

EXPLORING THE PURPOSES OF ADULT DAY PROGRAMS FROM DIRECTORIAL  
STAFF PERSPECTIVES

DEANNA VERVAECKE

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## **Abstract**

Adult Day Programs (ADPs) provide supervised recreational services to community-dwelling older people living with chronic conditions and their caregivers. Generally accepted ADP purposes exist; however, findings are mixed regarding the appropriateness of these purposes and the ability of ADPs to meet them. ADP directors' perspectives are also often missing from ADP literature. An exploratory sequential mixed methods study with integrated knowledge translation was used to answer three research questions: 1) What are the purposes of ADPs as perceived by ADP directors? 2) What factors enable ADP directors' pursuit of the purposes? and 3) What factors challenge ADP directors' pursuit of the purposes? Findings substantiated existing ADP purposes and discovered nuances. Several enablers of and challenges to directors' pursuit of ADP purposes were identified. Clearer understanding of ADPs' roles for clients, caregivers, and the health care system, and what makes these roles easier and harder to pursue, helps to modernize and optimize health care.

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## **Chapter One: Introduction & Review of Literature**

The first chapter of this thesis provides both an introduction and review of relevant literature. Existing literature is summarized and critiqued to provide background and build a rationale for the current study. The review begins with identifying trends of Canada's population and supports available to address these trends before narrowing to adult day programs (ADPs) as a health care and social support service for typically older people. Then, the established purposes of ADPs are explored, including potential reasons for inconsistent research findings to support the commonly accepted aims of ADPs. Gaps in the extant literature are identified with attention to the setting, primary population, and approaches of past research. The research aims and questions are presented. Finally, an overview of the study design used to answer these questions is provided.

### **Aging Population**

It is well-established that Canada's overall population is aging as large cohorts of people enter later life, while life expectancy increases and people continue to have fewer children (Statistics Canada, 2016a, 2020b, 2021). Many authoritative bodies, such as federal governments, establish "old age" as being aged 65 or older (Statistics Canada, 2021). As such, many of the statistics and research that are used throughout this thesis pertain to this chronological age group, while recognizing that cut-offs based on chronological age are arbitrary (Roebuck, 1979; World Health Organization, 2002). As of July 1, 2020, there were 6,835,866 Canadians aged 65 and older (Statistics Canada, 2021). When comparing this number to the size of the general population, older people constitute about 18% of Canada's population (Statistics Canada, 2020b). The patterns of an increasingly aging population are expected to continue with just over 25% of Canada's population being aged 65 and older by 2061 (Statistics Canada,



2016b). Further, trends are demonstrating that people aged 80 and over will make up a large portion of this 25% (Statistics Canada, 2016b).

The people that are classified within older age groups cannot and should not be characterized by dominant age stereotypes. These age stereotypes typically construct aging as a singular experience, generally one of decline and vulnerability, that all older people uniformly encounter during this stage of the life course (Gullette, 2004; World Health Organization, 2015). There is significant heterogeneity in aging experiences due to structural factors such as ethnicity, gender, income, and education, which shape more individual-level outcomes, such as the quality and quantity of relationships and recreation and leisure interests and opportunities (Bushnik et al., 2020; Ferraro et al., 2017). Nevertheless, in this diversity of aging experiences, many individuals undergo changes in their health as they age. For example, according to Statistics Canada (2020a), living with one or more chronic condition is more common for older people than for younger people. The remainder of this thesis focuses on research and services pertaining to older people who have experienced changes to their health status either before or during their later life, while acknowledging that this is not representative of all aging experiences.

As mentioned, it is common for older Canadians to be living with one or more chronic conditions and the prevalence of multimorbidity increases with age (Statistics Canada, 2020a). Dementia, Parkinson's disease, and the effects of stroke are common conditions that older people live with, and the incidence of these conditions are expected to increase (Statistics Canada, 2016b). Research also demonstrates that older people are now living with these conditions for longer periods of time than in the past (Statistics Canada, 2016b).

Both the prevalence and the extended length of time living with chronic conditions have also resulted in more individuals taking on unpaid informal caregiving roles (Arriagada, 2020).

Unpaid informal caregiving (referred to as caregiving moving forward) involves regularly providing unpaid support to others for everyday tasks and activities of daily living (Canadian Institute for Health Information, n.d.; Centers for Disease Control and Prevention, 2019). Most support for people living with chronic conditions comes from caregiving (Centers for Disease Control and Prevention, 2019; Zukewich, 2003). Adult children caring for parents or parents-in-law are the most common type of caregiving relationship (Arriagada, 2020; Chappell & Hollander, 2013). Some of these individuals are part of the “sandwich generation,” a term coined to describe those simultaneously caring for their children and older parents (Chappell & Hollander, 2013). It is also common for older people to care for other older people (Chappell & Hollander, 2013). In many caregiving situations, spouses tend to be the first option, with 34% of older caregivers providing care for a partner (Arriagada, 2020). When the 65 and older age group is separated into smaller age groups, the percentages of people caring for a partner or spouse increase, with just under half of caregivers aged 75 and older and half of caregivers aged 85 and older providing support to spouses (Arriagada, 2020).

As discussed with aging experiences, caregiving is another heterogeneous life experience that is also heavily influenced by intersections with other roles and identities, such as age, gender, occupation, and income (Chappell & Hollander, 2013). Feelings associated with the stress and burden of caregiving, such as worry, strain, and anxiety, are often discussed (Chappell & Hollander, 2013; Meisner & Binnington, 2017). Likewise, caregiver burnout, a state of biopsychosocial exhaustion that progresses from caregiver burden, is also a focus of caregiving discourse (Caregiver Burnout, n.d.; Kasuya et al., 2000). However, caregiving can also result in positive experiences from the emotional aspects of this role, such as creating closer relationships and building self-confidence (Chappell & Hollander, 2013; Meisner & Binnington, 2017; Schulz

& Sherwood, 2009). Research also demonstrates that many caregivers report they are coping well, which highlights how a person can feel stressed or burdened but still perceive their overall well-being to be good (Chappell & Hollander, 2013). Even if caregivers are experiencing stress, burden, or burnout, this might not cause a caregiver to relinquish their role (Chappell & Hollander, 2013).

These caregiving roles are most often fulfilled for people living in the community, with 85% of caregivers providing support for people in the community (Chappell & Hollander, 2013). This finding is consistent with Statistics Canada (2017) data which demonstrates that a large majority of older people (not just those living with chronic conditions) live in the community, not institutions. Together, these findings highlight how, unsurprisingly, it is common for older people to want to continue living in their homes as they age, instead of moving to institutions. This phenomenon is commonly referred to as aging in place (Allen & Ouslander, 2018; Hendig et al., 2017). Aging in place supports older people's desires to retain their independence, maintain their quality of life, and continue to live their lives in ways that are normal to them (Allen & Ouslander, 2018; Hendig et al., 2017; World Health Organization, 2007).

### **Home and Community Care**

The availability of home and community care can promote aging in place among those living with conditions that may require supports for both the older individual and their potential caregiver(s). Home and community care is a system of service delivery with multiple components. Chappell and Hollander (2013) identify case management, meal programs, home support services, home nursing, community physiotherapy and occupational therapy, group homes, and ADPs as core components of home and community care. Additional services can include transportation, discharge planning, and respite services, among others. Home and

community care services attend to both biomedical health as well as more holistic well-being due to origins in the social welfare sector (Chappell & Hollander, 2013). However, well-being tends to take a secondary position to biomedical health factors due in part to the positioning of home and community care in health departments of federal and provincial governments (Gardner, 2012). For example, although Ontario's ministries have been encouraged to consider how they are implicated in the health of Ontario's population (Ministry of Health and Long-Term Care, 2010), most ministries continue to ascribe to narrow definitions of health and believe that health is the responsibility of the Ministries of Health and LTC (Gardner, 2012).

Access to home and community care services is often controlled, or at least informed, by these health departments (Chappell & Hollander, 2013). For example, Ontario's Ministry of Health employs and organizes the delivery of home and community care at multiple levels, such as through health planners and advisors, care coordinators trained to determine service suitability and eligibility, and service agreements with organizations that provide direct services (Home and Community Care, 2021; Organizational Structure of the Ministry of Health, 2021). Ontario's home and community care system has experienced many changes over the years, influenced by federal and provincial policy decisions and elections, as well as evidence-informed decisions based on research regarding optimal models of home and community care service delivery (Home and Community Care Support Services, 2021; Update: Health System Integration, 2017). Home and community care is a particular focus of health systems for its ability to better meet people's care and support needs and potential for cost savings when compared to providing care in institutions (Chappell et al., 2004; Chappell & Hollander, 2013; Ham, 2010; Hollander & Chappell, 2007; MacAdam et al., 2009). At the time of this study, the organization of Ontario's home and community care was in flux as the provincial government introduced and began to

implement the Ontario Health Team model.

Ontario Health Teams are a change in the organization of service delivery that aim to flow services through an integrated team of primarily health, but also social service organizations in specific geographic regions within the province (Ontario Health Teams, 2021). These teams are meant to act as one coordinated, integrated organization by dismantling or blurring the distinctions between existing agencies to better meet the needs of people accessing services (Ontario Health Teams, 2021). To minimize the influence of the health system restructuring on direct service delivery, the Ministry of Health has taken a gradual approach to transitioning from Local Health Integration Networks (LHINs) to Ontario Health Teams. At the time of this study, the 14 LHIN regions had been transformed into five Ontario Health regions (Home and Community Care Support Services, 2021). With this restructuring, many people are continuing to refer to regions as “LHINs” or as “*legacy* LHINs.”

The reorganization of the health system from its previous structure (i.e., LHINs) to Ontario Health Teams is an ongoing, organic restructuring that allows each potential Ontario Health Team to define its membership, priority populations, and strategic aims, to some extent (Ontario Health Teams, 2021). As such, each Ontario Health Team looks slightly different; however, there are some consistencies required by the Ministry of Health. These requirements include that home and community care organization(s) be a member of the Ontario Health Team (Ontario Health Teams, 2021). The specific home and community care sectors, services, and organizations involved at each Ontario Health Team vary, but examples of home and community care currently included in Ontario Health Teams are the legacy LHINs home and community care, Alzheimer Societies, Meals on Wheels, March of Dimes, and ADPs.

## **Adult Day Programs**

ADPs are a community support service that falls under the home and community care umbrella. ADPs provide social, cognitive, and physical programming for adults in a supervised group setting (Ontario Community Support Association, 1999). The generally accepted purpose of ADPs is threefold: to provide support and respite opportunities for unpaid caregivers; to prevent or delay relocation to care facilities; and to preserve physical functioning of clients (Ontario Community Support Association, 1999). These three purposes have been acknowledged and established locally by the Ontario Community Support Association, an organization that advocates for home and community care services in Ontario, and the Ministry of Health, as well as globally by literature regarding ADP purposes (Anderson et al., 2012; Gaugler, 2014).

Research has established significant, positive outcomes of ADPs regarding respite for unpaid caregivers. However, significant outcomes have not been consistently found in the other two generally accepted purposes (i.e., delayed institutionalization and improved physical or functional health outcomes) (Anderson et al., 2018; Fields et al., 2014; Gaugler & Zarit, 2001). A lack of consistent findings in two of the three generally accepted purposes suggests that a closer exploration of the purposes of ADPs could be warranted.

### ***Potential Reasons for Inconsistent Research Findings***

There are many factors that could be contributing to the inconsistent findings of ADP purposes. The influence of the following factors on these findings will be addressed in this review: the operationalization of the purposes themselves; the origin and evolution of ADPs; ADPs' distinction from other age-related services; models of ADPs; types of ADPs; staff and staffing models; and the challenges and enablers that influence the pursuit of ADP purposes.

**Operationalization of Purposes.** In consideration of the inconsistent findings with two

of the ADP purposes, some researchers have questioned whether the current purposes are operationalized appropriately. For example, researchers suggest expanding delayed institutionalization from a focus on admission to long-term care (LTC) to a general decrease in health and social service use, including emergency department visits and hospital admissions (Anderson et al., 2018). Initial studies are demonstrating positive findings with this expansion of institutionalization (Kelly et al., 2016; Kelly, 2017). Researchers also suggest broadening the focus on physical health functioning to encompass other elements of health and well-being, such as psychosocial outcomes (Dabelko & Zimmerman, 2008). A recent scoping review of global literature suggests it is possible this purpose be split into two purposes regarding psychosocial well-being and physical functioning (Orellana et al., 2020b).

**Evolution of Adult Day Programs.** A lack of uniformity and standards across ADPs may also contribute to the mixed or non-significant findings regarding ADPs' purpose to delay institutionalization and improve clients' physical functioning (Anderson et al., 2012). ADPs are often discussed as originating in the mental health sector and gaining traction with the de-institutionalization movement, a shift from providing services and housing individuals in institutions to embedding services and people in the community (Fields et al., 2014), although some scholars label ADPs as "partial" institutions as they continue to provide services in designated facilities (Salari, 2002). Regardless of the specific sector and year of origin in each country, ADPs are largely described as having developed in communities based on their needs (Fields et al., 2014) and many, but not all, either initially emerged from or have eventually partnered with existing organizations to provide services (Ellen et al., 2017).

Due to the community focus, ADPs have evolved into person-centered services that are tailored to the unique make up of the community or communities they serve. That is, ADP

services account for the values, preferences, interests, and goals of clients to guide what and how services are offered (Orellana et al., 2020a). To gain insight into these areas, clients, caregivers, and ADP staff are involved (Orellana et al., 2020a). These transformations are a strength as they can increase relevance of programming to clients and responsiveness to local population health needs. However, the individuality of programs also makes it difficult to standardize policies, practices, procedures, and services that overarching purposes can inform; to communicate these purposes to stakeholders, especially those in decision-making positions such as health planners and advisors (Fields et al., 2014); and to advocate as a united collective of ADP providers.

**Distinction from Other Age-Related Services.** Perhaps due to the non-standardized origins of many ADPs, there is confusion regarding ADPs' distinction from other age-related services, namely LTC and Older Adult Centres (also referred to as senior centres). Research with potential or current ADP clients demonstrates that there is a lack of clarity between ADPs and LTC facilities for people accessing services, as many individuals conflate the two (Hopp et al., 2020; Ritchie, 2003). The confusion between the day services of ADPs and residential services of LTC are additionally obscured by their frequent co-location (Weeks, 1998).

The variety of terms used to refer to ADPs within and across countries further complicates understandings of this service, as there appears to be no common language. For example, Orellana et al. (2020b) list 10 different terms discovered in their scoping review of ADP literature involving studies from 11 different countries. Additionally, scholars conducting reviews of ADPs appear to consistently determine ADPs and Older Adult Centres to be similar enough to analyze together (Ellen et al., 2017; Orellana et al., 2020b); however, there are important distinctions between these two services. ADPs and Older Adult Centres are often funded differently in Ontario, with ADPs receiving funding from LHINs and only some Older



Adult Centres receiving funding from LHINs (Older Adult Centres' Association of Ontario, 2016). This difference in funding is likely a reflection of the different populations they program for. While ADPs and Older Adult Centres often serve older people (i.e., those aged 65 or older), their populations tend to be different. Older adults with “heavy care needs” (e.g., living with dementia) are not allowed to participate (overtly or covertly) at Older Adult Centres or independently cease to access Older Adult Centres (Calsyn et al., 1996; Hostetler, 2011; Rozanova et al., 2012). In contrast, ADPs are positioned to support these excluded individuals, sometimes in a directed manor through the various types of ADPs.

**Types of ADPs.** ADPs can be organized according to the type of ADP, which is largely based on clients served. The terms used for ADP types vary across regions. Commonly offered ADP types are: 1) integrated (also referred to as blended or supportive), which provide services for a variety of clients; and 2) dementia-specific (also referred to as specialized), which provide services to people living with dementia or memory problems. Other ADP types include acquired brain injury, aphasia, and stroke. Across these types of ADPs, ADP clients are typically older individuals (Fields et al., 2014); however, ADPs also provide services to populations younger than 65 according to community need (Anderson et al., 2014). It is possible that adherence to and conceptualization of ADP purposes differs according to the type of ADP. For example, dementia-specific ADPs may find it more difficult to preserve cognitive and physical functioning of clients as various types of dementia are typically progressive and can result in changes to memory, language, orientation, and ability to complete activities of daily living (World Health Organization, 2006). Expanding ADP purposes to acknowledge the potential impacts on psychosocial benefits, such as impacting quality of life, may be more appropriate for this client group (Fields et al., 2014; Orellana et al., 2020b). It is also possible that preventing transitions to

institutions, such as LTC, is not the goal of the client or the caregiver, and “delaying” might be a more appropriate conceptualization of this possible ADP purpose (MetLife Mature Market Institute, 2010), although it is difficult to operationalize “delay” (Dabelko & Zimmerman, 2008).

