V (American Psychiatric Association, 2013). The term intellectual disability is now used to refer to the same population of individuals who were previously labeled as having mental retardation (Schalock et al., 2010, p1). Throughout the body of this proposal, the term developmental disability will be used because it is a broader term that includes many persons with individualized care needs who receive special support services.

The exact number of individuals living with a developmental disability in the United States is unknown, due to data reporting inconsistencies across states; however, it is estimated that approximately 4.6 million Americans have a developmental disability (Bethesda Institute, 2012). Findings from a meta-analysis by Maulik and colleagues (2011) suggest that the worldwide prevalence of developmental disabilities is 10.37/1000 persons. Recent reports suggest that the diagnosis of developmental disabilities is on the rise among U.S. children aged 3-17, as the prevalence increased from 12.84% in 1997 to 15.04% in 2008 (Boyle et al., 2011). Just as the exact number of individuals with developmental disabilities is unknown at the national level, the same holds true for the State of Ohio. The Ohio Department of Developmental Disabilities reports providing
services to approximately 90,000 individuals with developmental disabilities across Ohio’s 88 counties, meaning that there are some individuals with developmental disabilities who are not receiving services.

**A.2. Funding and support services**

The funding structures are different for all persons with disabilities, due to individualized care needs, but people with developmental disabilities typically receive healthcare services (e.g. primary care visits) through state Medicaid funding (U.S. Centers for Medicare & Medicaid Services, 2016). Adults with developmental disabilities can also receive federal financial assistance in the form of checks from the Social Security Administration once they turn 18 in order to pay for their living expenses and other necessities (Social Security Administration, 2016). It has been noted in the literature that adults with developmental disabilities are three times more likely to live in poverty than members of the general U.S. population (U.S. Department of Health and Human Services, 2002). The Developmental Disabilities Assistance and Bill of Rights Act Amendment of 2000 states that individuals with developmental disabilities have the right to culturally appropriate support services, and most often times government dollars are used to pay for these support services. All states differ in how support services are financed; in Ohio funding for support services is operated by each of the 88 county boards of developmental disabilities, and all of these county boards are operated under the Ohio Department of Developmental Disabilities. Not all persons with developmental disabilities receive support services through their county boards for a variety of reasons, with some of the most common reasons being long waiting lists and families simply not knowing how to navigate the disability system. As noted above, persons with
developmental disabilities have rights to culturally competent support services, and there are a variety of ways that adults with developmental disabilities can access direct support services, with the most common being through state provider agencies or state independent providers themselves (Developmental Disabilities Assistance and Bill of Rights Act, 2000). In a 2006 report to Congress, it was estimated there will be a 38% increase in the number of persons with disabilities receiving support services between the years 2003 and 2020 (U.S. Department of Health and Human Services, 2006).

Some adults with developmental disabilities can qualify to receive waiver services, which serve the purpose of keeping adults with developmental disabilities out of institutionalized care settings by allowing them to live in the community and receive needed support services (The Ohio Department of Developmental Disabilities, n.d.,a). In Ohio, a case manager from the county board of developmental disabilities is typically responsible for working with families and individuals with disabilities to determine how government funding for support services is allocated (Ohio Department of Developmental Disabilities, n.d.,b). In Ohio, persons with developmental disabilities can qualify to receive four types of waiver services that provide support services in the community which are the: 1) Individual Options Waiver; 2) Level One Waiver; 3) Transitions Waiver; and 4) Self Empowered Life Funding [SELF] Waiver. The Individual Options waiver is for those with developmental disabilities who want to live in their family homes or in the community with roommates, but still require care services and supports. In order to qualify for the Individual Options Waiver, the individual with a developmental disability must meet strict financial criteria set forth by Ohio Medicaid. The Level One Waiver was designed for those with developmental disabilities who have
a strong network of family, friends or neighbors who can provide needed care for free, but offers up to $5,000 a year on support services (The Ohio Department of Developmental Disabilities, n.d.,a). The Transitions Waiver was created for those who are severely impaired by their disability and who require skilled-level care/therapy services; this waiver is no longer accepting new enrollees (Ohio Home Care Program, 2014). One method of financing support services that is in line with a person-centered approach to care for adults with developmental disabilities is through direct funding, where adults with developmental disabilities and their families choose how to spend the money they receive from the government on care services (Brown & Percy, 2007; Bogenschutz, Hewitt, Hall-Lande, & LaLiberte, 2010). This person-centered direct funding waiver is currently being piloted in the State of Ohio in the form of the SELF-waiver and allows up to $40,000 per year to be spent on the care needs for adults with developmental disabilities (The Ohio Department of Developmental Disabilities, n.d.,a).

A.3. Housing for adults with developmental disabilities

Adults with developmental disabilities live in a variety of residential settings, with more and more living in the community since the deinstitutionalization movement of the late 1970s (Brown & Percy, 2007; Hewitt & Larson, 2007; Lakin, Prouty, & Coucouvanis, 2006). The overarching purpose of the deinstitutionalization movement was to integrate persons with developmental disabilities into society, and increase their levels of self-determination and independence as members of society (Heaney & Burke, 1995; Hewitt & Larson, 2007; Brown & Percy, 2007). Where an adult with a developmental disability ends up living is based on a variety of factors such as: individualized care needs, funding availability, and family influence. Some of the most
common types of housing for adults with developmental disabilities are: family homes, independent or supported living, and nursing/residential care facilities (Brown & Percy, 2007). An estimated majority (78%) of adults with developmental disabilities live with family members, followed by 8% who live alone or with unrelated persons, 8% who live in institutionalized settings and 6% who live with a spouse (Larson, Doljanac, & Lakin, 2005; Lakin, Prouty, & Coucovanis, 2006). Regardless of where adults with developmental disabilities reside, the large majority of adults with developmental disabilities are eligible to receive some type of government-funded financial benefits to pay for the services provided by direct support professionals, and these services can be provided in a variety of different settings (e.g., family homes, supported living, worksites) (Brown & Percy, 2007; Hewitt & Larson, 2007). The waivers discussed in section A.2. cover direct support services provided by “homemaker personal care aides” (the term “homemaker personal care aide” is used by the waivers to refer to the direct support professionals who are employed to provide needed care to those with developmental disabilities). The job duties and work experiences of direct support professionals are discussed in the following section.

B. Direct Support Professionals

B.1. Description

A direct support professional is a title used to describe the group of workers who provide formal care to those with developmental disabilities (Hewitt & Larson, 2007). Other commonly used terms for direct support professionals in the disability literature are care aides, support worker and/or direct care staff (Hewitt & Larson, 2007). Direct support professionals differ from informal caregivers, such as family members and
friends, because direct support professionals receive payment to provide care to those with developmental disabilities as their job. According to the National Alliance for Direct Support Professionals, their job is to, “…assist those individuals with developmental disabilities to lead a self-directed life and contribute to his/her community, and encourage attitudes and behaviors that enhance inclusion in his/her community” (Hewitt & Larson, 2007). In addition to promoting inclusion, independence, and self-determination for their clients with developmental disabilities, which has been newly added to their job description, direct support professionals’ main responsibility is to assist their clients with basic care needs such as: personal hygiene, cooking, cleaning, grocery shopping, transportation, and finances (Hewitt & Larson, 2007; Brown & Percy, 2007; Gaventa, 2008). The job duties and responsibilities of direct support professionals have become more complex over the years, with a large shift in the field towards direct support professionals serving as advocates by promoting the psycho-social development of their clients in society, in addition to providing basic care needs (Hewitt & Larson, 2007). It has been noted in the literature that even with increased responsibility in their roles as care providers, direct support professionals receive very little training on how to perform their jobs (Test, Flowers, Hewitt, & Solow, 2004; Ducharme, Williams, Cummings, Murray, & Spencer, 2001). Direct support professionals have indicated that the training that they receive for their profession does not always align with their clients’ individualized care needs, and that they are oftentimes dissatisfied with the training that they receive (Test et al., 2004). Van Oorsouw and colleagues (2009) examined different types of training methods for direct support professionals, and determined that receiving job trainings by a job coach while actually working with their client was the most
effective method for communicating needed skills to direct support professionals. Not only must direct support professionals work to promote the psycho-social development and provide basic care needs to their clients, they also are required to complete daily paperwork documentation and follow Individualized Service Plans (ISPs) for their clients (Hewitt & Larson, 2007). This additional task of daily paperwork has been noted as taking up a large part of their work shifts, and direct support professionals have suggested that they could be more actively engaged with their clients if it was not for all of the paperwork (Gaventa, 2008).

Direct support professionals can play a very large role in the lives of people with developmental disabilities, and it has been suggested in the literature that persons with developmental disabilities often form strong emotional attachments to their direct support professionals and view them as key members of their social network and as role-models (de Schipper, & Schuengel, 2010; Hewitt & Larson, 2007). Dodevska and Vassos (2013) asked adults with developmental disabilities and supervisors what they valued most in a direct support professional, and it was consistently reported that adults with developmental disabilities value direct support professionals who have strong interpersonal skills, while supervisors noted valuing direct support professionals who had the knowledge and practical skills needed to perform their job. Interpersonal relationships between direct support professionals and clients have been deemed a necessity for providing high quality care to those with developmental disabilities, and it has been recognized that the quality of care provided to adults with developmental disabilities varies by direct support professional (Clegg & Lansdall-Welfare, 2010; Schuengel, Kef, Worm, & Damen, 2010). Hall and Hall (2002) noted that due to their large role in the
lives of people with developmental disabilities, direct support professionals “bring out the best and the worst in their clients.”

Direct support professionals can provide care to those with developmental disabilities in a variety of settings such as in a one-on-one setting (e.g., individual home/family home) or to multiple clients at a time (e.g., supported living home or a worksite setting) (Hewitt & Larson, 2007). The setting and frequency of visits that adults with developmental disabilities receive from direct support professionals varies based on individualized care needs and the level of financial support available (Brown & Percy, 2007). For instance, one person with a developmental disability may be able to receive 24/7 direct support care, while another person may only receive direct support services once or twice a week to help with basic needs such as finances and transportation.

It has been consistently noted in the literature that recruiting people to work as direct support professionals is difficult, with one of the main challenges being that a career as a direct support professional is not highly regarded and there is limited room for job mobility (Hewitt & Larson, 2007). However, there has been a push to enhance the prestige of the direct support professional profession by establishing credentialing programs (Hewitt & Larson, 2007). In general, the basic job qualifications for becoming a direct support professional include: having a high school diploma/GED, having a valid drivers license, passing a background check and receiving some type of disability training (Hewitt & Larson, 2007). Aside from the issues with recruiting/hiring direct support professionals, there are many job openings in the field due to the high rates of worker turnover. In a 2006 report to Congress by the Assistant Secretary for Planning and Evaluation, it was estimated that approximately 900,000 full-time direct support
professionals would need to be hired annually by the year 2020 to keep up with the demand due to high turnover rates in the field (U.S. Department of Health and Human Services, 2006).

**B.2. Direct support professionals’ work experiences**

Many studies have described the general demographic profile of direct support professionals, who provide care to those with developmental disabilities in the United States, noting that direct support professionals tend to be females with limited educational backgrounds, who often must work more than one job to support themselves and their families (Hewitt & Larson, 2007; Mutkins, Brown, & Thorsteinsson, 2011; Gray-Stanley et al., 2010; Test, Flowers, Hewitt, & Solow, 2003). In recent years, there has been a large increase in the number of immigrant female workers serving as direct support professionals (Hewitt & Larson, 2007). The wages for direct support professionals are very low, with many direct support professionals making barely over minimum wage (Hewitt & Larson, 2007). In agency settings, direct support professionals are typically the lowest-level employees and generally feel unable to express their work-related concerns with supervisors (Gaventa, 2008). In addition, health insurance coverage may not be offered to direct support professionals if they work part-time for disability staffing agencies or if they work for themselves as independent providers (Hewitt & Larson, 2007).

Most of the literature on the direct support professional population has focused on the low wages, and high levels of stress and depression experienced by this population as being contributing factors to the high turnover rates in the field (Hewitt & Larson, 2007; Frank, Dawson, van Kleunen, Wilner, & Seavey, 2000; Gray-Stanley et al., 2010; Test et
One of the most cited reasons for high turnover rates, is that direct support professionals experience worker burnout, which has been defined as, “when staff stay on the job without any commitment to it” (Maslach & Jackson, 1984; Gray-Stanley et al., 2010; Hewitt & Larson, 2007). Studies have consistently demonstrated that the feelings of burnout experienced by direct support professionals are related to the high turnover rates in the field (Hewitt & Larson, 2007). These high turnover rates usually mean that other direct support professionals are required to work overtime hours to provide the needed care to clients (Hewitt & Larson, 2007). Even though direct support professionals often financially rely on working additional hours, the additional hours spent working overtime has been associated with increased levels of exhaustion, stress and mistakes made by direct support professionals (Hewitt & Larson, 2007). The literature suggests that working as a direct support professional can be a socially isolating profession because they often work shifts alone without interaction with co-workers or supervisors (Hewitt & Larson, 2007; Gray-Stanley & Muramatsu, 2011). Direct support professionals who experience the highest levels of depression and lowest levels of social support are more likely to report worker burnout than those who do not experience depression and who report having adequate levels of social support (Mutkins et al., 2011). Experiencing high levels of social support from coworkers and supervisors, has a significant impact on direct support professionals’ willingness to stay in their job regardless of experiencing work-related stress (Gray-Stanley & Muramatsu, 2011; Hatton & Emerson, 1993). One study examined work stress experienced by direct support professionals and found that direct support professionals who reported experiencing the highest levels of job stress had the highest cortisol levels and were more likely to develop depression (Wright, 2011).
Hatton and colleagues (1999) examined stress levels among direct support professionals and found that over a third of the direct support professionals in the sample experienced levels of stress that were indicative of a mental health problem. Direct support professionals experience job stress for a variety of reasons with some of the most cited reasons being: problematic/aggressive behaviors of their clients, staffing problems, and a general lack of autonomy on the job (Mutkins et al., 2011; Mills & Rose, 2011; Mitchell & Hastings, 2001; Gray-Stanley & Muramatsu, 2011). The high turnover rates caused by feelings of burnout, stress, and lack of social support in the field are not only financially costly, but can also negatively impact the lives of clients with developmental disabilities by disrupting the continuity of care received (Hewitt & Larson, 2007; Gaventa, 2008; Hatton et al., 1999; Larson, Hewitt, & Lakin, 2004).

C. Health profile of adults with developmental disabilities and direct support professionals

C.1. Health care experiences, disparities and health conditions

Much of the research on health disparities for people with developmental disabilities has focused on access to quality healthcare; however, the Affordable Care Act has made some substantial changes for people with disabilities to be able to access care (The Arc, 2016). One of the most cited reasons for disparities in health for those with developmental disabilities is called “diagnostic overshadowing” where clinicians treat the symptoms of the person’s disability first and have a tendency to overlook other basic health care needs and medical conditions (Fisher, 2004; Ouellette-Kuntz et al., 2005). Many studies and doctors themselves have reported not having the proper training in medical school to be able to adequately treat people with developmental disabilities, and
there has been a call in the literature to provide more hands-on training about the population of people with developmental disabilities for medical students (Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012). Doctors have even noted feeling a general lack of confidence treating those with developmental disabilities (Wilkinson et al., 2012). Doctors have also reported holding negative attitudes and perceptions towards patients with developmental disabilities and have even described treating patients with developmental disabilities as an “overwhelming experience” (Wilkinson et al., 2012; Minihan, Dean, & Lyons, 1993; Ward, Nichols, & Freedman, 2010). In one qualitative study examining doctors’ feelings towards working with people with developmental disabilities, one doctor noted that working with people with developmental disabilities is like “operating without a map” (Wilkinson et al., 2012).

It has been cited in the literature that people with developmental disabilities are often unable to clearly communicate their specific health needs/concerns with their doctors and some adults with developmental disabilities may not even be aware of their pressing health issues; therefore, illnesses often go untreated and undiagnosed by physicians (Morin, Merineau-Cote, Ouellette-Kuntz, Tassé, & Kerr, 2012). Doctors have reported feeling more comfortable and prefer speaking to the care providers of adults with developmental disabilities about their patients’ healthcare needs (Wilkinson et al., 2012). One study found that over 50% of a sample of Special Olympics athletes had undiagnosed medical conditions that were not discovered until a brief medical examination at a Special Olympics site (Horwitz, Kerker, Owens, & Zigler, 2000). Oftentimes people with developmental disabilities cannot even find doctors to treat them, primarily due to Medicaid reimbursement rates, which have particularly been shown to
negatively impact the health outcomes of adults with developmental disabilities living in rural settings (Ward et al., 2010). People with developmental disabilities have also expressed dissatisfaction with their primary care doctors, which has been shown to lead to a decrease in the number of primary care visits and an increase in hospitalization rates for adults with developmental disabilities (Brown & Gill, 2009).

Many studies have noted disparities in chronic conditions experienced by adults with developmental disabilities in comparison to members of the general population (e.g., Reichard & Stolzle, 2011; Morin et al., 2012; Draheim, 2006; Fisher, 2004; Krahn, Hammond, & Turner, 2006). Studies have shown that adults with developmental disabilities are less likely to be screened for various health issues such as cancer (Havercamp, Scandlin, & Roth, 2004; Havercamp & Scott, 2015). Rates of coronary heart disease and diabetes have been consistently reported as being higher among persons with developmental disabilities (Draheim, 2006; Sohler, Lubetkin, Levy, Soghomonian, & Rimmerman, 2009; Morin et al., 2012, Havercamp et al., 2004; Reichard & Stolzle, 2011). Studies have shown that there are disparities in mortality rates associated with heart disease between those with developmental disabilities compared to members of the general population, and that those with developmental disabilities tend to develop heart disease at earlier ages (Day, Strauss, Shavelle, & Reynolds, 2005; Draheim, 2006; Sohler et al., 2009). Adults with mild developmental disabilities have been shown to have higher rates of heart disease than those with more severe developmental disabilities, and those who live in less restrictive housing settings have higher rates of heart disease than those who live in more supervised settings (Strauss & Kastner, 1996; Janicki & Jacobson, 1986). In addition to disparities in heart disease, Reichard and Stolze (2011) compared
the prevalence of diabetes between adults with cognitive limitations and those without such limitations using the Medical Expenditures Panel Survey (N=27,116) and found that adults with cognitive limitations had significantly higher rates of diabetes than those without (19.4% vs. 3.8%, respectively). These authors also noted that adults with cognitive limitations and diabetes were significantly more likely to experience four or more of the following chronic conditions: asthma, arthritis, heart disease, hypertension, stroke and high cholesterol. As the life expectancies for people with developmental disabilities increase, the literature as a whole has called for more attention to be paid to secondary health conditions experienced by this population in both clinical and research settings.

C.2. Health behaviors

The use of tobacco products, eating a poor diet and physical inactivity are the leading preventable causes of death in the United States (Yoon, Bastian, Anderson, Collins, & Jaffe, 2014; Mokdad, Marks, Stroup, & Gerberding, 2004). There is a surplus of literature available on how these three health behaviors continually contribute to morbidity/mortality among members of the general United States population; however, there is very limited literature available on tobacco use, physical activity, and dietary behaviors among people with developmental disabilities and their direct support professional providers. The following sections outline what is known about the health behaviors among those with developmental disabilities and their direct support providers.

C.2a. Tobacco use among those with developmental disabilities

The use of tobacco products is a behavioral factor that increases an individual’s risk for developing heart disease, cancer and respiratory illness (CDC, 2015a).
Approximately 16.8% of the general U.S. population currently smokes cigarettes, and men smoke cigarettes at higher rates than women (18.8% vs. 14.8%, respectively) (CDC, 2015b). In addition, those who are more socioeconomically disadvantaged smoke cigarettes at higher rates than those who are of higher socioeconomic status, such that those with less education and/or who live below the federal poverty line smoke at higher rates (CDC, 2015b). Cigarette smoking accounts for approximately 480,000 deaths each year, and secondhand smoke exposure has been shown to increase one’s risk of heart disease by up to 30% (CDC, 2014a). It is important to study secondhand smoke exposure experienced by adults with developmental disabilities because they may have difficulty expressing their concerns with others and standing up for themselves in regards to secondhand smoke exposure (Wehmeyer, 2004). Very little is known about the prevalence of cigarette smoking and secondhand smoke exposure among adults with developmental disabilities; however, the literature suggests that those with developmental disabilities do in fact use tobacco products (Steinberg, Heimlich, & Williams, 2009).

Steinberg and colleagues (2009) reviewed the literature on smoking and people with developmental disabilities and noted that people with developmental disabilities are not immune from the addictive properties of tobacco, and if they are smokers, they may spend a large portion of their government subsidized incomes on cigarettes. Studies have shown that just as in the general population, men with developmental disabilities smoke at higher rates than women with developmental disabilities (Rimmer, Braddock, & Marks, 1995; Robertson et al., 2000; Rimmer, Braddock, & Fujiura, 1994). In 2004, Havercamp and colleagues conducted the first study using a statewide random sample to calculate the smoking prevalence among adults with no disabilities (24.8%), with
disabilities (28.5%) and with developmental disabilities (17.8%) in North Carolina and found that although the smoking prevalence was lowest in the sample of individuals with developmental disabilities, there were no statistically significant differences between the smoking prevalence of those with developmental disabilities and members of the general North Carolina population. A similar study was repeated eleven years later, and in this study Havercamp and Scott (2015) found, using national population level data, that adults with developmental disabilities smoked at significantly lower rates (7.0%) than people with disabilities (26.7%) and those with no disabilities (15.2%), which suggests that smoking is on the decline within the population of people with developmental disabilities. Just as it has been established in the obesity literature, residential living environment and level of disability, play a role in smoking behaviors among those with developmental disabilities. Adults who live in the least restrictive environments smoke at higher rates than those who live in more restrictive housing environments and those with milder developmental disabilities smoke at higher rates than those with more severe disabilities (Rimmer et al., 1995; Lewis, Lewis, Leake, King, & Lindemann, 2002; Robertson et al., 2000; Tracy & Hosken, 1997; Hymowitz, Jaffe, Gupta, & Feuerman, 1997; Steinberg et al., 2009). The average age of smoking initiation for persons with developmental disabilities is unknown; however, it may be at a later age than members of the general population because of different experiences during adolescence (e.g., those with developmental disabilities are more likely to be supervised and have more structured environments during adolescence than those in the general population).

C.2b. Obesity, diet and physical activity among those with developmental disabilities

In Section C.1. it was noted that adults with developmental disabilities tend to
have higher rates of coronary heart disease and diabetes than members of the general population and obesity was noted as a risk factor for both diseases (Morin et al., 2012; Day et al., 2005). Obesity has been consistently shown in the literature to be linked to heart disease and diabetes, as well as a variety of other health conditions such as: hypertension, stroke, cancer, liver/gallbladder disease, arthritis and sleep apnea (CDC, 2015c). In the United States, 34.9% of adults in the general population are classified as obese, and in Ohio, 32.6% of the population is classified as obese (CDC, 2015d). Socioeconomic status and gender have been shown to be related to obesity status, such that females with lower education and income levels tend to experience obesity at higher rates than women who are more highly educated and have higher incomes (Ogden, Lamb, Carroll, & Flegal, 2010). However, there does not appear to be a relationship between socioeconomic status and male obesity rates (Ogden et al., 2010).

In a recent study, Havercamp and Scott (2015) found that 31.1% of adults with developmental disabilities were obese, and were 1.3 times more likely to be obese than members of the general population without disabilities (23.8%); however, those with other type of disabilities were most likely to experience obesity (38.2%). Studies have consistently reported that women with developmental disabilities have higher rates of obesity than men with developmental disabilities (Emerson, 2005; Bhaumick, Watson, Thorp, Tyrer, & McGrother, 2008; Melville, Hamilton, Hankey, Miller, & Boyle, 2007; Stancliffe et al., 2011). Some studies have also noted that women with developmental disabilities have higher rates of obesity than women in the general population (Melville et al., 2007; Bhaumik et al., 2008), while others have reported women with developmental disabilities as having similar rates of obesity (Emerson, 2005). Level of disability has
been consistently associated with obesity rates among those with developmental disabilities, such that those with milder disabilities have higher rates of obesity than those with more severe disabilities, who tend to have a higher prevalence of underweight, suggesting that there is a bimodal distribution of weight among members of the developmental disability population (Emerson, 2005; Melville et al., 2007; Stancliffe et al., 2011). In addition, it is thought that people with certain types of developmental disabilities such as Down syndrome and Prader-Willi experience higher rates of obesity than those with other types of developmental disabilities (Stancliffe et al. 2011; Humphries, Traci, & Seekins, 2009). Psychotropic medications have also been known to influence the weight status of people with developmental disabilities by causing weight gain (Stancliffe et al. 2011). The literature suggests that living environment plays a role in obesity rates among those with developmental disabilities, such that those who reside in the least restrictive settings have higher rates of obesity than those who live in more supervised settings (Melville et al, 2007; Rimmer & Yamaki, 2006; Stancliffe et al., 2011). However, when assessing the relationship between living environment and obesity rates, one must take into consideration the level of disability, because when the level of disability is controlled for, the relationship between housing setting and obesity rates is much less robust (Lewis et al., 2002; Melville et al., 2007; Stancliffe et al, 2011).

Diet and physical activity are two modifiable behavioral factors that contribute to obesity, and both are recognized as the second leading preventable causes of death in the United States, just under tobacco use (Yoon et al., 2014; Mokadad et al., 2004). Obesity occurs as a result of an energy imbalance in the body, when people consume more calories than they burn off (CDC, 2015e). Recommendations have been made at the
national level in attempt to control obesity and promote healthy lifestyles. These recommendations suggest that adults should participate in 30-minutes of moderate-to-vigorous physical activity at least five times a week and eat a balanced diet that is low in fat, and high in fruits/vegetables (CDC, 2015e). The consensus in the literature is that adults with developmental disabilities lead sedentary lifestyles and do not meet national recommendations for dietary intake of fruits/vegetables and fat (Draheim, Williams, & McCubbin, 2002; Peterson, Janz, & Lowe, 2008; Hilgenkamp, Reis, van Wijck, & Evenhuis, 2012; Humphries et al., 2009; Robertson et al., 2000). Temple and colleagues (2006) reviewed the physical activity literature for adults with developmental disabilities and found that among ambulatory adults, only 17.5-33% of adults were meeting the nationally recommended guidelines for physical activity. Commonly cited barriers to physical activity among adults with developmental disabilities are: staff attitudes, client-to-staff ratios, transportation, low-motivation, limited social support, lack of space and limited financial resources (Temple, Frey, & Stanish, 2006). In a recent study, Havercamp and Scott (2015) noted that 45.1% of adults with developmental disabilities did not participate in any physical activity within the past month of the survey, while only 22% of people with other disabilities and 10% of those without disabilities did not participate in any physical activity within the past month. Much of the current literature in the field of developmental disabilities focuses on designing/evaluating health promotion programs for adults with developmental disabilities in order to reduce obesity and promote health through the use of nutrition and physical activity interventions (e.g., Bodde, Seo, Frey, Lohrmann, & van Puymbroeck, 2012; Saunders et al., 2011; Marks, Sisirak, & Heller, 2010; Rimmer & Braddock, 2002). In a review of the literature, Heller
and colleagues (2011) noted that obesity reduction programs for people with developmental disabilities are most effective when both physical activity and nutrition components are included in the intervention.

C.2c. Health profile of direct support professionals

As noted in Section B, the majority of the literature on the direct support professional population focuses on stress, social support, burnout, and high turnover rates within the profession of direct support professionals. The health status and health behaviors of direct support professionals has yet to be explored in the literature. However, based on what is known about the health status of women of lower socioeconomic status, it could be expected that direct support professionals would be at risk for participating in many negative health behaviors. As noted above, those who are more socioeconomically disadvantaged smoke cigarettes at higher rates than those of higher socioeconomic status (CDC, 2015b). In addition, socioeconomic status and gender have been shown to be related to obesity status, such that females with lower education and income levels tend to experience obesity at higher rates than women who are more highly educated and have higher incomes (Ogden et al., 2010). In addition to socioeconomic status, the literature consistently suggests that high levels of stress, limited levels of social support and depression are associated with increased participation in negative health behaviors such as smoking, alcohol use, physical inactivity and poor diet (Heaney & Israel, 2008; Glanz & Schwartz, 2008).