**Adult Day Program Models.** To make sense of the variations between and types of ADPs, researchers and practitioners have created models of ADPs and typologies to organize these models. The most commonly referenced typology has three models: medical; social; and mixed (Anderson et al., 2012; Dabelko & Zimmerman, 2008; Harder et al., 1986; Leitsch et al., 2001). Practically, the different models illustrate what is prioritized in service delivery (Harder et al., 1986; Leitsch et al., 2001). Medical models focus on clinical personal care and overall functioning, while social models focus on social interaction and therapeutic recreation, and mixed models have a dual focus on clinical care/overall functioning and social interaction/therapeutic recreation (Harder et al., 1986; Leitsch et al., 2001). The decision of what to prioritize, and therefore what model to follow is influenced by how an ADP is funded. For example, in the United States, ADPs funded through Medicaid focus on clinical health and use a medical model, and those funded through the Older Americans Act or Social Service Block Grant follow the social model (Harder et al., 1986; Leitsch et al., 2001).

Although there is variation within and across these models (Dabelko & Zimmerman, 2008), and there is little research on how these models actually influence service delivery (Leitsch et al., 2001), many ADP directors refer to these models in practice to describe their approach to ADP services. As with ADP types, the aims of ADPs may differ according to the model of ADP. For example, an ADP following a medical model might align itself with and empirically demonstrate that it can meet the three generally accepted purposes, whereas an ADP following a social model might encourage the purposes to expand or add purposes that

acknowledge more social and holistic concepts, such as well-being, quality of life, and social connections.

**Staff and Staffing Models.** The previous factors discussed, specifically the combination of ADP model and type, can influence the staff and staffing models and potentially the purposes of an ADP. ADPs following a medical model employ regulated health care professionals, such as nurses and physiotherapists, who can attend to the clinical care needs of individuals (Harder et al., 1986; Leitsch et al., 2001). ADPs following a social model employ people with expertise in social connection and recreation, such as therapeutic recreationists (Harder et al., 1986; Leitsch et al., 2001). ADPs using a mixed model employ a mix of staff with these professional backgrounds (Harder et al., 1986; Leitsch et al., 2001).

Further, ADPs may seek out and employ staff with expertise according to their ADP type. For example, ADPs with aphasia programs employ speech language pathologists and/or communication disorder assistants, and dementia-specific ADPs ensure their staff have training in working with people with dementia such as the DementiAbility Methods (Leitsch et al., 2001). Directors are also often hired by organizations to ensure the individual leading the ADP has a background that aligns with the ADP's purpose. The intentional mixture of staff with various professional backgrounds influences the types of services that are appropriate and legal to provide. For example, medications can only be administered and delegated by regulated health care professionals (Health Profession Regulators of Ontario, n.d.). These services can in turn influence if and how the three generally accepted ADP purposes are met.

**Challenges and Enablers.** A mix of challenges and enablers to pursuing ADP purposes might also contribute to the inconsistent findings regarding ADP purposes and ADP providers' abilities to meet them. That is, the optimal delivery of ADPs may not be fully realized due to

various factors that influence ADPs in differentiating ways. Constraining factors may be hindering providers' capabilities to meet their ADP purposes. The most consistent challenges identified by the ADP literature primarily conducted in the United States are funding and financial concerns, which often stem from inadequate government reimbursements (Anderson et al., 2012; Fields et al., 2014; Harder et al., 1986; MetLife Mature Market Institute, 2010; O'Keeffe & Siebenaler, 2006; Partners in Caregiving, 2002; Sanders et al., 2009). Government funding given to ADPs does not usually cover the entire cost of service provision. The ADP administrators involved in Sanders et al.'s (2009) study speculated that funding concerns were embedded in the Adult Day Service system, as well as the broader system of services for older people. ADP directors have also commented on difficulties with recruiting and retaining staff given the influence of low funding on staff wages (Anderson et al., 2012; O'Keeffe & Siebenaler, 2006; Partners in Caregiving, 2002; Sanders et al., 2009).

The physical environment in which ADPs deliver services can also be constraining due to limitations in space needed to accommodate the increasing number of people eligible and interested in attending ADPs and the outdated structures out of which many ADPs operate (Anderson et al., 2012; MetLife Mature Market Institute, 2010). Travel to and from ADPs is also challenging in terms of cost and available transportation services that are appropriate for ADP clients (Anderson et al., 2012; O'Keeffe & Siebenaler, 2006), especially for ADPs operating in rural areas (Sanders et al., 2009). Many research studies have also found that a lack of community awareness regarding the role of ADPs and widespread misperceptions of ADPs as the equivalent to child daycare, coupled with low marketing of ADP services and low legislative support are challenges for ADPs (Anderson et al., 2012; MetLife Mature Market Institute, 2010; O'Keeffe & Siebenaler, 2006; Sanders et al., 2009). There are also challenges with respect to

clients. ADP directors have commented on how the increasing acuity, range of ages (i.e., both younger and older populations), variety of conditions (particularly cognitive abilities), and increasing number of people eligible and suitable for ADP services has introduced complexities for the pursuit of ADP purposes (Anderson et al., 2012; Gaugler, 2014; MetLife Mature Market Institute, 2010; Orellana et al., 2020a).

In contrast, some ADPs may experience enablers that uniquely encourage their capacity to meet ADP purposes. Enablers are much less often explored and discussed in the ADP literature. However, for research that has explored this topic, it is common for ADP directors to comment on the relationships staff build with participants and staff's dedication to their roles as enabling the pursuit of ADP purposes (O'Keeffe & Siebenaler, 2006; Sanders et al., 2009).

### **Research Gaps**

In addition to critically reviewing the characteristics of ADPs that can influence the ADP purposes and directors' abilities to meet them, it is also important to consider elements of the literature that have and continue to influence the understanding of what ADP purposes are and how ADPs do or do not meet these purposes. Much of the research published in this topic area has been conducted in the United States (Ellen et al., 2017; Orellana et al., 2020b). This body of literature from the United States is limited in its generalizability to a Canadian context due to a variety of factors, primarily differences in health care and social service systems and the absence of a national ADP organization in Canada.

The current ADP literature is also primarily informed by the experiences and perspectives of clients and caregivers in areas such as outcomes, effectiveness, and fit in health care and social services (Ellen et al., 2017). These studies have found positive results, as well as health system implications (Ellen et al., 2017). However, there is a gap in the literature examining the

influence and perspectives of ADP directors on the operation of ADPs (Ellen et al., 2017). Understanding the perspectives of ADP directors is important as they are responsible for guiding the operation of ADPs according to their perceived purpose(s) of ADPs. ADP directors are also positioned to interact with many, if not all, ADP stakeholders, such as clients, caregivers, frontline staff, transportation services, other health and social service providers, and health planners and advisors. Despite limited evidence and consultation with individuals working directly in ADPs, there is also a growing interest in ADPs from health planners and advisors for their potential health promotion and prevention capabilities, health system implications, cost-efficiencies, respite services, and ability to address the emerging health needs of an aging population (Ellen et al., 2017; Fields et al., 2014; Orellana et al., 2020b; Public Health Agency of Canada, 2019). An increased understanding of the purpose of ADPs and existing enablers and challenges to meeting these purposes is necessary to ensure that the heightened focus on ADPs is appropriate, well-supported, and sustainable.

### ***Collaborative Research***

ADP scholars have begun to engage with ADP directors in recent years (Anderson et al., 2012; Sanders et al., 2009). This research, while grounded in gaps in the literature, tends to take a traditional approach to research where investigators lead the research through methods such as researcher designed questionnaires, interviews, and focus groups (Anderson et al., 2012; Sanders et al., 2009). Although this research is valuable, there may be limitations in investigator-driven and designed research. For example, when scholars and individuals in health and social service systems attempt to create a genericized definition of ADP purposes, it often falls short of capturing the nuances that affect the outcomes ADPs have on those who use them and the broader health care and social service system (Fields et al., 2014). Greater involvement of those

who are directly connected to ADPs, such as ADP directors, staff, clients, and caregivers, through collaborative research approaches might overcome these challenges.

The implications of low levels of collaboration between researchers and those in the position to apply the research (referred to as knowledge users moving forward) is theorized to occur for two possible overarching reasons. The inconsistent uptake or low impact of research could be due to knowledge transfer difficulties, where the communication and dissemination of findings that occurs once a study is completed is ineffectual (Bowen & Graham, 2013; Gagliardi et al., 2017; Kothari & Wathen, 2013). The “know-do gap” could also be due to a knowledge production problem. That is, research may be somewhat or fully irrelevant to the needs and interests of potential knowledge users because they were not involved from the onset of the research (i.e., before guiding research questions are developed) (Bowen & Graham, 2013). Collaborative research approaches are positioned to address these challenges by partnering researchers and knowledge users for the entire research cycle (Nguyen et al., 2020).

There are many varieties of collaborative research, including, but not limited to, integrated knowledge translation, community-based participatory research, engaged scholarship, and mode 1 research (Nguyen et al., 2020). These approaches to research have many similarities, such as meaningful collaboration between researchers and knowledge users; shared values and principles (e.g., trust, reciprocity, fostering relationships, respect); responsiveness to study context; and extensive time and investment (Jull et al. 2017; Nguyen et al., 2020). Collaborative researchers also view knowledge users as holding a diverse range of expertise and perspectives, which researchers are perceived to not have, that can help to address complex situations under study (Gagliardi et al., 2016; Gagliardi & Dobrow, 2016; Jull et al., 2017; Kothari & Wathen, 2013).

Due in part to these shared traits, collaborative research approaches share many of the same challenges, including establishing partnerships; limited resources (e.g., time, funding, and staff); a lack of skills to engage in these research approaches coupled with inconclusive evidence on how “best” to conduct collaborative research; a lack of professional incentives for researchers to conduct collaborative studies; and assumptions that studies will result in useful findings (Bowen & Graham, 2013; Gagliardi et al., 2016; Kothari & Wathen, 2013, 2017; Nguyen et al., 2020). Potentially differing perspectives between researchers and knowledge users can also be challenging, especially when knowledge users are constructed as “other” or opposite to researchers (Kajner, 2015). The COVID-19 pandemic has also introduced unique challenges to conducting collaborative research (Michael Smith Foundation for Health Research, 2021), which is traditionally advocated to be conducted in-person to strengthen partnerships (Bowen & Graham, 2013). Although there are many challenges to collaborative research, these approaches do share common facilitators, including pre-established links between researchers and knowledge users; clearly defined roles; existence of systems to support dialogue; and performing progress assessments (Gagliardi et al., 2016).

Collaborative research approaches share many similarities, including many of the same constraints and facilitators; however, these modes of research do exhibit differentiating characteristics (Nguyen et al., 2020). The differences between integrated knowledge translation and other collaborative research approaches will be expanded upon as an example given the health-related focus of ADPs. Attention will be given to the differences between integrated knowledge translation and community-based participatory research specifically as community-based participatory research is the longest established collaborative research approach (Nguyen et al., 2020).



Nguyen et al. (2020) discovered four main differences between integrated knowledge translation and other collaborative research approaches, which are supported by Jull et al.'s (2017) comparison of integrated knowledge translation and community-based participatory research specifically. First, integrated knowledge translation is the only collaborative research approach developed in health research (Nguyen et al., 2020). It originated in the 1990s in the health care sector and was taken up by the Canadian Institutes of Health Research (CIHR) (2012), which currently defines it as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (p. 1). Second, when used as an approach, integrated knowledge translation is epistemologically neutral. That is, it can align with a variety of epistemologies, including pragmatism, realism, and positivism (Nguyen et al., 2020). This epistemological stance differs from that of other collaborative research approaches which tend to have a specific epistemological stance, such as engaged scholarship aligning with critical realism (Nguyen et al., 2020). Third, although it can be present, integrated knowledge translation does not require attention to empowerment and power relations. This contrasts with community-based participatory research specifically, which carries a distinct focus on power and the operation of power (Jull et al., 2017). Finally, the main motivation of integrated knowledge translation is to apply findings (Jull et al., 2017; Nguyen et al., 2020). In other words, it focuses on the “ends” of research to create change. This primary aim differs from community-based participatory research which has a main goal of emancipating or progressing towards social justice, often through enhancing the capacity of community members (Jull et al., 2017). While integrated knowledge translation approaches can emancipate, this is not their main motivation. Further, due to the

attention to practical applications, knowledge users of integrated knowledge translation tend to be people who can impact change, such as community service providers (Jull et al., 2017; Nguyen et al., 2020).

### **Research Aims and Questions**

With the research gaps outlined above and the increased interest in ADPs, it becomes important to explore these services in a Canadian context with ADP directors. As such, the aims of the research project are to add to the ADP knowledge base within a Canadian context and to increase understandings of ADPs in a large health region to create a more informed and sophisticated description of ADP purposes in this region. The purpose of this research is guided by three research questions: 1) What are the purposes of ADPs as perceived by ADP directors? 2) What factors enable ADP directors' pursuit of the purposes? and 3) What factors challenge ADP directors' pursuit of the purposes? This research aimed to use elements of integrated knowledge translation throughout the process of developing, asking, and answering these three research questions.

### **Overview of the Study Design**

An exploratory sequential mixed-methods study design with two phases was used to answer these questions. In the first phase, qualitative description methodology was used to guide the data collection and analysis of semi-structured interviews conducted with ADP directors. In the second phase, a survey informed by the results of the first phase and guided by quantitative description was disseminated and analyzed to further understand the findings shared in the first phase and to continue to ground the research in the experiences and perspectives of participants. The next chapter expands on the design, methodology, and methods of this study.

## **Chapter Two: Research Design and Methods**

This chapter outlines the research design and methods used for this study. It begins with a description of the research paradigm. This is followed by a discussion of how integrated knowledge translation was implemented in this research. An explanation of the two-phased mixed methods study design is provided next. Following this, the settings, participants, and recruitment of this study are described. Then, the data collection and data analysis for Phases 1 and 2 are provided. The ethical considerations of this research are detailed. This is followed by a discussion of the primary researcher's reflexivity and experiences. Finally, the dissemination strategies for this study are described.

### **Research Paradigm**

Paradigmatically, this research project was informed by pragmatism. As such, the focus of this research was on real-world practices regarding the phenomenon of ADP purpose(s) and on formatting the findings to support their tangible application through exploring enablers and challenges that influence the purposes of ADPs (Creswell, 2014; Murphy, 1990). Following Dewey's conceptualization of inquiry and knowledge (as referenced in Frey, 2018), research has the ability to reconstruct contexts and make practical improvements to situations. Importantly, when concepts of reconstructing and practically improving situations were applied to this research study, the focus was not on how to answer the research questions the fastest, but on how best to answer the research questions given the questions and the context in which the research was conducted. The goal of this research was also not to create an absolute understanding of ADP purpose(s), rather it was intended to contribute to the progress of exploring and understanding this phenomenon through description and to hold space for future reconstructions that may function "better" than those discovered through this research (Frey, 2018). A pragmatic

worldview also allowed for the recognition of various contexts and experiences, which will be important to the practical application of the research findings with ADP directors of different ADPs (Cherryholmes, 1992; Creswell, 2014).

### **Integrated Knowledge Translation**

As identified in Chapter One, the practical uptake of research findings by those who can apply them (i.e., knowledge users) can be inconsistent or have low impact due to both knowledge transfer and knowledge production challenges of investigator-led research (Gagliardi et al., 2017). To address some of the potential fallbacks of engaging with knowledge users only at the end of studies, elements of integrated knowledge translation were incorporated into this study. Integrated knowledge translation was a suitable collaborative research approach to use for this study as it was health research, used a pragmatic paradigm, and was focused on the practical application of findings (Bowen & Graham, 2013; Harrison & Graham, 2012; Nguyen et al., 2020). Further, pre-established and developing professional connections between the primary researcher and knowledge users (i.e., ADP directors) facilitated integrated knowledge translation (Gagliardi et al., 2016). These knowledge users were also participants of this study.

The level of engagement researchers and knowledge users share throughout the research cycle of an integrated knowledge translation study depends on the needs and contexts of knowledge users, the nature of the research, and the findings (Gagliardi et al., 2017). The knowledge users of this research (i.e., ADP directors) have a high number of roles and responsibilities, which were amplified by the COVID-19 pandemic. This research was also part of a master's thesis that has narrow deadlines, limiting the time to engage and integrate with knowledge users. As such, engagement with the research was offered as a voluntary role for knowledge users, where the primary researcher checked in with knowledge users at key points of

the research (e.g., research question development, data collection instrument development) with rough drafts of content for knowledge users to critique, adjust, and/or support.

All interactions with knowledge users were virtual, via Zoom or email, due to the COVID-19 pandemic. Interactions began at the stage of research question development, where the primary researcher checked in with knowledge users using her established professional connections to ensure the questions were relevant and timely to be explored and that knowledge users were interested in participating in the research to some degree. A key development from these interactions was the use of terms that were relevant to knowledge users. The primary researcher had initially proposed research questions using the language of “barriers” and “facilitators”; however, upon engaging with knowledge users, it was determined that “challenges” and “enablers” aligned better with the terms used in their professional context. Knowledge users also informed the types of methods used in Phase 1 by deciding between interviews and focus groups. Once interview methods were selected and an interview guide was drafted, this guide was pilot tested with five frontline staff of an ADP to ensure that the topic and organization of questions were suitable and invited answers relevant to the research questions. Pilot testing also provided the primary researcher with the opportunity to practice interview methods before data collection began.

Following these check-ins, one ADP director from each sub-region of the larger health region acted as a voluntary knowledge user informing the design of the research in some way. Two volunteer knowledge users were more consistently involved than the other two. For example, all four volunteer knowledge users provided input on the language used in the Phase 2 survey; however, two volunteered to review the formatting and design of the survey.

## **Mixed Methods Study**

This study used a mixed methods design to develop a description of the purposes of ADPs, as well as the enablers to and challenges of meeting these purposes. Mixed methods is a rigorous approach to research that integrates both qualitative and quantitative data collection and analysis methods to create a comprehensive understanding of a phenomenon (Creswell, 2014; Creswell & Plano Clark, 2017). It is a relatively new research approach, beginning in the 1980s, which has since developed into its own methodology (Creswell, 2014). Some of the original mixed methods studies were conducted in the field of health sciences and it continues to be a methodology used in this research area (Creswell, 2014).

Using a mixed methods approach aligned with the primary researcher's pragmatic methodological paradigm, as this paradigm is not committed to one specific philosophical or theoretical orientation, but rather allows researchers to use frameworks, designs, and methods that are most appropriate to meeting the research purpose and answering the research questions (Creswell & Plano Clark, 2017; Feilzer, 2010). Due to this paradigm's openness to methodology and methods, pragmatism is the worldview of many mixed methods researchers, although it is not restricted to this study design (Frey, 2018; Morgan, 2014). Mixed methods study designs are also commonly used with knowledge translation research (Gagliardi et al., 2017).

While mixed methods research has many strengths and aligned with the aims of this research and the primary researcher's paradigm, it is not without challenges. It is time-intensive to integrate qualitative and quantitative findings, especially for a master's level research study (Creswell, 2014). Not only are mixed methods study designs time intensive, but they also require researchers to become informed of and able to carry out two different methods and be carefully attentive to the interconnections between the two methods used (Creswell, 2014). These

challenges were addressed in this study with constant revisiting of the outline and timeline of the research study as well as the assistance and oversight of and consultation with methodological experts in mixed methods, qualitative research, and quantitative research. Having these experts on the primary researcher's thesis committee and available to access through York University's Institute for Social Research (ISR) also helped to ensure that no one method was taking precedence (Smith et al., 2012).

There are many types of mixed methods studies. This mixed methods study used an exploratory sequential design. That is, the study began with a phase of qualitative research, which was followed by a second phase of quantitative research (Creswell, 2014). This sequential design allowed the second phase to be responsive to and build on the findings of the first phase and was a strategy to further inform, develop, and refine findings (Creswell & Plano Clark, 2017; Feilzer, 2010). Specifically, the qualitative findings of Phase 1 were used to create the quantitative data collection instrument of Phase 2. The findings of both phases were then integrated with equal weight to the findings of each phase, as well as attention to differences in the findings of each phase (Creswell & Plano Clark, 2017; Hong et al., 2018). The integration of findings is further described in this chapter and the following chapters of this thesis.

### ***Phase 1: Qualitative Methods***

To answer the research questions in Phase 1, qualitative description was used as the methodology. Qualitative description is an approach to research that aims to collect as much data as possible to understand a phenomenon and create a "rich, straight description" (Neergaard et al., 2009, para. 7) of that phenomenon with as little interference from the researcher as possible. Low levels of influence on the description are often achieved by using the language of participants in descriptions (Neergaard et al., 2009). This approach was suited to answer this study's research

questions in Phase 1 as qualitative description aligned with the aim of this research to increase the understanding of ADP purposes, rather than create theories or interpret the reasons behind these purposes (Neergaard et al., 2009; Sandelowski, 2000, 2010). Qualitative description was also suitable for the first phase of this study as this research topic is an understudied area that can benefit from qualitative exploration (Neergaard et al., 2009) and is relevant to practitioners or people who can apply the findings (Sandelowski, 2000). By staying close to the participants' perspectives, a description of the purposes of ADPs, which includes both the universal and more nuanced factors, could be realized.

The overall pragmatic paradigm of this study also allowed the primary researcher to use qualitative description, as it was the methodology that was most appropriate to answer the research questions and meet the research purposes (Sandelowski, 2000). Striving to stay as close to participants' descriptions as possible was important to meeting the descriptive and applied research goals of this research. However, the primary researcher also acknowledged that "all description entails interpretation" (Sandelowski, 2000, p. 335). How the primary researcher's interpretation and values and experiences were kept as low interference as possible is described in the Researcher Reflexivity and Experiences section of this chapter.

Consistent with qualitative description methodology, semi-structured interviews were used to collect data (Neergaard et al., 2009; Sandelowski, 2000). Semi-structured interviews were appropriate for this phase of the study as they allowed the research questions to be organically answered (Creswell, 2007). Additionally, a semi-structured interview guide was suitable for this research as it allowed for the systematic exploration of the research questions, as well as off-script questions to understand and probe the research topic more deeply.



### ***Phase 2: Quantitative Methods***

The second phase of this mixed methods study consisted of a cross-sectional emailed survey with closed and open-ended components. The purpose of the survey was to assess the Phase 1 responses against specific criteria to refine the ADP purposes and rate the enablers and challenges provided in Phase 1. Due to the first phase of this mixed methods study informing the second, the survey instrument was not finalized until the semi-structured interviews were completed. The inclusion of a Phase 2 survey was another opportunity to ground the findings in the participants' experiences, rather than the researcher's, consistent with both pragmatism and integrated knowledge translation used in this research as well as the qualitative description methodology used in Phase 1.

Using a survey as the consensus tool was economical and met the timeline of a master's study (Creswell, 2014; Sue & Ritter, 2007). The online setting of the survey was also convenient, especially given the COVID-19 context. Emailing the surveys was appropriate given the professional nature of the research (Sue & Ritter, 2007). All the participants had access to email and internet. The primary researcher's contact with participants through integrated knowledge translation also helped to create survey questions that were less ambiguous, more meaningful to them, and better captured the language of ADPs in each health sub-region than if the primary researcher did not connect with knowledge users (Jull et al., 2017; Sue & Ritter, 2007). As this phase was not conducted with the primary researcher directly present, the participants might have also felt more empowered to provide "honest" answers (Sue & Ritter, 2007).

### **Setting, Participants, and Recruitment**

The research was remotely conducted in a newly established health region that represents about 30% of the provincial population. According to 2016 census data, approximately 30% of

residents are aged 65 years and greater. About half of people living in this region live in urban centres while 20% live in rural areas. This region includes four legacy LHIN sub-regions. The larger health region of ADPs was selected due to the primary researcher's professional connections in three of the four legacy LHIN sub-regions. These professional connections are elaborated upon in the Researcher Reflexivity and Experiences section of this chapter. Selecting this region was also timely given its new creation and a corresponding new collaboration of ADPs located in the region.

Participants for this study met the following inclusion criteria: 1) be a current director of a Ministry of Health-funded ADP in the health region; and 2) be English-speaking. The first criterion was established to ensure that ADP directors operated their organization under the health region jurisdiction. There are some ADPs that are managed privately or informally; however, they do not have LHIN/Ontario Health oversight in these cases and might not have the same experiences as those with Ministry of Health funding. Also, there are several labels for individuals in a director role of an ADP organization. As such, participants did not need to be labelled as a "director" specifically, but they did need to have managing ADPs as a primary responsibility in their portfolio and be primarily responsible for connecting with legacy LHIN/Ontario Health representatives regarding their organization's ADP(s). The second criterion was established as the primary researcher is monolingual and conducted the data collection and analysis for both phases of the research.

Some ADPs have multiple individuals who met the inclusion criteria for a variety of reasons, such as having multiple locations which each have their own director. While having one individual from each broader ADP organization may be sufficient to answer the research questions, all interested participants who met the inclusion criteria were not refused. It was

important that each eligible individual be given the opportunity to share their perspectives in both phases of the research to build a sense of respect, ownership, and collaboration throughout the research process and uphold the integrated knowledge translation approach of the research. As such, participants were able to participate in both or either phase of this study depending on their availability, but they were not required to participate in both. Greater engagement with the research helped to work towards the pragmatic goal of the research being taken up and implemented by the participants/knowledge users (Jull et al., 2017; Nguyen et al., 2021). Former ADP directors were not contacted.

This study used both purposeful and snowball sampling recruitment techniques. The professional connections of the primary researcher were used to purposefully recruit participants in both phases. Purposeful recruitment strategies ensured the recruitment of information-rich participants (Green & Thorougood, 2014). An email script was sent to potential study participants using their professional emails to advertise the study at the beginning of both Phases 1 and 2 (see Appendices A and B). The email scripts included the study title, researchers' names and contact information, estimated time to completion, a short study description, and a description of what participants were asked to do for the phase of the study. When purposeful sampling slowed, this study also used snowball sampling techniques. The primary researcher asked previous participants if they knew of other individuals who met the inclusion criteria who may be interested in participating. These individuals recruited through snowball sampling were also contacted via email using the email script. Eligible participants who were interested in participating in the study responded to the primary researcher directly to ask questions, arrange a time to conduct the interview (for Phase 1), and later send their responses to the survey (for Phase 2).

For the first phase of the study, a private interview location was decided upon by participants. This private location was used to join a secure Zoom meeting requiring a password to join for 17 participants and used for a telephone call for one participant. In both cases, the primary researcher conducted the interview in a private location that was quiet to support privacy, audio recording, and transcription. The second phase included a survey completed online through Microsoft Word and email. These virtual options were offered due to the COVID-19 pandemic.

### **Phase 1 Data Collection**

Phase 1 data collection began with a review of the interview informed consent form (see Appendix C). Any questions participants had about the study and their participation in it were answered. Based on that information, all participants consented to participate. Participants who consented to participate provided their signature electronically after which the primary researcher returned an electronic copy with both her signature and the participant's signature.

After consenting to participate, participants began the semi-structured interviews (if over Zoom, using a password protected meeting; if over the phone, in a quiet private room) (see Appendix D for interview guide). At the beginning of semi-structured interviews, the Zoom recording and an audio recording device were turned on, with the consent of participants (which was reviewed in the informed consent form). No participants declined consent to audio recording the interview, but the primary researcher was prepared to take hard copy notes by hand if this occurred. Interviews occurred between December 4, 2020 and February 19, 2021. The interviews lasted between 39 to 118 minutes per participant.

As part of the Phase 1 data collection, the primary researcher also kept a reflective journal to make her perspectives “visible” (Lowes & Prowse, 2001). Content included in this

reflective journal were the primary researcher's values, moments during interviews when she shared her assumptions or withheld them, personal speculation as to why she chose to share her perspectives or not, and participant statements or topics that resonated with the research questions and/or the primary researcher.

### **Phase 1 Data Analysis**

Following Sandelowski (2000) and Neergaard et al.'s (2009) recommendations for the analysis of research using a qualitative description methodology, qualitative content analysis was used to analyze the data. Qualitative content analysis was appropriate for this study as it aimed to create a description of a phenomenon and a practical guide to action, rather than create a theory (Elo & Kyngäs, 2008). These aims were consistent with the Phase 1 methodology (i.e., qualitative description), the primary researcher's pragmatic worldview, and the integrated knowledge translation approach (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Kondracki et al., 2002). Content analysis is also appropriate for textual data, such as the transcripts of interviews (Kondracki et al., 2002). Although there is debate on where content analysis fits in qualitative and quantitative paradigms, the integration of both deductive and inductive approaches in this analysis reflected the integrative characteristics of the overall mixed methods study design (Elo & Kyngäs, 2008; Feilzer, 2010). Finally, the descriptions created from content analysis are only generalizable to the sample of participants, which aligned with the goals of this research to make the findings practical for ADP directors in a specific health region (Elo & Kyngäs, 2008).

To facilitate analysis, audio recordings of the semi-structured interviews were transcribed as close to verbatim as possible (Poland, 1995). As a strategy to stay "data-near" during analysis, transcripts included notes containing personal reflections on when the primary researcher noticed her assumptions and influence, as well as critical thinking of the interview process to strengthen

or guide future interviews (e.g., how “well” questions were posed). Once the transcripts were completed, the primary researcher iteratively read and familiarized herself with the transcripts. To ensure the analysis process was systematic, the primary researcher followed Elo and Kyngäs’ (2008) three broad stages to qualitative content analysis: preparation, organization, and reporting. Throughout these stages, the primary researcher used word processing software (i.e., Microsoft Word).

In the first preparation stage, the primary researcher identified the unit of analysis with which the data would be analyzed. These units can include concepts, topics, and other characteristics (Kondracki et al., 2002). Consistent with qualitative description’s aims to use participant language as much as possible, significant statements were used as the unit of analysis (Neergaard et al., 2009). Specifically, the primary researcher focused on the latent pattern content of these significant statements (Potter & Levine-Donnerstein, 1999). That is, when a surface-level indicator, such as an explicit word or synonym of a word pertaining to the research questions, was found, other indicators of that concept were sought out and coded if present (Hsieh & Shannon, 2005; Potter & Levine-Donnerstein, 1999).

For the second phase of organization, the primary researcher took a primarily deductive approach by using the research questions to create a predetermined or directed framework to organize the significant statements into categories that capture similar experiences. In alignment with the research questions, the primary researcher read and reread the interview transcripts for statements regarding ADP purposes and enablers to and challenges of these purposes. Once these significant statements were identified using the method and criteria described in the preparation phase, the primary researcher grouped them into the appropriate categories of purposes, enablers, and/or challenges. She then looked for patterns within these broader categories that suggested

statements capture the same content. This grouping of significant statements was accomplished by using an unconstrained matrix, the inductive element of this stage (Elo & Kyngäs, 2008). Specifically, the primary researcher allowed sub-groupings to emerge within the overall bounds of the broader categories that connected to the research questions (Elo & Kyngäs, 2008).

The success of these phases rested on the coding process. Therefore, to maintain intracoder consistency and accuracy, the primary researcher kept a codebook with definitions, preliminary codes, and reminders to return to the research questions and purpose when coding (Elo & Kyngäs, 2008). This codebook complemented the reflexive journal. Intracoder reliability and the uncovering of the primary researcher's less "visible" perspectives were also established through regular meetings with her supervisor who verified codes and encouraged new ways of seeing the phenomenon. These approaches also contributed to the trustworthiness of the research (Shenton, 2004). In addition, prolonged engagement with participants through integrated knowledge translation efforts, including attending large health region and sub-region network meetings prior to and during data collection, were used to strengthen credibility (Lincoln & Guba, 1985 as cited in Krefting, 1991). All of these processes were instrumental to completing the last reporting stage of content analysis that is provided in Chapter Three, which is the third and final phase.

Potter and Levine-Donnerstein (1999) also suggest that analysis of latent pattern content should meet standards set by experts. The importance of expert involvement in content analysis supported the integrated knowledge translation development of the Phase 2 survey, where four voluntary knowledge users from each sub-region iteratively provided input on the language, content, and formatting of the survey. Specifically, all four volunteer knowledge users provided input on the language used in the survey, and two reviewed the survey format and content.