Even though literature is not available on the prevalence of the health behaviors (e.g., smoking, diet, physical activity) among the profession of direct support professionals, it makes sense to look at the literature about health behaviors of other types
of caregivers. When looking at the informal caregiver literature, it is well-established that caregivers have poorer health status than non-caregivers. Studies have examined the health of informal family caregivers providing care to their loved ones, and found that family caregivers have greater odds of smoking cigarettes, being obese and participating in negative health behaviors such as: sedentary behavior, lower fruit/vegetable intake, higher rates of soda consumption and higher rates of fast food consumption than non-caregivers (Hoffman, Lee, & Mendez-Luck, 2012; Reeves, Bacon, & Fredman, 2002; Mochari-Greenberger & Mosca, 2012; Burton, Newsom, Schulz, Hirsch, & German, 1997; Castro et al., 2007). Yamaki, Hsieh and Heller (2009) examined the health of family caregivers of adults with developmental disabilities (N=206) and found that family caregivers aged 40-59 had higher rates of hypertension and diabetes than members of the general population, but perceived their health as being better than members of the general population. One study examined the health profiles of Head Start childcare workers in Pennsylvania and found that Head Start workers reported being in poorer health and having higher rates of depression than members of the general population (Whitaker, Becker, Herman, & Gooze, 2013). This study also found that Head Start childcare workers were more likely to suffer from diabetes, obesity, hypertension, asthma, lower back pain and severe headaches compared to members of the general population (Whitaker et al., 2013). The study by Whitaker and colleagues (2013) highlights the importance of good health for childcare workers because they are responsible for being role models and meeting the daily needs of children, and the authors note that being in poor health comprises their ability to serve as positive role models. Even though informal caregivers and childcare workers do not work with the
same populations as direct support professionals, they all have the responsibility of caring for those who cannot fully care for themselves, which makes their health profiles relevant when studying direct support professionals.

D. Social and physical environments and health behaviors

D.1. Social environment: role-modeling

The literature on the construct of role-modeling among those in the population of adults with developmental disabilities has tended to focus on role-modeling as a method for teaching activities of daily living skills (e.g., cooking, grooming) (e.g., Cannella-Malone, O’Reilly, Sigafoos, & Lancioni, 2006; Mechling, 2005). The construct of role-modeling from Social Cognitive Theory has consistently been shown in the literature as having an impact on health behaviors related to diet, physical activity and smoking, which suggests that people learn health behaviors from those around them (McAlister, Perry, & Parcel, 2008). The literature-base on role-modeling of healthy/unhealthy behaviors among those with developmental disabilities is scant. Therefore, it makes sense to explore the role-modeling literature on the topic of how youth learn to partake in certain health behaviors—as children are similar to adults with developmental disabilities because both groups are dependent on others for their basic care needs.

Smoking. Most of the smoking initiation literature focuses on adolescents, because adolescence is the developmental time period where individuals start to try risky-health behaviors (e.g., Freedman, Nelson, & Feldman, 2012). It is well-established in the smoking literature that smoking cigarettes is heavily impacted by the social influences of family members and peers (Flay et al., 1994). Peer smoking status has been consistently reported in the literature as being a key predictor of one’s smoking behavior and peer
smoking status has been shown to both directly and indirectly influence smoking behavior (Flay et al., 1994). Although parents are cited as having influence over the smoking behaviors of their children, there is more evidence that suggests that peer influence is stronger than family influence in smoking initiation (Flay et al., 1994). It has also been noted that among adolescents who are already smokers, they are more likely to quit smoking if they are part of a non-smoking peer group (Go, Green, Kennedy, Pollard, & Tucker, 2010).

*Physical activity and diet.* Research has shown that parental role-modeling of health behaviors in the home environment does impact the behaviors of their children, such that parental eating behavior is associated with child food preferences (Ostbye et al., 2013; Brown & Ogden, 2004; Oliveria et al., 1992, Eisenberg et al., 2012, Wyse, Campbell, Nathan, & Wolfended, 2011). In childcare center settings, staff’s role-modeling of healthy eating practices has been shown to be linked to children’s willingness to try certain foods (Hendy & Raudenbush, 2000); however, many studies have found that childcare workers do not always consume healthy foods in front of children (Larson, Ward, Neelon, & Story, 2011). In addition to child food preferences, role-modeling has also been associated with child physical activity levels, such that children whose parents participate in more frequent sedentary behavior are more sedentary as well (Sallis, Patterson, McKenzie & Nader, 1988; Moore et al., 1991; Spurrier, Magarey, Golley, Curnow, & Sawyer, 2008). In the childcare setting, staff physical activity behavior on the playground has been shown to be associated with child physical activity behavior (Trost, Ward, & Senso, 2010). Maitland and colleagues (2013) reviewed the literature on the impact of social and physical environments on child
physical activity behavior, and found children whose parents were physically active were more likely to participate in physical activity than those whose parents were not active. In this same study, parental use of video games was related to child inactivity behavior. In this review, six of the eight studies that examined the relationship between parent TV viewing and child TV viewing found there to be a positive association between parent TV use and child TV use (Maitland, Stratton, Foster, Braham, & Rosenberg, 2013). In addition, Maitland and colleagues (2013) reported that in six out of seven studies, parental social support for physical activity was positively related to child physical activity behavior.

D.2. Social environment: incentive motivation

The theoretical construct of incentive motivation (reward/punishment) and its relationship to behavior modification has been discussed in the psychology literature ever since the 1950s when BF Skinner first studied operant conditioning. Much of the literature on positive/negative reinforcement through the use of rewards/punishments has been explored in the developmental disability literature as a way to modify problem/aggressive behaviors among individuals with developmental disabilities and for negotiating purposes, especially in the applied behavioral analysis literature for children with autism (Heward, 2008). In the past, cigarettes have been used as a rewards for “good behavior” for those with developmental disabilities (Minihan, 1999; Tyler & Bourguet, 1997). No known studies have focused on the use of food as a reward, and its association with weight status among those with developmental disabilities. In general, studies that have focused on the use of food as rewards for behaviors have shown that when parents provide food as rewards, children develop preferences for the rewarded food items.
In the childhood obesity prevention literature, it has been recommended that food never be used for rewards or punishments because food rewards teach children that it is acceptable to eat when they are not hungry, increases dietary intake of fat/sugar and helps to create unhealthy food preferences for children (CDC, 2009).

D.3. Physical environment

It is well-established that an individual’s environment helps to shape his or her behavior and that individuals can help shape their environments through the theoretical construct of *reciprocal determinism*. However, some populations, such as adults with developmental disabilities and children, may have less control over their own environments and rely on others to determine what their home environment is like. It is unknown how the home environment shapes the health behaviors of adults with developmental disabilities; however, research has examined how the home environment has shaped the health behaviors of children and adolescents. In the smoking literature, the use of home smoking policies has been shown to promote antismoking attitudes in youth and home smoking bans have even been associated with future smoke-free housing choices for young adults who move out of the family home (Albers, Biener, Siegel, Cheng, & Rigotti, 2009). The childcare obesity prevention literature has noted that children who attend childcare centers with more supportive physical environments (e.g., physical activity promotion policies, limited availability of computers/televisions, play equipment, supportive staff) are more likely to participate in moderate-to-vigorous levels of physical activity and less likely to be sedentary compared to children who attend centers with less supportive environments (Bower et al., 2008). Research has also suggested that the home environment is the place where eating behaviors are formed and
the availability of unhealthy foods in the home has been associated with poorer diet quality for children (Golan, 2006; Wang et al., 2013). This is just a brief overview of how the physical environment has been shown to impact the health behaviors of children, and this literature may be helpful in understanding how the environment shapes the health behaviors of adults with developmental disabilities.

**E. Conceptual Framework**

This purpose of this dissertation research was to better understand how interpersonal factors impact the health behaviors of adults with developmental disabilities; specifically, this dissertation research examined how direct support professionals influence the health behaviors of their clients with developmental disabilities. It is recognized that in addition to direct support professionals, there are other potential sources of influence over the health behaviors of adults with developmental disabilities (e.g., family members, roommates); however, this dissertation research only focused on the influence of direct support professionals. Even though the job duties of direct support professional may be viewed as more parental in nature (e.g., bathing, grooming, cooking, etc.) they are often viewed as “peers” or “friends” by their clients with developmental disabilities. Direct support professionals were selected for this dissertation research because of this unique role they have in the lives of their adult clients with developmental disabilities and it is well-established in the literature, as described in Section D, that peers can influence an individual’s health behaviors.

In attempt to better understand the interpersonal factors associated with the health of those with developmental disabilities, the constructs of role-modeling, incentive motivation and facilitation from Social Cognitive Theory were assessed to help explain
how direct support professionals influence the health behaviors of their clients. Even though Social Cognitive Theory is comprised of multiple constructs, only these three constructs were explored in this dissertation research because these constructs were thought to be the most relevant to the relationship between direct support professionals and their clients with developmental disabilities. The construct of role-modeling, also referred to as observational learning, suggests that behaviors are acquired by observing others perform the behavior. Because direct support professionals make up a large portion of adults with developmental disabilities’ social networks and spend time with their clients on a weekly/daily basis, there is the opportunity for many health behaviors to be role-modeled from direct support professional to client. The construct of incentive motivation suggests that behaviors can be encouraged or discouraged through the use of rewards/punishments. Because direct support professionals have the responsibility of supervising adults with developmental disabilities, it is likely that rewards/punishments may be used to get a client with a developmental disability to perform a certain task (e.g., get dressed) or stop doing a certain behavior (e.g., stop being aggressive). Finally, the construct of facilitation suggests that behaviors can be influenced by providing certain resources in the environment to encourage behavior and direct support professionals often have control over the home environments of their clients (e.g., deciding what food to purchase, deciding what meals to prepare, etc.).

F. Conclusion

The population of people with developmental disabilities has not yet been included in many of the population-level public health surveillance surveys such as the Behavioral Risk Factor Surveillance System survey or the National Health and Nutrition
Examination Survey, which is a large reason why such a limited amount of population-level data is available on the health of those with developmental disabilities. However, *Healthy People 2020* calls for better surveillance efforts to assess the health of those with disabilities and their caregivers. In 2001, the Surgeon General’s report, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* set the primary goal of integrating health promotion into community environments for adults with intellectual disabilities through promoting the wellness of those with disabilities and their caregivers, and developing strategies for reducing burdens and turnover in nonfamily caregivers.

This study aligns with the goals set forth by *Healthy People 2020* and the Surgeon General’s report *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*. In addition, this study is unique in that it examines the health behaviors of adults with developmental disabilities through a social influence lens, by exploring how direct support professionals influence the health behaviors of their clients with developmental disabilities. This study is the first to: 1) explore key members of the developmental disability community’s perceptions of the role direct support professionals play in the health promotion efforts of adults with developmental disabilities; 2) describe the relationship between direct support professionals’ health behaviors and those of their clients with developmental disabilities; and 3) describe how direct support professionals’ use of health promotion strategies (e.g., role-modeling, incentive motivation and facilitation) relate to the dietary and physical activity behaviors of their clients with developmental disabilities.
Chapter 2: Overview of Research Design & Methods

This chapter is broken into two sections—specific aims and methods used for each of the three manuscripts.

A. SPECIFIC AIDS

This study used a mixed methods approach to better understand the role that direct support professionals have in promoting the health of their clients with developmental disabilities. Specifically, the study addressed the following aims:

Manuscript #1: Explore how key members of the developmental disability community perceive the role of direct support professionals in the health promotion efforts of their clients with developmental disabilities.

1. How do members of the developmental disability community (e.g., direct support professionals, family members, agency administrators, adults with developmental disabilities) define "health" for people with developmental disabilities?

2. How do members of the developmental disability community perceive the role/influence of direct support professionals in the health promotion efforts of their clients with developmental disabilities?

3. What are the barriers that direct support professionals experience when trying to promote the health of their clients with developmental disabilities and what
strategies could be used to make it easier for direct support professionals to promote the health of their clients with developmental disabilities?

**Manuscript #2:** Describe the smoking behaviors of direct support professionals and their clients with developmental disabilities and examine the relationship between the smoking behaviors of direct support professionals and their clients.

1. What are the smoking behaviors of direct support professionals and their clients with developmental disabilities and is there a relationship between direct support professionals’ smoking behaviors, and the smoking behaviors of their clients with developmental disabilities?

2. How do direct support professionals facilitate (e.g., using incentive motivation and other facilitators of behavior) the cigarette smoking behaviors of their clients with developmental disabilities, and how is this related to client behavior?

3. How much of a role do direct support professionals perceive themselves as having in the health promotion efforts of their clients with developmental disabilities and what is the perceived difficulty of helping their clients smoke less cigarettes if they smoke?

**Manuscript #3:** Describe the dietary and physical activity behaviors of direct support professionals and their clients with developmental disabilities and examine the relationship between the dietary and physical activity behaviors of direct support professionals and their clients.

1. What are the dietary and physical activity behaviors of direct support professionals and their clients with developmental disabilities, and is there a relationship between direct support professionals’ dietary/physical activity
behaviors and the dietary/physical activity behaviors of their clients with developmental disabilities?

2. How do direct support professionals facilitate (e.g., using incentive motivation and other facilitators of behavior) the dietary and physical activity behaviors of their clients with developmental disabilities, and how is this related to client behavior?

3. How much of a role do direct support professionals perceive themselves as having in the health promotion efforts of their clients with developmental disabilities and what is the perceived difficulty of helping their clients perform healthier dietary and physical activity behaviors?

B. OVERVIEW OF METHODS: MANUSCRIPT #1

B.1. Methods

B.1.a Study design. This study was a qualitative study and focus groups were used to collect data.

B.1.b Eligibility criteria. Persons aged 18 and older who were involved in the developmental disability community (e.g., direct support professionals, persons with developmental disabilities, family members, agency administrators) were eligible to participate in this qualitative study.

B.1.c Sample recruitment and study registration. Participants were recruited via e-mail. The Franklin Country Board of Developmental Disabilities, Goodwill Industries, and the researcher e-mailed recruitment invitations to clients, direct support professionals, and families. Interested participants contacted the researcher to register for the study. The researcher registered more participants than needed, with the expectation
that not all registered participants would show up on the day of the focus group. Once registered, participants received directions to the study site via e-mail and a reminder call the day before the focus group.

**B.1.d Sample size.** Six focus groups (n=48) were conducted. One focus group was held with adults with mild developmental disabilities (n=6), one focus group was held with agency administrators (n=10), two focus groups were held with family members (n=17) of adults with developmental disabilities, and two focus groups were held with direct support professionals (n=15).

**B.1.e Study site.** The focus groups took place in private conference rooms at local disability organizations.

**B.2. Measures**

Focus group participants were asked to fill out a brief demographic questionnaire (e.g., age, gender, race, affiliation with the developmental disability community) at the beginning of the study. The goal of this qualitative research was to gain a better understanding of how members of the developmental disability community view the role of direct support professionals in the health promotion efforts of their adult clients with developmental disabilities. Two qualitative focus group guides were created for this the focus groups, one for family members/agency administrators/direct support professionals and another guide was specifically developed for adults with developmental disabilities. The focus group question guides were developed and organized based on specific health behavior theoretical concepts (e.g., role-modeling, barriers, facilitating factors, etc.).

**B.3. Data collection procedures**
The researcher moderated all qualitative focus groups and followed the scripted interview guides described above. All focus groups were audio-recorded using two audio recorders. Focus groups lasted an average of 75 minutes.

**B.3.a Informed consent.** In order to participate in the study, participants were required to provide informed consent. The informed consent form provided details about the study, the potential risks and benefits of participating in the study, who to contact with questions about the study, as well as described the incentive that participants would receive. The informed consent form also informed participants that their participation in the study was completely voluntary and that they could end their participation at anytime. Prior to providing their informed consent, participants who were adults with developmental disabilities completed a capacity assessment to determine their understanding of the research study. All adults with developmental disabilities in the study were their own guardians and therefore could sign their own consent forms.

**B.3.b Confidentiality.** All data collected for this study was kept confidential and all identifying information was removed from the data. The only people with access to the data were the PI, the doctoral student, and those listed on the IRB application as key personnel.

**B.3.c Incentives.** Participants received a $25 gift card to a local retailer as a thank you for their time.

**B.4. Data management and data analysis.** The focus group audio recordings were transferred to the researcher’s password protected computer and stored. The focus group audio recordings were transcribed verbatim by the researcher. The transcripts were initially read to get a general overview of the data; each member of the team (the
researcher and two trained research assistants) independently coded the text using an open coding method. Each unit of text was given a primary code, and if necessary, a secondary code. Once the research team reached consensus on coding, codes were categorized into thematic areas.

C. OVERVIEW OF METHODS: MANUSCRIPTS #2 and #3

C.1. Study design. This study used an observational, cross-sectional study design.

C.2. Study population

C.2.a Participant characteristics. Demographic information about direct support professionals within the state of Ohio was unavailable prior to conducting the study. However, nationally, the majority of direct support professionals are female (90%), while 48% are white, 29% black and 22% Hispanic (Hewitt, Larson, Edelstein, Seavey, Hoge, & Morris, 2008). Educational backgrounds of direct support professionals have ranged from 33%-66% having high school educations or less (Hewitt et al., 2008; Gray-Stanley & Muramatsu, 2011).

C.2.b Eligibility criteria. In order to be eligible to participate in this study, participants had to: 1) have been 18 years or older; 2) have worked with at least one adult client with a developmental disability in the State of Ohio; 3) have worked at least 10 hours a week with the client identified in #2; 4) have worked as a direct support professional for the client in #2 for at least three months; 5) not have been the parent of the client identified in #2; 6) have received payment from the I/O Waiver or the Level One Waiver (both waivers allow people with developmental disabilities to receive home-based care services from direct support professionals); and 7) have worked as an independent provider of services.
C.3. Sample Selection

C.3.a Sampling frame. The Ohio Developmental Disabilities provider search database was used as the sampling frame for this study. The phone numbers, e-mail addresses and standard mail addresses were available as public knowledge in an online database of direct support professionals in the State of Ohio. This sampling frame contained a list of direct support professionals who were classified as independent providers working as “homemaker personal care aides” and who worked with clients with developmental disabilities who received I/O Waiver or Level One Waiver services. The classification of “independent provider” refers to the direct support professionals who are considered independent contractors and work for themselves in the eyes of the government. The I/O Waiver and the Level One Waivers were selected for this dissertation research because one of the purposes of these waivers is to provide as needed care (e.g., respite) to those with developmental disabilities; the Ohio Transitions Waiver another type of home-based care waiver was being discontinued and therefore direct support professionals were not included if they provided direct care services under the Ohio Transitions Waiver. The sampling frame (n=5,283) was created after receiving final IRB approval for the study on February 12, 2015.

C.3.b Sample size calculation. G*Power3 software was used to perform an a priori power analysis to determine the required sample size (n=417) for this proposed study. Prior to calculating the sample size, a 2x2 table was constructed to estimate the smoking distribution of clients with developmental disabilities and direct support professionals. Using smoking prevalence data available at the time, the sample size was calculated. It was estimated that approximately 20% of clients with developmental
disabilities would smoke (Havercamp et al., 2004). However, recent research suggests that a much smaller number (7%) of adults with developmental disabilities smoke (Havercamp & Scott, 2015). Based on what was known about the smoking rates among women with limited educational backgrounds in Ohio, an *a priori* power analysis, was conducted estimating that approximately 30% of clients with developmental disabilities would have direct support professional providers who smoked cigarettes. Because there was no available data on the odds of smoking among clients with developmental disabilities whose direct support providers smoke, for the purposes of this *a priori* power analysis it was estimated that clients with developmental whose direct support providers smoked would have twice the odds of smoking cigarettes than clients whose direct support providers did not smoke cigarettes. The values entered into G*Power3* software to determine the required sample size using a two-tailed hypothesis are as follows: alpha=0.05, beta=0.80, p₁=0.30, p₂=0.175, and n₂/n₁=2.33.

**C.3.c Sampling procedures.** To account for non-response and eligibility criteria, the researcher oversampled from the sampling frame to achieve the required sample size. Simple random sampling without replacement was used to draw the random sample of direct support professional providers. A total of 86.62% (n=4682/5283) of the sampling frame was sampled for this study; however, 410 participants were ineligible and 168 survey invitations bounced back as undeliverable. With the ineligible participants and the undeliverable participants removed, the sampling frame consisted of 4,727 direct support professionals. A total of three samples were drawn at different times from the original sampling frame (n=5,283) once the first sample and second samples did not yield enough survey respondents. The first sample (n=1851) yielded 176 completed surveys. For the
first sample, survey invitations were e-mailed to participants in three randomly allocated batches two weeks a part. The order of the survey invitation batches was randomly assigned. After removing the original sample from the sampling frame, a second sample (n=2700) was drawn which yielded 235 completed surveys. Again, the survey invitations were e-mailed out in three randomly allocated batches two weeks a part. Finally, a third sample (n=130) was drawn from the original sampling frame (minus those selected in sample #1 and sample #2), which yielded 9 completed surveys. A total of 420 completed the survey; however, 22 were removed after exporting the data because they did not meet eligibility criteria. The final response rate for the survey was 9.7% (398/4104).

**C.4. Data collection procedures**

**C.4.a Survey.** The online survey site, SurveyMonkey.com, was used to administer the survey to direct support professionals. Participants received an e-mail invitation to participate in the online survey. All e-mail addresses that bounced back as undeliverable were removed from the denominator.

**C.4.b Recruitment.** All sampled participants were all recruited via e-mail. All sampled participants received a survey invitation by e-mail with a link to the survey from the researcher inviting them to participate in the study. This recruitment e-mail explained the purpose of the survey and explained the details of the study. Sampled participants received up to three reminder e-mails from the researcher after the initial survey invitation e-mails were sent. In addition to reminder e-mails, participants who started the survey but who did not finish the survey also received reminder phone calls from the researcher.
C.4.c Informed consent. In order to participate in the study, participants were required to provide informed consent. The informed consent form provided details about the study, the potential risks and benefits of participating in the study, who to contact with questions about the study, and the incentive they would receive. The informed consent form informed participants that their participation in the study was completely voluntary and that they could have ended their participation at anytime. By pressing “agree” on the online informed consent form, participants provided their informed consent.

C.4.d Confidentiality. All data collected for this study has been kept confidential, and only those listed as the PI, doctoral student and key personnel on the IRB application were able to access the data.

C.4.e Incentives. Participants who completed the study received a $20 electronic gift card to an online mass merchant as a thank you for their time. After completing the survey, participants were prompted to provide contact information and select the type of gift card they wanted. Participants received their gift card within 48 hours of completing the survey.

C.4.f Test-retest reliability. After completing the online survey, participants were asked if they were willing to be contacted for future survey research. Of the participants who indicated that they were willing to be contacted again, 17% were randomly selected to complete the survey a second time two weeks later. Test-retest reliability of survey items was established using Pearson/Spearman correlation coefficients. Participants were offered an additional $20 gift card to an online mass merchant as a thank you for their time.
C.4.g Cognitive Interviewing. Prior to implementation of the full survey, the survey materials were pre-tested and cognitive interviews were conducted with five direct support professionals. These five participants received a $20 gift card to a local retailer as a thank you for their time. Direct support professionals who participated in the focus group study and who worked on the Transitions Waiver were asked to participate in the survey pretests and cognitive interviews. Transitions Waiver direct support professionals were used for pre-testing and cognitive interviewing because they were not included on the sampling frame for this study and because they provided care to clients with developmental disabilities. The purpose of pretesting and cognitive interviewing was to allow the researcher to make changes to the survey instrument prior to survey implementation; benefits of cognitive interviewing include being able to understand the thought processes used by respondents when answering survey items (Groves et al., 2009).

C.5. Measures

Direct support professionals were asked to think about the client they provided the most care for and serve as a proxy reporter for the health behaviors of that client.

C.5.a Measures for Manuscript #2—Smoking Behaviors:

Smoking behaviors. Standard-smoking questions from the BRFSS telephone survey were used to assess lifetime smoking and current smoking status. Nelson and colleagues (2001) concluded that the smoking questions on the BRFSS have high levels of reliability-validity and are able to successfully identify smoking status. Participants were asked, “Have you smoked 100 cigarettes in your lifetime?” and “Do you currently smoke cigarettes every day, some days or not at all?” The following questions from
NHANES were asked to assess the number of cigarettes smoked, “During the past 30 days, on how many days did you smoke cigarettes?” and “During the past 30 days, on the days that you smoked, how many cigarettes did you smoke per day?” Direct support professionals were asked to report to the best of their knowledge about the smoking behaviors of their client, using the same questions listed above.

Health Promotion Strategies.

Role-modeling. Direct support professionals were asked the following questions about role-modeling cigarette smoking behavior: “Thinking about the past month, how often did you smoke cigarettes during your work shift?” Response options: never, seldom, several times a month, several times a week, most days, or everyday. “During your work shift, where do you usually smoke cigarettes?” Response options: inside the client’s house, outside of the client’s house, I do not smoke while at work, or other. “Does anyone living in your client’s home smoke cigarettes?” Response options: yes or no.

Incentive motivation. Direct support professionals were asked the following questions about incentive motivation: “How often do you allow your client to smoke cigarettes as a reward?” and “How often do you take away cigarettes from your client (if he/she smokes) for poor behavior?” Response options: never, seldom, several times a month, several times a week, most days, or everyday.

Facilitation. Direct support professionals were asked the following question about facilitating the smoking behaviors of their clients: “How often do you purchase or give cigarettes to your client?” and “How often do you take your client someplace to smoke?” and “How often do you wait for your client to finish smoking before doing an activity?
and “How often do you allow your client to smoke cigarettes around you?” Response options: never, seldom, several times a month, several times a week, most days, or everyday.

Policy. Direct support professionals were asked the following questions about smoking policies: “Does your client or his/her guardian have any household rules or policies about smoking?” Response options: yes or no. “What are the rules or policies about smoking in your clients’ house?” Response options: no one can smoke inside the house, no one can smoke outside the house, you may not smoke at all during your shift, client can smoke inside the house, client can smoke outside of the house, or other.

Perceptions of role in health promotion. Participants were asked, “How much of a role do you think you have in promoting the health of your client with a developmental disability?” Response options: not much of a role, somewhat of a role, or a large role. Participants were also asked, “How easy or difficult would it be for you to help your client quit smoking (if he/she smokes)?” Response options: very difficult, somewhat difficult, neither difficult or easy, somewhat easy, or very easy.

C.5.b Measures for Manuscript #3—Dietary/Physical Activity Behaviors:

Fruit and vegetable consumption. This was assessed using two brief survey items that have been shown to have acceptable psychometric properties (Yaroch et al., 2012). Participants were asked, “How many servings of vegetables do you eat each day? Think of a serving as being about 1 cup of raw leafy vegetables, ½ cup of other cooked/raw vegetables, or ¾ cup of vegetable juice” and “How many servings of fruit do you eat or drink each day. Think of a serving as being about 1 medium piece, or ½ cup or ¾ cup of
fruit juice.” Direct support professionals were asked to report to the best of their knowledge on the above questions for their clients with developmental disabilities.

***Sugar-sweetened beverage consumption.*** This was assessed by using questions from the BRFSS survey asking, “In a typical week, during the past 30 days, how often did you drink regular soda pop that contains sugar?” and “In a typical week, during the past 30 days, how many times did you drink sugar-sweetened fruit drinks such as Kool-Aid or lemonade, sweet tea, sweetened coffee drinks or sports/energy drinks?” Direct support professionals were asked to report to the best of their knowledge on the above questions for their clients with developmental disabilities.