## Phase 2 Data Collection

Once the survey was created, participants were invited to participate in Phase 2 (see Appendix B). Interested participants were emailed instructions (see Appendix E) to review and sign the survey consent form (see Appendix F) before completing the Microsoft Word documents containing the survey reporting and rating instructions (see Appendix G). The first page of the survey reporting document asked participants to complete demographic questions of age, gender, ethnicity/cultural background, highest level of education and additional certificates and qualifications, job title, and duties and responsibilities. On the second page, participants were asked questions about the ADP(s) they direct. These questions included: sub-region in which their ADP(s) operate; average number of clients served before COVID-19 (daily and yearly); client populations served before COVID-19 (i.e., integrated, dementia-specific, aphasia, specialized); organizational structure (i.e., standalone, under umbrella organization); building status (i.e., housed in partnership with long-term care, rent shared space, rent/own standalone location); and ADP model (i.e., social, medical, mixed).

Sections three to five of the survey asked participants to rate the Phase 1 findings regarding ADP purposes and enablers to and challenges of these purposes using Likert scales ranging from 0 to 10. The rating criteria and corresponding Likert scale descriptions were different for each section. The criteria and scales were provided in a separate instructions document based on feedback from knowledge users that they needed to access the scales more frequently than if they were only provided at the top of each section (see Appendix G).

For section three, participants were asked to rate potential purposes first based on how *relevant* they were to the *current operation* of the ADP(s) they direct and second based on how *relevant* they were to their *desired operation* using a Likert scale ranging from 0 to 10, with 0



being not at all relevant and 10 being highly relevant. For section four, participants were asked to rate enablers first according to how *strongly they support* ADP purposes and second according to the *degree to which they promote* ADP purposes using a Likert scale ranging from 0 to 10, with 0 being no support and no promotion and 10 being extreme support and extreme promotion, respectively. Finally, for section five, participants were asked to rate challenges first according to how *prominent* they were and second according to their *perceived urgency to address* using a Likert scale ranging from 0 to 10, with 0 being not at all prominent or not at all urgent and 10 being extremely prominent or extremely urgent, respectively.

For sections three to five of the survey, participants were also provided the opportunity to add items they felt were missing from the lists provided under an “Other” column. Participants were also asked to rate an item as “not applicable” if it did not apply to their experiences with ADP purposes. Finally, participants were given the opportunity to provide additional qualitative comments. The survey was initially designed to take approximately 30 to 45 minutes for participants to complete; however, feedback from participants demonstrated that it took some of them much longer to critically think about their responses and use the survey instruments. Based on feedback from early survey responders regarding the time needed to complete the survey and feedback from some knowledge users that the initial timeline (i.e., the end of April) coincided with the development of their ADP budgets, the data collection period for Phase 2 was extended. Data collection for Phase 2 started March 15, 2021 and ended May 7, 2021.

### **Phase 2 Data Analysis**

Data collection and data management of quantitative survey responses occurred simultaneously as survey responses were sent to the primary researcher. Consistent with the quantitative descriptive approach of Phase 2, for data analysis, survey item’s measures of

frequency (i.e., counts and percentages), central tendency (i.e., means, medians, and modes), and variance (i.e., minimum, maximum, standard deviation) were calculated using SPSS (Creswell, 2014; Porta et al., 2014; Sue & Ritter, 2007). For categorical survey items, counts, percentages, and modes were calculated. For continuous survey items, means, medians, modes, minimums, maximums, and standard deviations were calculated. For survey sections three to five, means were sorted from highest to lowest ratings to support description of the findings. Additional qualitative comments provided by participants were used to contextualize participants' quantitative responses to these three sections. Descriptive statistics described the group-level responses of each survey question and are provided in Chapter Three.

### **Ethical Considerations**

Ethical considerations are important to the respectful, humane, and conscientious completion of research. As such, data collection did not begin until after approval from the Office of Research Ethics at York University was received (Protocol #: e2020-354) and, for those ADPs that required it, additional organizational ethics approval (see Appendix H for draft statement provided to participants to sign). The following paragraphs outline the informed consent process, the attention to privacy and confidentiality of participants, the potential risks of participation, and the potential benefits of participation. The Tri-Council Policy Statement (CIHR, Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences and Humanities Research Council [SSHRC], 2018) was referenced throughout the creation of this research proposal to inform these ethical considerations.

### ***Informed Consent***

As described in the data collection sections of both phases, informed consent forms were sent to potential participants prior to the interview and survey to establish ongoing consent.

Providing the consent forms before the interviews and with the surveys ensured participants had the chance to read the forms and think of any questions they may have had about the study and/or participation. In both data collection phases, participants were also either given a short period of time at the beginning of data collection, or asked to provide themselves this time in the case of the survey, to ask the primary researcher or her supervisor questions. As soon as participants felt that their questions and concerns had been adequately addressed, if any, they were asked to sign the forms and email them to the primary researcher.

### ***Privacy and Confidentiality***

The one-on-one nature of the interviews and email submission of the survey responses did not allow participants to remain anonymous to the primary researcher (CIHR, NSERC, & SSHRC, 2018). However, all interactions and data provided were anonymized, and kept strictly private and confidential, unless participants consented otherwise. The opportunity to disclose identity was provided out of acknowledgement that individuals may want to be credited for their contributions to the research by being named (CIHR, NSERC, & SSHRC, 2018, Articles 5.1 and 10.4). However, due to the geographical nature of the research and close working relationships of participants, when a few participants expressed a desire to remain anonymous, the primary researcher and her supervisor determined that waiving anonymity of consenting participants could compromise the anonymity and/or welfare of non-consenting participants. Out of respect for all participants, all interview transcripts were initially de-identified, which supported the eventual decision to maintain all participants' anonymity.

### ***Data Security***

A password-protected computer on a secure network was used to store, manage, and analyze all audio recorded and resulting transcript data, as well as survey data (CIHR, NSERC,

& SSHRC, 2018, Article 5.2). After the audio recordings were transcribed, the audio recorded files and survey results were protected on an encrypted hard drive that was stored at the primary researcher's home and will be stored on York University property when in-person attendance resumes. The transcript data and printed survey results were locked in a filing cabinet when not in use in the primary researcher's home during data analysis and will be stored on York University property after data analysis is complete and COVID-19 precautions allow for in-person attendance. Data will be retained for seven years after the conclusion of the study for both Phases 1 and 2. This time frame is consistent with the discipline and allows for potential further analyses. After this time, all digital files will be wiped from the hard drive, and hard copies will be destroyed using paper shredders. Throughout the research, only the primary researcher and her supervisor had access to the data.

### ***Risks and Risk Mitigation Strategies***

Many participants regularly engage in conversations regarding the research questions, such as at adult day service network meetings, with LHIN/Ontario Health representatives, and with local health planning partners, such as Ontario Health Teams. Due to this, risks were classified as 'minimal' by York University's Office of Research Ethics as the "probability and magnitude of possible harms implied by participation in the research is no greater than those encountered in day-to-day life" of their professional roles (CIHR, NSERC, & SSHRC, 2018, p. 22). However, the potential for social, economical, and data security risks remained. There is potential for economic risk to the ADPs participants direct. For example, interview findings and survey results referred to those who provide funding to ADPs, positively and negatively. Whether positive or negative, the findings may impact funding and governance. There is also potential for professional or social risk. For example, findings may alter the perceptions of ADPs

by others in health and social services that lead to changes to relationships and administration, either positively or negatively. Finally, through using Zoom via the internet, privacy could not be guaranteed if the meetings were intercepted by a third party.

These risks were, and will continue to be, managed by preserving privacy and confidentiality of individual participants through data management (e.g., anonymized interview transcripts, safely secured paper and electronic data, etc.). Further, findings that pertain to topics or details relating to potential social, professional, and/or economic risk were reported at the group-level and were not directly labeled. In future reporting and sharing of the findings, the primary researcher will work collaboratively with participants to design and disseminate knowledge translation products to ensure content reflects their perspectives and their comfort level to mitigate risks further. As part of the informed and ongoing consent process, the researcher noted that each participant had the right to skip any questions or withdraw from the study completely at any time. Finally, to decrease the likelihood of a third-party interception, Zoom meetings had a password to enter. Participants were also given the opportunity to use the telephone instead, which one participant did.

### ***Potential Benefits***

There were, and continue to be, a variety of potential benefits for participants. Participants may have benefited by gaining experience with collaborative research and mixed methods research methods firsthand. It was also an opportunity to reflect upon their experiences with ADPs. Participants may have also found it cathartic to voice their experiences throughout the research process. Participants will be able to use findings to communicate the purpose(s) of ADPs with stakeholders and prioritize actions as a larger network using the findings regarding the description and ratings of purposes, challenges, and enablers.

### ***Conflict of Interest***

The primary researcher has worked as an unpaid intern with 15 of the potential participants (seven actual participants) in a sub-region of the larger health region. She has also worked closely with one participant and voluntary knowledge user in a student-supervisor relationship, as well as in past roles as a paid frontline worker and student. This potential conflict of interest was managed by having the primary researcher's supervisor involved in all major research decisions and the research process (e.g., data analysis). Further, as outlined in the consent forms (see Appendices C and F), participants were given the opportunity to complete data collection with the primary researcher's supervisor if they felt uncomfortable or thought there would be a conflict if they proceeded with her. The primary researcher also regularly reflected upon her dual role throughout the research process using a reflective journal. Further, her dual role strengthened the integrated knowledge translation component of the research through building relationships with knowledge users and helping to ensure the research is relevant and useful to knowledge users.

### **Researcher Reflexivity and Experiences**

Pragmatism's focus on utility for "socially useful knowledge" (Feilzer, 2010, p. 6) resonated with the primary researcher and therefore how the research questions were asked and answered. As the concept of utility is ambiguous, it became important for the primary researcher to reflexively consider the research purpose and stakeholders involved (outlined previously), as well as her own values and how they influenced the research (Feilzer, 2010). The primary researcher began volunteering with ADPs in high school which eventually developed into positions as a student and frontline worker in a variety of departments, including recreational therapy, speech language pathology, kinesiology, health promotion, and social work. Her

involvement with ADPs for ten years has influenced her professional aspirations greatly, encouraging her to pursue an undergraduate degree in health promotion at Dalhousie University. This undergraduate degree cultivated a keen interest in upstream approaches and system level adjustments to address the health care experiences of older people. The primary researcher's experiences with ADPs suggested that ADPs could play a more upstream role in the system, which encouraged her to pursue experience with ADPs in system-level roles, including as an intern with an ADP director as her supervisor. As part of this internship position, she worked with a portion of the current participant population, completing projects regarding ADP best practices, ADP accreditation, program evaluation, and knowledge translation with stakeholders. Throughout these projects, she heard and was involved with many conversations regarding the purposes of ADPs and their fit in broader health care and social service systems. These conversations and her pragmatic worldview motivated the primary researcher to pursue graduate level studies and to conduct the current study with the goal of increasing understanding of ADP purposes.

The primary researcher's experiences with ADPs and ideas of their potential role in health care and social services systems influenced the research. For example, the primary research understood most of the jargon and acronyms used by participants and recognized the role funders play in meeting the purpose(s) of ADPs through discussions overheard in past paid and unpaid positions. However, there were details of the research and research process that helped to question and make these values visible. First, while the primary researcher was familiar with many of the health region ADP directors, she was only closely familiar with one sub-region. The complete unfamiliarity with one sub-region and infrequent contact with two sub-regions provided opportunities for her to develop her understanding and engage with ADP directors with

new and different perspectives than those with which she was familiar. Second, as described in the conflict-of-interest section, the primary researcher's supervisor was involved in every stage of the research, and she used a reflective journal throughout. These details of the research process encouraged the primary researcher, and others, to question her values and assumptions. Finally, the primary researcher's experiences throughout post-secondary education encouraged her to be a critical thinker that questions assumptions.

The primary researcher was also qualified to conduct this research. She is a current MSc student in Kinesiology and Health Science at York University. As mentioned previously, she completed her BSc (Honours) in Health Promotion at Dalhousie University in 2019 for which she completed research methods, data analysis, and aging-related courses. She also completed multivariate analysis, qualitative research methods, and aging courses during the first year of her master's degree. Although the primary researcher could be considered a novice interviewer, she gained interview experience during an undergraduate women and aging course and a graduate qualitative research methods course before this study began. She also completed the Tri-Council Policy Statement 2: Course on Research Ethics (TCPS 2: CORE) in 2018 and refamiliarized herself with this content in July 2020. Finally, she completed MobilizeYU, a knowledge mobilization course offered by Innovation York that involves topics such as integrated knowledge translation, the importance of ongoing consent in community-based research, and the creation of knowledge translation plans and products (see Appendix I).

### **Dissemination Strategies**

Both community and academic audiences will be considered in dissemination of the research findings. For community audiences, presentations at annual/monthly meetings of ADPs and other health services providers (e.g., local health advisory boards, city councils, etc.);



community health care and social service conference presentations (e.g., Ontario Community Support Association Conference); fact sheets; data visualization; and advocacy materials will be co-created with participants as desired and requested. For academic audiences, conference presentations (e.g., Annual Scientific Meeting of the Canadian Association on Gerontology in 2021) and a refereed journal article will be produced.

### **Chapter Two Summary**

This chapter provided a comprehensive and detailed description of the research design, methodology, and methods for this study. Pragmatism and elements of integrated knowledge translation were two approaches used to guide the two phased mixed-methods study design. Qualitative description and quantitative description were described as methodologies that instructed the semi-structured interviews and surveys used to collect data from participants in a large health region of Ontario. Phase 1 data were analyzed using qualitative content analysis and Phase 2 data were analyzed using descriptive statistical measures of frequency, central tendency, and variance. The process in which the findings of Phase 1 informed the development and analysis of the Phase 2 survey were also described. Ethical considerations were addressed as well, with attention to the positionality of the primary researcher. This chapter ended with a description of possible dissemination opportunities of the study findings for community and academic audiences. The Phase 1 and 2 findings are detailed in the next chapter.

### Chapter Three: Results

This chapter contains the results of both the qualitative content analysis of Phase 1 and the quantitative description analysis of Phase 2. In alignment with the exploratory sequential mixed methods study design, the results of these phases are presented separately and in sequence (Fetters & Freshwater, 2015). Phase 1 results begin with a description of participants, followed by the findings related to the overarching categories of purposes, challenges, and enablers. Phase 2 results are reported next, also beginning with a description of participants and the ADPs they directed. Then, descriptive measures of frequency (i.e., counts and percentages), central tendency (i.e., means, medians, and modes), and variance (i.e., minimum, maximum, standard deviation) for the survey sections are provided.

#### Phase 1

##### *Participants*

A total of 18 ADP directors participated in Phase 1. These participants will be referred to as “interview participants” moving forward to delineate them from Phase 2 “survey participants.” A summary of interview participant details is provided in Table 1. Interview participant characteristics were discussed in response to the first question of the semi-structured interview guide. Most interview participants were female and Caucasian. Interview participants’ work experience with Community Support Services (which included but was not limited to ADPs) ranged from 9 to 30 years.

Table 1. *Phase 1 Participant Characteristics*

<b>Categorical Variables</b>	<b>n</b>	<b>%</b>
<i>Gender</i>		
Female	17	94.4
Male	1	5.6
<i>Ethnicity or Cultural Background</i>		
Caucasian	16	88.8
Indigenous	1	5.6

Other	1	5.6
<i>Title</i>		
CEO	2	11.1
Coordinator	1	5.6
Director	7	38.8
Manager	5	27.8
Supervisor	3	16.7
<b>Continuous Variable</b>	<b>M(SD)</b>	<b>Min - Max</b>
Years of CSS* Experience	19.6(5.8)	9 - 30

\*CSS: Community Support Services

Interview participants shared characteristics of the ADPs they directed in response to the second semi-structured interview guide question. A summary of ADP details is provided in Table 2. Interview participants represented each of the four health sub-regions that comprise the larger health region included in this study. Most interview participants were directors of ADPs under the umbrella of a larger organization, six of which also provided LTC services. Most participants directed ADPs according to a mixed model.

Table 2. *Adult Day Program Characteristics*

	<b>n</b>	<b>%</b>
<i>Legacy LHIN</i>		
Region 1	5	27.8
Region 2	8	44.4
Region 3	3	16.7
Region 4	2	11.1
<i>Organizational Structure</i>		
Standalone	2	11.1
Under the umbrella	16	88.9
<i>Model of ADP</i>		
Mixed	11	61.1
Social	7	38.9

### ***Presentation of Results***

Interviews with participants resulted in a wealth of rich data on the purposes of ADPs, as well as the enablers of and challenges to meeting the purposes of ADPs. Responses are categorized into three sections according to the overarching research question they addressed.

Given the number, length, and richness of quotations used to support Phase 1 findings, longer direct example quotations are included in Tables 3, 4, and 5 (found in Appendix J) which pertain to the purposes, enablers, and challenges, respectively. These direct example quotations are numbered using an identifier (e.g., T3.Q1), and these identifiers are referenced throughout the written portion of the following sections. Consistent with qualitative description, the language of participants is also integrated throughout the results section. As mentioned previously in this chapter, to distinguish Phase 1 participants from Phase 2 participants, participants will be referred to as numbered “interview participants” or “IP#” throughout this section.

### ***What are the purposes of ADPs as perceived by ADP directors?***

The purposes category represents interview participants’ perspectives on the reasons, aims, and objectives of ADPs; essentially, what ADPs are intended to do and provide to clients and caregivers. Interview participants’ descriptions of these purposes demonstrated areas of consensus, as well as differences in perspective. The following purposes were not formally sub-categorized because sub-categorization was not as emergent as with the enablers and challenges categories (Elo & Kyngäs, 2008). How the Phase 1 findings regarding purposes would be presented in the Phase 2 survey was also contemplated when considering the suitability of sub-categories for this category. However, the following findings are organized to create a flow from what could be considered direct service delivery purposes to systems-related purposes.

All interview participants mentioned “therapeutic recreation” (IP9) services were a central purpose of their ADP organizations (T3.Q1). It is important to note that all interview participants described the time spent at ADPs participating in recreational programs as “meaningful engagement” (IP3) for clients, rather than just occupying their time. In addition to this client-specific purpose, interview participants also shared caregiver-specific purposes to

provide resources, education, and support to people in this role (T3.Q2). These supports sometimes extended to coaching caregivers to advocate for their person who attends ADP (T3.Q3), while also recognizing that ADP directors themselves serve a purpose of advocating on behalf of clients and caregivers who use, or could benefit from, ADP services (T3.Q4).

All interview participants also stated that ADPs should intend to provide “respite for caregivers” (IP14). While respite was universally acknowledged as a purpose for caregivers, some interview participants noted that their respite services are for both caregivers and clients who can equally benefit from time spent in other settings and/or apart from each other (T3.Q5). Some interview participants recognized the out of home nature of caregiver and/or client respite as another important quality of ADP respite purposes (T3.Q6).

In addition to these recreational, supportive, and respite services, interview participants described ADPs as providing social connections between both clients and caregivers (T3.Q7) as well as “with the staff” (IP10). While some interview participants questioned whether the connections made could be categorized as “friendships” (T3.Q8), they strongly believed that their ADPs are intended to create relationships in ways that foster a sense of belonging within the ADP (T3.Q9). Meal services were discussed by some interview participants as achieving this social connection purpose, while also meeting an aim to support clients nutritionally (T3.Q10).

Interview participants shared outcome-oriented purposes as well; that is, purposes that existed as a result of the direct services they aimed to provide. Some interview participants mentioned that their ADP services met a purpose to “maintain the function” (IP3) of clients, which included “not just physical, but cognitive” (IP8) aspects. Other interview participants used language related to a “holistic perspective” (IP1) of health and well-being, with some actively resisting “cold” (IP10) language of “functioning.” Holistic perspectives were described as

ranging from a focus on supporting physical, social, and cognitive health to more expansive descriptions including emotional and spiritual health and well-being (T3.Q11). Interview participants' perspectives also demonstrated a nuance in terms of the extent to which ADPs aimed to influence client functioning or health and well-being broadly defined. As noted above, for some interview participants, ADPs were limited to "maintenance," (IP3) whereas for other interview participants ADPs were perceived as intending to "promote and maintain" (IP10) and "make some gains" (IP9) in their abilities, if it was appropriate and of interest to the client.

Interview participants also described overarching purposes that related to how the provision of services was implemented. For example, interview participants described how ADP services should be offered in such a way that client and caregiver "independence and choice" (IP11) are respected. Relatedly, all interview participants held the perspective that ADPs should aim to provide person-centered services to clients and caregivers, despite potential differences in specific services offered (T3.Q12). At a broader community level, interview participants discussed the purpose to be "reflective of our community and our constituents, those who we serve" (IP6).

Some interview participants discussed their purposes in terms of the ADP environment. Interview participants mentioned that it was their duty to provide environments that are safe and secure for clients based on their diverse interests and needs. Safety and security were sometimes discussed as physical concepts related to addressing exit seeking of clients, and other times as emotional concepts (T3.Q13). Some interview participants also discussed their purpose to provide environments that facilitated their recreational services, such as designing rooms for engagement (T3.Q14).

Interview participants also described ADP purposes related to other health, wellness, and

social services. All interview participants discussed connecting clients and caregivers with other services to meet their interests and abilities. For some interview participants, this connection was described as formal “care coordination services” (IP3), whereas for others, connections were described as “linking and connecting” (IP9). This linking was sometimes described as “referrals” (IP1) and other times discussed as providing information about services which clients and caregivers could independently seek out. Interview participant 9 went on to speculate that the differences in care coordination and connections could occur depending on the “capabilities” of each ADP organization. In terms of potential transitions, interview participants discussed ADPs as serving a purpose to keep people living in the community by preventing or delaying broader “institutionalization” (IP2), which was specified as referring to long-term care, retirement homes, and hospitals. Finally, interview participants discussed ADPs as supporting the overall operation of the health care system (T3.Q15).

***What enablers do ADP directors experience in pursuing ADP purposes?***

This section describes interview participants’ perspectives on what they found supported their ability to meet the ADP purposes described in the preceding section. Interview participants discussed a variety of ADP purpose enablers. Through qualitative content analysis, the following sub-categories were identified: funding and resources; organizational affiliations and governance; collaboration and partnerships; referrals; built or physical environments; approach to services and operations; staff; client and caregiver involvement; and advocacy and awareness.

**Funding and Resources.** Statements organized under the funding and resources sub-category of enablers capture interview participants perspectives on the financial and technological resources that supported their ADP purposes. Some interview participants identified the funding all ADPs receive from Ontario’s Ministry of Health as supporting their

ability to meet their ADP purposes, especially in contrast to the funding received by ADPs in the United States (T4.Q1). Interview participants also shared that “community grants have been very helpful” (IP13) to augment the base funding received from the Ministry of Health. Finally, interview participants described having “the proper technology” (IP10) and digital resources, such as “company laptops to access databases” and “Zoom accounts” (IP13), as supporting their ability to meet ADP purposes, especially during the COVID-19 pandemic.

**Organizational Affiliations and Governance.** Interview participants commented on how their various affiliations with broader organizations and the governance structures of their ADP organizations enabled them to meet their ADP purposes. Interview participants nested within larger organizations discussed a greater access to resources as a result of operating under the umbrella of a larger organization (T4.Q2). These interview participants also described how their larger associated organizations supported ADP purposes through other services offered by the organization, such as in-home respite, that complemented the services offered in their ADPs (T4.Q3). In contrast, two interview participants were not affiliated with larger organizations and described their standalone status as a smaller organization focused on ADP as supporting their purposes, specifically through their ability to make quick, responsive decisions (T4.Q4).

Both interview participants associated with smaller standalone organizations and those attached to larger organizations described their governance structure as “very, very key” (IP15) to meeting their ADP purposes when it allowed them to operate at systems levels, such as developing “quality improvement metrics or implementing new strategies or new theories or best practices” (IP15) and participating with Ontario Health Teams (IP9). Finally, some interview participants described formal affiliations with businesses that provided their ADP with resource support as an enabler of meeting their ADP purposes (T4.Q5).



**Collaboration and Partnerships.** Beyond formal affiliations, interview participants also described collaboration and partnerships as supportive of their ADP purposes. Many interview participants discussed the legacy LHIN ADP sub-region networks as “massively beneficial” (IP2) to sharing struggles, solutions, and successes related to meeting their ADP purposes (T4.Q6). A few interview participants also mentioned a recently created network of ADPs from across the larger Ontario Health region as supportive of ADPs and helping them grow into the future (T4.Q7). The relationships between ADP directors were also described by many interview participants as focused on collaboration, with some interview participants sharing that ADP directors are “not competitive as a group” (IP1).

Interview participants also described collaboration and partnerships outside of ADPs and ADP networks. Interview participants discussed supportive partnerships with other health care and support services, such as Behavioural Supports Ontario, and local community supports outside of health care, such as municipalities, post-secondary institutions, and research organizations. Larger health system changes related to “what’s happening with the government and with Ontario Health Teams” (IP4) were also discussed by interview participants as something that enabled “integrated collaboration” (IP4) with services and organizations outside of ADP networks, such as primary care. Finally, many interview participants discussed how relationships with certain LHIN or Ontario Health representatives with knowledge of and passion for ADPs and the broader community support services sector were “supportive of day programs” (IP1) and a “really great advocate” (IP12) of their purposes at higher system levels. Interview participants spoke of these representatives by name and described a familiarity from working with them.

**Referrals.** As with the collaboration and partnership discussions, LHIN staff familiarity

with ADP services was mentioned by interview participants in relation to referrals. Specifically, interview participants discussed how referrals were more likely to be suitable (i.e., people who are interested, willing, and able to attend ADP) and support social connections for clients when LHIN staff had a familiarity with their ADP and other ADPs in the area (T4.Q8). Some interview participants described the amount and depth of client information included in these referrals received from the legacy LHIN as supportive of their ADP purposes in helping to determine if and how they could support the person referred (T4.Q9). Interview participants also reflected on how changes in how people are seeking out and self-referring or referring others helped them to meet their ADP purposes (T4.Q10). Interview participants found referrals from clients and caregivers to be supportive, but also those from health care professionals outside of the legacy LHIN referral pathways.

**Built or Physical Environment.** For some interview participants, their ADP buildings were purposefully designed for the services they offered. Purposeful design was found to support recreational programming through being able to host and sometimes reorganize the room(s) to lead a variety of recreational activities (T4.Q11). Purposeful design was described as important to facilitating ADP purposes when it came to supporting clients navigate ADP environments (T4.12). The overall welcoming feeling created by the physical attractiveness of the design of the building was also described as an enabler by some interview participants (T4.Q13).

Interview participants discussed the location of their ADP as something that could enable them to meet their ADP purposes. For some interview participants, their co-location with LTC had “some beautiful benefits” such as “easy access to food, supports, and potential piggybacking of learning opportunities” (IP15), whereas others found their standalone location to be supportive. One interview participant had a unique perspective of switching from co-location

with LTC to a standalone location and shared “the advantages [of being standalone] definitely outweigh any disadvantages of not being in the long-term care home anymore” (IP6). Some interview participants who had their ADP building centrally located in their community also described this as an enabler to achieving their ADP purposes (T4.Q14). Finally, some interview participants found their location within a “smaller community” (IP9) assisted their ability to meet their ADP purposes through factors such as “less service providers” (IP9).

**Approach to Services and Operations.** This sub-category reflects the methods applied to and perspectives behind services and operations that interview participants described as supportive of their ADP purposes. These approaches to services existed at a variety of levels including direct care and operations. Some interview participants discussed specific care approaches or frameworks that they found helpful in meeting their ADP purposes. Two approaches that were explicitly mentioned were the DementiaAbility framework and a strengths-based or restorative approach (T4.Q15).

In terms of the operations of ADP services, some interview participants discussed structured or routine services as supporting their ADP purposes (T4.Q16). While structured services were considered important, interview participants (some of whom described structured services as a facilitator) also described a need for flexibility in the recreational opportunities provided (T4.Q17). Interview participants most often discussed the balance between structure and flexibility as a service approach encouraged through staff. Some interview participants also described their assessment processes as facilitating their ability to understand clients’ interests and needs, which in turn supported their ADP purposes to maintain or promote client abilities (T4.Q18).

Operations at the organizational level were also discussed by some interview participants

as supportive of their ADP purposes. These interview participants used the term “culture” (IP2, IP8) to refer to these perspectives and methods of operating ADP services and often tied it to how they intentionally interacted with staff to support ADP purposes (T4.Q19). Operations at the organizational level also expanded beyond staff to include broader methods of achieving diversity and inclusion and “anti-racist, anti-oppressive” (IP3) perspectives that enabled their ability to support the identities of various clients and caregivers (T4.Q20).

**Staff.** All interview participants discussed enablers focused on ADP staff in the areas of expertise, roles, and characteristics of staff care. Interview participants described a variety of staff professional backgrounds as facilitators of meeting their ADP purposes, including therapeutic recreation, personal support, and nursing. Some interview participants found that having a mix of these staff professional backgrounds as part of an inter- or multi-disciplinary staffing model was particularly supportive (T4.Q21). Interview participants discussed “the benefits of having been in the system for a really long time” (IP5) to meeting their ADP purposes as well, through areas such as insight and resourcefulness (T4.Q22).

Interview participants also brought forward enablers related to the roles of staff. Many interview participants discussed having a staffing model where all staff share responsibilities as supportive. Staff sharing responsibilities was most often described in terms of all frontline staff providing personal care support, such as toileting, regardless of professional background (T4.Q23). A few interview participants also mentioned having a staff member dedicated to providing caregiver support as a facilitator of their ADP purposes (T4.Q24). Interview participants discussed a few methods that facilitated these and other staff roles, such as providing “education for our staff” (IP13), maintaining good staff communication systems (T4.Q25), and building relationships between and with staff (T4.Q26).

The enabling characteristics of care and supports provided by staff were enthusiastically discussed by many interview participants. Interview participants stressed their staff's genuine interest and dedication to working in community support services and with ADP clients as a strong enabler to meeting their ADP purposes (T4.Q27). Interview participants also described the close professional relationships created between clients and staff as a facilitator as staff could draw on the knowledge created from these relationships to meet ADP purposes (T4.Q28). Staff were described as not only drawing on keen interest in and familiarity with clients and caregivers, but also being "very knowledgeable of all community resources" (IP9), which supported ADP aims to connect clients and caregivers with appropriate services.

**Client and Caregiver Involvement.** Many interview participants discussed how involving clients and caregivers through "feedback in our client satisfaction surveys" (IP17) helped to affirm their services were meeting their ADP purposes. Responding to client interests and goals by involving them in the creation of programs was also described as supporting ADP purposes, namely providing meaningful therapeutic recreation (T4.Q29). Interview participants also discussed having and facilitating close, trusting relationships with clients and caregivers as supporting their ADP purposes to meet the needs of ADP clients and caregivers and prevent or delay institutionalization (T4.Q30). Finally, while described as less connected to their direct services, a few interview participants mentioned that when clients and caregivers proactively planned for care transitions, it facilitated their purpose to support the operation of the health care system (T4.Q31).

**Advocacy and Awareness.** Interview participants discussed supportive advocacy and awareness building efforts at many levels. Some interview participants mentioned their connections to the Ontario Community Support Association and their efforts to advocate for

ADPs and community support services more broadly as something they found supportive (T4.Q32). The enhanced recognition of ADPs created by “being a member of the Ontario Health Team” (IP10) was described as “improving” interview participants’ ability to meet ADP purposes. A few interview participants discussed attending “age-friendly events and fairs” (IP16) before the COVID-19 pandemic and found these events increased awareness of their ADP purposes. Interview participants also mentioned the collective advocacy that occurred within their ADP sub-region and the newly established Ontario Health region networks (T4.Q33).

At the internal ADP level, many interview participants discussed how they use the data they tracked to advocate for resources to both meet their ADP purposes and demonstrate they are meeting their purposes (T4.Q34). The types of data collected varied. Some interview participants described quantitative metrics, such as “medical tracking” (IP10) in client charts. Others described “responses” and “comments” (IP9) from clients, caregivers, and staff regarding their experiences with ADPs that were helpful to advocate and increase awareness of ADP purposes.

***What challenges do ADP directors experience in pursuing ADP purposes?***

The challenges section contains interview participants’ perspectives of factors they perceived to present difficulties or act as barriers to achieving their ADP purposes. Many of the sub-categories contained in this section reflect the enablers described in the preceding section, demonstrating that some factors can be beneficial or constraining depending on the context. Challenges sub-categories include orientation within the health care system; funding and resources; organizational affiliations and governance; built or physical environment; staff; ability to support clients; perceptions of ADPs; awareness of ADPs; and measuring ADP outcome metrics.