***Fast-food consumption.*** This was measured by asking participants, “During the past 7 days, how many times did you eat fast food, including fast food meals eaten at work, at home or at fast-food restaurants, carryout or drive thru?” Response options were as follows: never, once during the past seven days, twice during the past seven days, three times during the past seven days, four times during the past seven days, five times during the past seven days, six times during the past seven days, seven times during the past seven days, or more than seven times during the past seven days. Direct support professionals were asked to report to the best of their knowledge on the above question for their clients with developmental disabilities.

***Physical activity.*** This was measured by using questions from the NHANES questionnaire for days and minutes during a typical week spent in moderate recreational activities, vigorous recreational activities and minutes participating in sedentary behavior. Participants were asked, “How much time do you spend walking or bicycling for travel on a typical day?” “In a typical week do you participate in vigorous intensity sports,
fitness or recreational activities?” “How many minutes do you participate in vigorous intensity sports, fitness or recreational activities on a typical day when you do these vigorous-intensity activities?” “In a typical week, do you participate in any moderate-intensity sports, fitness or recreational activities?” “In a typical week, how many days do you participate in moderate intensity sports, fitness or recreational activities?” “How many minutes do you spend participating in moderate-intensity sports, fitness or recreational activities on a typical day when you do these moderate-intensity sports?” “How much time do you usually spend sitting on a typical day?” “Thinking about the past 30 days, on average, how many hours per day do you sit and watch TV or videos?” “Thinking about the past 30 days, on average, how many hours per day do you use the computer or play video games?” Direct support professionals were asked to report to the best of their knowledge on the same physical activity and sedentary behaviors of their clients with developmental disabilities.

_Highlight Promotion Strategies._ The following survey items were compiled from published survey instruments in the existing food/physical activity parenting practices literature. The systematic review of parenting practices conducted by Vaughn and colleagues (2013) was used to identify relevant survey instruments. The survey items listed below were adapted from the healthy parenting practices literature to fit the needs of this study; therefore, not all items from the original scales were included because they were not all applicable to the population of interest, which is a recognized weakness of this study. Survey items for this study were adapted from survey instruments in the following articles: Bryant and colleagues (2008), Gattshall and colleagues (2008), Musher-Eizenman and Holub (2007), Hendy and colleagues (2009), and Dave and
colleagues (2012). The psychometric properties of all of the scales from the articles listed above were considered acceptable for each individual scale. Survey items are listed below and grouped according to constructs from Social Cognitive Theory.

**Role-modeling.** Direct support professionals were asked to report on the following dietary and physical activity behaviors. “Thinking about the past month, how often did you… 1) eat the same foods you offered to your client?; 2) tell your client that you liked the food that was being served?; 3) eat sweets or salty snacks in front of your client?; 4) drink sugary drinks, such as soda pop, in front of your client?; and 5) do something physically active with your client?” Response options for the preceding questions were: never, seldom, several times a month, several times a week, most days, or everyday. “How much do you agree with the following statements? 1) I eat healthy foods in front of my client, even if they aren’t my favorites foods; 2) I show enthusiasm towards eating healthy foods to my client; 3) I eat fruits and/or vegetables in front of my client. 4) I eat meals from fast-food restaurants in front of my client; 5) My client sees me being physically active; and 6) My client sees me watch TV, use my cell phone, use the computer, or play video games.” Response options were as follows: strongly disagree, somewhat disagree, neither agree nor disagree, somewhat agree, or strongly agree.

**Incentive motivation:** Direct support professionals were asked to report on their use of rewards/punishments for their clients’ behaviors. “How often do you… 1) give your client special treats such as sweets, soda or salty snacks as a reward?; 2) allow your client to watch extra TV, use the computer or play video games as a reward?; 3) praise your client for being physically active?; 4) praise your client for eating fruits and vegetables?; 5) withhold special treats such as sweets, soda or salty snacks for your
client’s poor behavior?; and 6) take away your client’s TV, computer, or videos for your client’s poor behavior?” Response options for the preceding questions were: never, seldom, several times a month, several times a week, most days, or everyday.

_Facilitation:_ Direct support professionals were asked the following questions to identify the ways they facilitate the health behaviors of their clients. “How often do you… 1) watch TV, use your cell phone, watch movies or play video games with your client?; 2) give your client soda pop?; 3) set limits on how many sweets, sodas, or salty snacks your client can have?; 4) sit with your client during meals?; 5) let your client eat whatever he or she wants to eat?; 6) give your client fruit?; 7) give your client vegetables?; 8) give your client treats such as candy, cookies, brownies or cakes?; 9) prepare meals for your client that includes fruits and vegetables?; 10) help your client set goals to improve their eating habits?; 11) take your client to the grocery store?; 12) help your client make a healthy snack?; 13) help your client prepare a meal that includes fruits and vegetables?; 14) allow your client to eat snacks whenever he/she wants?; 15) allow your client to choose his/her own meals and snacks?; 16) involve your client in meal planning?; 17) allow your client to participate in meal preparation?; 18) transport your client someplace for him/her to be physically active?; 19) allow your client to choose an activity that involves being physically active?; 20) encourage your client to drink water?; and 21) take your client to get meals from fast food restaurants?” Response options for the preceding questions were: never, seldom, several times a month, several times a week, most days, or everyday.

_Perceptions of role in health promotion for client._ Direct support professionals were asked, “How much of a role do you think you have in promoting the health of your
client with a developmental disability?” Response options: not much of a role, somewhat of a role, or a very large role. Participants were also asked, “How easy or difficult would it be to help your client…1) be physically active; 2) eat more fruits and vegetables; 3) eat less meals from fast food restaurants; 4) drink less sugary drinks such as soda pop; and 5) watch less TV?” Response options were: very difficult, somewhat difficult, neither difficult or easy, somewhat easy, or very easy.

C.5.c Measures included in both manuscripts #2 and #3

Potential covariates. Data was collected on the following variables: length of time spent working with the client, the number of hours a week spent working with the client, length of time working as a direct support professional, number of hours a week spent working as a direct support professional, client living environment, number of persons residing in the client’s home, physical disability status of the client/direct support professional, dietary restrictions of the client, general health of client/direct support professional, client’s barriers to diet and physical activity, and chronic disease status of the client/direct support professional. Questions about direct support professionals’ levels of perceived stress, psychological distress, and social support were also asked.

Demographics: Standard questions for age, gender, and race were asked about direct support professionals and their client with developmental disabilities. Direct support professionals were asked to report on their education-level and marital status.

C.6 Data management and data analysis

C.6.a Data management. Data collected for this dissertation research was stored on the researcher’s computer and was password protected. All data collected for this survey was deidentified. Data was cleaned (e.g., checked for outliers, recoded variables,
checked for missing data) and then analyzed. SPSS 22.0 software was used to analyze data.

C.6.b Response rates. The final response rate for this survey was 9.7% (398/4104). As noted in section C.3.c, from the original sample of 4,682 direct support professionals, 410 were ineligible and 186 survey invitations were undeliverable and were removed from the denominator. A total of 139 participants were eligible for the survey but did not complete the survey, with many stopping after the consent form. For the test-retest survey, the response rate was 47.2% (34/72).

C.6.c Statistical analysis.

Manuscript #2: Descriptive statistics were used to describe the smoking behaviors of direct support professionals and their clients with developmental disabilities, as well as the ways that direct support professionals facilitate the smoking behaviors of their clients with developmental disabilities. Descriptive statistics were also used to describe direct support professionals’ perceptions of their role in the health promotion efforts of their clients with developmental disabilities and the perceived difficulty of helping their clients quit smoking. Chi-square tests of associations were used to assess the relationship between direct support professional current smoking status and the current smoking status of their clients with developmental disabilities. Independent sample t-tests were used to examine the difference in mean number of daily cigarettes smoked by people with developmental disabilities and their direct support professionals’ facilitation of smoking behaviors.

Manuscript #3: Descriptive statistics were used to describe the dietary and physical activity behaviors of direct support professionals and their clients with
developmental disabilities, as well as the ways that direct support professionals facilitate the dietary and physical activity behaviors of their clients with developmental disabilities. Descriptive statistics were also used to describe direct support professionals’ perceptions of their role in the health promotion efforts of their clients with developmental disabilities and the perceived difficulty of helping their clients perform healthy dietary and physical activity behaviors. Pearson correlations were used for continuous variables (e.g., sugar-sweetened beverage consumption, fruit/vegetable intake) and Spearman correlations were used for categorical variables (e.g., weekly fast food consumption, daily TV time) to assess the relationship between direct support professionals’ and clients’ health behaviors. Spearman correlations were used to examine the relationship between direct support professionals’ use of health promotion strategies (role-modeling, incentive motivation and facilitation) and the dietary and physical activity behaviors of their clients with developmental disabilities. Simple logistic regression was used to predict the odds of how difficult direct support professionals perceived helping their clients perform healthy dietary/physical activity behaviors based on clients’ preferences for eating healthy and being physically active.
Chapter 3: The Perceived Role of Direct Support Professionals in the Health Promotion Efforts of their Clients with Developmental Disabilities

(Manuscript #1)

Introduction

People with developmental disabilities experience disparities in their health when compared to members of the general population (Reichard & Stolzle, 2011; Morin et al., 2012). Current literature suggests that adults with developmental disabilities are more likely to suffer from chronic health conditions such as diabetes and heart disease than those without disabilities (Reichard & Stolzle, 2011; Draheim, 2006). People with developmental disabilities have even been shown to develop heart disease at earlier ages than those without developmental disabilities (Reichard & Stolzle, 2011; Draheim, 2006; Morin et al., 2011; Sohler et al., 2009; Day et al., 2005). Reichard and Stolzle (2011) compared the prevalence of diabetes between adults with cognitive disabilities and those without such limitations and found that adults with cognitive limitations had significantly higher rates of diabetes than those without cognitive limitations, 19.4% vs. 3.8%, respectively. In addition, this same study found that adults with cognitive limitations and diabetes were significantly more likely to suffer from chronic conditions such as asthma, arthritis, heart disease, high blood pressure, stroke and high cholesterol.

It is well-established in the literature that the use of tobacco products, eating a poor diet and being physically inactive are all modifiable behaviors that contribute to
chronic health conditions; however, the literature is just recently starting to describe the health behaviors of adults with developmental disabilities. In one recent study, Havercamp and Scott (2015) noted that adults with developmental disabilities were more likely to be obese and much less likely to participate in physical activity than people without disabilities. This same study noted that adults with developmental disabilities were less likely to smoke than people with other types of disabilities and those without disabilities; however, in the past, adults with developmental disabilities were thought to smoke at similar rates as members of the general population (Havercamp, Scandlin, & Roth, 2004). Havercamp and Scott (2015) also found that in comparison to people without disabilities, adults with developmental disabilities were 4.4 times less likely (prevalence ratio) to receive adequate emotional support. This finding is consistent with past research that suggests that adults with developmental disabilities experience social isolation; studies have also shown that direct support professionals often make up the primary social networks of adults with developmental disabilities (Havercamp, Scandlin, & Roth, 2004; de Schipper & Schuengel, 2010; Hewitt & Larson, 2007).

The term “direct support professional” is a term used to describe the group of paid workers who provide care services to those with developmental disabilities. Direct support professionals are responsible for assisting their clients with developmental disabilities with their activities of daily living such as: personal hygiene, cooking, cleaning, grocery shopping, transportation, and finances (Hewitt & Larson, 2007). In addition to assisting with activities of daily living, direct support professionals also provide support so that their clients can lead as self-directed and as independent lives as possible (Hewitt & Larson, 2007). Research has suggested that direct support
professionals play a large social role in the lives of their clients with developmental disabilities, and that people with developmental disabilities may form strong emotional attachments to their direct support professional providers and often view them as role-models and peers (de Schipper & Schuengel, 2010; Hewitt & Larson, 2007). In one study, Dodevska and Vassos (2013) asked adults with developmental disabilities what that they valued the most in a direct support professional and it was consistently reported that adults with developmental disabilities value direct support professionals who have strong interpersonal skills. Authors have noted that the quality of care provided to clients with developmental disabilities varies among direct support professionals, and that direct support professionals can “bring out the best and the worst in their clients” (Clegg & Landsall-Welfare, 2010; Schuengel et al., 2010; Hall & Hall, 2002).

While we know that adults with developmental disabilities experience higher rates of chronic conditions than members of the general population, very little is known about the behavioral factors that contribute to these chronic conditions. The literature has consistently shown that an individual’s social environment can influence one’s health (e.g., McAlister, Perry, & Parcel, 2008; Flay et al., 1994; Hendy & Raudenbush, 2000; Maitland et al., 2013). Because direct support professionals make up such a large part of the social networks of adults with developmental disabilities, it makes sense to explore the influence that direct support professionals have on the health behaviors of their clients with developmental disabilities.

Constructs from Social Cognitive Theory can help provide a framework for better understanding the role direct support professionals play in the lives of their clients with developmental disabilities. Research has suggested that the concept of role-modeling,
where people learn from those around them, has consistently been shown to impact health behaviors such as diet, physical activity and tobacco use (McAlister, Perry, & Parcel, 2008). In addition to role-modeling, the use of rewards or punishments, known as incentive motivation, has been shown to influence health behaviors, particularly in the childhood obesity literature (Birch, 1999). In the past, cigarettes were used as rewards for good behavior with adults with developmental disabilities; however, research has yet to explore the use of food as rewards among adults with developmental disabilities (Minihan, 1999; Tyler & Bourget, 1997). Finally, the concept of reciprocal determination suggests that an individual’s environment helps to shape his or her behavior and that an individual can help shape his or her own environment as well (Bandura, 1986). However, some populations, such as adults with developmental disabilities may lack control over their own environments; others such as direct support professionals may play a large role in shaping the home environments of their clients with developmental disabilities.

The purpose of this study was to qualitatively explore how members of the developmental disability community (e.g., direct support professionals, family members, agency administrators and adults with developmental disabilities) define “health” for people with developmental disabilities and how these disability community members perceive the role/influence of direct support professionals in the health promotion efforts of their clients with developmental disabilities. In addition, a goal of this study was to better understand the barriers to health promotion for people with developmental disabilities and the ways to overcome these barriers to health promotion.
Methods

Participants

This study was approved by The Ohio State University’s Institutional Review Board. Study participants had to be adults (18 and older), who were involved in the developmental disability community (e.g., direct support professionals, persons with developmental disabilities, family members, agency administrators). Participants were recruited via e-mail. Local disability organizations hung recruitment flyers and e-mailed recruitment invitations to their members. The researcher e-mailed recruitment invitations to a list of direct support professionals taken from the Ohio Department of Developmental Disabilities website. Participants who were interested in the study contacted the researcher to register for the study. Once registered, participants received directions to the study site via e-mail and a reminder call the day before the focus group. Participants provided informed consent. Prior to providing their informed consent, participants who were adults with developmental disabilities completed a capacity assessment to determine their understanding of the research study. All adults with developmental disabilities in the study were their own guardians.

Six focus groups were conducted with a total of n=48 participants. One focus group was held with adults with mild developmental disabilities (n=6), one focus group was held with agency administrators (n=10), two focus groups were held with family members (n=17) of adults with developmental disabilities, and two focus groups were held with direct support professionals (n=15). The focus groups were held in private conference rooms at local disability organizations.
Procedures

The focus group discussion facilitator followed a scripted interview guide. All focus groups were audio-recorded using two audio recorders. Discussions lasted an average of 75 minutes and participants received a $25 gift card to a local retailer for participation in the study. Participants were asked to fill out a brief demographic questionnaire (e.g., age, gender, race, affiliation with the developmental disability community) after the focus groups ended.

Measures

Two qualitative focus group guides were developed for the discussions. One guide was developed for the discussions with family members, agency administrators, and direct support professionals and the other guide was developed specifically for adults with developmental disabilities (Table 1). The focus group question guides were developed and organized based on specific theoretical health behavior concepts (e.g., role-modeling, barriers, facilitating factors, etc.).

Data Analysis

The focus groups were transcribed verbatim by the researcher. The transcripts were initially read to get a general overview of the data; each member of the team (the researcher and two trained research assistants) independently coded the text using an open coding method. Each unit of text was given a primary code, and if necessary, a secondary code. Once the research team reached consensus on coding, codes were categorized into thematic areas.
<table>
<thead>
<tr>
<th>Concept</th>
<th>Questions</th>
</tr>
</thead>
</table>
| General thoughts on health | • When you think about adults with DD “being healthy” what comes to mind? When you think about being healthy, what do you think about?  
• What concerns do you have about the health of those with DD? What makes you worry or be concerned about your own health? |
| General thoughts on DSPs | • What makes someone a “good” DSP? What makes someone a “good” staff person?  
• What makes someone a “bad” DSP? What makes someone a “bad” staff person? |
| Norms                   | • Thinking about the adult(s) with developmental disabilities that you know, what is their typical day like with their staff? What kinds of activities do they do with their staff? What types of things or activities do you do on a typical day with your staff? |
| Impact                  | • How much of impact do you think that DSPs have on health of those with developmental disabilities? Specifically, how about their impact on diet, physical activity and tobacco use?  
• What role do you think that DSPs should play, if any, in promoting the health of their clients? |
| Barriers                | • What makes it difficult for a DSP to promote the health of his/her client with DD? What makes it difficult or hard for you or other people like you to be healthy each day?  
• What kinds of unhealthy things does your staff do? |
| Facilitating factors    | • What could make it easier for a DSP to promote the health of his/her clients with DD? What does your staff do to help you be healthy? What could your staff do to help you be a healthier person?  
• Are there any healthy activities that you would like to be more involved with? What are these activities? |

Table 1. Focus group question guide

Abbreviations: DSPs, direct support professionals; DD, developmental disabilities

*Italics*: questions asked to people with DD
Table 1 continued

<table>
<thead>
<tr>
<th>Concept</th>
<th>Questions</th>
</tr>
</thead>
</table>
| **Role-modeling/policies**      | • What are your thoughts about DSPs being able to smoke while working with their clients? Should there be restrictions on smoking? What are your concerns with this issue? *Do you think that your staff or other peoples’ staff should be allowed to smoke while working? What are your thoughts and feelings about your staff being able to smoke around you?*  
• How about eating meals and snacks? Should DSPs be able to eat while at work, and should any restrictions be placed on the kinds of foods that they should be allowed to eat or drink? *Do you think your staff or other peoples’ staff should be allowed to eat meals and snacks while working? What are your thoughts and feelings about your staff eating meals and snacks around you?*  
• What are your thoughts about DSPs being able to watch TV, use their computer or cell phones while working with their clients? *Do you think that your staff or other peoples’ staff should be allowed to watch TV, use their computer or cell phone while working? What are your thoughts and feelings about your staff watching TV, using their computer or cell phone while working with you?*  
• Should the organizations that employ DSPs be required to have any policies that regulate the health behaviors of their employees during their work shifts? What benefits do you see to having organizational-level health behavior policies? What are the barriers to having organizational-level health behavior policies? |
| **Knowledge/skills**            | • In general, do you think that adults with DD have the knowledge and ability to understand the importance of eating healthy, being physically active and refraining from smoking cigarettes? *Do you think you have enough information about how to be healthy? What could you use more information about?*  
• Do you believe that DSPs have the knowledge and training needed to promote healthy behaviors for their clients with DD? *How much help would you like to get from your staff when it comes to being healthy?*  
• What suggestions do you have to increase health knowledge and healthy practices for those with DD and their DSPs? |
| **Conclusion**                  | • If you had one final message about promoting the health of those with DD what would it be? *Do you have anything else you would like to say to me about being healthy or your staff?* |
Results

Sample Characteristics

Table 2 contains the demographic characteristics of focus group participants. A total of n=48 participants participated in six focus groups. The average age of participants was 50.9±14 years, and the majority (70.8%) were female. The majority had some type of college training (77.1%), while 10.4% did not graduate from high school, 14.6% had a high school diploma/GED. The majority of participants were White (54.2%), while 31.3% identified as African American, and 4.2% as Hispanic. Direct support professionals in the study worked an average of 12.1±8 years in the field of direct care, while agency administrators worked an average of 17.3±15 years in the field.

<table>
<thead>
<tr>
<th>Demographic Variables</th>
<th>Total (N=48)</th>
<th>DSPs (n=15)</th>
<th>Family (n=17)</th>
<th>DD (n=6)</th>
<th>Agency (n=10)</th>
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<td>50.8(14) --</td>
<td>69.3(3) --</td>
<td>50.9(11) --</td>
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<td>Female</td>
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<td>12 80</td>
<td>13 76.5</td>
<td>4 66.7</td>
<td>5 50.0</td>
</tr>
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<td></td>
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<td>0 0</td>
<td>0 0</td>
<td>5 83.3</td>
<td>0 0</td>
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<td>2 13.3</td>
<td>4 23.5</td>
<td>1 16.7</td>
<td>0 0</td>
</tr>
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<td>9 60.0</td>
<td>3 17.7</td>
<td>0 0.0</td>
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</tr>
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<td>College+</td>
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<td>5 26.7</td>
<td>10 47.1</td>
<td>0 0.0</td>
<td>9 90.0</td>
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<td>Race</td>
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<td></td>
</tr>
<tr>
<td>Black</td>
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<td>9 60.0</td>
<td>1 5.9</td>
<td>2 33.3</td>
<td>3 30.0</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 4.2</td>
<td>1 7.1</td>
<td>0 0.0</td>
<td>0 0.0</td>
<td>1 10.0</td>
</tr>
<tr>
<td>White</td>
<td>26 54.2</td>
<td>4 26.7</td>
<td>13 76.5</td>
<td>4 66.7</td>
<td>5 50.0</td>
</tr>
<tr>
<td>Other/Refused</td>
<td>5 10.3</td>
<td>1 7.1</td>
<td>3 17.7</td>
<td>0 0.0</td>
<td>1 10.0</td>
</tr>
<tr>
<td>Years in field</td>
<td>-- --</td>
<td>12.1(8) --</td>
<td>-- --</td>
<td>-- --</td>
<td>-- --</td>
</tr>
</tbody>
</table>

Table 1. Demographic characteristics of individuals who participated in the focus groups

Abbreviations: DSPs, direct support professionals; DD, developmental disabilities
Findings

Defining Health among People with Developmental Disabilities

Participants noted that there is no one single definition of health that is applicable to all people with developmental disabilities because of the individualized needs and differences within the population. Even though “being healthy” has different meanings for all people with developmental disabilities, the general consensus among focus group participants was that in order for people with developmental disabilities to achieve good health, they need to eat a healthy diet, be physically active and be in a good state of mental/emotional health. In addition to the physical and emotional components of health, participants noted that for people with developmental disabilities, “being healthy” means having as much independence and control over their lives as possible (Table 3).

<table>
<thead>
<tr>
<th>Theme: What being healthy means for people with developmental disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #1: Practicing healthy behaviors</strong></td>
</tr>
<tr>
<td>( P ): I think about how staff help me choose the right kinds of foods to eat. They go to the store and pick them out for me and bring them home. I eat whatever they bring home. Adult with developmental disability</td>
</tr>
<tr>
<td>( P ): I would say being healthy is having some sort of activity where they are keeping their muscles moving in someway, obviously it depends on abilities. Family #1</td>
</tr>
<tr>
<td><strong>Subtheme #2: Having autonomy</strong></td>
</tr>
<tr>
<td>( P ): I was thinking of health as in allowing them as much independence as possible. Family #1</td>
</tr>
<tr>
<td>( P ): Being able to function at a level where they are able to provide for some of their own needs. Being healthy is being able to provide for yourself and being able to care for yourself and maintain yourself without having someone to take care of you. DSP#1</td>
</tr>
<tr>
<td><strong>Subtheme #3: Mental emotional/well-being</strong></td>
</tr>
<tr>
<td>( P ): I think contentment. Being happy and seeing a smile on their face. Family #2</td>
</tr>
<tr>
<td>( P ): I just think that in every area, mentally, physically, emotionally all concern being healthy. That they are in a stable environment and being cared for properly. They have everything that they need. That’s what being healthy means to me. DSP#1</td>
</tr>
</tbody>
</table>

Table 2. Perceptions of health for people with developmental disabilities
Role of Direct Support Professionals in Health Promotion

In general, participants viewed the basic responsibility of direct support professionals as keeping their clients with developmental disabilities safe, while successfully implementing their client’s Individualized Service Plan (ISP). In addition, many participants indicated that direct support professionals were responsible for providing their clients with social interactions, as a way to promote emotional health and well-being. However, participants had different opinions in regards to how much of a role direct support professionals should have in promoting the healthy behavioral choices of their clients related to diet and physical activity. Some participants thought that direct support professionals should actively make choices for their clients, while others thought that making healthy or unhealthy behavioral choices should be left to the client (Table 4).

<table>
<thead>
<tr>
<th>Theme: Direct support professionals’ responsibilities in promoting health of their clients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #1: Basic role</strong></td>
</tr>
<tr>
<td><em>P:</em> A good direct support professional should ensure that the health and safety of the individual is first, it is paramount, to providing these services. Agency administrator</td>
</tr>
<tr>
<td><em>P:</em> That’s the reason why you are there—that Individualized Service Plan [ISP]. If you are not going by the ISP and just on your own, then I think you are shorting your client because the purpose of you being in that ISP. They didn’t make that stuff up [in the ISP] because they didn’t have anything better to do. DSP#1</td>
</tr>
<tr>
<td><strong>Subtheme #2: Different interpretations of role in relation to health</strong></td>
</tr>
<tr>
<td><em>P:</em> Your job is to provide them with information, education, show them some things that can help them, but the choice is theirs. It’s really no different with people without disabilities. You’ve got certain scenarios where it might be a little different, but the same thing holds true. Your job is to provide information, educate, show them modeling, that kind of stuff, but at the end of the day it’s their decision. Agency administrator</td>
</tr>
<tr>
<td><em>P:</em> But one thing that I have an issue with is that my clients don’t want to do that [go out into the community]. So I have to, and excuse the word, but force them or convince them, so that I can get them out into the community. Family #2</td>
</tr>
</tbody>
</table>

Table 4. Perceived role of direct support professionals (DSPs) in health promotion efforts of clients (continued)
Table 4 continued

| Subtheme #3: Providing social interactions | P: I always like it when she’s brought out of the house, taken swimming or to whoever is taking care of her, their family events or other social aspects where maybe we wouldn’t provide that to her the same way that they would. Family #1 |
|                                             | P: In addition to the care we provide with their hygiene, care and appointments, I think we also are providing them a social component. I consider my girls my friends, the one, I have known for about four years and she knows just as much about me as I know about her. She knows that I love her. I can tell her that I love her and tuck her into bed. I think that it’s more than just making sure that they are alive and eating. We are basically a social aspect, I mean some of them may not have extensive social lives and that is one of the big reasons that we are there. DSP #1 |

Barriers to Health Promotion

Participants discussed the general importance of being healthy for adults with developmental disabilities; however, several barriers to achieving good health were noted. The barriers to health promotion described during the focus groups can best be organized into individual-level factors of the person with a developmental disability (e.g., personal preferences, rights, etc.), individual-level factors of the direct support professional (e.g., motivation, rights, etc.), interpersonal factors between the client with a developmental disability and the direct support professional (e.g., role-modeling, use of rewards, etc.) and finally organizational factors (e.g., turnover among direct support professionals, unenforceable policies, etc.).

Individual-level (Person with a developmental disability)

Even though having as much autonomy over their own lives was noted as contributing to the overall health of people with developmental disabilities, it was also brought up as a major concern that participants had about the health of people with
developmental disabilities. Participants noted that some people with developmental disabilities, just like anyone else, may have personal preferences for or against certain health promoting behaviors such as being physically active or eating a healthy diet. Due to these personal preferences, and concern over violating the rights of their clients, participants noted that it can be difficult at times for direct support professionals to promote the health of their clients. In general, direct support professionals reported a general fear over doing anything that could be perceived as violating the rights of their clients; while, some family members and agency administrators noted that direct support professionals could be doing more to promote their clients’ health. It was also noted that adults with developmental disabilities often live on fixed incomes, which may impact their ability to afford to purchase healthy foods. Some participants also suggested that people with developmental disabilities may also have medical conditions or physical limitations that impact their ability to make healthy lifestyle choices (Table 5).