**Orientation within Health Care System.** Many interview participants discussed

challenges with determining and actualizing the scope of ADP services; that is, where and when their ADP responsibilities for clients and caregivers began and ended because ADPs are often “everything to everyone” (IP5) (T5.Q1). Many interview participants shared that they struggled with wanting to provide a degree of standardized ADP services across different health regions and/or geographical areas in a context where there is “no true standardization in day program” (IP9). While interview participants expressed a desire to standardize, they also wanted to refrain from creating “cookie cutter” (IP4) programs. Interview participants also shared that their relationship with the Ministry of Health in terms of standards is a “double-edged sword” (IP9) because interview participants “want that guidance, want to know what the rules are” (IP1) but perceive they will “lose flexibility” (IP1) if they do. One interview participant theorized that the lack of standard ADP purposes is due in part to ADPs being encouraged to focus on new services that lie outside of their perceived core ADP purposes (T5.Q2). With no clear standards related to ADP purposes, some interview participants also described how they found it difficult to balance ADP purposes in relation to clients and caregivers. Many participants described prioritizing one group over the other either in the past or currently (T5.Q3).

Interview participants shared that some of these scope challenges exist due to a disconnect between the holistic approach of ADPs (i.e., where many or all domains of health and wellness are considered) and the narrower “clinical or medical” (IP4) orientation that most of the health care system takes on. As most interview participants discussed purposes that related to the “whole person” (IP4, IP15), many interview participants shared challenges with pressures to operate under more and more medically oriented models. Some interview participants shared that they could see themselves “slipping” (IP1) into a medical model due to the biomedical services they provided, such as medication management. This gradual progress into a medical model was

perceived as an outside pressure by funders reinforced by the purpose of ADPs to support the overall operation of the health care system (T5.Q4). Some interview participants described that it is particularly challenging to resist these pressures because “there’s obviously a need for medical adult day program” (IP2).

Interview participants also described how the narrow focus on medical needs and on crisis over prevention negatively impacted their ability to serve clients and caregivers as clients were referred later in their condition and quickly became more suitable for other health services, such as LTC (T5.Q5). Interview participants shared that the focus on crisis was also experienced by clients and caregivers who interview participants described as feeling pressured to apply for and accept LTC placements (T5.Q6). Interview participants shared that the acceptance of LTC placements impacted their ability to meet their ADP purposes, specifically delaying relocation to other care facilities (T5.Q7). The “real disconnect” (IP12) and sometimes “no communication pathways” (IP4) with other health care providers, such as primary care and LTC providers, was described as exacerbating these challenges.

Some interview participants also described poor connections with health, wellness, and social services beyond transitions. Interview participants discussed feelings of competition for resources and recognition with LTC and home care specifically (T5.Q8). Due to the low awareness and advocacy power of ADPs in the broader health care system, some interview participants questioned whether this competition was one sided (T5.Q9).

**Funding and Resources.** All interview participants discussed pressures related to funding and resources. The Ministry of Health, as the primary funder of ADPs, was a frequent topic of challenges. The largest constraint experienced was a lack of base funding increases in many years, despite changes in the context of ADPs, such as client interests, needs, abilities, and



overhead fees (T5.Q10). Some interview participants shared that they “increased their client fees” (IP12) and/or were more selective in their client admissions (T5.Q11) to offset the lack of base funding increases. One interview participant pointed out ADPs are “one of the few services out there that has a copayment, in terms of community support services” (IP3). Funding expectations were also described as having “not enough flexibility” (IP15) and accompanied by minimal opportunities “to experiment and pilot” (IP6), which participants felt limited their purpose to respond and adapt to community needs and interests (T5.Q12).

The challenges with base funding and funding expectations resulted in a negative impact on human resources. Many interview participants shared they had to operate with a high staff to client ratio and paid their staff low wages (T5.Q13). They also experienced a lack of time in their own roles to manage all their responsibilities which resulted in working on multiple projects “off the side of their desks” (IP3, IP9). One interview participant (IP12) shared that lack of appropriate human resources outside of ADPs was challenging, particularly not having a geriatrician who can support people with dementia through diagnosis and referral to ADPs.

Some interview participants speculated about why these funding and resource challenges existed. Many interview participants shared assumptions that ADPs can operate on “shoestring budgets” (IP6) or on “bare bones” (IP1) which resulted in low funds and resources. These assumptions were potentially born out of real circumstances as, after years of experience, participants have “made it work” (IP1) with low funding. However, interview participants felt that the assumptions about ADPs and limited ADP funding constrained the extent to which they were able to meet their ADP purposes. Interview participants also recognized that funding and resource challenges existed for “not just us but health care in general” (IP3). Challenges with funding were concerning for interview participants as they perceived there to be an increasing

demand for ADPs, but “the infrastructure that we presently have” (IP4) was insufficient to support the demand.

**Organizational Affiliations and Governance.** Interview participants discussed how organizations with more than just ADP services under their umbrella have their own overarching purposes which prevented or at the very least complicated the standardization of ADP purposes across the region because it depended on “if an organization wanted to take that on” (IP13). Differences in affiliate organizations, and the size of these organization, were also thought to create “inequity” (IP6) in resources because umbrella organizations “all have different resources” (IP6). Interview participants shared that “being a smaller, single organization” (IP5) also influenced the governance of their ADPs. ADP directors of smaller, standalone organizations felt expected to take on many roles and responsibilities because they “don’t have all the other departments to pull on” (IP5). In contrast, interview participants affiliated with large organizations shared that the governance and size of their umbrella organization limited their autonomy to make decisions and slowed progress on ADP-specific actions, a factor that was particularly challenging during the COVID-19 pandemic (T5.Q14).

Interview participants also shared a concern that the system transformation of blurring organizational governance through the Ontario Health Team model would influence ADP purposes through changes to service delivery (T5.Q15). Prevailing LHIN affiliations were also described as challenges for some interview participants as they created differences in the operation of ADPs across sub-regions (T5.Q16). Finally, creating connections with transportation services, while outside of the formal health care system, was described as a challenge when it came to procuring “safe transportation, particularly for people who have dementia” (IP14).

**Built or Physical Environment.** The built or physical environment sub-category captures the challenging factors of the physical buildings in which ADPs operated. For some interview participants, the buildings where they provided their ADP services were “very challenging for a day program design” (IP15) and finding or retrofitting the physical space was difficult (T5.Q17). Interview participants also described the size of the building or the safety features as limiting their ability to serve more clients and caregivers. Some interview participants that were co-located with LTC described this physical placement as challenging to meeting their ADP purposes (T5.Q18). Finally, interview participants that were operating ADPs in “rural communities” found their location to be a challenge for transportation, staff, ability to “build or locate” (IP8) ADP facilities, and providing supports for clients during the pandemic.

**Staff.** Providing and maintaining education and training for staff was described as a “perennial issue that comes up year after year” (IP1). Interview participants shared that it was difficult “keeping up with” the “complexity” of client needs and “diverseness” (IP3) of client interests through staff education and training. Some interview participants also discussed a “bit of a divide between what staff were taught versus what’s actually in front of them at that time” (IP4) which resulted in staff having “pre-set expectations of what day program should be” (IP4) that did not align with current ADP purposes and created confusion and reluctance to fulfill staff roles. Interview participants also described some staff as holding a “mentality of doing for, instead of doing with” (IP2). This mentality negatively influenced the degree of meaning and purpose clients experienced in recreational programs and interview participants described questioning these assumptions to help shift staff perspectives (T5.Q19). For some interview participants ensuring staff were building relationships that did not overstep professional boundaries or the personal “privacy” (IP8) of clients and caregivers who “don’t want everybody

to know what's going on" (IP8) was a challenge, particularly when their ADPs were "in a smaller community" (IP6) where clients were served by people who knew them and wanted to "forge relationships based on their past knowledge or interactions" (IP6). A few interview participants also discussed how it was challenging to hire and retain an inter- or multi-disciplinary staff team that reflects the needs of clients and the diversity of the communities where their ADPs operate (T5.Q20).

**Ability to Support Clients and Caregivers.** The ability to support all client interests, needs, and qualities in just one program was discussed as a challenge by many interview participants (T5.Q21). Relatedly, interview participants shared concerns with supporting "more complex" (IP9) clients in their programs. In tandem with the complexity of client conditions, interview participants described "very high levels of stress and burnout" (IP6) experienced by caregivers (exacerbated by the COVID-19 pandemic) as challenging to appropriately meet amidst their other purposes. In recognizing that these higher need factors placed these clients and caregivers on a faster trajectory to LTC, some interview participants discussed difficulties with ensuring clients and caregivers were considering transition planning and communicating those plans with ADP staff (T5.Q22).

Some interview participants also discussed difficulties with reaching and supporting diverse client populations in their communities which they felt meant they were not meeting their ADP purposes (T5.Q23). Interview participants understood that they needed to make their ADPs "inclusive and welcoming as possible" (IP6) but found it challenging to adapt as changes to programming, languages offered, food, and other aspects of the environment required funds, which were described as limited.

**Perceptions of ADPs.** Many interview participants discussed the perceptions of ADPs

held by a variety of stakeholders, including members of the community, health care professionals, caregivers, and clients, as challenging. Community members were discussed as having perceptions about ADPs that prevented their attendance or use of ADP services (T5.Q24). The perceptions and stigma health care professionals held about ADPs were also described as influencing interview participants' ability to meet their ADP purposes through multiple avenues, most notably a lack of referrals (T5.Q25). Many interview participants shared they think health care professionals do not consider ADPs as part of the health care system (T5.Q26). Caregivers were also described as sometimes feeling a responsibility for supporting their older family members without accessing health care and support services, which prevented them from accessing ADPs, even if they could benefit from them (T5.Q27). Interview participants also shared initial perspectives of caregivers thinking "the client won't enjoy the program" (IP2) (T5.Q28). Interview participants described some current clients as judging the suitability of potential clients and creating "cliques" (IP18) within programs. Finally, interview participants discussed how client and caregiver desires to keep their attendance at ADPs private limited interview participants' ability to use their experiences in efforts to advocate and increase awareness of ADPs (T5.Q29).

**Advocacy and Awareness.** In relation to the perceptions of ADPs, interview participants described a low awareness and recognition of their ADP services that challenged their ability to meet their purposes. Interview participants described a limited understanding and awareness of ADP services by health care professionals, community members, and potential clients and caregivers (T5.Q30). The low awareness or recognition of ADPs was not limited to the community and health care as some interview participants noted the lack of research on ADP services, specifically in an Ontario or Canadian context (T5.Q31). Interview participants

understood that “marketing” (IP3) and “promotion of day program” (IP9) needed to improve to address awareness challenges, but shared they find marketing challenging due to low funding and a lack of expertise in communications.

**Measuring ADP Outcome Metrics.** Interview participants discussed how existing indicators used to measure the performance of ADPs are “outdated” (IP1) or unable to capture the nuances introduced by differences in ADPs (e.g., services, clients) and an overall lack of best practices or standards for the region’s ADPs by which to measure their ADP outcomes (T5.Q32). Interview participants recognized that finding or creating meaningful or suitable metrics has been and will continue to be difficult because there are many elements that can contribute to the outcomes of ADPs and many of these factors are challenging to define (T5.Q33). Interview participants described how there are many different systems of tracking metrics that also introduced differences in how metrics were collected and reported (T5.Q34). Some interview participants discussed the current types of evidence they had, such as informal client testimonials, but expressed barriers to sharing this evidence as it was not considered “valuable” (IP9). Further, while recognizing a desire to update metrics, interview participants shared concerns with impacts to funding if and when metrics change (T5.Q35). Finally, keeping track of all these metrics was potentially burdensome for some interview participants who described limited staff capacity to track meaningful data (T5.Q36).

### ***Phase 1 Summary***

This first section of this chapter provided a thorough account of the Phase 1 findings. Participants described several ADP purposes. Participants’ descriptions of ADP purposes demonstrated consensus, elaborated on nuances, and identified areas of differing perspectives. The Phase 1 findings also demonstrated a wealth of enablers and challenges described by

participants. Some of the sub-categories for enablers and challenges overlapped, and others were specific to the enablers and challenges categories. These Phase 1 findings were used to create the Phase 2 quantitative data collection method. Specifically, results pertaining to purposes, enablers, and challenges were transformed into a survey for participants to further inform and refine the Phase 1 findings through rating items according to criteria. The results of Phase 2 are provided next.

## **Phase 2**

This section of the chapter provides the results of Phase 2 of this exploratory sequential mixed methods study. Specifically, the descriptive analyses of responses to the Phase 2 survey, which was created from Phase 1 interview findings and with input from knowledge users, are presented. This section begins with a description of the demographic characteristics of the Phase 2 participants. This is followed by descriptive statistics for the responses pertaining to survey participants' ADPs and their professional roles and responsibilities. Next, descriptive statistics for the purposes, enablers, and challenges sections are provided. The results of responses to open-ended survey questions, specifically additional comments, are integrated with corresponding sections. Most survey participants provided additional comments, with the exceptions of survey participants 5, 8, 10, and 14.

### ***Participants***

A total of 18 participants from 15 ADP organizations participated in Phase 2. One organization completed the survey collaboratively with four people due to the organizational design of their ADP and changes in staff holding director positions. ADP directors who participated in the Phase 1 interviews were invited to participate in Phase 2. A total of 13 Phase 1 participants, representing 13 unique organizations, provided responses to the Phase 2 survey.

Phase 1 and Phase 2 participants are not linked across the two phases for ethical reasons (described in the Risks section of the Research Design and Methods Chapter) and because the data analysis plan did not require this linking. ADP directors who did not participate in Phase 1 were also invited to participate in Phase 2. Five new participants representing two unique organizations participated in Phase 2. Moving forward, participants are referred to as “survey participants” or “SP” to distinguish them from Phase 1 “interview participants” or “IP.”

### *Participants’ Demographic Characteristics*

Descriptive statistics of the survey participant responses to demographic questions can be found in Table 6. The ADP organization that collaboratively completed the survey responded to demographic questions with the lead survey participant’s demographic information, rather than with all four survey participants’ information; therefore, counts total 15. Survey participants were mostly female (86.7%,  $n = 13$ ) and self-identified as Caucasian (86.7%,  $n = 13$ ). The mean age was 47.4 years old ( $SD = 9.0$ ) with ages ranging from 27 to 60.

Table 6. *Phase 2 Survey Participant Demographic Characteristics*

<b>Categorical Variables</b>	<b>n</b>	<b>%</b>
<b><i>Gender</i></b>		
Female	13	86.7
Male	2	13.3
<b><i>Ethnicity or Cultural Background</i></b>		
Caucasian	13	86.7
Indigenous	1	6.7
Other	1	6.7
<b><i>Highest Level of Education</i></b>		
Diploma	4	26.7
Bachelor’s Degree	8	53.3
Master’s Degree	3	20.0
	<b>M(SD)</b>	<b>Min - Max</b>
<b>Continuous Variable</b>		
Age	47.4(9.0)	27 - 60

Responses to the open-ended question of highest level of education and relevant



certificates varied considerably. Post-secondary education responses included bachelor's and master's degrees in areas such as sociology, psychology, nursing, health services, and quality improvement, and diplomas in areas such as nursing, health care, and horticulture. Survey participants also reported certificates in business management, volunteer management, project management, health care administration, and leadership. Some survey participants also reported training, such as for working with people with dementia (e.g., DementiAbility, Gentle Persuasive Approaches), exercise, and cultural competence.

### ***Participants' Adult Day Program Characteristics***

The descriptive statistics of survey participants' responses to the ADP Questions survey section are shown in Table 7. As 15 ADP organizations participated in the survey (represented by 18 survey participants), counts total 15. Most survey participants directed their ADPs in Region 2 (46.7%,  $n = 7$ ). Most survey participants directed ADPs funded to provide dementia/specialized types of ADPs (40%,  $n = 6$ ). Responses to the primary client population question were categorized according to the client population with the highest percentage. Based on this classification, most survey participants' primary client population was people living with dementia (66.7%,  $n = 10$ ). In terms of organizational structure and location, most survey participants operated under the umbrella of a larger organization (73.3%,  $n = 11$ ) and rented or owned a standalone location (33.3%,  $n = 5$ ). Just over half of survey participants reported that they use a social model of ADP (53.3%,  $n = 8$ ).