<table>
<thead>
<tr>
<th>Theme: Barriers to health promotion: individual level, pertaining to the person with a developmental disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #1: Basic rights/client preference</strong></td>
</tr>
<tr>
<td><strong>P:</strong> All she wants is the pop and it’s her right to have the pop. She has a developmental disability; she isn’t able to make decisions the way that you or I do. She isn’t able to fully grasp, most likely, the consequences of drinking a ton diet soda. <strong>DSP#1</strong></td>
</tr>
<tr>
<td><strong>P:</strong> I know my brother gets so stubborn, he doesn’t want to do anything. And he has rights and you can’t violate his rights. But you want to keep him active so he can stay healthy. <strong>Family member #2</strong></td>
</tr>
</tbody>
</table>

Table 5. Individual-level barriers of clients (continued)
Table 5 continued

<table>
<thead>
<tr>
<th>Theme: Barriers to health promotion: individual level, pertaining to the person with a developmental disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #2: Fear</strong></td>
</tr>
<tr>
<td><strong>P:</strong> It’s like a double edge. Because then you have to fight the fight of breaking that habit, because nobody wants to get written up or bitten because this person is going off because you won’t do what they want. So it’s like, “Alright, alright. Calm down.” So nobody wants to fight the fight. I don’t. You don’t want to be part of the cycle. But then you don’t want to be that person who tries to stop it, but then you get in trouble because you wouldn’t give them that Diet Coke and then they went off and it was on you. It’s like, “Why didn’t you just give it to them? They want the Diet Coke.” Then you are in trouble because you didn’t.</td>
</tr>
<tr>
<td><strong>DSP#1</strong></td>
</tr>
<tr>
<td><strong>P:</strong> If you are even borderline taking somebody’s rights away, you are on the abuser registry, you are done. DSP#1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Subtheme #3: Interpretation of clients’ rights</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>P:</strong> What you get caught up in sometimes, I’ve heard this before, the staff, they’ve been told in their training that people have their rights. So they go to an extreme and they’ll let them do whatever they want to do basically, whether good or not good for their health or whatever. If it’s eating or smoking or whatever you might be talking about, or sitting around all day or whatever. Family #1</td>
</tr>
<tr>
<td><strong>P:</strong> I think from time to time the Department of Developmental Disabilities sends us to gunfights with a knife. And the reason I say that is because, this big focus on the rights of people with developmental disabilities, which I whole heartedly agree with, but at the same time, if we are responsible for health, because we wouldn’t be in their homes if they didn’t need us, and if we cannot provide that healthy meal, that encouragement and support of exercise, those types of things, then we’re held accountable and nobody is assuming the responsibility. And I think that when we talk about individual rights, they also have to be able to accept the responsibilities and understand the side effects of eating poorly. Agency Administrator</td>
</tr>
<tr>
<td><strong>P:</strong> I had a boy, a young man who was two hundred ninety pounds. He loved McDonald’s, Wendy’s, Taco Bell, and drank a case of pop or two cases per week. So as I went through the review with the state reviewers...my documentation had to be right there. So Johnny, knowing him, I didn’t want Johnny to have heart problems or respiratory problems. I said, “Sometimes Johnny would ask me to take him to McDonald’s” and I said to him, “No, Johnny we’re going to cook at home. I’ll help you cook.” What the reviewers reply was, “Your heart might be in the right place but you’re violating his rights. So you cannot tell him that he can’t have that food.” I said, “But he’s going to get sick.” The reviewer said, “Does anybody tell you that you can’t go to McDonald’s?” I said, “No.” She said, “If you decide you’re going are you going?” And I said, “Yeah.” She said, “He’s no different.” DSP #2</td>
</tr>
</tbody>
</table>

(continued)
Table 5 continued

<table>
<thead>
<tr>
<th>Theme: Barriers to health promotion: individual level, pertaining to the person with a developmental disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #4: Limited income</strong></td>
</tr>
<tr>
<td>P: I just say that they are on a fixed income, which definitely takes away their ability to eat a balanced diet of three meals a day. I think we are finding out more and more that the healthy foods that people want or need such as organic or gluten free is expensive. I think that individuals with developmental disabilities on their fixed income, deters them from being as healthy as they could possibly be. DSP #1</td>
</tr>
<tr>
<td>P: I worry about the people that I work with, I worry about their food a lot of the time. They don’t have a lot of money, so sometimes it’s the cheapest thing or the most affordable thing that they can buy and it’s loaded with sodium. DSP#2</td>
</tr>
<tr>
<td>P: It’s very interesting because two of my clients are roommates and they don’t get along at all. One of my client’s food stamps just got increased a lot, but the other one doesn’t get as much and she runs out of them. Recently, they’ve even been looking at community resources like food pantries. But recently, she’s been eating very unhealthy. DSP #1</td>
</tr>
<tr>
<td><strong>Subtheme #5: Limitations pertaining to specific disabilities</strong></td>
</tr>
<tr>
<td>P: Wheelchair accessibility is a huge. With my sister there’s a wheelchair van, so it’s got a ramp, and you just wheel her in there and lock her in. So if you don’t have that, you could sit with her in the car, but it might not even be that safe. And it’s really hard to get her in the car at this point too. She’s not a full size adult, I wouldn’t say she’s petite, but she’s pretty big, so maneuvering her in and out of a car without a wheelchair is actually really difficult. So going to a place, it has to be fully wheelchair accessible. No matter where, like if we’re going to a library, you’ve got to walk her out on the curb, then get her up on the thing, and hit the button so the door comes open, so I can’t push her through unless I’ve got somebody else. Family #2</td>
</tr>
<tr>
<td>P: I’m working with an individual now who has Prader Willi syndrome. What they do is that they constantly want to eat. Agency Administrator</td>
</tr>
</tbody>
</table>

**Individual-level (Direct support professional)**

Participants consistently noted that some direct support professionals may have a general lack of motivation/interest in helping their clients be healthy, which serves as a barrier to health promotion for clients with developmental disabilities. In addition, some
direct support professionals indicated that they have rights themselves (e.g., being able to eat what they want), which should not be violated while they are working (Table 6).

<table>
<thead>
<tr>
<th>Theme: Barriers to health promotion: individual level, pertaining to the direct support professional</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #1: Motivation</strong></td>
</tr>
<tr>
<td><em>P:</em> I’d say the provider’s desire plays a huge a role in what goes on because our daughter is very stubborn. Our cupboards are all locked at home because otherwise she’ll go in and get whatever she wants. But as a provider you could make it so she was well-behaved by just being like, “Fine, eat this.” Just meeting her needs by just being like, “Just do whatever. Eat it.” Where we, as parents, will fight with her, not fight with her physically, but fight with her, not just let her sit there and eat the whole time. So, out of our own willingness to be like, “No, you can’t just eat the entire three hours. You have to stop eating.” It’s easier just to be like, “Here, yeah you can keep eating.”</td>
</tr>
<tr>
<td>Family #1</td>
</tr>
</tbody>
</table>

| **Subtheme #2: Direct support professionals’ rights** |
| *P:* Sometimes they [direct support professionals] don’t want to take you no where. Then I just go to my room and not think about it. Adult with developmental disability. |

| *P:* Sometimes they [direct support professionals] bring their lunches from home or they go out and go get something from a restaurant and then bring it back here. They would like heat it up in the microwave and they would sit down and have their lunch first before they do anything for me or my roommate. They eat first and then they would get around to helping me. Adult with developmental disability. |

| *P:* If you think about the provider as a provider or an employee, you have your own rights too. So if I’m going to be with somebody for ten hours or eight hours or however long, I have the right to bring whatever I want. You can’t tell me what I can and can’t eat. I can’t flaunt it or leave it out for somebody else to eat, but that’s a fine line. Family #1 |

Table 6. Individual-level barriers of direct support professionals

**Interpersonal-level (Relationship between direct support professionals and their clients)**

Participants described direct support professionals as peers and role-models for their clients with developmental disabilities, as well as having a lot of power/influence
over their client’s daily activities. It was also noted that some direct support professionals may use food-based rewards to get their clients to do something (Table 7).

<table>
<thead>
<tr>
<th>Theme: Barriers to health promotion: interpersonal level, pertaining to the relationship between direct support professionals and their clients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #1: Role-modeling</strong></td>
</tr>
<tr>
<td>P: And in all cases, our individuals bond very tightly with the staff. Whatever staff has as a cell phone is the cell-phone our consumers want. Whatever the staff are eating is the food our consumers want to eat. So if you’re bringing McDonald’s in as your dinner on your shift, and then encouraging our consumer to have broccoli and baked chicken, there’s a disconnect there. If our staff are taking smoke breaks the clients want to go with them. If the staff are using those e-cigarettes, that’s what the smokers want to switch to. So there’s just a lot of bonding and connecting and relating to the performer of these services, and that’s a good thing, because then obviously it’s easier to mentor and role model. But also, as their supervisor, I can’t dictate that they all quit smoking, exercise, and not eat fast food. Agency Administrator</td>
</tr>
<tr>
<td>P: I think that as a provider, you have to realize that you are modeling all of the time. That consumer is watching everything that you do. DSP #1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme #2: Power dynamic</th>
</tr>
</thead>
<tbody>
<tr>
<td>P: They [direct support professionals] can have a great deal of influence because she can’t do much of anything for herself, so she’s going to be along for whatever ride they’re going to go on. So it’s important to structure activities. Family #1</td>
</tr>
<tr>
<td>P: We are the provider and we are mentoring, modeling these behaviors in front of folks that give us an expert status. You have more power than your supervisee and you are influencing them. So that’s the concern for me. It’s that what we are modeling and dictating, we have way too much power to not regulate this better, but I don’t know how to regulate it better. Agency Administrator</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme #3: Rewards</th>
</tr>
</thead>
<tbody>
<tr>
<td>P: I think that a lot of times in the field, in general, that people tend to offer things like soda or fast food as a reward or to appease people. I’ve seen almost it as a bribing situation. “Like if you behave, we are going to go to McDonald’s” and sometimes it’s even in a behavior plan. I really just don’t think that food and soda should be used. DSP #1</td>
</tr>
<tr>
<td>P: I do that. It’s like, “If you do good then we will go to Dairy Queen or Taco Bell. That’s where we are going if you do good.” I try not to, but I have done it. DSP #1</td>
</tr>
</tbody>
</table>

Table 7. Interpersonal-level barriers between clients and direct support professionals
Organizational-Level

Participants discussed how high turnover rates in the field of direct care lead to a lack of continuity in the care provided to their clients with developmental disabilities. Participants noted that it might be difficult for organizations that employ direct support professionals to have rules or policies regulating direct support professionals’ health behaviors because the rules are not always enforceable when the care is being provided in someone’s home and because all people with developmental disabilities are uniquely different (Table 8).

<table>
<thead>
<tr>
<th>Theme: Barriers to health promotion: organizational level, pertaining to the field of direct care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #1: Turnover</strong></td>
</tr>
<tr>
<td><em>P:</em> That’s part of the vicious cycle, because with the field that we are in, the turnover is so high. It’s hard for people to get that trust. It can take a little while. DSP#1</td>
</tr>
<tr>
<td><em>P:</em> We’ve been very fortunate to have the same set of providers, and we’re working together, and that kind of thing. When you have a question, you can call me or my mom. But if you had changeover all the time with different people, they would never understand what was going on with her. It’s even hard for me sometimes, a lot of times, to figure out exactly what’s going on. Without having knowledge, I mean I’ve been around her for twenty years now, so I have some idea, but for somebody who’s just stepping in on day one, it’s not really fair to expect them to be able to provide a level of care that is even going to be sufficient. Family #1</td>
</tr>
</tbody>
</table>

| **Subtheme #2: Unenforceable policies** |
| *P:* Who’s going to watch what time somebody smokes and who’s going to watch what foods they bring? It’s not enforceable. It’s not realistic to think, because most of the care is in the home. Family #1 |
| *P:* I think it would be very difficult to develop a policy that’s going to work for everybody. “This is our policy and this is the way we do it for everybody,” because the people that are being served are all individuals. Family #1 |

Table 8. Organizational-level barriers (continued)
Table 8 continued

<table>
<thead>
<tr>
<th>Theme: Barriers to health promotion: organizational level, pertaining to the field of direct care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #3: Training</strong></td>
</tr>
<tr>
<td><strong>P:</strong> They don’t get trained to do that kind of thing and they don’t have time to sit down and talk through these kinds of things very often. They may at staff meetings, I’m not sure. But for me, it doesn’t seem like our staff have that many meetings where they are all together at one time and work through those kind of things. It takes quite a bit of effort and for them to share their own experiences with each other. It’s like one person is leaving while the other is coming in and it’s like a quick review. Maybe there’s four staff in the home and they don’t see each other all together unless it’s like once a month or every few weeks or something like that. Family #2</td>
</tr>
<tr>
<td><strong>P:</strong> They’re in my office daily saying, “I wish I could help her. I wish I could convince her. I wish I could get him to make these different choices. I don’t know how.” And so, I would say for the majority of our team, the motivation is there. It’s the tools that are lacking. Another barrier would be, let’s say our agency took on the idea of promoting health more actively for all of our consumers, it would probably be a drain on our resources, as far as staff time, supervisor’s time, coming up with a program, implementing a program. And so I think it’s probably not billable and all these other issues. I think that’s a systematic barrier that would make it harder. Not only do our folks not come in with the skillset necessary to educate our consumers about better choices, we do not have the time or ingenuity to come up with a cookie cutter plan that says, “Here’s all topics to review and here’s how to approach each of these topics.” Agency administrator</td>
</tr>
</tbody>
</table>

**Strategies for Overcoming Barriers to Health Promotion**

Even though several barriers to health promotion for people with developmental disabilities who receive direct support services were noted, focus group participants also provided potential strategies for overcoming these barriers. One of the most cited strategies for encouraging direct support professionals to successfully promote the health of their clients with developmental disabilities was to place health promotion goals in clients’ ISPs. In addition to adding health goals to the clients’ ISPs, participants also recommended that the organizations that employ direct support professionals should offer
more health-focused educational training opportunities for direct support professionals and their clients. Even though the concept of role-modeling unhealthy behaviors was cited as a common barrier to health promotion, participants indicated that role-modeling healthy behaviors could have a positive impact on clients’ health as well. It was also recommended that direct support professionals should try to provide social support to their clients and use creative strategies to help their clients make healthy choices, while at the same time recognizing and respecting the rights of their clients (Table 9).

<table>
<thead>
<tr>
<th>Theme: Strategies for overcoming barriers to health promotion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme #1: Individualized Service Plan</strong></td>
</tr>
<tr>
<td><em>P</em>: I think what they [direct support professionals] do get, if anything as far as training, is what’s in the ISP for that individual. So, they’ll try to at least implement the ISP properly and everything. So if it’s in there, they’ll probably have some understanding of what is being requested to be done. But if it’s not in there, I don’t think that you’re going to be doing healthy stuff with people necessarily, for the most part. Family #1</td>
</tr>
<tr>
<td><em>P</em>: And so if it’s in the ISP and you’re working with good people, in my experience we’ve never actually had problems with independent providers doing everything they could to help. And they would always try to make sure that the food is right, the meds are administered at the right time, all the things that are important. But it was because all these things were in the ISP and because there was somebody to say, “This is what we need to do.” Family #1</td>
</tr>
</tbody>
</table>

| **Subtheme #2: Trainings** |
| *P*: We talked about training and people not getting enough training, and all of us seem to want outings for our kids [adults with developmental disabilities]. So, if you had a class that was geared towards our children, that the providers had to bring them to, you are going to kill two birds with one stone. So you’re going to be able to provide the education, maybe not to the same extent, but it would give an outing for our kids. It would give social interactions. Family#1 |
| *P*: Maybe have the county or state set up some type of culinary classes, where the provider and consumer can go and have classes together like healthy cooking and healthy eating. You eat healthier when you realize that it doesn’t taste as bad as you thought it would. DSP#1 |

Table 9. Strategies for overcoming barriers to health promotion (continued)
<table>
<thead>
<tr>
<th>Theme: Strategies for overcoming barriers to health promotion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtheme #3: Role-modeling</td>
</tr>
<tr>
<td><strong>Sub-sub theme #3a: indirect role-modeling</strong></td>
</tr>
<tr>
<td>P: Four years ago, I lost 150 pounds. And every one of my consumers lost weight too. Like when I got into it and started walking and eating better, they started. I kind of encouraged them too. So I think that we have a very big impact or we can. DSP#1</td>
</tr>
<tr>
<td>P: If you want your kid to be healthy, I think that it’s important to surround them by those kinds of people as well, because I think that does eventually rub off. My brother, he loves his providers and they all live healthy lifestyles. Family #2</td>
</tr>
<tr>
<td><strong>Sub-sub theme #3b: direct role-modeling</strong></td>
</tr>
<tr>
<td>P: Like when I lost weight, I think it can also be symbiotic. Like, “Let’s go out and go for a walk. It’s good for me and it’s good for you.” It’s not always just control over their life, it’s just leading my example. It’s like we are going to do this together. Let’s go out and walk and talk about what we can get into instead of just sitting here watching TV. DSP#1</td>
</tr>
<tr>
<td>P: But if she [the direct support professional] was there all day and Coke was something that she had to have, if it was a caffeine kick or whatever and she had to have it, I might ask her to put it in a cup or something where they weren’t seeing it. Don’t flaunt it in front of them or something. Family #1</td>
</tr>
<tr>
<td><strong>Subtheme #4: DSPs should be creative</strong></td>
</tr>
<tr>
<td><strong>Sub-sub theme #4a: Make small changes</strong></td>
</tr>
<tr>
<td>P: Cut a little sliver of cake. Here, start off with this and we’ll go from there. Nobody’s rights feels like they’re being violated. She’s still getting what she wants, which is the cake, but slice a little piece. Family #2</td>
</tr>
<tr>
<td>P: I think a big advantage now is that they make a lot of things low calorie. Like the Oreos or chocolate chips, you can get them in 100 calorie packs. I think that’s a huge advantage now than it was before. I think that if you like Oreos then I’m just going to go get the 100 calorie pack. If it’s something that they like, then I would just get the lower calorie ones. “I know you like Oreos, but they have these Oreos. Why don’t we try these ones? ” You’re still making them feel like they are in control. DSP#2</td>
</tr>
<tr>
<td><strong>Sub-sub theme #4b: Directly teach/show clients healthy foods</strong></td>
</tr>
<tr>
<td>P: Sometimes when I pack my lunch, I pack too much and I don’t pack the right kind of foods. That’s where I think the staff can help me too. Staff tell me how to pack my lunch. If I don’t pack the right kinds of foods, they say that I’m not eating the right kinds of foods and that they want me to eat more of the right kinds of foods. That’s part of eating healthy for me. Adult with developmental disability</td>
</tr>
<tr>
<td>P: There’s a person who likes junk food and as a provider it can be really hard to redirect them. The best way I find is to go to the store with him and point out things that maybe he hasn’t seen before and ask him to try it. Agency administrator</td>
</tr>
</tbody>
</table>
Discussion

This is the first study to explore the role of direct support professionals in the health promotion efforts of their adult clients with developmental disabilities from the perspectives of key members in the developmental disability community. Recently, the literature has called attention to the importance of direct support professionals in the lives of their clients with developmental disabilities, suggesting that direct support professionals serve as key members of the social networks of people with developmental disabilities (de Schipper & Schuengel, 2010; Hewitt & Larson, 2007; Dodevska & Vassos, 2013). Results from this study echo previous work in the area by suggesting that adults with developmental disabilities view their direct support professional providers as role-models (Humphries, Traci & Seekins, 2009; de Schipper & Schuengel, 2010). The findings from this study help to clarify the ways in which direct support professionals can be more involved in the health promotion efforts of their clients, while recognizing the barriers to promoting health among adults with developmental disabilities.

When asked to describe what “being healthy” means for people with disabilities, participants offered a variety of responses including eating right/exercise, being emotionally/mentally well and having control over their lives. These definitions of health offered by members of the developmental disability community illustrate that the community has different views about health, which can sometimes be in conflict with each other. For instance, having control over their lives was cited as a way in which people with developmental disabilities can be healthy, which may not always align with eating healthy/exercising should a person with a developmental disability choose not to eat right and exercise. Since both autonomy and healthy eating/exercise were noted as
ways in which people with developmental disabilities can be healthy, it is important for people with developmental disabilities to receive encouragement and support from members of their social networks to make healthy dietary and physical activity choices.

Participants also reported that direct support professionals should promote the health of their clients by ensuring their client’s safety, following their client’s ISP and providing their client with social interactions; however, participants reported mixed feelings about the role of direct support professionals in helping their clients make healthy choices, mainly due to concern over violating the rights of their clients. Several participants noted that direct support professionals might want to help their clients make healthy choices, but that the choice to make healthy decisions has to ultimately be left to the client. The concern over violating a client’s rights is a valid concern, as the disability field has emphasized the importance of protecting the rights and promoting self-determination for people with developmental disabilities over the past several decades (Bannerman, Sheldon, Sherman, & Harchik, 1990). However, it must be recognized that people with developmental disabilities may lack the cognitive ability to make fully informed health decisions as a result of their disability; therefore, efforts should be made by their support networks to encourage healthy behavioral practices (especially due to the high rates of chronic conditions within the population). Aside from the concern expressed over violating the rights of clients with developmental disabilities, other barriers to health promotion were noted such as direct support professionals’ motivation to promote the health of their clients, role-modeling unhealthy behaviors and using unhealthy rewards with their clients. In addition, more systemic barriers to health promotion were noted such as a general lack of training for direct support professionals on health-related topics.
and high turnover rates in the field of direct care. High turnover rates in the field of direct care have been thought to negatively impact the lives of clients with developmental disabilities by disrupting the continuity of care received (Hewitt & Larson, 2007; Gaventa, 2008; Hatton et al., 1999; Larson, Hewitt, & Lakin, 2004).

Focus group participants offered several creative strategies that direct support professionals could use to support and encourage healthy behavioral practices among their clients without violating any rights. Role-modeling healthy behaviors in front of their clients, including health promotion goals into the clients’ ISPs, showing interest towards health promoting behaviors, receiving training, and helping their client choose healthier food options were all suggested as strategies that direct support professionals could use to support the health of their clients.

Participants discussed the concept of role-modeling as both a potential barrier to health promotion, as well as a potential facilitator of health promotion depending on whether the behavior being role-modeled by the direct support professional was a healthy or an unhealthy behavior. The discussion of role-modeling in this study is consistent with previous literature that suggests that members of one’s social network can influence an individual’s health behaviors; however, previous studies have not yet emphasized the importance of role-modeling healthy dietary/physical activity behaviors to people with developmental disabilities (McAlister, Perry, & Parcel, 2008; Flay et al., 1994; Go et al., 2010; Hendy & Raudenbush, 2000).

Many participants in this study consistently stated that one of the best strategies for encouraging direct support professionals to become more involved in the health promotion efforts of their clients with developmental disabilities was to include a health
promotion category as a goal in the clients’ ISPs; this is consistent with recent research that suggests that food choices and healthy living goals should be explicitly stated in a client’s care plan (Cartwright, Reid, Hammersley, Blackburn, & Glover, 2015). The ISP is a tool used by service organizations that provides details about the client’s diagnosis and outlines the way in which support services can be used to help the client participate in life activities (Reinders & Schalock, 2014; Thompson et al., 2009). A client’s ISP is typically developed by members of the client’s support team (e.g., client, family members, case manager, and other health professionals) and is specific to the individual client with a developmental disability who is receiving support services; the ISP is typically viewed as a legally binding contract between the service organization and the client (Reinders & Schalock, 2014). Viewing the ISP as a legal contract, participants in this study indicated that if health promotion goals were included in the ISP, then direct support professionals would have no other choice but to follow the ISP because following the ISP is part of a direct support professional’s job responsibilities.

In addition to including a health promotion goal in the client’s ISP, participants noted that more health educational training opportunities are needed for the direct support workforce. Research has suggested that trainings for direct support professionals often focus on safety and handling aggressive client behaviors (Cox, Dube, & Temple, 2014). As a strategy for health promotion in the current study, participants recommended that both clients and direct support professionals should attend health-related educational trainings together; previous research has shown that trainings for direct support professionals are the most effective when the client is included (Van Oorsouw et al., 2009; Bogenschutz, Nord, & Hewitt, 2015).
Limitations

The primary limitation of this study is that the sample size for the focus groups was small with n=48 total participants. Only one focus group was held with people with developmental disabilities and only one was held with agency administrators; therefore, researchers could not know if a saturation of themes occurred in these groups. Another potential limitation of this study, was that the average age of the adults with developmental disabilities was close to 70 years, therefore, younger adults with developmental disabilities were not represented in this study. As with all qualitative work, the findings are not fully generalizable to the entire population of people with developmental disabilities, but rather only to those who took part in the research (Salazar, Crosby, & DiClemente, 2006).

Conclusions and Future Directions

The findings from this study suggest that direct support professionals have a role in the health promotion efforts of their clients with developmental disabilities, as well as have the potential to influence their clients’ health behaviors both positively and negatively through role-modeling. Future research should explore the relationship between the health behaviors of direct support professionals and their clients with developmental disabilities to better understand how role-modeling impacts client health behaviors. In addition, a future study should be conducted to examine the difference in health behaviors of clients with health promotion goals added to ISP plans vs. those with standard ISP plans. Should the addition of health promotion goals prove to be effective, targeted research will be needed with people with developmental disabilities, their guardians and care team members to better understand the best action steps to take in
order to get health promotion goals included as standard policy in clients’ ISPs. Organizations that employ direct support professionals should consider implementing relevant trainings for their direct care staff on the topic of health promotion for their clients with developmental disabilities; these trainings should not only provide education about the importance of health promotion for clients with developmental disabilities, but also provide strategies for overcoming the barriers (e.g., client’s preferences, limited incomes, etc.) to promoting the health of their clients. Overall, the findings from this study outline some core action steps that the organizations that employ direct support professionals and care team coordinators should consider in order to promote the health of their clients with developmental disabilities.
Chapter 4: Smoking Behaviors of Adults with Developmental Disabilities and their Direct Support Professional Providers

(Manuscript #2)

Introduction

In recent years, the field of developmental disabilities has started to examine the health status of this vulnerable population and findings suggest that people with developmental disabilities experience disparities in their health when compared to members of the general population (Reichard & Stolzle, 2011; Morin et al., 2012; Fisher, 2004; Krahn, Hammond, & Turner, 2006). Studies have shown that adults with developmental disabilities experience higher rates of heart disease and diabetes than members of the general population, and are more likely to develop heart disease at earlier ages (Draheim, 2006; Sohler, et al., 2009; Morin et al., 2013). Adults with mild developmental disabilities and those who live in more independent settings are more likely to suffer from heart disease than those with more severe disabilities and those who live in more supervised settings (Strauss & Kastner, 1996; Janicki & Jacobson, 1986). Research has suggested that medical providers often have a general lack of confidence when treating people with developmental disabilities and often treat the symptoms of a person’s disability while overlooking other basic health care needs and medical conditions (Ouellette-Kuntz et al., 2005; Wilkinson et al., 2012).
The use of cigarettes is responsible for approximately 480,000 deaths each year and secondhand smoke exposure increases one’s risk of heart disease by up to 30% (CDC, 2015a). In the United States, approximately 17% of the population smokes cigarettes; men smoke at higher rates (18.8%) than women (14.8%), and people who have less education (43% of people with a GED smoke) and those who live below the federal poverty line (26.3%) smoke at higher rates (CDC, 2015b). In the past, it was thought that adults with developmental disabilities smoked at similar rates as members of the general population (Havercamp et al., 2004); however, in a recent study, Havercamp and Scott (2015) examined the smoking rates of adults with developmental disabilities in a national sample and found that only 7% of the sample of adults with developmental disabilities were current smokers. Just as in the general population, men with developmental disabilities smoke at higher rates than women with developmental disabilities (Rimmer, Broaddock, & Marks, 1995; Roberston et al., 2000; Rimmer, Braddock, & Fujiura, 1994). Adults with mild developmental disabilities and those who live in more independent settings smoke at higher rates than those with more severe disabilities and those who live in more supervised settings (e.g., Lewis et al., 2002; Hymowitz et al., 1997; Steinberg et al., 2009). Steinberg and colleagues (2009) reviewed the literature on the topic of smoking among adults with developmental disabilities and noted that adults with developmental disabilities who smoke may spend a large portion of their government subsided incomes to purchase cigarettes and that they experience the same addictive effects of cigarette smoking as anyone else.