On average, survey participants directed two ADP locations ( $SD = 2.1$ ) with a minimum of one and maximum of eight. The mean number of clients served per year was 166.6 ( $SD = 134.5$ ) with a minimum of 12 and maximum of 514. The mean number of clients served per day was 35.1 ( $SD = 29.2$ ) with a minimum of 7 and maximum of 85.

Table 7. *Adult Day Program Questions*

<b>Categorical Variables</b>	<b>n</b>	<b>%</b>
<b><i>Legacy LHIN</i></b>		
Region 1	4	26.7
Region 2	7	46.7
Region 3	3	20.0
Region 4	1	6.7
<b><i>Types of ADPs</i></b>		
Acquired Brain Injury and Dementia/Specialized	1	6.7
Acquired Brain Injury and Stroke	1	6.7
Acquired Brain Injury, Aphasia, Dementia/Specialized, Integrated/Blended/Supportive, and Stroke	1	6.7
Aphasia and Integrated/Blended/Supportive	3	20.0
Dementia/Specialized	6	40.0
Integrated and Stroke	1	6.7
Integrated/Blended/Supportive	2	13.3
<b><i>Primary Client Population</i></b>		
Acquired Brain Injury	1	6.7
Dementia	10	66.7
Frail Elderly	4	26.7
<b><i>Organizational Structure</i></b>		
Standalone	4	26.7
Under the Umbrella	11	73.3
<b><i>Location Status</i></b>		
Housed with LTC	3	20.0
Rent Shared Space	3	20.0
Rent/Own Standalone	5	33.3
Housed with LTC and Rent/Own Standalone	1	6.7
Rent Shared Space and Rent/Own Standalone	3	20.0
<b><i>Model of ADP</i></b>		
Mixed	7	46.7
Social	8	53.3
<b><i>Professional Title</i></b>		
CEO	2	13.3
Manager	3	20.0
Supervisor	3	20.0
Coordinator	1	6.7

Director	6	40.0
	<b>M(SD)</b>	<b>Min - Max</b>
<b>Continuous Variable</b>		
Number of ADP Locations	2.33(2.1)	1 - 8
Clients Served per Year	166.6(134.5)	12 - 514
Clients Served per Day	35.1(29.2)	7 - 85

### *Participants' Professional Roles and Responsibilities*

Most of the survey participants held the title of director (40%, n = 6) in their role at their ADP organization. Survey participants responded with a range of professional duties and responsibilities. All survey participants reported being responsible for the overall operation of their ADP in accordance with the eligibility criteria. Duties related to ADPs at an organization level included tracking statistics; financial management such as drafting budgets; reporting to funders; outreach; performance management; health and safety; maintenance and repair of equipment; procurement of program supplies; risk management; quality assurance; representing ADPs at health planning tables; communicating with regional partners and other organizations; and reporting to their board of directors and/or larger organization if applicable. Staff-related management responsibilities included supervising; scheduling; tracking attendance; communicating with staff and addressing any needs and concerns; training; completing payroll; and liaising with unions. Client and caregiver direct support duties included creating client service plans; taking vitals; providing foot care; maintaining ongoing communication with clients and caregivers; planning programs; documenting client progress; and providing personal care or support (e.g., toileting, feeding, mobility assistance). Finally, client and caregiver administrative responsibilities involved tracking attendance; billing; and performing intake assessments.

### *Rating ADP Purposes*

The descriptive statistics of the third survey section further illustrate the first research

question, *what are the purposes of ADPs as perceived by ADP directors?* Specifically, this section describes survey participants' ratings of the relevance of purposes identified in Phase 1 according to their *current* ADP purposes and their *desired* ADP purposes. Starting with survey participants' ratings of current ADP purposes, Table 8 found in Appendix K (pp. 167-168) shows the means, standard deviations, medians, modes, minimums, and maximums of survey responses. These responses are sorted in Table 8 from highest to lowest mean. As can be seen, all means were 7.5 or higher in relevance to survey participants' current ADP purposes, with the highest mean being 8.8. The highest mean of 8.8 was for both 'provide person-centered services for all clients and caregivers' and 'provide clients with purposeful, dynamic engagement and therapeutic recreational opportunities.' The lowest mean of 7.5 was for 'provide caregivers with resources, education, and support.'

Moving to survey participants' ratings of *desired* ADP purposes, Table 9 found in Appendix K (pp. 169-170) displays the descriptive statistics of survey participants' responses sorted from highest to lowest mean. The means of all desired purposes were 8.8 or higher. The highest mean was 9.8. The highest mean of 9.8 was for both 'enable social connections between staff and clients and caregivers that create a sense of community and belonging' and 'provide person-centered services for all clients and caregivers.' The lowest mean of 8.8 was for 'provide and encourage client and caregiver independence and choice.'

### ***Rating ADP Enablers***

This section describes survey participants' responses to the fourth survey section, which asked survey participants to rate the enablers identified in Phase 1 according to how strongly they *support* and the degree to which they *promote* the purposes of their ADPs. The descriptive statistics for each strength of support item rating can be seen in Table 10, found in Appendix K

(pp. 171-174). Survey items are presented according to the Phase 1 sub-categories and organized within sub-categories from highest to lowest mean in Table 10. Overall, the means for strength of support item ratings ranged from 4.1 to 9.5. The lowest mean was for the item ‘having an affiliation with long-term care.’ The ‘providing structured services (e.g., consistent schedule for activities, exercise, meals)’ item had the highest mean. The highest five means for the strength of support of provided enablers fell under the approach to services and operations; staff; and client and caregiver involvement sub-categories. The lowest five means for strength of support of provided enablers fell under the organizational affiliations and governance; built or physical environments; funding and resources; and advocacy and awareness sub-categories. The approach to services and operations sub-category had the highest average of means across sub-category survey items and the funding and resources sub-category had the lowest average of means across sub-category survey items.

The descriptive statistics for the ratings of the degree to which enabler survey items promoted ADP purposes are provided in Table 11, found in Appendix K (pp. 175-178). The means for all ratings of the degree to which enabler items promoted ADP purposes ranged from 4.3 to 9.7. The lowest mean of 4.3 was for the item ‘having an affiliation with long-term care.’ The item ‘having familiar and trusting professional relationships with clients and caregivers’ had the highest degree of promotion mean at 9.7. As with the strength of support question, the highest five means for the degree provided enablers promoted ADP purposes fell under the client and caregiver involvement; approach to services and operations; and staff sub-categories. The lowest means for these ratings fell under the organizational affiliations and governance; built or physical environments; and funding and resources sub-categories. Further, the items ‘having an affiliation with long-term care’; ‘being co-located with long-term care’; and ‘having the ability to

meet ADP purposes without sufficient funding’ all had the lowest means for both the strength of support and degree of promotion enabler ratings. The sub-categories approach to services and operations and staff had the highest average of means across sub-category survey items and the funding and resources sub-category had the lowest average of means across sub-category survey items.

A few survey participants provided additional comments regarding the enablers of their ADP purposes. Some survey participants provided background on the enabler survey items suggesting that some of the enablers are a result of their “focused” actions and “much time and energy” (SP11). Survey participant 15 also commented on how changes to “more one-on-one supports” due to the COVID-19 pandemic created “insurmountable benefits” for their ability to support clients and caregivers.

### ***Rating ADP Challenges***

The descriptive statistics of the last survey section explored survey participants’ ratings of challenges identified in Phase 1 according to their prominence and urgency to address. Beginning with the prominence ratings, the descriptive statistics for each prominence item rating can be seen in Table 12 (see Appendix K, pp. 179-183) and are organized according to sub-category and mean ratings. The means for the prominence ratings of challenge items ranged from 3.4, with the item ‘staff expectations of roles/responsibilities based on professional background, rather than ADP models’, to 8.7, with the item ‘experiencing a lack of base funding increases.’ The highest five means for the prominence of challenges ratings fell under the funding and resources; ability to support clients; measuring ADP outcome metrics; and ADP awareness sub-categories. The lowest five means fell under the sub-categories of staff; built or physical environments; organizational affiliations and governance; and orientation within health care

system. The advocacy and awareness sub-category had the highest average of means across sub-category survey items and the staff sub-category had the lowest average of means across sub-category survey items.

The descriptive statistics for the urgency to address challenge survey items can be found in Table 13, Appendix K (pp. 184-188). The means for the urgency to address ratings ranged from 4.0 to 9.1. The lowest mean rating of 4.0 was for the item ‘being under the umbrella of an organization which decreases autonomy and slows progress’ and the highest mean rating of 9.1 was for the ‘supporting level of caregiver needs and burnout’ item. The highest five means for the urgency to address question fell under the ability to support clients and caregivers; perceptions of ADPs; built or physical environment; funding and resources; and awareness and advocacy sub-categories. The lowest five means fell under the organizational affiliations and governance; staff; built or physical environment; orientation within health care system; and funding and resources sub-categories. The advocacy and awareness sub-category had the highest average of means across sub-category survey items and the organizational affiliations and governance sub-category had the lowest average of means across sub-category survey items.

Survey participants provided additional comments related to the challenges they face when meeting ADP purposes. Survey participant 13 commented: “funding pressures continue to affect recruitment, retention, and service provision” demonstrating how funding challenges can trickle down to impact staff and direct supports for clients and caregivers. This survey participant also clarified they are they obligated: “to level off staff wages based on collective agreement” which made low staff wages not applicable for them. Survey participants 11 and 15 also noted how their organizational affiliations (affiliated and standalone, respectively) negatively influenced their “staff resources” (SP11) and “staffing” (SP15).

In terms of built or physical environments, survey participant 15 commented that co-location with LTC “confuses and deters potential clients” from attending their ADP. Survey participant 13 also commented on how the wide geographic coverage due to their rural location impacts client attendance and their “ability to provide programming at lower costs.” Survey participant 7 shared that “each LHIN area has taken a different approach with this sector” which has resulted in varying levels of engagement with ADP directors to understand their purposes. This survey participant also commented on the challenges of achieving “a united approach” across ADPs in the larger health region while retaining their “uniqueness in each community.”

Many survey participants provided additional comments on challenges regarding awareness and perceptions of and advocacy for ADPs. Specifically, the challenges of limited awareness, misunderstandings, and low advocacy power of some organizations. For example, SP4 commented: “ADPs are hidden gems, sometimes too hidden or misunderstood as ‘adult day care’ or ‘last place before LTC’.” Survey participant 15 offered insight that “caregivers are unaware of services available to them other than LTC placement” which they perceived to be preventing early referrals and creating a greater need for medical models of ADPs. When discussing increasing awareness through advocacy, survey participant 7 commented how ADP directors: “Should have a common voice to rep [represent] ADP, as many directors do not have a lot of extra time to advocate and participate in many outside groups.” This comment highlights the limited capacity some ADP directors experience when addressing ADP purposes.

### **Chapter Three Summary**

This chapter described the results of both Phase 1 and Phase 2. The findings of Phase 1 demonstrated a variety of ADP purposes and results of Phase 2 substantiated their relevance for participants. With some of these purposes, interview participants demonstrated high consensus,



such as when discussing person-centered care and services, meaningful therapeutic recreation, and social connections. These consensus areas discovered through Phase 1 were also highly rated in Phase 2. Within some of these areas, participants described nuances, including that the out of home setting and applicability to both clients and caregivers were important elements of ADP respite. The nuances of ADP respite were contained in two separate survey items and highly rated by survey participants. Interview participants also demonstrated different perspectives on some purposes. These differing descriptions related to whether ADPs maintain or improve client abilities, whether ADPs address functioning or well-being, and whether ADPs are intended to provide care coordination or, perhaps more informally, connect clients and caregivers with other appropriate services. The Phase 2 findings suggest differences of these purposes described in Phase 1 may be equally relevant for most survey participants.

As Phase 1 findings were used to design the Phase 2 survey, enablers and challenges sub-categories remained the same. As discovered in Phase 1, some of these sub-categories were the same across enablers and challenges categories, including funding and resources; organizational affiliations and governance; built or physical environment; staff; and advocacy and awareness. Other sub-categories were specific to the enablers and challenges categories. Sub-categories specific to enablers were approach to services; client and caregiver involvement; collaboration and partnerships; and referrals. Sub-categories specific to challenges included measuring ADP outcome metrics; orientation within health care system; ability to support clients; and perceptions of ADPs.

Phase 2 findings expanded Phase 1 findings by demonstrating survey items and sub-categories survey participants found to be most enabling, including approach to services and operations, staff, and client and caregiver involvement. Phase 2 findings also identified survey

items described in Phase 1 that survey participants found to be most challenging. These most urgent and prominent challenges included funding and resources, ability to support clients and caregivers, and advocacy and awareness. The following chapter integrates and situates these findings in the broader literature. It also uses this literature to interpret and describe the insights, implications, and significance of these findings.

## **Chapter Four: Discussion**

### **Overview of Findings**

This two-phased exploratory sequential mixed methods study investigated the purposes of ADPs from the perspectives of ADP directors in a health region of Ontario. This study also examined the enablers and challenges that ADP directors experience when pursuing ADP purposes. In Phase 1, descriptive qualitative methods were used to create an initial understanding of ADP purposes and enabling and challenging factors to meeting these purposes. Phase 2 built on Phase 1 by providing participants with the opportunity to rate Phase 1 descriptions of ADP purposes, enablers, and challenges using descriptive quantitative methods. Together, Phase 1 and 2 produced several consistent, nuanced, and sometimes contrasting findings.

In this chapter, the results of Phases 1 and 2 are integrated to discuss the major findings of this study. This discussion begins by situating the purposes identified by participants within the broader ADP literature regarding ADP purposes. Then, a comparison between participants' current and desired purposes is provided, and areas for potential future action based on these comparisons are considered. This is followed by a discussion of the enablers and challenges shared by study participants using the sub-categories from Phase 1 and Phase 2 as a structure. Areas of future research based on the findings are outlined next. This chapter ends with a discussion of the strengths and limitations of this study, followed by a conclusion.

### **Comparison to Generally Accepted Purposes**

The current study findings showed that participants' perspectives of ADP purposes align with the three generally accepted purposes of ADPs: to provide support and respite opportunities for caregivers; to prevent or delay relocation to care facilities; and to preserve functioning of clients, each of which are discussed in detail below. Findings are also consistent with existing

suggestions to expand the operationalization of ADP purposes (Dabelko et al., 2008; Dabelko & Zimmerman, 2008). However, participants' descriptions of ADP purposes and relevance ratings of these purposes demonstrated some novel nuances to these accepted purposes that may influence the operationalization of them in this health region.

### ***Provide Support and Respite for Caregivers***

The purpose of ADPs to provide support and respite opportunities for caregivers is well-established in previous literature (Anderson et al., 2018; Zarit, 1998), and was reinforced by all participants in this study. However, participants also shared two nuances to respite that warrant further consideration. First, some participants discussed how the respite ADPs provide can be considered as applying to both caregivers and clients. Current and past discussions of ADP purposes and efforts to measure ADP respite tend to focus on relief from caregiving roles and responsibilities, rather than relief for both parties of the caregiving relationship (Mason et al., 2017; Zarit et al., 2017). It should be further explored whether caregiver and client respite are intertwined or should be operationalized as separate ADP purposes. Researching the connections between these experiences of respite can also support any future efforts to measure ADPs' ability to meet these purpose(s).

Second, some participants stressed the importance of ADP respite being offered outside of client and caregiver homes. This study's participants acknowledged that the out-of-home quality of ADP respite allowed caregivers to experience a "full break" from their caregiving roles and to engage in a variety of tasks and activities that would otherwise not be possible. Participants' explicit recognition of how the setting of ADP services influenced the types of respite caregivers and clients experience is an important finding of this study. Existing studies and descriptions of ADP purposes tend to focus on the provision of ADP services in a facility

when discussing socialization purposes, rather than as meeting respite purposes because services are offered outside of client and caregiver homes (Dabelko et al., 2008; Orellana et al., 2020b). Emphasizing the out-of-home aspect of ADP respite purposes could help to distinguish ADPs from other health care and social services. Using this trait to differentiate from other services might be particularly useful given the confusion some stakeholders have with delineating ADP services from other health care and social services, such as home care (Dabelko-Schoeny et al., 2020; Hopp et al., 2020). However, the out-of-home quality of ADP respite found in this study may be complicated by the existence and development of in-home or mobile ADPs.