Very little is known about the reasons why people with developmental disabilities initially start smoking; however, based on previous literature it can be inferred that
people with developmental disabilities may be influenced by members of their social networks. Peer smoking status has been consistently reported in the literature as being a key predictor of one’s smoking behavior (Flay et al., 1994; Powell, Tauras, & Ross, 2005). Peer smoking influence is stronger than family influence when it comes to smoking initiation and quit attempts (Flay et al., 1994; Go et al., 2010). In the past, cigarettes were given to people with developmental disabilities as rewards, which likely contributed to the maintenance of smoking behavior among members of this population (Minihan, 1999; Tyler & Bourguet, 1997).

Direct support professionals, are paid workers who provide care to people with developmental disabilities and often make up a large part of their social networks. Even though one of the primary responsibilities of direct support professionals is to assist their clients with developmental disabilities with activities of daily living (e.g., grooming, grocery shopping, cleaning, cooking, etc.), many adults with developmental disabilities form strong emotional attachments to their direct support professionals and view them as role-models and friends (de Schipper & Schuengel, 2010; Hewitt & Larson, 2007). Because of the large social role that direct support professionals play in the lives of adults with developmental disabilities, research should explore their potential influence over the smoking behaviors of their clients with developmental disabilities.

The concept of social influence is the foundation of Social Cognitive Theory, which posits that one way that behavior can be influenced is through members of one’s social network through constructs such as role-modeling (e.g., observing others perform certain health behaviors), incentive motivation (e.g., using rewards/punishments to
modify behavior), and facilitation (e.g., providing tools or resources that make behaviors easier to perform) (Bandura, 1998; McAlister, Perry, & Parcel, 2008).

Because direct support professionals play such a large social role in the lives of their adult clients with developmental disabilities, the overall purpose of this study was to better understand how direct support professionals, as key members of the social networks of their clients with developmental disabilities, influence the smoking behaviors of their clients. It was hypothesized, based on what is known about the impact of role-modeling on smoking behavior, that there would be an association between the smoking status of direct support professionals and their clients with developmental disabilities. This study also sought to examine the ways in which direct support professionals help to facilitate the smoking behaviors of their clients with developmental disabilities.

**Methods**

**Participants**

The sampling frame consisted of direct support professionals (n=5,283) who were listed as homemaker personal care aides in the Ohio Department of Developmental Disabilities online provider search database. To be eligible for the survey, direct support professionals had to have 1) been 18 years or older; 2) worked with at least one adult client with a developmental disability in the State of Ohio; 3) worked at least 10 hours a week with the client identified in #2; 4) worked as a direct support professional for the client in #2 for at least three months; 5) not been the parent of the client identified in #2; 6) have received payment from either the Ohio Individual Options waiver or the Level One waiver (both waivers allow people with developmental disabilities to receive home-
based care services from direct support professionals); and 7) have worked as an independent provider of services.

**Procedures**

Participants were recruited via e-mail between March 2015 and July 2015 to complete an online survey on SurveyMonkey.com. Survey invitations were sent in three batches during this timeframe and sampled participants received up to three reminder e-mails. Those who started the survey, but who did not finish, received up to three reminder phone calls. A total of 4,682 survey invitations (88.6% of the sampling frame) were sent and interested participants completed a brief screener to determine eligibility for full participation in the study. Surveys took approximately 25 minutes to complete and participants were given a $20 electronic gift card to an online mass merchant of their choice as a thank you for their time. Participants were asked if they were willing to be contacted in the future; of those who answered yes, 17% were contacted two-weeks later and asked to complete the survey a second time to establish test-retest reliability of survey items. To assess the test-retest reliability, Pearson correlations were calculated for continuous variables and Spearman correlations were calculated for categorical variables. Test-retest reliability was considered acceptable if $r$ or $\rho$ was greater than 0.70; however, if test-retest reliability was less than 0.70 then a Kappa coefficient was calculated (only items with fair agreement or higher, $\kappa = 0.20+$ according to Landis and Koch, 1977 were kept in the analysis). The Ohio State University Institutional Review Board approved this study.
Measures

Prior to implementation of the full survey, the survey was pre-tested and cognitive interviews were conducted with five direct support professionals; changes to the survey were made based on these pretests/cognitive interviews.

*Demographic characteristics.* Age (in years), race (white/African American/other) and gender (male/female) were collected for both direct support professionals and their clients with developmental disabilities. Direct support professionals were asked to answer survey questions about an adult client with a developmental disability; if they provided care to more than one adult client, they were asked to report on the client that they provided the most hours of care to each week. For direct support professionals, educational status (high school/some college/college+) and marital status (married/never married/unmarried couple/divorced/separated/widowed) were also collected. For clients with developmental disabilities, direct support professionals reported on the type of developmental disability the client had (autism, cerebral palsy, Down syndrome, intellectual disability, two or more, or other).

*Smoking behaviors.* Direct support professionals were asked to report on their own smoking behaviors and the smoking behaviors of their clients with developmental disabilities. Participants were asked, “Have you/has your client smoked 100 cigarettes in your/your client’s lifetime?” and “Do you/does your client currently smoke cigarettes every day, some days or not at all?” Participants were classified as “never smokers” if they had never smoked 100 cigarettes, while participants were classified as “current smokers” if they currently reported smoking cigarettes and former smokers were reported as having smoked 100 cigarettes in their lifetime but currently not smoking cigarettes.
Participants were also asked, “During the past 30 days, on how many days did you/your client smoke cigarettes?” and “During the past 30 days, on the days that you/your client smoked, how many cigarettes did you/your client smoke per day?” Test-retest reliability for current smoking status was high (clients with developmental disabilities $\rho = 1$; direct support professionals, $\rho = 0.825$). Test-retest reliability was also high for the number of daily cigarettes smoked by clients with developmental disabilities ($r = 1$) and direct support professionals ($r = 0.897$).

**Role-modeling.** Direct support professionals were asked the following questions about role-modeling cigarette smoking behaviors to their clients: 1) Thinking about the past month, how often did you smoke cigarettes during your work shift? Response options were dichotomized into “more frequently” (several times a week, most days, or everyday) and “less frequently” (never, seldom, or several times a month); 2) During your work shift, where do you usually smoke cigarettes? Response options were: inside the client’s house, outside of the client’s house, I do not smoke while at work, or other; and 3) Does anyone living in in your client’s home smoke cigarettes? (Yes/No). Test-retest reliability was acceptable and ranged from $\rho = 0.796-1.0$ for these measures.

**Facilitation.** Direct support professionals were asked the following questions about facilitating the smoking behaviors of their clients: 1) How often do you purchase or give cigarettes to your client?; 2) How often do you take your client someplace to smoke?; 3) How often do you wait for your client to finish smoking before doing an activity?; and 4) How often do you allow your client to smoke cigarettes around you? Response options for all facilitation questions were dichotomized into “more frequently” (several times a week, most days, or everyday) and “less frequently” (never, seldom, or
several times a month). Test-retest reliability was low (<0.70) and ranged from $\rho = 0.316$-
0.410 for these measures; however, Kappa was fair to moderate ($\kappa = 0.244$-$0.409$).

**Policy.** Direct support professionals were asked the following questions about
smoking policies: 1) Does your client or his/her guardian have any household rules or
policies about smoking? (Yes/No); and 2) What are the rules or policies about smoking in
your clients’ house? Response options included: no one can smoke inside the house, no
one can smoke outside the house, you may not smoke at all during your shift, client can
smoke inside the house, client can smoke outside of the house, or other. Test-retest
reliability was low ($\rho < 0.70$) at $\rho = 0.449$ for having a home smoking policy or not;
however, Kappa was fair ($\kappa = 0.361$).

**Perceptions of role in health promotion.** Participants were asked: 1) How much of
a role do you think you have in promoting the health of your client with a developmental
disability? Response options were not much of a role, somewhat of a role, or a large role;
and 2) How easy or difficult would it be for you to help your client quit smoking (if
he/she smokes)? Response options included: very difficult, somewhat difficult, neither
difficult or easy, somewhat easy, or very easy. Test-retest reliability was low (<0.70) and
values ranged from $\rho = 0.352$-$0.469$ for these measures; however, Kappa was fair-to-
moderate ($\kappa = 0.312$-$0.490$).

**Data analysis**

Data were exported from SurveyMonkey.com into SPSS Version 22.0 software,
which was used to analyze all survey data. Descriptive statistics were calculated to
characterize the smoking behaviors of direct support professionals and their clients with
developmental disabilities, as well as to explore possible facilitators of client smoking
behavior. Chi-square tests of association were used to test the association between current smoking status of direct support professionals and their clients with developmental disabilities. Independent sample t-tests were used to examine the difference in mean number of daily cigarettes smoked by people with developmental disabilities and their direct support professionals’ facilitation of smoking behaviors.

Results

Surveys were completed by 398 direct support professionals, giving a response rate of 9.7% (398/4104). Of the 4,682 invitations sent, 168 were undeliverable and 410 did not meet eligibility criteria and were removed from the denominator.

Sample characteristics

Table 10 provides detailed demographic characteristics of study participants and their clients with developmental disabilities. Direct support professionals were predominately white (73%) and female (87%). The age of direct support professionals ranged from 19 to 76, with a mean age of 43±12.7. The majority (80%) of direct support professionals had some form of academic training above high school and 50% reported being married. Eighty-two percent of direct support professionals reported being unrelated to their client, while 18% were siblings or other non-parental family members.
<table>
<thead>
<tr>
<th></th>
<th>DSPs (n=398)</th>
<th>Clients with DD (n=398)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, M (SD)</td>
<td>43.0 (13)</td>
<td>36.4 (14)</td>
</tr>
<tr>
<td>18-24</td>
<td>30 (7.5%)</td>
<td>109 (27.4%)</td>
</tr>
<tr>
<td>25-44</td>
<td>185 (46.5%)</td>
<td>171 (43.0%)</td>
</tr>
<tr>
<td>45-64</td>
<td>169 (42.5%)</td>
<td>102 (25.6%)</td>
</tr>
<tr>
<td>65+</td>
<td>14 (3.5%)</td>
<td>16 (4.0%)</td>
</tr>
<tr>
<td>Female</td>
<td>346 (86.9%)</td>
<td>196 (50.5%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>292 (73.4%)</td>
<td>324 (81.4%)</td>
</tr>
<tr>
<td>African American</td>
<td>83 (20.9%)</td>
<td>55 (13.8%)</td>
</tr>
<tr>
<td>Other</td>
<td>23 (5.8%)</td>
<td>19 (4.8%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School/GED</td>
<td>78 (19.6%)</td>
<td></td>
</tr>
<tr>
<td>Some college/Associates</td>
<td>184 (46.2%)</td>
<td></td>
</tr>
<tr>
<td>College+</td>
<td>135 (33.9%)</td>
<td></td>
</tr>
<tr>
<td>Martial Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>199 (50.0%)</td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>85 (21.4%)</td>
<td></td>
</tr>
<tr>
<td>Unmarried Couple</td>
<td>31 (7.8%)</td>
<td></td>
</tr>
<tr>
<td>Divorced/Separated/Widowed</td>
<td>79 (19.8%)</td>
<td></td>
</tr>
<tr>
<td>Refused</td>
<td>4 (1.0%)</td>
<td></td>
</tr>
<tr>
<td>Relationship to client</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unrelated</td>
<td>328 (82.4%)</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>39 (9.7%)</td>
<td></td>
</tr>
<tr>
<td>Other (e.g., aunt/uncle, niece)</td>
<td>31 (7.8%)</td>
<td></td>
</tr>
<tr>
<td>Hours working with client per week, M (SD)</td>
<td>31.4 (32)</td>
<td></td>
</tr>
<tr>
<td>10-19</td>
<td>177 (44.5%)</td>
<td></td>
</tr>
<tr>
<td>20-39</td>
<td>127 (31.9%)</td>
<td></td>
</tr>
<tr>
<td>40+</td>
<td>94 (23.6%)</td>
<td></td>
</tr>
<tr>
<td>Years working with client, M (SD)</td>
<td>5.3 (5)</td>
<td></td>
</tr>
<tr>
<td>.25-1</td>
<td>69 (17.3%)</td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>172 (43.2%)</td>
<td></td>
</tr>
<tr>
<td>5+</td>
<td>157 (39.4%)</td>
<td></td>
</tr>
<tr>
<td>Disability Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism only</td>
<td>41 (10.7%)</td>
<td></td>
</tr>
<tr>
<td>Cerebral Palsy only</td>
<td>44 (11.5%)</td>
<td></td>
</tr>
<tr>
<td>Down Syndrome only</td>
<td>36 (9.4%)</td>
<td></td>
</tr>
<tr>
<td>Intellectual Disability only</td>
<td>79 (20.7%)</td>
<td></td>
</tr>
<tr>
<td>2 + disabilities</td>
<td>134 (35.1%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>48 (12.7%)</td>
<td></td>
</tr>
<tr>
<td>Client Living Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives alone</td>
<td>90 (22.6%)</td>
<td></td>
</tr>
<tr>
<td>Lives with family</td>
<td>239 (60.1%)</td>
<td></td>
</tr>
<tr>
<td>Lives in home with 1+ roommates</td>
<td>35 (8.8%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>34 (8.5%)</td>
<td></td>
</tr>
</tbody>
</table>

Table 10. Demographic characteristics of direct support professionals (DSPs) and clients with DD (developmental disabilities)
Just over half (51%) of clients with developmental disabilities in this sample were female. The majority of clients with developmental disabilities in this sample were white (81%), and the majority (60%) lived with family members. The age of clients with developmental disabilities ranged from 18 to 86, with a mean age of 36±14.5. Thirty-five percent of clients with developmental disabilities were reported as having more than two developmental disabilities.

**Smoking behaviors**

The majority of direct support professionals (86.9%, n=345) and clients (93.8%, n=362) with developmental disabilities reported being never smokers or former smokers, while 13.1% (n=52) of direct support professionals and 6.2% (n=24) of clients reported being current smokers. Among current smokers, those with developmental disabilities smoked an average of 10.9±10.2 cigarettes per day, while direct support professionals reported smoking 9.7±7.2 cigarettes per day. There was no significant difference (t=-1.8, p=0.076) between the ages of current smokers (41.3±11.3) and non-smokers (35.8±14.5) with developmental disabilities. However, current smokers with developmental disabilities were significantly more likely to live alone than non-smokers ($\chi^2=20.0, p=0.00$), with 58% (n=14) of current smokers living alone. Among current smokers with developmental disabilities, significantly more (t=6.78, $p=0.00$) were males (67%, n=16) than females (33%, n=8).

There was no association between the current smoking status of direct support professionals and the current smoking status of their clients with developmental disabilities ($\chi^2=0.300, p=0.584$). Among direct support professionals who reported being current smokers, the majority (54%, n=28) reported smoking outside of their client’s
house during their shift, while less than half (44%, n=23) reported not smoking at all during their shift and only one reported smoking inside the client’s home. There was no significant association between direct support professionals smoking during their work shift and their client’s current smoking status ($\chi^2=3.56, p=0.059$).

Close to half (46%, n=182) of clients with developmental disabilities were reported to have some type of home smoking policy, while 35% (n=140) did not have a policy and 19% (n=72) of direct support professionals were unaware if their client had a home smoking policy or not. The majority of those with home smoking policies (60%, n=110) lived with family members compared to 40% (n=72) who lived alone, with roommates or in other residential settings. Among those with home smoking policies, not being allowed to smoke inside the client’s house (88%, n=160) was the most commonly cited policy, while 20% (n=37) of clients had a smoking policy stating that no one could smoke outside of the client’s home as well. The majority (82%, n=327) of clients with developmental disabilities were reported to live in a non-smoking home.

Direct support professionals were most likely to facilitate the smoking behaviors of their clients with developmental disabilities by allowing their clients to smoke in front of them and waiting for their clients to finish smoking before moving on to another activity; however, facilitation of smoking behavior was not associated with the daily number of cigarettes smoked by the client (Table 11). Of the 24 clients with developmental disabilities in the sample who were reported as current smokers, only four of their direct support professionals were reported as current smokers. The majority of direct support professionals reported that it would be difficult to help their clients with developmental disabilities quit smoking, while most perceived themselves as having a
role in the health promotion efforts of their clients with developmental disabilities (Table 12).

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
<th>Mean Daily Cigarettes Smoked by Clients</th>
<th>t*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purchases cigarettes for client (n=24)</td>
<td></td>
<td></td>
<td></td>
<td>-0.186</td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
<td>16.7</td>
<td>12.6</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>66.7</td>
<td>11.4</td>
<td></td>
</tr>
<tr>
<td>Don’t know/Refused</td>
<td>4</td>
<td>16.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allows client to smoke in front of DSP (n=24)</td>
<td></td>
<td></td>
<td></td>
<td>0.839</td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>41.7</td>
<td>6.7</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>25</td>
<td>11.0</td>
<td></td>
</tr>
<tr>
<td>Don’t know/Refused</td>
<td>8</td>
<td>33.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waits for client to finish smoking (n=24)</td>
<td></td>
<td></td>
<td></td>
<td>0.449</td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>41.7</td>
<td>11.6</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>20.8</td>
<td>8.8</td>
<td></td>
</tr>
<tr>
<td>Don’t know/Refused</td>
<td>9</td>
<td>37.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Takes client someplace to smoke (n=24)</td>
<td></td>
<td></td>
<td></td>
<td>-0.569</td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>29.2</td>
<td>13.3</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>50.0</td>
<td>10.3</td>
<td></td>
</tr>
<tr>
<td>Don’t know/Refused</td>
<td>5</td>
<td>20.8</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 11. Facilitation of client smoking behaviors by direct support professionals among clients who were reported to be current smokers (n=24)

* all p-values were greater than 0.05
### Table 12. Direct support professionals’ perceptions about health promotion for clients

<table>
<thead>
<tr>
<th>Perceived difficulty of helping client quit smoking (n=24)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very difficult</td>
<td>13</td>
<td>54.2</td>
</tr>
<tr>
<td>Somewhat difficult</td>
<td>6</td>
<td>25.0</td>
</tr>
<tr>
<td>Neither difficult nor easy</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Somewhat easy</td>
<td>3</td>
<td>12.5</td>
</tr>
<tr>
<td>Very easy</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Don’t know/Refused</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Perceived role in health promotion (n=398)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not much of a role</td>
<td>26</td>
<td>6.5</td>
</tr>
<tr>
<td>Somewhat of a role</td>
<td>140</td>
<td>35.2</td>
</tr>
<tr>
<td>A large role</td>
<td>223</td>
<td>56.0</td>
</tr>
<tr>
<td>Don’t know/Refused</td>
<td>9</td>
<td>2.2</td>
</tr>
</tbody>
</table>

Discussion

This is the first study to characterize the smoking behaviors of direct support professionals and examine the association between direct support professionals’ current smoking status and the current smoking status of their clients with developmental disabilities. In this sample, the prevalence of current smoking among direct support professionals (13%) was less than that of the general population (17%); while the sample smoking prevalence among clients with developmental disabilities (6%) was similar to the national smoking prevalence (7%) for people with developmental disabilities (CDC, 2015b; Havercamp & Scott, 2015). The demographics of current smokers with developmental disabilities in this study mirrors the previous literature on the smoking characteristics of people with developmental disabilities where men smoke at higher rates than women with developmental disabilities and those who live alone smoke at higher rates than those who live with family members (Robertson et al., 2000; Steinberg et al., 2009).
A large percentage (46%) of clients with developmental disabilities were reported to have a home smoking policy; of those who had a home smoking policy, the large majority (60%) lived with family members which suggests that families may play a large role in developing smoking policies. However, nearly 20% of direct support professionals were unaware of whether or not their clients had a home smoking policy, which suggests that in a fifth of all cases, there is a lack of communication among parents/guardians, clients and direct support professionals about the expectations related to smoking in a client’s home. Even if a direct support professional is a non-smoker, it is important for him or her to know the rules and expectations regarding smoking in their clients’ homes so that the smoking policy can be enforced with visitors to the home. This study also found that over half of direct support professionals who were reported as being current smokers, smoked outside of the client’s house during their shifts; this suggests that the client is either not being supervised when the direct support professional is taking a smoke break or that the direct support professional is smoking in front of the client outside of the house.

In this study, no association was found between the direct support professionals’ use of direct role-modeling (smoking in front of client) and indirect role-modeling (being a current smoker) and the current smoking status of the client. The lack of association between role-modeling and client smoking behavior was somewhat surprising given that in a recent study, focus group participants indicated that clients with developmental disabilities would likely be willing to try smoking cigarettes if their direct support professional providers smoked (Leser, unpublished), as well as it has been consistently suggested in the literature that peers influence smoking initiation (and many adults with
developmental disabilities view their direct support professionals as peers) (Flay et al., 1994; Powell, Tauras, & Ross, 2005; de Schipper & Schuengel, 2010). However, previous research on peer influence has typically focused on peer influence in relationship to smoking initiation during the developmental stage of adolescence and young adulthood (e.g., Freedman, Nelson, & Feldman, 2012; Flay et al., 1994); the current study only focused on the current smoking status of adults with developmental disabilities and did not examine when they initiated smoking. The current study confirms previous work on the topic of smoking among those with developmental disabilities, by suggesting that clients who live alone are more likely to smoke than those who live with family members or roommates, which strongly suggests that the severity of one’s disability (because those who live alone are thought to have less severe disabilities) impacts their risk of being a current smoker.

In general, among clients who were reported as current smokers, less than half of direct support professionals reported facilitating the smoking behaviors of their clients (e.g., waiting for client to finish smoking, taking the client someplace to smoke, etc.). However, in this study, only a small percentage of clients with developmental disabilities were reported as current smokers and several direct support professionals refused to answer questions about the ways they facilitate the smoking behaviors of their clients. Due to the refusal to answer certain facilitation questions, it makes it difficult to interpret the findings related to how direct support professionals influence the smoking behaviors of their clients with developmental disabilities.
Limitations

Even though this is one of the first studies to use random sampling to study direct support professionals, the response rate was low at 9.7%; however, response rates for online surveys are generally low (Nulty, 2008). Several participants (n=139) completed the eligibility screener and qualified for the survey but did not successfully complete the survey, with the majority stopping after the consent form; several attempts were made to contact these participants but to no avail. The sampling frame used for this study contained the names of direct support professionals who provided care to both adults and children with developmental disabilities; therefore, it is very possible that those who cared for children did not attempt to complete the survey and remained in the denominator when calculating the response rate for the study. Future work in this area should consider methods such as respondent driven sampling to recruit direct support professionals; this method allows researchers to collect data from hard-to-reach populations by using a method similar to snowball sampling while being able to track the number of people who are invited to participate in the survey (Heckathorn, 1997).

Another potential limitation of the study is that participants may have underreported their current smoking status due to social desirability. Non-response bias is also a limitation of this study; several direct support professional participants refused to answer survey items about the current smoking status of their clients and how they facilitate the smoking behaviors of their clients. Perhaps one of the reasons for item non-response on the smoking facilitation survey items was that participants might have been fearful of how any potential disclosure of study data to their employers could impact their employment status (Tourangeau & Yan, 2007). The smoking facilitation items may have also been
perceived as especially sensitive due to concern over violating the rights of their clients with developmental disabilities, which may have also led participants to misreport how frequently they facilitate the smoking behaviors of their clients (Tourangeau & Yan, 2007). While many survey items had acceptable test-retest reliability, several surveys items had less than ideal test-retest reliability, which is a notable limitation of the study. However, for items with questionable reliability, only those with greater than “fair” Kappa values ($\kappa=0.20+$), according to Landis and Koch (1977) were included in this manuscript. For instance, survey items were asked about how direct support professionals use cigarettes as incentive motivation with their clients; however, for these items test-retest reliability was under $\rho=0.70$ and Kappa was less than 0.20 (therefore these items were not included in the analysis). Possible explanations for low test-retest reliability scores on some survey items include participants reacting to the first set of survey items by changing their smoking behaviors or by purposefully changing their responses to survey items the second time they completed the survey (Bless & Higson-Smith, 2000).

This study only focused on independent direct support professional providers who provided home-based care services to adults with developmental disabilities and did not examine the smoking status of direct support professionals who work for agencies; therefore, the results are only generalizable to independent direct support professionals.

**Conclusions and Future Directions**

Even with its noted limitations, the findings from this study add to the literature by providing insight about the smoking behaviors of direct support professionals and their adult clients with developmental disabilities. In addition, this is the first study to explore the use of home smoking policies in homes of clients with developmental
disabilities. Disability service organizations should encourage their clients and their client’s families/guardians to communicate with direct support professionals about the smoking policies within the client’s living environment. Even though no significant relationship was detected between the smoking status of direct support professionals and their clients, future research is needed to better understand the reasons why people with developmental disabilities initially start smoking and continue to smoke. Future research on the topic of smoking and adults with developmental disabilities should not only address direct support professionals, but also other key members of the social networks of adults with developmental disabilities such as family members, roommates, and day-habilitation providers. Even though the reported sample smoking prevalence among direct support professionals and clients with developmental disabilities was not as high as in the general population, smoking is still a public health concern that must be addressed in these populations due to its detrimental health effects. Direct support professionals should be included in any tobacco prevention/cessation programs targeted towards adults with developmental disabilities, especially since such a large portion of direct support professionals view themselves as having a role in the health promotion efforts of their clients.
Chapter 5: Dietary and Physical Activity Behaviors of Adults with Developmental Disabilities and their Direct Support Professional Providers

(Manuscript #3)

Introduction

Obesity is one of the biggest public health problems facing the United States, as 34.9% of the general population is considered obese and are thus at risk for heart disease and diabetes, as well as other conditions such as high blood pressure, stroke, and cancer (CDC, 2015c, CDC, 2015d). Studies have shown that adults with developmental disabilities experience similar or slightly higher obesity rates than members of the general population (Yamaki, 2005; Stancliffe et al., 2011; Havercamp & Scott, 2015). Women with developmental disabilities experience higher rates of obesity than males with developmental disabilities; and some studies have shown that women with developmental disabilities have higher rates of obesity than women in the general population (Stancliffe et al., 2011; Melville et al., 2007; Bhaumik et al., 2008). People with mild developmental disabilities and those who live in more independent settings experience higher rates of obesity than those with more severe disabilities and those who live in more supervised settings (Melville et al., 2007; Stancliffe et al., 2011). People with certain types of developmental disabilities may experience obesity at higher rates as a result of their disability (e.g., Down syndrome and Prader-Willi), while some people with developmental disabilities may be more likely to be obese as a result of taking
psychotropic medications which are known to cause weight gain (Stancliffe et al., 2011; Humphries, Traci, & Seekins, 2009).

Even though genetics and use of psychotropic medications can impact the obesity rates of those with developmental disabilities, people with developmental disabilities also experience obesity for the same reasons as members of the general population—poor diet and physical inactivity. Overeating and leading a sedentary lifestyle are two behavioral factors that contribute to the soaring rates of obesity in this country (CDC, 2015e). National recommendations for reducing obesity include participating in 30-minutes of moderate-to-vigorous physical activity at least five times a week and eating a balanced diet that is low in fat, and high in fruits and vegetables (CDC, 2012e). The dietary and physical activity behaviors of adults with developmental disabilities have not yet been assessed on a population-level; however, in smaller studies researchers have consistently noted that the majority of adults with developmental disabilities do not meet the national recommendations for physical activity and dietary intake (Drahiem et al., 2002; Peterson, Janz & Lowe, 2008; Hilgenkamp, et al., 2012; Humphries et al., 2009; Robertson et al., 2000; Temple et al., 2006).

Very little is known about the reasons why adults with developmental disabilities are not meeting national recommendations for healthy diet and physical activity. However, people with developmental disabilities often rely on other people, such as their direct support professional providers, to assist them with making decisions related to their health behaviors. Direct support professionals are workers who provide paid care services to people with developmental disabilities. The primary role of direct support professionals is to help people with developmental disabilities live independent, self-
directed lives, while assisting them with activities of daily living such as cooking, cleaning, grocery shopping, transportation, grooming and finances (Hewitt & Larson, 2007; Brown & Percy, 2007; Gaventa, 2008). Direct support professionals make up a large part of the social networks for people with developmental disabilities, and many people with developmental disabilities view their direct support professional providers as role-models and as friends (de Schipper & Schuengel, 2010; Hewitt & Larson, 2007).

In general, direct support professionals are paid low wages, with some direct support professionals making just over minimum wage (Hewitt & Larson, 2007; Mutkins, Brown, & Thorsteinnson, 2011; Grey-Stanley, et al., 2010; Test et al., 2003). The direct support workforce experiences high rates of turnover, as many direct support professionals experience high rates of stress, depression and burnout (Hewitt & Larson, 2007; Frank et al., 2000; Gray-Stanley et al., 2010; Test et al., 2003). Some reasons for high levels of work-related stress include aggressive client behaviors, staffing issues, and a general lack of autonomy over their jobs (Mutkins et al., 2011; Mills & Rose, 2011; Gray-Stanley & Muramatsu, 2011). Studies have not yet examined the specific health behaviors of the direct support professional workforce; however, the literature has suggested that people who experience high levels of stress are more likely to participate in negative health behaviors such as physical inactivity and eating a poor diet (Heany & Israel, 2008; Glanz & Schwartz, 2008). While little is known about non-family caregivers, studies have shown that family caregivers are more likely to be sedentary, to drink soda pop and eat fast food, as well as eat less fruits and vegetables than non-caregivers (Hoffman et al., 2012; Reeves et al., 2002; Mochari-Greenberger & Moska, 2012; Burton et al., 1997; Castro et al., 2007).
The concept of social influence is a large part of Social Cognitive Theory which posits that one way that behavior can be influenced is through members of one’s social network through constructs such as role-modeling (e.g., observing others perform certain health behaviors), incentive motivation (e.g., using rewards/punishments to modify behavior), and facilitation (e.g., providing tools or resources that make behaviors easier to perform) (Bandura, 1998; McAlister, Perry, & Parcel, 2008). Research has shown how people, especially peers, influence the health behaviors (e.g., physical activity, dietary, smoking, etc.) of members of their social networks; however, the potential influence that direct support professionals have over the health behaviors of their clients with developmental disabilities has yet to be explored (Hendy & Raudenbush, 2000; Sallis et al., 1988; Spurrier et al., 2008; Maitland et al., 2013).

Because direct support professionals play such a large social role in the lives of their adult clients with developmental disabilities, the overall purpose of this study was to examine the relationship between the dietary and physical activity behaviors of direct support professionals and their clients with developmental disabilities. It was hypothesized, based on what is known about role-modeling health behaviors, that there would be a positive relationship between the dietary and physical activity behaviors of direct support professionals and their clients with developmental disabilities. An additional exploratory aim of this study was to examine how health promotion strategies (e.g., role-modeling, incentive motivation) used by direct support professionals are related to their client’s dietary and physical activity behaviors.
Methods

Participants

The sampling frame consisted of direct support professionals (n=5,283) who were listed as homemaker personal care aides in the Ohio Department of Developmental Disabilities online provider search database. To be eligible for the survey, direct support professionals had to have: 1) been 18 years or older; 2) worked with at least one adult client with a developmental disability in the State of Ohio; 3) worked at least 10 hours a week with the client identified in #2; 4) worked as a direct support professional for the client in #2 for at least three months; 5) not been the parent of the client identified in #2; 6) received payment from either the Ohio Individual Options waiver or the Level One waiver (both waivers allow people with developmental disabilities to receive home-based care services from direct support professionals); and 7) worked as an independent provider of services.

Procedures

This study was approved by The Ohio State University Institutional Review Board. Participants were recruited via e-mail between March 2015 and July 2015 to complete an online survey on SurveyMonkey.com. Survey invitations were sent in three batches during this timeframe and sampled participants received up to three reminder e-mails. Those who started the survey, but who did not finish, received up to three reminder phone calls. A total of 4,682 survey invitations (88.6% of the sampling frame) were sent and interested participants completed a brief screener to determine eligibility for full participation in the study. Surveys took approximately 25 minutes to complete and participants were given a $20 electronic gift card to an online mass merchant of their
choice as a thank you for their time. Participants were asked if they were willing to be contacted in the future; of those who answered yes, 17% were contacted two-weeks later and asked to complete the survey a second time to establish test-retest reliability of survey items. To assess the test-retest reliability of the dietary, physical activity, and strategies for behavior change items on the survey, Pearson correlations were calculated for continuous variables and Spearman correlations were calculated for categorical variables. Test-retest reliability was considered acceptable if $r$ or $\rho$ was greater than 0.70; however, if test-retest reliability was less than 0.70 then a Kappa coefficient was calculated (only items with fair agreement or higher, $\kappa = 0.20+$ according to Landis and Koch, 1977 were kept in the analysis).

**Measures**

Prior to implementation of the full survey, the questionnaire was pre-tested using cognitive interviews with five direct support professionals. Changes to the survey were made based on these cognitive interviews.

**Demographic characteristics.** Age (in years), race (white/African American/other) and gender (male/female) were collected for both direct support professionals and their clients with developmental disabilities. Direct support professionals were asked to answer survey questions about an adult client with a developmental disability; if they provided care to more than one adult client, they were asked to report on the client that they provided the most hours of care to each week. For direct support professionals, educational status (high school/some college/college+) and marital status (married/never married/unmarried couple/divorced/separated/widowed) were also collected. For clients with developmental disabilities, direct support
professionals reported on the type of developmental disability the client had (autism, cerebral palsy, Down syndrome, intellectual disability, two or more, or other).

*Fruit and vegetable consumption.* This was assessed using two brief survey items that have been shown to have acceptable psychometric properties (Yaroch et al., 2012). Participants were asked: “How many servings of vegetables do you/does your client eat each day?” and “How many servings of fruit do you/does your client eat or drink each day?” The number of fruits and vegetables were added together to obtain the total daily servings of fruits and vegetables consumed. Test-retest reliability for daily fruit and vegetable consumption ranged from $r=0.597 (\kappa=0.672)$ for direct support professionals to $r=0.729$ for clients with developmental disabilities.

*Sugar-sweetened beverage consumption.* Participants were asked: “In a typical week, during the past 30 days, how often did you/did your client drink regular soda pop that contains sugar?” Test-retest reliability was $r=0.779$ for direct support professionals and $r=0.918$ for clients with developmental disabilities.

*Fast-food consumption.* This was measured by asking participants, “During the past 7 days, how many times did you/did your client eat fast food, including fast food meals eaten at work, at home or at fast-food restaurants, carryout or drive thru?” Responses were: never, once during the past seven days, twice during the past seven days, three times during the past seven days, four times during the past seven days, five times during the past seven days, six times during the past seven days, seven times during the past seven days, or more than seven times during the past seven days. Test-retest reliability was $\rho=0.535 (\kappa=0.260)$ for direct support professionals and $\rho=0.714$ for clients with developmental disabilities.
Physical activity. Participants were asked the following questions separately for vigorous and moderate physical activity: 1) In a typical week do you/do your client participate in vigorous/moderate intensity sports, fitness or recreational activities? (Yes/No) and 2) Thinking about the past 30 days, on average, how many hours per day do you sit and watch TV or videos? (0-5+ hours). Test-retest reliability for physical activity measures ranged from $\rho = 0.290-0.527$ (Kappa coefficients ranged from $\kappa = 0.385-0.525$) for clients with developmental disabilities to $\rho = 0.239-0.469$ (Kappa coefficients ranged from $\kappa = 0.238-0.430$) for direct support professionals.

Health Promotion Strategies. No survey instruments currently exist which assess the health promotion strategies used by direct support professionals to influence the dietary and physical activity behaviors of people with developmental disabilities; therefore for this study, survey items were adapted from survey instruments taken from studies that examined social cognitive constructs and the relationship between parental and child dietary/physical activity behaviors (Bryant et al., 2008; Gatthasall et al., 2008; Musher-Eizenman & Holub, 2007; Hendy et al., 2009; Dave et al., 2012). The psychometric properties of all of instruments from the articles listed above were considered acceptable for each individual scale.

Role-modeling. Direct support professionals were asked to report how frequently in the past month they role-modeled healthy dietary behaviors (e.g., eat healthy food in front of client, eat fruits/vegetables in front of client) and unhealthy dietary behaviors (e.g., eat fast food in front of client, drink sugary drinks in front of client). Participants were also asked to report on how often in the past month they role-modeled healthy physical activity behaviors (e.g., client sees direct support professional being physically
active, doing something physically active with client) and unhealthy physical activity behaviors (e.g., client sees direct support professional watch TV, use cell phone, use the computer or play video games) in front of their clients. Response options for the preceding questions were “less frequent” (never, seldom, several times a month) and “more frequent” (several times a week, most days, or every day). Test-retest reliability for these items ranged from $\rho=0.327-0.761$; Kappa coefficients ranged from $\kappa=0.213-0.608$.

**Incentive motivation:** Participants were asked to report on how frequently they use positive/negative reinforcement with food (e.g., giving/withholding special treats such as sweets/soda/salty snacks) and physical activity (e.g., allowing their client to watch extra TV and withholding TV from client). Response options for the preceding questions were “less frequent” (never, some days, several times a month) or “more frequent” (several times a week, most days, or every day). Test-retest reliability for these items ranged from $\rho=0.277-0.589$; Kappa coefficients ranged from $\kappa=0.220-0.551$.

**Facilitation:** Direct support professionals were asked several questions about how frequently they facilitate certain dietary and physical activity behaviors of their clients. Example questions include: How often do you…1) give your client soda pop?; 2) set limits on how many sweets, sodas, or salty snacks your client can have?; 3) prepare meals for your client that includes fruits and vegetables?; and 4) transport your client someplace for him/her to be physically active? Response options for the preceding questions were “less frequent” (never, some days, several times a month) and “more frequent” (several times a week, most days, or every day). Test-retest reliability for these items ranged from $\rho=0.282-0.804$; Kappa coefficients for these items ranged from $\kappa=0.201-0.565$. 

104
Perceptions of role in health promotion for client. Direct support professionals were asked, “How much of a role do you think you have in promoting the health of your client with a developmental disability?” Response options: not much of a role, somewhat of a role, or a very large role. Participants were also asked, “How easy or difficult would it be for you to help your client…1) be physically active; 2) eat more fruits and vegetables; 3) eat less meals from fast food restaurants; 4) drink less sugary drinks such as soda pop; and 5) watch less TV?” Response options were: very difficult, somewhat difficult, neither difficult or easy, somewhat easy, or very easy. Test-retest reliability for these items ranged from $\rho=0.352-0.769$, Kappa coefficients ranged from $\kappa=0.361-0.483$.

Data Analysis

Descriptive statistics were used to describe the dietary and physical activity behaviors of direct support professionals and their clients with developmental disabilities, as well as to examine the possible ways that direct support professionals use behavior change strategies to influence their client’s health behaviors. Pearson correlations were used for continuous variables (e.g., sugar-sweetened beverage consumption, fruit/vegetable intake), and Spearman correlations were used for categorical variables (e.g., weekly fast food consumption, daily TV time) to assess the relationship between direct support professionals’ and clients’ behaviors. Spearman correlations were used to examine the relationship between direct support professionals’ use of behavior change strategies (role-modeling, incentive motivation and facilitation) and the dietary and physical activity behaviors of their clients with developmental disabilities. A series of five simple logistic regression models were used to predict the odds of perceived difficulty in helping clients perform health behaviors (dependent variable) based on their
clients’ preference to be healthy (independent variable). Specifically, the client’s preference for not eating healthy was used to predict the direct support professionals’ perceptions of the difficulty of helping their client: 1) eat more fruits/vegetables; 2) eat less fast food meals; and 3) drink less sugary drinks. For physical activity, the client’s preference to not be physically active was used to predict the direct support professionals’ perceptions of the difficulty of helping their client: 1) be physically active; and 2) watch less TV. All analyses were conducted in SPSS 22.0.

Results

Survey data were collected from a total of 398 direct support professionals who completed survey information about themselves, as well as their clients with developmental disabilities. The response rate for this study was 9.7% (398/4104). Of the 4,682 invitations sent, 168 were undeliverable and 410 did not meet eligibility criteria and were removed from the denominator.

Sample Characteristics

Three hundred and ninety-eight direct support professionals completed the survey and provided health behavior information about themselves, as well as their clients with developmental disabilities. The majority of direct support professionals were white (73%) and female (87%), while 21% identified as African American and 6% identified their race as “other.” The age of direct support professionals ranged from 19 to 76 with a mean age of 43±12.7. Eighty percent of direct support professionals had some form of academic training above high school and 50% reported being married. Eighty-two percent of direct support professionals reported being unrelated to their client, while 18% were siblings or other non-parental family members. The majority of clients with developmental
disabilities in this sample were white (81%), 14% were African American and 5% reported their race as “other.” Just over half (51%) of clients with developmental disabilities in this sample were female. Sixty-percent lived with family members, 23% lived alone, 9% lived with roommates with developmental disabilities, and 9% resided in other environments. The age of clients with developmental disabilities ranged from 18 to 86, with a mean age of 36±14.5. Thirty-five percent of clients with developmental disabilities were reported to have more than two developmental disabilities. Table 10 (previous chapter) describes the detailed demographic characteristics of this sample.

**Dietary and Physical Activity Behaviors**

*Prevalence:* Table 13 provides an overview of the prevalence of the dietary and physical activity behaviors of direct support professionals and their clients with developmental disabilities, as well as the correlations illustrating the relationship between direct support professional and client behavior. The majority (58.8%) of direct support professionals reported consuming the daily recommended number of fruits/vegetables a day, while less than half (38.9%) of clients with developmental disabilities were reported as consuming the daily recommended number of fruits/vegetables each day. The majority of direct support professionals (83.7%) and their clients (72.1%) with developmental disabilities reported consuming less than one soda pop per day. Eighty-five percent of direct support professionals and 78% of clients with developmental disabilities were reported as consuming fast food at least once a week. The majority (59.3%) of direct support professionals reported watching less than two hours of television each day, while only 34.4% of those with developmental disabilities watched less than two hours of television each day. The majority (74.6%) of direct support professionals reported
participating in some sort of moderate-to-vigorous physical activity each week, while only 32.7% of clients with developmental disabilities were reported as participating in some type of moderate-to-vigorous physical activity each week. Small-to-moderate, yet significant correlations ($\rho \text{ or } r = 0.127-0.333$) between direct support professionals and client behaviors existed for all dietary and physical activity health behaviors except for participation in some sort of moderate-to-vigorous physical activity each week ($\rho = 0.098, p = 0.06$). The age of the client was associated with minutes the client spent watching TV ($\rho = 0.138, p = 0.007$) and whether the client participated in any weekly moderate-to-vigorous physical activity ($\rho = -0.121, p = 0.018$). Length of time the direct support professional worked with the client was associated with the following dietary behaviors: daily fruit/vegetable consumption ($r = 0.128, p = 0.011$) and daily sugar sweetened beverage consumption ($r = -0.109, p = 0.032$).
### Health Behaviors

<table>
<thead>
<tr>
<th>Health Behaviors</th>
<th>Prevalence of behavior- DSP’s</th>
<th>Prevalence of behavior- DD’s</th>
<th>Correlations of behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n %</td>
<td>n %</td>
<td></td>
</tr>
<tr>
<td><strong>Dietary Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Servings of Fruit and Vegetables/Day, M (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;5 servings per day</td>
<td>164 41.2</td>
<td>243 61.1</td>
<td>0.333***</td>
</tr>
<tr>
<td>5+ servings per day</td>
<td>234 58.8</td>
<td>155 38.9</td>
<td></td>
</tr>
<tr>
<td>Soda Pop/Day, M (SD)</td>
<td>0.37(0.90)</td>
<td>0.72(1.40)</td>
<td>0.149***</td>
</tr>
<tr>
<td>≤ 1 per day</td>
<td>333 83.7</td>
<td>287 72.1</td>
<td></td>
</tr>
<tr>
<td>&gt;1 per day</td>
<td>63 15.8</td>
<td>107 26.9</td>
<td></td>
</tr>
<tr>
<td>Don’t know/refused</td>
<td>2 0.5</td>
<td>4 1.0</td>
<td></td>
</tr>
<tr>
<td><strong>Fast food meals per week</strong></td>
<td></td>
<td></td>
<td>0.227**b</td>
</tr>
<tr>
<td>None</td>
<td>60 15.1</td>
<td>67 16.8</td>
<td></td>
</tr>
<tr>
<td>Once</td>
<td>177 44.5</td>
<td>110 27.6</td>
<td></td>
</tr>
<tr>
<td>Twice</td>
<td>90 22.6</td>
<td>93 23.4</td>
<td></td>
</tr>
<tr>
<td>Three+</td>
<td>71 17.8</td>
<td>108 27.1</td>
<td></td>
</tr>
<tr>
<td>Don’t know/Refused</td>
<td>--</td>
<td>20 5.0</td>
<td></td>
</tr>
<tr>
<td><strong>Physical Activity Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participates in Weekly Physical Activity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>304 76.4</td>
<td>130 32.7</td>
<td>0.098b</td>
</tr>
<tr>
<td>No</td>
<td>77 19.3</td>
<td>249 62.6</td>
<td></td>
</tr>
<tr>
<td>Don’t know/refused</td>
<td>17 4.8</td>
<td>19 4.8</td>
<td></td>
</tr>
<tr>
<td><strong>Time spent watching TV per day</strong></td>
<td></td>
<td></td>
<td>0.258**b</td>
</tr>
<tr>
<td>0-120 minutes</td>
<td>236 59.3</td>
<td>125 31.4</td>
<td></td>
</tr>
<tr>
<td>121-300 minutes</td>
<td>138 34.7</td>
<td>169 42.5</td>
<td></td>
</tr>
<tr>
<td>301+ minutes</td>
<td>17 4.3</td>
<td>89 22.3</td>
<td></td>
</tr>
<tr>
<td>Don’t know/refused</td>
<td>7 1.8</td>
<td>15 3.8</td>
<td></td>
</tr>
</tbody>
</table>

Table 13. Prevalence of health behaviors, and correlations between direct support professionals’ (DSPs) and clients with developmental disabilities’ (DD) behaviors

*p<0.05; ** p<0.01; a=Pearson Correlation; b=Spearman Correlation
Health Promotion Strategies used by Direct Support Professionals: A series of health promotion strategies (e.g., role-modeling, incentive motivation, etc.) used by direct support professionals were assessed in relationship to their client’s specific dietary behaviors (sugar sweetened beverage intake, daily fruit and vegetable consumption, weekly fast food consumption) and physical activity behaviors (participating in some type of weekly physical activity or not, daily time spent watching TV) using Spearman correlations. Some small, yet significant associations ($\rho=0.105-0.517$) were found between direct support professionals’ use of health promotion strategies and their clients’ dietary (Table 14) and physical activity behaviors (Table 15).

<table>
<thead>
<tr>
<th>Behavior change strategy used by DSP</th>
<th>DSP Performance of Behavior</th>
<th>Correlation to Client Dietary Health Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Role-modeling</td>
<td>n=387</td>
<td></td>
</tr>
<tr>
<td>Drink sugary drinks in front of client</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>27</td>
<td>7.0</td>
</tr>
<tr>
<td>Less frequent</td>
<td>360</td>
<td>93.0</td>
</tr>
<tr>
<td>Eat healthy foods in front of client</td>
<td>n=375</td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>272</td>
<td>72.5</td>
</tr>
<tr>
<td>Less frequent</td>
<td>103</td>
<td>27.5</td>
</tr>
<tr>
<td>Show enthusiasm towards eating healthy</td>
<td>n=371</td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>308</td>
<td>83.0</td>
</tr>
<tr>
<td>Less frequent</td>
<td>63</td>
<td>17.0</td>
</tr>
</tbody>
</table>

Table 14. Direct support professionals’ (DSP) use of behavior change strategies and dietary behaviors of clients with developmental disabilities (DD)
*p<0.05; ** p<0.01, all correlations presented above are Spearman correlations (continued)
Table 14 continued

<table>
<thead>
<tr>
<th>Behavior change strategy used by DSP</th>
<th>DSP Performance of Behavior</th>
<th>Correlation to Client Dietary Health Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td><strong>Role-modeling</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eat fruits/vegetables in front of client n=371</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>275</td>
<td>74.1</td>
</tr>
<tr>
<td>Less frequent</td>
<td>96</td>
<td>25.9</td>
</tr>
<tr>
<td>Eat fast food meals in front of client n=370</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>27</td>
<td>7.3</td>
</tr>
<tr>
<td>Less frequent</td>
<td>343</td>
<td>92.7</td>
</tr>
<tr>
<td>Eat sweets or salty snacks in front of client n=382</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>355</td>
<td>92.9</td>
</tr>
<tr>
<td>Less frequent</td>
<td>27</td>
<td>7.1</td>
</tr>
<tr>
<td><strong>Incentive Motivation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Praise client for eating fruits/vegetables n=356</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>233</td>
<td>65.4</td>
</tr>
<tr>
<td>Less frequent</td>
<td>123</td>
<td>34.6</td>
</tr>
<tr>
<td>Reward client with snack food n=367</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>39</td>
<td>10.6</td>
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<tr>
<td>Less frequent</td>
<td>328</td>
<td>89.4</td>
</tr>
<tr>
<td>Withhold snack food from client n=358</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>13</td>
<td>3.6</td>
</tr>
<tr>
<td>Less frequent</td>
<td>345</td>
<td>96.4</td>
</tr>
<tr>
<td><strong>Facilitation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive Behaviors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Give client fruit n=361</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>271</td>
<td>75.1</td>
</tr>
<tr>
<td>Less frequent</td>
<td>90</td>
<td>24.9</td>
</tr>
<tr>
<td>Give client vegetables n=363</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>264</td>
<td>72.7</td>
</tr>
<tr>
<td>Less frequent</td>
<td>99</td>
<td>27.3</td>
</tr>
<tr>
<td>Prepare meals with fruits/vegetables n=359</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>258</td>
<td>71.9</td>
</tr>
<tr>
<td>Less frequent</td>
<td>101</td>
<td>28.1</td>
</tr>
</tbody>
</table>
Table 14 continued

<table>
<thead>
<tr>
<th>Behavior change strategy used by DSP</th>
<th>DSP Performance of Behavior</th>
<th>Correlation to Client Dietary Health Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Facilitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive Behaviors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Set limits on client’s snack food</td>
<td>353</td>
<td></td>
</tr>
<tr>
<td>n=353</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>141</td>
<td>39.9</td>
</tr>
<tr>
<td>Less frequent</td>
<td>212</td>
<td>60.1</td>
</tr>
<tr>
<td>Sit with client during meals n=385</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>305</td>
<td>79.2</td>
</tr>
<tr>
<td>Less frequent</td>
<td>80</td>
<td>20.8</td>
</tr>
<tr>
<td>Unsupportive Behaviors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Give client treats n=367</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=367</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>69</td>
<td>18.8</td>
</tr>
<tr>
<td>Less frequent</td>
<td>298</td>
<td>82.2</td>
</tr>
<tr>
<td>Take client to get fast food n=368</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=368</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>47</td>
<td>12.8</td>
</tr>
<tr>
<td>Less frequent</td>
<td>321</td>
<td>87.2</td>
</tr>
<tr>
<td>Give client soda pop n=378</td>
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<td></td>
</tr>
<tr>
<td>n=378</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>49</td>
<td>13.0</td>
</tr>
<tr>
<td>Less frequent</td>
<td>329</td>
<td>87.0</td>
</tr>
<tr>
<td>Encourages Client Involvement</td>
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<tr>
<td>Help client make a healthy snack n=352</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>202</td>
<td>57.4</td>
</tr>
<tr>
<td>Less frequent</td>
<td>150</td>
<td>42.6</td>
</tr>
<tr>
<td>Help client prepare meal with</td>
<td></td>
<td></td>
</tr>
<tr>
<td>fruits/vegetables n=344</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=344</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>202</td>
<td>58.7</td>
</tr>
<tr>
<td>Less frequent</td>
<td>142</td>
<td>41.3</td>
</tr>
<tr>
<td>Allow client to eat snacks whenever</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=357</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>145</td>
<td>40.6</td>
</tr>
<tr>
<td>Less frequent</td>
<td>212</td>
<td>59.4</td>
</tr>
<tr>
<td>Allow client to help prepare meal n=336</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>207</td>
<td>61.6</td>
</tr>
<tr>
<td>Less frequent</td>
<td>129</td>
<td>38.4</td>
</tr>
<tr>
<td>Help client set goals to improve eating habits n=353</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>207</td>
<td>58.6</td>
</tr>
<tr>
<td>Less frequent</td>
<td>146</td>
<td>41.4</td>
</tr>
<tr>
<td>Take client to the grocery store n=365</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>117</td>
<td>32.1</td>
</tr>
<tr>
<td>Less frequent</td>
<td>248</td>
<td>67.9</td>
</tr>
</tbody>
</table>
Table 15. Direct support professionals (DSP’s) use of behavior change strategies and physical activity behaviors of clients with developmental disabilities

* p< 0.05; ** p< 0.01, all correlations presented above are Spearman correlations

<table>
<thead>
<tr>
<th>Behavior change strategy used by DSP</th>
<th>DSP Performance of Behavior</th>
<th>Correlation to Client Physical Activity Health Behaviors</th>
<th>Participates in Weekly Physical Activity</th>
<th>Daily Hours Spent Watching TV</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Role-modeling</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watch TV, use other electronics in front of client n=374</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More frequent</td>
<td>56</td>
<td>15.0</td>
<td>0.107*</td>
<td>-0.027</td>
</tr>
<tr>
<td>Less frequent</td>
<td>318</td>
<td>85.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do something physically active with client n=373</td>
<td></td>
<td></td>
<td></td>
<td>0.205**</td>
</tr>
<tr>
<td>More frequent</td>
<td>124</td>
<td>33.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less frequent</td>
<td>249</td>
<td>66.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Incentive Motivation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Praise client for being physically active n=365</td>
<td></td>
<td></td>
<td></td>
<td>0.176**</td>
</tr>
<tr>
<td>More frequent</td>
<td>266</td>
<td>72.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less frequent</td>
<td>99</td>
<td>27.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reward client with TV and other electronics n=348</td>
<td></td>
<td></td>
<td></td>
<td>-0.044</td>
</tr>
<tr>
<td>More frequent</td>
<td>74</td>
<td>21.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less frequent</td>
<td>274</td>
<td>78.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withhold TV, videos, computers, video games n=359</td>
<td></td>
<td></td>
<td></td>
<td>0.130*</td>
</tr>
<tr>
<td>More frequent</td>
<td>8</td>
<td>2.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less frequent</td>
<td>351</td>
<td>97.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Facilitation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transport client someplace to be physically active n=357</td>
<td></td>
<td></td>
<td></td>
<td>0.224**</td>
</tr>
<tr>
<td>More frequent</td>
<td>175</td>
<td>49.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less frequent</td>
<td>182</td>
<td>51.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Perceptions of Ability to Promote Clients’ Dietary/Physical Activity Behaviors:

The majority (57%, n=223) of the direct support professionals in this study perceived themselves as having a large role in promoting the health of their clients, while 35% (n=140) perceived themselves as having somewhat of a role and 7% (n=26) did not believe they had much of a role in promoting the health of their clients. Direct support professional participants reported that it would be somewhat or very easy to help their clients perform healthier dietary behaviors such as eating more fruits/vegetables (62.1%, n=239), eating less meals from fast food restaurants (58.5%, n=210) and drinking less sugary drinks (57.3%, n=196); however, in regards to physical activity behaviors, direct support professionals were more divided in their perceptions of how easy or difficult it would be to help their clients be more physically active (40.6% very/somewhat difficult vs. 43% very/somewhat easy) or watch less TV (44.2% very/somewhat difficult vs. 39.8% very/somewhat easy) (Table 16). Direct support professionals’ perceptions of how difficult it would be to help their clients perform healthy dietary and physical activity behaviors was consistently predicted by their client’s preference to eat healthy or be physically active (Table 16).

Discussion

This is the first study to characterize the dietary and physical activity behaviors of direct support professionals and examine the relationship between direct support professionals’ health behaviors and the health behaviors of their clients with developmental disabilities. Aside from consuming fast food on a weekly basis, the majority of direct support professionals in this study reported participating in healthy dietary and physical activity behaviors, which is somewhat surprising and unlikely, given
<table>
<thead>
<tr>
<th>Health Behavior</th>
<th>N (%)</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Activity&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be physically active n=379</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very/somewhat difficult/ Neither</td>
<td>216 (57)</td>
<td>2.74</td>
<td>1.77-4.25</td>
</tr>
<tr>
<td>Difficult nor Easy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat/Very easy</td>
<td>163 (43.0)</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Watch less TV n=361</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Very/somewhat difficult/ Neither</td>
<td>217 (60.1)</td>
<td>2.22</td>
<td>1.41-3.49</td>
</tr>
<tr>
<td>Difficult nor Easy</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Somewhat/Very easy</td>
<td>144 (39.9)</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Dietary&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eat more fruits and vegetables n=384</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very/somewhat difficult/ Neither</td>
<td>145 (37.8)</td>
<td>3.91</td>
<td>2.47-6.21</td>
</tr>
<tr>
<td>Difficult nor Easy</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Somewhat/Very easy</td>
<td>239 (62.2)</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Eat less fast food meals n=359</td>
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<td></td>
<td></td>
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<tr>
<td>Very/somewhat difficult/ Neither</td>
<td>149 (41.5)</td>
<td>2.34</td>
<td>1.48-3.71</td>
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<tr>
<td>Difficult nor Easy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat/Very easy</td>
<td>210 (58.5)</td>
<td>--</td>
<td></td>
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<tr>
<td>Drink less sugary drinks n=342</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very/somewhat difficult/Neither</td>
<td>146 (42.7)</td>
<td>3.34</td>
<td>2.06-5.40</td>
</tr>
<tr>
<td>Difficult nor Easy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat/Very easy</td>
<td>196 (57.3)</td>
<td>--</td>
<td></td>
</tr>
</tbody>
</table>

Table 16. Client preference for physical activity/healthy diet associated with direct support professional’s perceived difficulty of helping client perform healthy behaviors

<sup>a</sup> independent variable: client does not want to be physically active (Yes=1, No=0)

<sup>b</sup> independent variable: client does not want to eat healthy food (Yes=1, No=0)

*Simple logistic regression model: Very/somewhat difficult/neither difficult nor easy coded as 1; Very/somewhat easy coded as 0; all p-values=0.00

that the estimates reported in this study were higher than what would be expected in the general population (CDC, 2015d). In general, the demographic profile of direct support professionals who participated in this study was similar to the general workforce of direct support professionals. In this study, 50% were white (48% general profession) and 86.9% were female (90% general profession); however, participants in the current study may have been slightly more educated than those in previous studies (19% high school
In this study, the majority of adults with developmental disabilities were reported as consuming less than five fruits/vegetables a day, eating fast food on a weekly basis, and not participating in weekly physical activity. These findings are consistent with previous work in this area related to diet and physical activity for people with developmental disabilities (Draheim, Williams, & McCubbin, 2002; Peterson, Janz, & Lowe, 2008; Hilgenkamp, Reis, van Wijck, & Evenhuis, 2012; Humphries et al., 2009; Robertson et al., 2000). In the current study, there were small to moderate correlations between all dietary and physical activity behaviors (except for participation in weekly physical activity) of direct support professionals and their clients with developmental disabilities. These findings suggest that direct support professionals may play somewhat of a role in the health behaviors of their clients through role-modeling. Even though some significant correlations existed between direct support professionals’ use of role-modeling, incentive motivation, and other facilitators of behavior change it is somewhat surprising that the correlations were not stronger given that previous research suggests that these health promotion strategies play a large role in influencing one’s health behaviors (Hendy & Raudenbush, 2000; Sallis et al., 2008; Spurrier et al., 2008). Because some correlations between clients’ and direct support professionals’ health behaviors and use of health promotion strategies were small, it is likely that there are other social influences (e.g., family members, roommates, other direct support professional providers) impacting a client’s dietary and physical activity behaviors that should be explored in future research.
Limitations

This study has several limitations that should be noted. Even though this is one of the first studies to use random sampling to study the population of direct support professionals, the response rate for this study was low at 9.7%; however, response rates for online surveys are generally low (Nulty, 2008). A number of participants (n=139) completed the eligibility screener and qualified for the survey but did not complete the survey, with the majority stopping after the consent form; several attempts were made to contact these participants but to no avail. In addition, the sampling frame for this study contained the names of all direct support professionals who provided care to both children and adults with developmental disabilities in the state; therefore, it is possible that the direct support professionals who provided care to children with developmental disabilities did not even attempt to complete the survey (and remained in the denominator when calculating response rates). Future work in this area should consider methods such as respondent driven sampling to recruit direct support professionals; this method allows researchers to collect data from hard-to-reach populations by using a method similar to snowball sampling while being able to track the number of people who are invited to participate in the survey (Heckathorn, 1997).

Another potential limitation of this study is non-response bias, as several direct support professionals refused to answer questions about the dietary and physical activity behaviors of their clients with developmental disabilities, as well as refused to answer questions about role-modeling, use of incentive motivation, and other facilitators of their clients’ health behaviors. One possible explanation for why direct support professionals may have refused to answer particular questions about their use of health promotion
strategies was concern about reporting about the possibility of violating the rights of their clients, which was a major concern expressed in recent focus group research with direct support professionals (Leser, unpublished). Even though participants completed the survey online and in privacy, which is thought to reduce the effects of social desirability, social desirability may have also been a potential limitation of the study. Direct support professionals reported higher than expected levels of socially desirable behaviors (e.g., fruits/vegetables, physical activity) and lowers levels of undesirable behaviors (e.g., sugar sweetened beverage consumption, TV viewing). While many survey items had acceptable test-retest reliability, several surveys items had less than ideal test-retest reliability, which is a notable limitation to the study. However, for items with questionable reliability, only those with greater than “fair” Kappa values (κ=0.20+) according to Landis and Koch (1977) were included in this manuscript. Possible explanations for low test-retest reliability scores on some survey items include participants reacting to the first set of survey items by changing their dietary/physical activity behaviors or by purposefully changing their responses to survey items the second time they completed the survey (Bless & Higson-Smith, 2000).

Conclusions and Future Directions

This study adds to the literature in a number of ways including: 1) characterizing the health behaviors of direct support professionals and their clients with developmental disabilities; 2) describing the association between direct support professionals’ health behaviors and the health behaviors of their clients with developmental disabilities; and 3) examining how health promotion strategies are used by direct support professionals to influence their clients’ health behaviors. A large portion of direct support professionals in
this study considered themselves as having a role in the health promotion efforts of their clients with developmental disabilities; therefore, disability service organizations and families/guardians of clients with developmental disabilities should work together to include direct support professionals in the client’s programming/services related to health promotion. Future research on the topic of dietary and physical activity behaviors among adults with developmental disabilities should not only address direct support professionals, but also other key members of the social networks of adults with developmental disabilities such as family members, roommates, and day-habilitation providers. Examining how social influences impact the health behaviors of adults with developmental disabilities is a new concept in the field of developmental disabilities and merits continued study given that adults with developmental disabilities often depend on the assistance of others.
Chapter 6: Conclusion

This dissertation research was the first study to examine the role that direct support professionals have in promoting the health behaviors of their clients with developmental disabilities. Specifically, six focus groups were conducted with key members (n=48) from the developmental disability community (e.g., people with developmental disabilities, family members, direct support professionals, agency administrators); participants were asked a series of questions to better understand the perceived role of direct support professionals in the health promotion efforts of their clients with developmental disabilities. Findings from this qualitative research suggest that in general, members of the developmental disability community perceive direct support professionals as playing an important role in promoting the health of their clients; however, direct support professionals experience several barriers when trying to help their clients be healthy. Barriers to promoting the health of clients with developmental disabilities described in this qualitative research include: individual-level factors of the clients (e.g., preference to be unhealthy, rights, limited income), individual-level factors of direct support professionals (e.g., lack of motivation, own rights), interpersonal-level factors between clients and direct support professionals (e.g., role-modeling, incentive motivation) and finally organizational-level factors (e.g., turnover in the field of direct care, unenforceable policies, lack of training). Protecting the rights of their clients with developmental disabilities, while at the same time trying to promote their client’s health
was the most commonly cited challenge to health promotion that direct support professionals experience. Even though several barriers to promoting the health of their clients were noted, focus group participants offered creative strategies for overcoming these barriers including: adding health promotion goals to clients’ ISPs, offering educational trainings for direct support professionals/clients, and having direct support professionals role-model healthy behaviors in front of their clients.

The findings from the qualitative study helped to inform the development of a quantitative survey used to characterize and assess the relationship between the smoking, dietary and physical activity behaviors of 398 direct support professionals and their clients with developmental disabilities. In addition, this survey contained items about direct support professionals’ use of health promotion strategies such as role-modeling, incentive motivation and facilitation to influence smoking, dietary and physical activity behaviors of their clients with developmental disabilities. Findings from this study suggest that there is no association ($\chi^2=0.300, p=0.584$) between direct support professionals’ current smoking status and the current smoking status of their clients with developmental disabilities; however, there were small-to-moderate, yet significant correlations ($\rho=0.127-0.333$) between the dietary and physical activity behaviors of direct support professionals and their clients. In addition, small-to-strong significant associations ($\rho=0.105-0.517$) existed between direct support professionals’ use of health promotion strategies and clients’ dietary and physical activity behaviors. The majority 57% (n=223) of direct support professionals in this study perceived themselves as having a large role in the health promotion efforts of their clients with developmental disabilities, and many reported that it would be very or somewhat easy to help their clients perform
healthy behaviors. However, based on what was learned during the focus groups, direct support professionals most likely feel the need to get permission in order to help their clients be healthy due to concerns over violating their client’s rights.

One of the original specific aims for this study was to better understand direct support professionals’ current levels of stress, psychological distress and social support in order to examine how these variables impact a direct support professional’s participation in smoking, dietary and physical activity behaviors. However, the decision was made not to include an exploration of these three variables in the final manuscripts, because these variables did not fit with the overarching purpose of the manuscripts—to describe how direct support professionals influence the smoking, dietary and physical activity behaviors of their clients through role-modeling, use of incentive motivation and other facilitators of behavior. In addition, an exploration of these three variables (stress, psychological distress, social support) in relationship to direct support professionals’ participation in health risk behaviors were not included in the manuscripts because the data did not suggest that participants in this study had particularly high levels of stress/distress or low levels of social support, which was expected based on previous work in the field (e.g., Hewitt & Larson, 2007; Frank, Dawson, van Kleunen, Wilner, & Seavey, 2000; Gray-Stanley et al., 2010; Test et al., 2003).

In this study, direct support professionals reported generally low levels of psychological distress with a mean score on the Kessler-6 scale of 9.10±3.63. Scores on the Kessler-6 range from 6-30 and are broken into three categories low (scores 6-11), mild/moderate (12-19), and high (20-30) levels of psychological distress. The Perceived Stress Scale short form was used to measure stress among direct support professionals; in
this sample, the mean score of perceived stress was 3.60±2.85. Scores on the Perceived Stress Scale short form could range from 0-16 (with higher scores indicating a higher level of perceived stress); no cut-off points are used with this scale because this scale is not meant for use as a diagnostic tool. Finally, direct support professionals in this sample reported high levels of social support, with a mean score of 5.61±1.40 on the Multidimensional Scale of Perceived Social Support. Scores on this scale range from 1-7 with higher scores indicating a higher level of social support; no cut-off points are used with this scale.

Multiple logistic regression was used to assess the relationship between direct support professionals’ levels of stress, psychological distress and social support and their odds of participating in smoking, dietary and physical activity behaviors while controlling for age, race, gender and educational status. Stress, psychological distress and social support were not predictive of direct support professionals’ current odds of smoking (stress, AOR=0.984, 95% CI=0.880-1.099, p=0.771; psychological distress, AOR=0.978, 95% CI=0.891-1.073, p=0.641; social support, AOR=1.012, 95% CI=0.818-1.253, p=0.912). In regards to daily fruit and vegetable consumption, stress (AOR=0.959, 95% CI = 0.890-1.034, p=0.276), psychological distress (AOR=1.00, 95% CI=0.940-1.06, p=0.993), and social support (AOR=0.915, 95% CI=0.766-1.064, p=0.247) were all unrelated to odds of eating the recommended daily value (5+ servings) of fruits/vegetables. When examining fast food consumption, stress (AOR=1.091, 95%=0.980-1.215, p=0.113), psychological distress (AOR=1.048, 95% CI= 0.954-1.152, p=0.326), and social support (AOR=0.952, 95%=0.773-1.171, p=0.639) were not associated with odds of consuming fast food more than once a week. In regards to daily
sugar sweetened beverage consumption, stress (AOR=1.121, 95% CI=1.027-1.223, 
$p=0.011$) and psychological distress (AOR=1.095, 95% CI=1.025-1.170, $p=0.007$) were 
associated with increased odds of drinking more than one sugar sweetened beverage per 
day; however, social support was not (AOR=0.967, 95% CI= 0.816-1.146, $p=0.699$).
Higher levels of reported stress (AOR=0.837, 95% CI=0.764-0.916, $p=0.00$) and 
psychological distress (AOR=0.860, 95% CI=0.802-0.924, $p=.001$) were associated with 
reduced odds of direct support professionals participating in some sort of 
moderate/vigorous physical activity each week, while social support (AOR=1.04, 95% 
CI=0.868-1.236, $p=0.694$) was not. Lastly, stress (AOR=1.149, 95% CI=1.062-1.240, 
$p=0.001$) and psychological distress (AOR=1.093, 95% CI= 1.025-1.164, $p=0.006$) were 
also associated with increased odds of watching two or more hours of TV per day, while 
social support was not (AOR=0.931, 95% CI= 0.804-1.078, $p=0.339$).

This study had several limitations including: a low overall response rate, low test-
retest reliability on certain survey items, and non-response bias since several direct 
support professionals refused to answer certain survey items. In regards to less than ideal 
test-retest reliability ($r$ or $\rho <0.70$) for survey items, a Kappa coefficient was calculated. 
If Kappa was greater than 0.20 (indicating fair or better agreement according to Landis 
and Koch, 1977), the survey item was included in the analysis. However, certain survey 
items were removed (e.g., incentive motivation for smoking, minutes spent in moderate-
to-vigorous physical activity, time spent sitting, etc.) because both the test-retest 
reliability was less than 0.70 and the Kappa coefficient was less than 0.20. Even with its 
limitations, this was the first study to explore the influence of direct support 
professionals’ health behaviors and use of health promotion strategies in relationship to
the smoking, dietary and physical activity behaviors of their clients with developmental disabilities and the findings from this study can be used to inform future work in the field.

Focus group participants consistently discussed the importance of including health promotion goals in their clients’ ISPs as a way to formally enable direct support professionals to help their clients be healthy, without fear over violating the rights of their clients. The ISP is typically viewed as a “legally binding” contract between the service organization and the client; people with developmental disabilities who utilize state-based waiver services are usually required to have an ISP (e.g., Ohio Department of Developmental Disabilities, 2016a; Reinders & Schalock, 2014). A client’s ISP is typically developed and revised by members of the client’s support team (e.g., client, family members, case manager, and other health professionals) on an annual basis and all items included in the ISP are specifically tailored to the individual client (Reinders & Schalock, 2014; Thompson et al., 2009; Brown & Percy, 2007). In order to get health promotion goals voluntarily added to a client’s ISP, case managers would need to become aware of the importance of health promotion activities for their clients with developmental disabilities. However, especially if not mandated by the state, one could anticipate barriers (e.g., creating more work for case managers, lack of support by family/client, etc.) to getting health promotion goals incorporated into clients’ ISPs. Future research is needed to better understand how adding health promotion goals to a client’s ISP impacts the client’s health outcomes. Should the findings from this research provide evidence in support of better health outcomes for clients with developmental disabilities as a result of including health promotion goals in ISPs, perhaps state-based
waiver programs would be more likely to include health promotion goals as requirements for ISP planning.

The findings from this study also suggest a need for relevant trainings and educational opportunities for direct support professionals, and even their clients with developmental disabilities about the importance of health promotion in this population. Because rights violations are such a large and valid concern for direct support professionals, members of the developmental disability community should help support clients with developmental disabilities in developing healthy behavioral practices, so that people with developmental disabilities ultimately choose to make healthy choices for themselves, if they are able to do so.

Since direct support professionals play such a large role in the lives of their clients with developmental disabilities and the majority perceive themselves as having a role in the health promotion efforts of their clients, we must work to create an environment where direct support professionals feel comfortable helping their clients make healthy choices without having fear over losing their jobs due to concern over rights violations. Even though the focus of the current study was on the role of direct support professionals in the health promotion efforts of their clients with developmental disabilities, it is worth exploring how other members of a client’s social network (e.g., family members, roommates, etc.) influence the client’s health behaviors. In addition, future work in this area should consider examining the how children/adolescents with developmental disabilities’ health behaviors are influenced by members of their social networks. Because this population experiences such large disparities in their health outcomes, the challenge for public health and the field of developmental disabilities is to find a balance
where the rights of people with developmental disabilities are protected but not at the expense of their health.
References


Appendix A: Focus Group Consent Form
The Ohio State University Consent to Participate in Research

Study Title: Study #1: Direct Support Professionals and Adults with Developmental Disabilities: A study of the role direct support professionals have in the health behaviors of their clients with developmental disabilities

Researcher: Phyllis Pirie, PhD

Sponsor: N/A

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose: The purpose of this study is to better understand the perceived role that direct support professionals have in the health behaviors of their adult clients with developmental disabilities from the perspective of people with developmental disabilities, family members of people with developmental disabilities, direct support professionals and agency/organization administrators serving those with developmental disabilities. The findings from these focus groups will be used to inform the development of a larger survey and will be used to inform the scientific and developmental disability community about the perceived role that direct support professionals have over the health behaviors of their clients with developmental disabilities.

Procedures/Tasks: If you decide to participate in this study, you will participate in a focus group that will last approximately 60-90 minutes. The focus group will be audio recorded; however, your participation in this study is confidential and your name will not be linked to what you say during this focus group session. You will be asked to share your thoughts/opinions about a variety of questions related to the role of direct support professionals in the health behaviors of clients with developmental disabilities. After the focus group is finished, you will be asked to complete a brief questionnaire and sign a receipt to receive your gift card.

Duration:
Study participation will take between 60-90 minutes. You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.
Risks and Benefits:
The risks of participation in this study are minimal; you may feel some emotional discomfort answering some of the questions. There may be no direct benefits to you from participating in this research study.

Confidentiality:
Efforts will be made to keep your study-related information confidential. Because this study is a focus group study, with multiple participants, confidentiality can only be guaranteed to the extent that all members of the focus group maintain one another’s confidentiality. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):
- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:
You will receive a $25 gift card to Wal-Mart or Kroger as a thank you for your time.

Participant Rights:
You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:
For questions, concerns, or complaints about the study, or you feel you have been harmed as a result of study participation, you may contact Dr. Phyllis Pirie at 614-292-4756.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.
CONSENT
Behavioral/Social Science

IRB Protocol Number: 2014B0346
IRB Approval date: 9/10/2014
Version:

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to
participate in a research study. I have had the opportunity to ask questions and have had them
answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

Printed name of subject

Signature of subject

Date and time

Printed name of person authorized to consent for subject (when applicable)

Signature of person authorized to consent for subject (when applicable)

Relationship to the subject

Date and time

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the
signature(s) above. There are no blanks in this document. A copy of this form has been given
to the participant or his/her representative.

Printed name of person obtaining consent

Signature of person obtaining consent

Date and time

Page 3 of 3 Form date: 02/11/13
Appendix B: Focus Group Capacity Screener
Capacity Assessment

1. The potential participant understands that they are participating in a focus group, where they will be asked to talk and share their opinions? *What are you about to do?*
   - Yes
   - No

2. The potential participant understands what the focus group topic is about? *What are we going to be talking about in the focus group?*
   - Yes
   - No

3. The potential participants understand that participation in the study is voluntary and that they can end participation at any time? *If you do not want to participate in this focus group do you have to?*
   - Yes
   - No

4. The potential participant understands that there is minimal risk to participation? *What are the risks or things that might make you uncomfortable if you participate in the focus group study?*
   - Yes
   - No

5. The potential participant understands that they may receive no benefit from participating in the study? *What type of benefits may you receive if you participate in this focus group? Do you still wish to participate?*
   - Yes
   - No

6. The potential participant is not under any duress that may impair their capacity to consent to participation in this research? *Observe (e.g. family pressure)*
   - Yes
   - No

If any of the above answers to the questions are “no” the informed consent form and research study will be re-explained to the potential participant and the capacity assessment will be administered again up to three times. If after three times, the answers to the above questions are still “no” the potential participant will not be able to participate in the study. If the answers to the questions above are “yes,” then the potential participant has been assessed as being capable of providing informed consent and will be able to participate in the study.
Appendix C: Focus Group Demographic Form
Focus Group Demographic Questionnaire

1. Which of the following best describes you?
   - ☐ A person with a developmental disability
   - ☐ Family member of a person with a developmental disability
     - ☐ ___________________ (please specify relationship)
   - ☐ An agency/organization administrator
     - ☐ How many years have you worked as an agency/organization administrator? _____(# years)
   - ☐ A direct support professional
     - ☐ How many years have you worked as a direct support professional? _____(# years)

2. What is your gender?
   - ☐ Male
   - ☐ Female

3. What is your age? _________(years)

4. What is the highest degree or level of school that you have completed?
   - ☐ Less than high school
   - ☐ High school diploma or GED
   - ☐ Some college, post high school vocational, or Associate’s degree
   - ☐ 4-year college degree, or
   - ☐ Post-graduate
   - ☐ Don’t know

5. Which of the following best describes you? You may choose more than one.
   - ☐ African American or Black
   - ☐ Asian American or Asian
   - ☐ Hispanic or Latino
   - ☐ Native American Indian, or
   - ☐ White
   - ☐ Other ___________(please specify)
   - ☐ Don’t know
   - ☐ Refused
Appendix D: Focus Group Recruitment Flyer
Focus Groups:
The Role of Direct Support Professionals in the Health Behaviors of People with Developmental Disabilities

You’re invited to participate in a focus group if you are:
- an adult with a developmental disability,
- a family member of an adult with a developmental disability,
- a direct support professional (paid caregiver), or
- an agency/organization administrator serving people with developmental disabilities

1) Participation in focus groups will take approximately 90 minutes
2) The topic of this focus group is the role direct support professionals play in the health behaviors of their clients with developmental disabilities and what makes it difficult/easy to promote the health of their clients with developmental disabilities
3) All focus group participants must be 18 years or older
4) Focus groups will take place at Franklin County Board of Developmental Disabilities during selected weekdays/weeknights in October. Please call or e-mail for more details about the dates/times of the focus groups
5) As a thank you, each participant will receive a $25 gift card to Wal-Mart or Kroger

Register Today!
Call 614-947-9867 or E-mail LESER.5@osu.edu

The Ohio State University
College of Public Health

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Appendix E: Survey Recruitment E-mail
Initial E-mail Invitation

Dear (insert direct support professional’s name):

My name is Kendall Leser and I am a graduate student at The Ohio State University’s College of Public Health working on a project about the health of direct support professionals and their clients with developmental disabilities.

I would like to invite you to see if you qualify to complete a survey about the role of direct support professionals in the health behaviors of adults with developmental disabilities in Ohio. You may access the survey at the following link: (insert link to Survey Monkey).

If you qualify, the survey is expected to take between 25-35 minutes and you will receive a $20 e-gift card to Wal-Mart or Amazon.com as thank you for your time.

*Participation in this survey is completely voluntary and you may end your participation at anytime.*

We ask that the survey be completed in one sitting, so please make sure you have a reliable connection to the Internet. After clicking on the above link, you will be asked a few questions to see if you qualify to take the survey. If you qualify, you will then be asked to provide your informed consent to participate, answer survey questions, and then select your gift card.

If you have any questions about the survey or your participation in the survey, please contact me at leser.5@buckeyemail.osu.edu or call me at 614-947-9867.

Thank you,
Kendall A. Leser, M.S.
Graduate student at The Ohio State University’s College of Public Health
Appendix F: Survey Online Consent
You qualify to participate in the study entitled, “Study #2: Direct Support Professionals and Adults with Developmental Disabilities: A study of the role direct support professionals have in the health behaviors of their clients with developmental disabilities.”

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully.

Your participation is voluntary.

Purpose of the study: The purpose of this study is to better understand the health behaviors of adults with developmental disabilities and their direct support professionals. The findings from this study will be used to inform the community about health behaviors and may also be used to develop educational trainings and policies.

Procedures/Tasks: If you decide to participate in this study, you will be asked to complete an online survey about your health behaviors and the health behaviors of your client with a developmental disability.

Duration: Study participation will take approximately 25-35 minutes of your time. You may end your participation in the study at anytime. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits: The risks of participation in this study are minimal; you may feel some emotional discomfort answering some of the questions. There may be no direct benefits to you from participating in this research study.

Confidentiality: Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives: After you complete the study, you will receive a $20 electronic gift card to Wal-Mart or Amazon.com as a thank you for your time. The gift card will be e-mailed to you within 48 hours of completing the survey.
**Participant Rights:** You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status. If you choose to participate in the study, you may discontinue participation at any time without penalty. By agreeing to participate in the research, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

**Contacts and Questions:**
For questions, concerns, or complaints about the study, or you feel you have been harmed as a result of study participation, you may contact Dr. Phyllis Pirie at 614-292-4756.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

Please print a copy of this consent form for your records, if you so desire.

You are being asked to provide your electronic consent to participation. Please select your choice below.

By clicking on the “I Agree” button below it indicates that:
• you have read and understand the above information
• you voluntarily agree to participate
• you are 18 years of age or older

If you do not wish to participate in the research study, please decline participation by clicking on the "I Disagree" button.
Appendix G: Survey Disqualification Webpage
Disqualification Webpage

Thank you for taking the time to complete the survey screener to see if you qualify to participate in the survey research. Unfortunately, based on your answers you do not qualify to participate in the survey research.

Below are the reasons why you may not have qualified to take the survey:

- ☐ Being a parent and a direct support professional of a client with a developmental disability
- ☐ Working less than 10 hours a week with a client with a developmental disability
- ☐ Working less than 3 months for a client with a developmental disability
- ☐ Being under the age of 18
- ☐ Not providing care to an adult client with a developmental disability

If you have questions, please feel free to contact Kendall Leser at leser.5@buckeyemail.osu.edu or call 614-947-9867.

Thanks again for taking the time to answer the questions.
Appendix H: Survey Instrument
Survey

Screener
1. Are you 18 years of age or older?
   - Yes
   - No

2. Do you provide care to at least one client over the age of 18 with a developmental disability in the State of Ohio?
   - Yes
   - No

3. Have you worked with any of your clients with a developmental disability for at least three months or longer?
   - Yes
   - No

4. Do you work with any of your clients with a developmental disability for an average of 10 hours a week or more?
   - Yes
   - No

5. Are you a parent to any of your clients with a developmental disability?
   - Yes
   - No

6. Are you the parent of…
   - All of your clients with a developmental disability
   - Some of your clients with a developmental disability
   - None of your clients with a developmental disability

Demographics: Client with development disability

Please answer the following questions about an adult client with a developmental disability that you are unrelated to by blood. If you provide care to more than one adult client with a developmental disability that you are unrelated to, please answer the following questions about the client who you provide the most care for each week. It is important that you answer survey items only about an adult client that you are unrelated to by blood.

1. How old is this client? _____ (# years)

2. Is this client male or female?
   - Male
   - Female
   - Don’t know
   - Refused

3. Are you related to this client?
   - Yes
   - No

4. What is your relationship to this client?
   - Sibling
   - Aunt
5. On average, during the past few months, how many hours do you provide care to this client in a typical week? _____ (# hours)

6. How long have you been caring for this client? ____________ (# of years) or ____________(# of months)

7. What type of developmental disability does your client have? (check all that apply)
   □ Autism
   □ Cerebral Palsy
   □ Down syndrome
   □ Intellectual disability
   □ Fetal alcohol syndrome
   □ Fragile X Syndrome
   □ Pervasive developmental disorder
   □ Other ____________ (please specify)
   □ Don’t know
   □ Refused

8. Which of the following best describes your client’s race? (Check all that apply)
   □ White/Caucasian
   □ African American or Black
   □ Native American or Alaskan Native
   □ Asian
   □ Pacific Islander
   □ Other
   □ Don’t know
   □ Refused

9. Where does your client live?
   □ Lives along in own home or apartment
   □ Lives with family members
   □ Lives in a home or apartment with one roommate with a developmental disability
   □ Lives in a home or apartment with two or more roommates with developmental disabilities
   □ Refused
   □ Other ____________
   □ Independent living (own home/apartment)
   □ Family’s home
   □ Other ____________ (please specify)

10. Including your client, how many people live in your client’s home? (Please include family members, providers, and/or roommates) ______ (# people)

11. Does your client have any health problems that require him/her to use special equipment, such as a cane, wheelchair, special bed or special telephone?
   □ Yes
   □ No
   □ Don’t know
   □ Refused

12. Does your client have any dietary restrictions that affect what he/she can eat?
13. In general, how would you describe the overall health of your client?
- Excellent
- Very good
- Good
- Fair
- Poor
- Don’t know
- Refused

14. Which of the following conditions does your client have, if any? (Check all that apply)
- Heart disease
- High blood pressure/hypertension
- Arthritis
- Diabetes
- Other __________________ (please specify)

Health Behaviors: Client with developmental disability

Please continue to answer the following questions to the best of your knowledge about the same client you are unrelated to and who you provide the most care for in a typical week.

Smoking behaviors
1. Has your client smoked at least 100 cigarettes in their lifetime?
- Yes
- No (skip to Q.5)
- Don’t know (skip to Q.5)
- Refused (skip to Q.5)

2. Does your client currently smoke cigarettes every day, some days or not at all?
- Everyday
- Some days
- Not at all
- Don’t know
- Refused

3. During the past 30 days, on how many days did your client smoke cigarettes? _____ (# days)

4. During the past 30 days, on the days that your client smoked, how many cigarettes did your client smoke per day? ______ (# cigarettes)

5. Does anyone living in your client’s home smoke cigarettes? (include those who smoke, even if they do not smoke inside the home)
- Yes
- No
- Don’t know
- Refused

Physical Activity

Please continue to answer the following questions to the best of your knowledge about the same client. If your client is in a wheelchair, please count the physical activity that your client gets from wheeling himself or herself in the wheelchair. Do not count when you or someone else pushes the client in the wheelchair and/or if the client uses a motorized wheelchair as physical activity.
1. Below is a list of barriers or challenges that you may experience when trying to help your client with a developmental disabilities be physically active. Please select the challenges/barriers to physical activity that apply to your client. Check all that apply.

☐ Aggressive behaviors from the client
☐ Client does not want to be physically active
☐ Client prefers to watch TV or movies during your shift
☐ Client is in a wheelchair or uses a walker
☐ Client has physical impairments that limits his or her ability to move or get around
☐ You have a physical impairment that limits your ability to move or get around
☐ The client lacks the financial resources
☐ The client’s parents or legal guardian
☐ The goals written in the client’s Individualized Service Plan (ISP)
☐ Your client’s daily routine
☐ None
☐ Other ______

2. How much time does your client spend walking or bicycling for travel on a typical day? _________ (# minutes)

3. In a typical week, does your client participate in any vigorous-intensity sports, fitness or recreational activities that cause large increases in breathing or heart rate such as running or basketball for at least 10 minutes continuously?

☐ Yes
☐ No [skip to question #5]
☐ Don’t know [skip to question #5]
☐ Refused [skip to question #5]

4. In a typical week, how many days does your client participate in vigorous-intensity sports, fitness or recreational activities? ______(# of days)

5. How much time does your client spend participating in vigorous-intensity sports, fitness or recreational activities on a typical day when they do these vigorous activities? _______(HH:MM)

6. In a typical week, does your client participate in any moderate-intensity sports, fitness or recreational activities that cause a small increase in breathing or heart rate such as brisk walking, bicycling, swimming, or golf for at least 10 minutes continuously?

☐ Yes
☐ No [skip to question #8]
☐ Don’t know [skip to question #8]
☐ Refused [skip to question #8]

7. In a typical week, how many days does your client participate in moderate-intensity sports, fitness or recreational activities? ______(# of days)

8. How much time does your client spend participating in moderate-intensity sports, fitness or recreational activities on a typical day when they do these moderate activities? _______(HH:MM)

9. How much time does your client spend sitting on a typical day? _______(HH:MM)

10. During the past 30 days, on average, how many hours per day does your client sit and watch TV, movies or videos?

☐ 0-60 minutes (0-1 hour)
☐ 61-120 minutes (1-2 hours)
☐ 121-180 minutes (2-3 hours)
☐ 181-240 minutes (3-4 hours)
☐ 241-300 minutes (4-5 hours)
☐ 301+ minutes (5 hours or more)
☐ My client does not watch TV or videos
☐ Refused
11. During the past 30 days, on average, how many hours per day does your client use the computer or play video games?

☐ Don’t know
☐ 0-60 minutes (0-1 hour)
☐ 61-120 minutes (1-2 hours)
☐ 121-180 minutes (2-3 hours)
☐ 181-240 minutes (3-4 hours)
☐ 241-300 minutes (4-5 hours)
☐ 301+ minutes (5 hours or more)
☐ My client does not watch TV or videos
☐ Refused
☐ Don’t know

Nutrition

Again, please continue to answer the following questions to the best of your knowledge about the same client you are unrelated to and who you provide the most care for in a typical week.

1. Below is a list of barriers or challenges that you may experience when trying to help your client with a developmental disability eat a healthy diet. Please select the challenges/barriers to healthy eating that apply to your client. Check all that apply.

☐ Aggressive behaviors from the client
☐ Client does not want to eat health foods
☐ Client prefers junk food
☐ Client uses a G-tube to eat
☐ The food available in the client’s home is unhealthy
☐ Your client has a menu for his or her meals that you must follow
☐ The lacks lacks the financial resources to purchase healthy foods
☐ The client’s parents or legal guardian
☐ The goals written in the client’s Individualized Service Plan (ISP)
☐ Your client’s daily routine
☐ None
☐ Other ______

2. In a typical week, during the past 30 days, how many servings of FRUIT does your client usually eat or drink each day? Think of a serving as being about 1 medium piece, or ½ cup of fruit, or ¾ cup of fruit juice. ______ (# servings)

3. In a typical week, during the past 30 days, how many servings of VEGETABLES does your client usually eat or drink each day? Think of a serving as being about 1 cup of raw leafy vegetables, ½ cup of other cooked or raw vegetables, or ¼ cup of vegetable juice. ______ (# servings)

4. In a typical week, during the past 30 days, how often did your client drink regular soda pop that contains sugar? Do not count diet soda pop. ______ (# times per week) or ______ (# times per day)

5. In a typical week, during the past 30 days, how often did your client drink sugar-sweetened fruit drinks such as Kool-Aid or lemonade, sweet tea, coffee drinks, and sports/energy drinks (such as Gatorade and Red Bull). Do not include 100% fruit juice, diet drinks or artificially sweetened drinks. ______(# times per week) ______(# times per day)

6. During the past 7 days, how many times did your client eat fast food, including fast food meals eaten at work, at home or at fast-food restaurants, carryout or drive thru?

☐ Never
☐ Once during the past seven days
☐ Twice during the past seven days
☐ Three times during the past seven days
☐ Four times during the past seven days
☐ Five times during the past seven days
Six times during the past seven days
☐ Seven times during the past seven days
☐ More than seven times during the past seven days

Social cognitive constructs

Again, please continue to answer the following questions to the best of your knowledge about the same client you are unrelated to and who you provide the most care for in a typical week.

Environment

1. Does your client have…

<table>
<thead>
<tr>
<th>A. …exercise equipment in his/her house?</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. …a space to exercise inside his/her house?</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>C. …access to outdoor recreational places such as parks nearby?</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>D. …access to indoor recreational facilities such as gyms, pools, or recreation centers?</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
</tbody>
</table>

2. How much do you agree or disagree with the following statements?

<table>
<thead>
<tr>
<th>A. Most of the food in your client’s house is healthy.</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly Agree</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. There are snack foods such as potato chips, pretzels, corn chips, or cheese puffs in your client’s house.</td>
<td>Disagree</td>
<td>Somewhat Disagree</td>
<td>Neither agree nor disagree</td>
<td>Somewhat agree</td>
<td>Strongly Agree</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>C. There are a variety of healthy foods available in your client’s house.</td>
<td>Disagree</td>
<td>Somewhat Disagree</td>
<td>Neither agree nor disagree</td>
<td>Somewhat agree</td>
<td>Strongly Agree</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>D. There are a lot of sweets such as candy, ice cream, cake, pies, or pastries in your client’s house.</td>
<td>Disagree</td>
<td>Somewhat Disagree</td>
<td>Neither agree nor disagree</td>
<td>Somewhat agree</td>
<td>Strongly Agree</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>E. There is fruit (either fresh, frozen or canned) in your client’s house.</td>
<td>Disagree</td>
<td>Somewhat Disagree</td>
<td>Neither agree nor disagree</td>
<td>Somewhat agree</td>
<td>Strongly Agree</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>F. There are vegetables (either raw, frozen or canned) in your client’s house.</td>
<td>Disagree</td>
<td>Somewhat Disagree</td>
<td>Neither agree nor disagree</td>
<td>Somewhat agree</td>
<td>Strongly Agree</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
</tbody>
</table>

Incentive motivation

It is well-known that working in the field of developmental disabilities can be overwhelming at times for care providers. One way care providers may encourage or discourage their clients from doing things is by giving or taking away rewards. The following questions ask you about
strategies you may have used with your client. Please think about the same client when answering the following questions.

<table>
<thead>
<tr>
<th>3. How often do you…</th>
<th>Never</th>
<th>Seldom</th>
<th>Several times a month</th>
<th>Several times a week</th>
<th>Most days</th>
<th>Everyday</th>
<th>Don’t know/NA</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. … give your client special treats such as sweets, soda or salty snacks as a reward?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>B. …allow your client to watch extra TV or videos, use the computer or play video games as a reward?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>C. …praise your client for being physically active?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>D. …praise your client for eating fruits and vegetables?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>E. …allow your client to smoke cigarettes as a reward?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>F. …withhold special treats such as sweets, soda, or salty snacks for your client’s poor behavior?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>G. …take away your client’s TV, computer or video games for poor behavior?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>H. …take away cigarettes from your client (if they smoke) for poor behavior?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
</tbody>
</table>

Facilitation

<table>
<thead>
<tr>
<th>4. While working with your client, how often do you…</th>
<th>Never</th>
<th>Seldom</th>
<th>Several times a month</th>
<th>Several times a week</th>
<th>Most days</th>
<th>Everyday</th>
<th>Don’t know/NA</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. …watch TV, movies or play videos games with your client?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
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<tr>
<td>B. …give your client soda pop?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>C. …set limits on how many sweets, sodas, or salty snacks your client can have?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>D. …sit with your client during meals?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
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<tr>
<td>E. …let your client eat whatever he or she wants to eat?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
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<td>Question</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
<td>Refused</td>
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<td>F. …give your client fruit?</td>
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<td>G. …give your client vegetables?</td>
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<td>H. …give your client treats such as candy, cookies, brownies or cakes?</td>
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<tr>
<td>I. …prepare meals for your client that includes fruits and vegetables?</td>
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<td>J. …help your client set goals to improve their eating habits?</td>
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<td>K. …take your client to the grocery store?</td>
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<td>L. …help your client make a healthy snack?</td>
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<tr>
<td>M. …help your client prepare a meal that includes fruits and vegetables?</td>
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<tr>
<td>N. …allow your client to eat snacks whenever he/she wants?</td>
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<tr>
<td>O. …allow your client to choose his or her own meals and snacks?</td>
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<tr>
<td>P. …involve your client in meal planning?</td>
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</tr>
<tr>
<td>Q. …allow your client to participate in meal preparation?</td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>R. …transport your client someplace for him/her to be physically active?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>S. …allow your client to choose an activity that involves being physically active?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>T. …encourage your client to drink water?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>U. …take your client to get meals from fast food restaurants?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>V. … allow your client to smoke cigarettes around you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
W. … wait for your client to finish smoking before doing an activity? | Never | Seldom | Several times a month | Several times a week | Most days | Everyday | Don’t know/ NA | Refused
---|---|---|---|---|---|---|---|---
X. … take your client someplace to smoke | Never | Seldom | Several times a month | Several times a week | Most days | Everyday | Don’t know/ NA | Refused
Y. … purchase or give cigarettes to your client? | Never | Seldom | Several times a month | Several times a week | Most days | Everyday | Don’t know/ NA | Refused

**Role-modeling**

5. Thinking about the past month, how often did you…

<table>
<thead>
<tr>
<th>Never</th>
<th>Seldom</th>
<th>Several times a month</th>
<th>Several times a week</th>
<th>Most days</th>
<th>Everyday</th>
<th>Don’t know/NA</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. … eat the same foods you offered to your client?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
</tr>
<tr>
<td>B. … tell your client that you liked the food that was being served?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
</tr>
<tr>
<td>C. … eat sweets or salty snacks in front of your client?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
</tr>
<tr>
<td>D. … drink sugary drinks, such as soda pop or sweet tea, in front of your client?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
</tr>
<tr>
<td>E. … do something physically active with your client such as taking a walk or doing exercises together</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
</tr>
<tr>
<td>F. … smoke cigarettes in front of your client?</td>
<td>Never</td>
<td>Seldom</td>
<td>Several times a month</td>
<td>Several times a week</td>
<td>Most days</td>
<td>Everyday</td>
<td>Don’t know/NA</td>
</tr>
</tbody>
</table>

6. Thinking about the past month, please select how often the following happens

<table>
<thead>
<tr>
<th>All the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. I eat healthy foods in front of my client</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know</td>
</tr>
<tr>
<td>B. I show enthusiasm towards eating healthy foods to my client.</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know</td>
</tr>
<tr>
<td>D. I eat fruits and/or vegetables in front of my client.</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know</td>
</tr>
<tr>
<td>E. I eat meals from fast-food restaurants in front of my client.</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know</td>
</tr>
<tr>
<td>F. My client sees me being physically active.</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>
### G. My client sees me watch TV, use my cell phone, use the computer or play video games.

<table>
<thead>
<tr>
<th>All the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
</table>

#### Policy

1. Does your client or his/her guardian have any household rules or policies about smoking?
   - Yes [go to question #2]
   - No [skip to question #3]
   - Don’t know [skip to question #3]
   - Refused [skip to question #3]

2. What are the rules or policies about smoking in your client’s household? (Check all that apply)
   - No one can smoke inside the house
   - No one can smoke outside the house
   - You may not smoke at all during your shift
   - Client can smoke inside the house
   - Client can smoke outside of the house
   - Other ___________________(please specify)
   - Don’t know
   - Refused

3. Does your client or his/her guardian have a rule or policy about what types of foods or drinks you are allowed to have during your shift?
   - Yes ___________________(please specify rule)
   - No
   - Don’t know
   - Refused

#### Health Behaviors: Direct Support Professional

**Smoking behaviors**

1. Have you smoked at least 100 cigarettes in your entire life?
   - Yes
   - No [skip to physical activity section]
   - Don’t know [skip to physical activity section]
   - Refused [skip to physical activity section]

2. Do you now smoke cigarettes everyday, some days or not at all?
   - Everyday
   - Some days
   - Not at all
   - Don’t know
   - Refused

3. During the past 30 days, on how many days did you smoke cigarettes? _____(# days)

4. During the past 30 days, on the days that you smoked, how many cigarettes did you smoke per day? ____ (# cigarettes)

5. During your work shift, where do you usually smoke cigarettes?
   - Inside client’s house
   - Outside of the client’s house
   - I do not smoke at all while at work
   - I do not smoke
   - Other ____________(please specify)

#### Physical activity

1. How much time do you spend walking or bicycling for travel on a typical day? ________ (# minutes)
2. In a typical week, do you participate in any vigorous-intensity sports, fitness or recreational activities that cause large increases in breathing or heart rate such as running or basketball for at least 10 minutes continuously?
  □ Yes
  □ No [skip to question #5]
  □ Don’t know [skip to question #5]
  □ Refused [skip to question #5]

2. How many days in a typical week, do you participate in vigorous-intensity sports, fitness or recreational activities? _____(# of days)

4. How many minutes do you spend participating in vigorous-intensity sports, fitness or recreational activities on a typical day when you do these vigorous activities? _____(# minutes)

5. In a typical week, do you participate in any moderate-intensity sports, fitness or recreational activities that cause large increases in breathing or heart rate such as brisk walking, bicycling, swimming, or golf for 10 minutes continuously?
  □ Yes
  □ No
  □ Don’t know
  □ Refused

8. In a typical week, on how many days do you participate moderate-intensity sports, fitness or recreational activities? _____(# of days)

7. How many minutes do you spend participating in moderate-intensity sports, fitness or recreational activities on a typical day when you do these moderate-intensity activities? _____(# minutes)

8. How much time do you usually spend sitting on a typical day? ______(HH:MM)

9. Thinking about the past 30 days, on average, how many hours per day do you sit and watch TV, movies, or videos?
  □ 0-60 minutes (0-1 hour)
  □ 61-120 minutes (1-2 hours)
  □ 121-180 minutes (2-3 hours)
  □ 181-240 minutes (3-4 hours)
  □ 241-300 minutes (4-5 hours)
  □ 301+ minutes (5 hours or more)
  □ My client does not watch TV or videos
  □ Refused
  □ Don’t know

10. Thinking about the past 30 days, on average, how many hours per day do you use the computer or play video games?
  □ 0-60 minutes (0-1 hour)
  □ 61-120 minutes (1-2 hours)
  □ 121-180 minutes (2-3 hours)
  □ 181-240 minutes (3-4 hours)
  □ 241-300 minutes (4-5 hours)
  □ 301+ minutes (5 hours or more)
  □ My client does not watch TV or videos
  □ Refused
  □ Don’t know

**Nutrition**

1. In a typical week, during the past 30 days, how many servings of FRUIT do you usually eat or drink each day? Think of a serving as being about 1 medium piece, or ½ cup of fruit, or ¾ cup of fruit juice. _____# servings

2. In a typical week, during the past 30 days, how many servings of VEGETABLES do you usually eat or drink each day? Think of a serving as being about 1 cup of raw leafy vegetables, ½ cup of other cooked or raw vegetables, or ¼ cup of vegetable juice. _____# servings
2. In a typical week, during the past 30 days, how often did you drink regular soda pop that contains sugar? Do not count diet soda pop. ______(# times per week) ______(# times per day)

3. In a typical week, during the past 30 days, how often did you drink sugar-sweetened fruit drinks such as Kool-Aid or lemonade, sweet tea, coffee drinks, and sports/energy drinks (such as Gatorade and Red Bull). Do not include 100% fruit juice, diet drinks or artificially sweetened drinks. ______(# times per week) ______(# times per day)

4. During the past 7 days, how many times did you eat fast food, including fast food meals eaten at work, at home or at fast-food restaurants, carry out or drive thru?
   - Never
   - Once during the past seven days
   - Twice during the past seven days
   - Three times during the past seven days
   - Four times during the past seven days
   - Five times during the past seven days
   - Six times during the past seven days
   - Seven times during the past seven days
   - More than seven times during the past seven days

**Demographics: direct support professional**

1. How old are you? _____(years)

2. Gender (select one)
   - Male
   - Female
   - Don’t know
   - Refused

3. How long have you worked as a direct care provider? _____(#months) or _____(#years)

4. About how many hours a week do you work as a direct care provider? _____(# hours)

5. What is the highest degree or level of school that you have completed?
   - Less than high school
   - High school diploma or GED
   - Some college or Associate’s degree
   - College degree or higher
   - Don’t know
   - Refused

6. What best describes your martial status?
   - Married
   - Divorced
   - Widowed
   - Separated
   - Never married
   - A member of a unmarried couple
   - Don’t know
   - Refused

7. Which of the following best describes your race? (Check all that apply)
   - White/Caucasian
   - African American or Black
   - Native American or Alaskan Native
   - Asian
   - Pacific Islander
   - Other
   - Don’t know
   - Refused

8. Which of the following conditions do you have, if any? (Check all that apply)
   - Heart disease
   - High blood pressure/hypertension
   - Arthritis
   - Asthma
☐ Diabetes
☐ Other condition __________________ (please specify)

9. Do you have any health problems that require you to use special equipment, such as a cane, wheelchair, special bed or special telephone?
☐ Yes
☐ No
☐ Don’t know
☐ Refused

10. Would you say that in general your health is?
☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Don’t know
☐ Refused

11. On average, how many hours of sleep do you get in a 24-hours period? ______ (# hours)

**Stress**

<table>
<thead>
<tr>
<th>1. In the past month, how often have you felt…</th>
<th>Never</th>
<th>Almost never</th>
<th>Sometimes</th>
<th>Fairly often</th>
<th>Very often</th>
<th>Don’t know/NA</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. …that you were unable to control the important things in your life?</td>
<td>Never</td>
<td>Almost never</td>
<td>Sometimes</td>
<td>Fairly often</td>
<td>Very often</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>B. …confident about your ability to handle your personal problems?</td>
<td>Never</td>
<td>Almost never</td>
<td>Sometimes</td>
<td>Fairly often</td>
<td>Very often</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>C. …that things were going your way?</td>
<td>Never</td>
<td>Almost never</td>
<td>Sometimes</td>
<td>Fairly often</td>
<td>Very often</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
<tr>
<td>D. …difficulties were piling up so high that you could not overcome them?</td>
<td>Never</td>
<td>Almost never</td>
<td>Sometimes</td>
<td>Fairly often</td>
<td>Very often</td>
<td>Don’t know/NA</td>
<td>Refused</td>
</tr>
</tbody>
</table>

**Social Support**

<table>
<thead>
<tr>
<th>2. Please tell me how much you agree or disagree with the following statements?</th>
<th>Very strongly disagree</th>
<th>Strongly disagree</th>
<th>Mildly disagree</th>
<th>Neutral</th>
<th>Mildly agree</th>
<th>Strongly agree</th>
<th>Very strongly agree</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. There is a special person who is around when I am in need.</td>
<td>Very strongly disagree</td>
<td>Strongly disagree</td>
<td>Mildly disagree</td>
<td>Neutral</td>
<td>Mildly agree</td>
<td>Strongly agree</td>
<td>Very strongly agree</td>
<td>Refused</td>
</tr>
<tr>
<td>B. There is a special person with whom I can share my joys and sorrows.</td>
<td>Very strongly disagree</td>
<td>Strongly disagree</td>
<td>Mildly disagree</td>
<td>Neutral</td>
<td>Mildly agree</td>
<td>Strongly agree</td>
<td>Very strongly agree</td>
<td>Refused</td>
</tr>
<tr>
<td>C. My family really tries to help me.</td>
<td>Very strongly disagree</td>
<td>Strongly disagree</td>
<td>Mildly disagree</td>
<td>Neutral</td>
<td>Mildly agree</td>
<td>Strongly agree</td>
<td>Very strongly agree</td>
<td>Refused</td>
</tr>
<tr>
<td>D. I get the emotional help and support I need from my family.</td>
<td>Very strongly disagree</td>
<td>Strongly disagree</td>
<td>Mildly disagree</td>
<td>Neutral</td>
<td>Mildly agree</td>
<td>Strongly agree</td>
<td>Very strongly agree</td>
<td>Refused</td>
</tr>
<tr>
<td>E. I have a special person who is a real source of comfort to me.</td>
<td>Very strongly disagree</td>
<td>Strongly disagree</td>
<td>Mildly disagree</td>
<td>Neutral</td>
<td>Mildly agree</td>
<td>Strongly agree</td>
<td>Very strongly agree</td>
<td>Refused</td>
</tr>
</tbody>
</table>
### Psychological Distress

<table>
<thead>
<tr>
<th>3. During the past 30 days, about how often did you feel…</th>
<th>All the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
<th>Don’t know/refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. …nervous?</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know/refused</td>
</tr>
<tr>
<td>B. …hopeless?</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know/refused</td>
</tr>
<tr>
<td>C. …restless or fidgety?</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know/refused</td>
</tr>
<tr>
<td>D. …so depressed that nothing could cheer you up?</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know/refused</td>
</tr>
<tr>
<td>E. …that everything was an effort?</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know/refused</td>
</tr>
<tr>
<td>F. …worthless</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
<td>Don’t know/refused</td>
</tr>
</tbody>
</table>

### Perceptions of ability to promote health

1. How much of a role do you think you have in promoting the health of your client with a developmental disability?
   - [ ] Not much of a role
   - [ ] Somewhat of a role
   - [ ] A large role
   - [ ] Don’t know
   - [ ] Refused
<table>
<thead>
<tr>
<th>2. How easy or difficult would it be for you to help your client…</th>
<th>Very difficult</th>
<th>Somewhat difficult</th>
<th>Neither difficult nor easy</th>
<th>Somewhat easy</th>
<th>Very easy</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. … be physically active?</td>
<td>Very difficult</td>
<td>Somewhat difficult</td>
<td>Neither difficult nor easy</td>
<td>Somewhat easy</td>
<td>Very easy</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>B. … eat more fruits and vegetables?</td>
<td>Very difficult</td>
<td>Somewhat difficult</td>
<td>Neither difficult nor easy</td>
<td>Somewhat easy</td>
<td>Very easy</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>C. … eat less meals from fast food restaurants?</td>
<td>Very difficult</td>
<td>Somewhat difficult</td>
<td>Neither difficult nor easy</td>
<td>Somewhat easy</td>
<td>Very easy</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>D. … drink less sugary drinks such as soda pop?</td>
<td>Very difficult</td>
<td>Somewhat difficult</td>
<td>Neither difficult nor easy</td>
<td>Somewhat easy</td>
<td>Very easy</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>E. … watch less T.V.?</td>
<td>Very difficult</td>
<td>Somewhat difficult</td>
<td>Neither difficult nor easy</td>
<td>Somewhat easy</td>
<td>Very easy</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>F. … help your client quit smoking (if they smoke)?</td>
<td>Very difficult</td>
<td>Somewhat difficult</td>
<td>Neither difficult nor easy</td>
<td>Somewhat easy</td>
<td>Very easy</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
</tbody>
</table>

This concludes the survey. Thank you for taking the time to complete this survey. After pressing submit, you will be directed to a webpage to register for your $20 Wal-Mart gift card. Please feel free to leave any comments in the space below.
Appendix I: Gift Card Documentation
Gift Card Documentation

In order to process your electronic gift card, we need the following information: name, e-mail address and best phone number to reach you. This personal information will be kept confidential and stored separately from the responses you provided in the survey.

Name: ______________(first) ____________ (last)
E-mail address to send the gift card: ______________________________
Best phone number to reach you: XXX-XXX-XXXX
You will receive your $20 gift card to Wal-Mart by e-mail within the next 48 hours.

If you have any questions, please e-mail me at leser.5@osu.edu or call me at 614-947-9867.

Thank you for your time.