In-home or mobile ADPs are described as services that travel to clients' homes to provide one-on-one recreational activities (Elechko, 2015). They differ from home care services which focus on personal care and support needs of clients rather than meaningful recreation opportunities (Dabelko-Schoeny et al., 2020). The provision of ADPs in a community facility and in a group setting is a component of many ADP definitions that is complicated by in-home ADP services provided to clients one-on-one (Harder et al., 1986; Ontario Community Support Association, 1999; Orellana et al., 2020a). A discussion with ADP directors about where these in-home therapeutic recreation services fall in the home and community care continuum and how they align with ADP purposes could enhance an understanding of the setting of ADP services. To support this discussion, ADP directors could consider if ADPs that provide in-home or mobile ADP services tend to exist under the umbrella of an organization that also provides home care services.

### ***Prevent or Delay Relocation to Care Facilities***

This study's participants also reinforced the generally accepted ADP purpose of preventing or delaying people from relocating to care facilities and, therefore, affording them

greater opportunity to remain in their homes for longer (Gaugler et al., 2005; Gitlin et al., 2006). The expansion of the types of institutionalization ADPs might delay or prevent is one factor that researchers have proposed could be contributing to the mixed findings of ADPs' ability to meet this purpose (Kelly et al., 2016). Participants' descriptions of this purpose were consistent with calls to expand "care facilities" from a focus on LTC to other health services, namely hospital services (Kelly et al., 2016). Research into the ability of ADPs to meet this particular purpose is likely growing because delaying or preventing relocation to care facilities aligns with the Ministry of Health's aim to provide cost-effective services (Premier's Council on Improving Healthcare and Ending Hallway Medicine, 2019) and many clients and caregivers' desire to age in place (Allen & Ouslander, 2018; Hendig et al., 2017).

Given the potential interest in this specific purpose, it would be beneficial for ADP directors to be clear in the types of institutionalization they are preventing or delaying, as well as to acknowledge some of the factors that influence their ability to meet this purpose. Research demonstrates a variety of influential factors, such as the ADP "dose" (i.e., frequency with which clients attend ADPs) and clients' goals regarding where they live (i.e., in the community or in a facility), that could be used to contextualize this purpose (Gaugler & Zarit, 2001; Harder et al., 1986; Kelly et al., 2016; MetLife Mature Market Institute, 2010). Some of the enablers and challenges of this study pertain directly to this purpose (e.g., late referrals, LTC waitlists and placements) and could also be referenced when further refining this ADP purpose.

### ***Preserve Functioning of Clients***

As with the purpose to prevent or delay relocation to care facilities, participants reinforced both the generally accepted purpose to preserve functioning of clients as well as calls to expand the concept of "functioning." The elaboration of functioning appears to be consistent

with a biopsychosocial approach, where physical, cognitive, and social engagement are considered and valued (Hopp et al., 2020; Shahbazi et al., 2016). However, a few participants resisted or rejected the “functioning” term and described ADPs’ influence on clients in ways that might align better with “wellness” or “well-being” as these terms might engender more holistic ideas of health (Smith et al., 2006). Framing the influence on clients as preserving wellness or well-being might also align with most participants’ mixed approach to ADP services where biomedical needs are considered in tandem with social supports (Dabelko, 2006; Dabelko & Zimmerman, 2008; Ritchie, 2003). However, research outside of ADPs demonstrates that wellness or well-being terms can be ambiguous (Bishop & Yardley, 2010) and could present challenges when ADP directors attempt to measure if they are meeting this purpose, a particular concern of participants demonstrated by some of the challenges they discussed. The language of “preserving” might also warrant consideration as some participants aligned with notions of maintaining clients, whereas others considered the possibility that ADPs improve or promote client abilities and wellness. Further discussion with ADP directors to refine these terms and support communication and potential measurement of these purposes would be beneficial.

### ***Greater Number of Purposes***

A significant finding of this research was that participants described a greater number of ADP purposes than what is commonly discussed in ADP research and grey literature. There are several possible reasons for the greater number of purposes generated by this research. First, many participants referred to ADPs being “everything to everyone” or focusing on “extra things” instead of the “meat and potatoes” (i.e., core) of ADP purposes. The number and variety of ADP purposes could reflect the number and variety of services ADP directors were offering to clients and caregivers, or vice versa. To ensure that ADP directors’ capacity is respected by both those

funding ADP services and people accessing ADP services, this region's ADP directors might consider clarifying core and auxiliary purposes. Clarifying the purposes that all ADPs should aim to meet and the purposes that could be considered supplementary to core purposes may also support efforts to measure and optimize ADP services. These efforts to clarify ADP purposes might also help with the confusion clients, caregivers, and community members often express when trying to understand how ADPs can support them (Hopp et al., 2020; Ritchie, 2003).

Additionally, the subtle differences in the description of some ADP purposes provided by Phase 1 participants were reflected in the Phase 2 survey. Including these nuances in survey items was intended to clarify the relevance of potential differences at the group level. However, due to the lower than anticipated survey response rate, delineating these nuances was not possible to the extent envisioned. Purposes also often go through multiple revisions with many stakeholders to refine them before they are disseminated more broadly to ensure they capture the desired content and are succinct or easy to communicate and comprehend (Wagenmaker & Oberly, 2016). However, it was not the aim of this research to create a finalized definition of ADP purposes, but rather to explore and improve upon the knowledge of purposes that currently exist. ADP directors, if interested, could collectively refine ADP purposes using the findings of this study as they and other ADP stakeholders, including their funders, affiliate organizations, staff, clients, and caregivers, deem suitable. These refined ADP purposes should be attentive and responsive to how they align with other organizational practices, such as mission and vision statements. It is also possible that these refined purposes be used to inform specific policies implemented by each ADP organization.

### **Comparison Between Current and Desired Purposes Ratings**

To support future discussions of ADP purposes, Phase 1 and 2 participants were asked if



current ADP purposes differed in relevance from their desired ADP purposes. Section three of the Phase 2 survey provided an opportunity to explore the relative difference between participants' current and desired purposes. The relative difference results can be used as a guide to future action, demonstrating the purposes ADP directors might want to focus on in the future, and those that might not be as relevant or important to concentrate their efforts.

Chapter Three reported the results pertaining to participants' ratings of current and desired purposes, and these findings are summarized in this chapter in Table 14. As can be seen in Table 14, all relative differences were greater than 0 and ranged from 4.8% to 25.1%. The finding that all relative differences were above 0 appears to suggest that Phase 2 participants perceived all purposes identified in this study as increasing in relevance from its current state to a desired state. The capacity for ADP directors in this region to address these relative differences is a vital consideration, especially given the challenges they shared with having multiple duties and responsibilities. The purposes with the greatest relative differences might be appropriate initial focal points for ADP directors in this region to build upon compared to the purposes with the least relative differences.

Table 14. *Comparison Between Current and Desired Purposes Ratings*

<b>Survey Item</b>	<b>Current Relevance</b>	<b>Desired Relevance</b>	<b>Absolute Difference</b>	<b>Relative Difference</b>
Provide caregivers with resources, education, and support	7.5	9.4	1.9	25.1%
Provide services that reflect the current community and client population interests and needs	8.0	9.6	1.6	19.6%
Provide safe and secure environments that meet the interests, needs, and diversity of clients	8.1	9.6	1.5	19.4%
Provide clients with meals to meet nutritional and social needs	8.2	9.7	1.5	19.1%
Provide services that address and support client overall functioning	8.2	9.6	1.4	18.3%

Provide caregivers and clients with out-of-home respite	8.2	9.6	1.4	18.3%
Provide physical environments that support purposeful engagement and recreational opportunities	8.2	9.7	1.5	18.0%
Enable social connections between staff and clients and caregivers that create a sense of community and belonging	8.3	9.8	1.5	17.8%
Empower caregivers to advocate for their person	8.0	9.4	1.4	17.0%
Provide care coordination and system navigation for clients and caregivers	8.2	9.4	1.2	14.9%
Enable meaningful social connections within and among clients and caregivers that create a sense of community and belonging	8.5	9.7	1.2	14.8%
Maintain and promote or improve client abilities (where appropriate)	8.5	9.7	1.2	13.1%
Provide services that consider a holistic concept of health (e.g., physical, cognitive, emotional)	8.5	9.5	1.0	12.3%
Provide services that support the overall functioning of the system	8.5	9.5	1.0	12.3%
Connect clients and caregivers with services and resources	8.4	9.4	1.0	11.6%
Maintain client abilities	8.4	9.4	1.0	11.5%
Provide person-centered services for all clients and caregivers	8.8	9.8	1.0	11.4%
Keep people living in the community to prevent or delay relocation to care facilities (e.g., long-term care, retirement homes, hospital), if that is what they want	8.4	9.3	0.9	10.7%
Provide clients with purposeful, dynamic engagement and therapeutic recreational opportunities	8.8	9.6	0.8	9.1%
Advocate for clients and caregivers	8.4	9.1	0.7	7.8%
Provide and encourage client and caregiver independence and choice	8.4	8.8	0.4	4.8%

The purpose with the greatest relative difference was to ‘provide caregivers with resources, education, and support’ at 25.1%. The high relative difference for this purpose reflects the high ratings of the prominence and urgency to address the challenge of ‘supporting level of

caregiver needs and burnout.’ There are a variety of factors that could be influencing this relative difference. For example, this data was collected during the COVID-19 pandemic when caregivers had decreased access to in-person services and were possibly communicating different or increased needs and burnout (Greenberg et al., 2020). An increased focus on this purpose that pertains to caregivers could also reflect the primary client group participants of this current study reported (i.e., people living with dementia). Canadian data demonstrates that caregivers of people with dementia experience higher stress and provide 75% more support than other caregivers (Health Care Council of Canada, 2012), and the incidence of people living with dementia is increasing (Statistics Canada, 2016b). It is possible that these trends are encouraging ADP directors to reconsider their prioritized direct services. It is also important to note that this purpose likely differs from the purpose to provide respite for caregivers which might be more passive than actively providing resources, education, and support. There are several actions ADP directors could take to address this relative difference. For example, an environmental scan of the caregiver resources, education, and support ADP directors of this health region currently provide could be conducted to gain an understanding of their current state and used to inform their desired state.

The second greatest relative difference was found for the purpose to ‘provide services that reflect the current community and client population interests and needs.’ The concern of participants to meet the interests and needs of their community aligns with the origins of ADPs as services that individually evolved out of the interests and needs of their respective communities (Fields et al., 2014). With an awareness of their individual origins, it is logical that ADP directors would want to remain relevant to their community. However, participants’ descriptions of challenges to the awareness and understanding of ADPs by clients, caregivers,

and community members, as well as highly rated challenges of supporting clients and caregivers, might suggest that participants do not perceive they are meeting this purpose as much as they think they should. Challenges with reflecting the potentially evolving social and medical interests and needs of clients and community members as different generations attend ADPs and clients' acuity increases are documented in ADP literature (Anderson et al., 2012; Gaugler, 2014; Orellana et al., 2020b; Sanders et al., 2009) and Older Adult Centre research (Hostetler, 2011).

The purpose with the third greatest relative difference was to 'provide safe and secure environments that meet the interests, needs, and diversity of clients.' This purpose also aligns with the two previous relative differences as it references the interests and needs of clients, but from an environmental perspective. There is limited research assessing ADP physical environments (Hodges et al., 2006; Moore et al., 2006), especially in Canada (Brown, 2012; Franko, 2014). However, an assessment tool for the physical environment of ADPs for people living with dementia was created in Nova Scotia using literature from prominent environmental gerontologists (Brown, 2012). This tool has a variety of benchmarks, including to ensure that ADP spaces are safe and secure (Brown, 2012). While it is likely that designing physical environments for people living with dementia will also benefit other ADP client groups, and people living with dementia were the primary client group of participants of the current study, it would be useful to explore the transferability of these studies and tools to ADP clients with conditions other than dementia. Participants also discussed the importance of environments in reference to ADP purpose enablers and challenges, demonstrating that environment is an important consideration when it comes to pursuing ADP purposes (Hopp et al., 2020). Further implications of this study's findings regarding environment are expanded in the Built or Physical Environment sub-category of this chapter.

Based on these relative differences, attention to supporting the needs and interests of clients and caregivers was a central focus of participants. As such their future priorities could be aimed at caregiver resources, education, and support; reflecting ADPs' communities; and ensuring ADP environments are safe and secure. As mentioned previously, the capacity of ADP directors to address these top three areas is uncertain given the multitude of their roles and responsibilities. In a study exploring capacity building for ADP administration, Sanders et al. (2009) recommended the establishment of a region-wide task force to form and address goals. This recommendation could also be appropriate for this health region, especially as ADP directors already collaborate at regional and sub-regional levels. Hiring a staff person to lead the task force might address capacity challenges and follow through on action items (Sanders et al., 2009). Considering the already limited funding participants described, the staff person could be, or supported by, a student, intern, or volunteer (Sanders et al., 2009). This task force could also integrate the key findings of the challenges and enablers to pursuing ADP purposes outlined next in this chapter.

### **Enablers and Challenges**

In addition to investigating the purposes of ADPs, this study explored both the enablers of and challenges to meeting ADP purposes. The Phase 1 and Phase 2 analyses demonstrated that the enablers and challenges described by participants could be grouped into sub-categories that fall under broader challenge and enabler categories. A significant finding of this study was that some overall sub-categories and sub-category items both enabled and challenged ADP purposes depending on the context. While some sub-categories were shared across enabler and challenge sections, Phase 1 interview participants often did not provide mixed factors, but rather identified items as distinctly enablers or challenges. The Phase 2 survey reflected these distinctions made

by participants by keeping the enablers and challenges sub-category items in separate survey sections. With this recognized, for purposes of interpretation and situating key findings within existing literature, the results will be discussed at the sub-category level. This section begins with the sub-categories that were only described as challenging, followed by the sub-categories that were only discussed as enablers, and ends with sub-categories that spanned across the enabler and challenge sections depending on context. The possible influence and connections between sub-categories are also explored.

### ***Challenges***

There were several challenges to pursuing ADP purposes identified by participants of Phase 1 and rated by Phase 2 participants. Overall, Phase 1 participants focused on challenges more than the other research questions, which was reflected in the development of the Phase 2 survey. The focus on challenges of ADP purposes is consistent with Sanders et al.'s (2009) study which found that the strengths of ADPs were minimally discussed by ADP administrators. The sub-categories that were uniquely challenges in the current study included measuring ADP outcome metrics; orientation within health care system; ability to support clients; and perceptions of ADPs, each of which are discussed in detail below. The average ratings of these sub-categories can be found in Table 15.

Table 15. *Average Mean Ratings of Challenges Sub-Categories*

<b>Sub-Category</b>	<b>Prominence</b>	<b>Urgency to Address</b>
Measuring ADP Outcome Metrics	7.1	7.5
Orientation within Health Care System	6.4	6.6
Ability to Support Clients and Caregivers	6.8	8.0
Perceptions of ADPs	6.2	7.3

**Measuring ADP Outcome Metrics.** The extent of Phase 1 discussions regarding measuring ADPs and the high ratings of Phase 2 survey items demonstrates that the

measurement of ADPs was a prioritized challenge for participants. The challenge of measuring ADP outcomes is particularly salient for this study as experiencing difficulty with metrics made it harder for participants to demonstrate if they were meeting their ADP purposes. Difficulties with measuring ADP purposes are acknowledged within the existing ADP literature (Dabelko, 2004; Zarit et al., 2017) and broader research into measuring complex health phenomena (Ward et al., 2011). It is challenging to measure the degree to which health services achieve their purposes because there are many levels of factors that can contribute to whether or not a purpose is met. For example, delaying or preventing institutionalization could be influenced by clients accessing ADPs, but also intrapersonal factors (e.g., the condition(s) of the client), interpersonal factors (e.g., the experiences of the caregiver), organizational factors (e.g., accessing other health services), community factors (e.g., the distance to the ADP), and policy factors (e.g., the frequency with which a client can attend an ADP based on service maximums).

Study participants also expressed challenges with identifying valid and reliable measures of ADP purposes. It is possible that standardizing measures across this health region would support the identification and use of valid and reliable indicators and metrics; however, ADP scholars caution that uniform indicators of ADPs can be medically oriented and may emphasize biomedical health changes over psychosocial indicators (Gaugler & Dykes, 2019; Orellana et al., 2020b). The unequal attention to medical purposes of ADPs would be disconnected from the mixed or social ADP model all participants described using. As one of the study participants acknowledged, it will take a dedicated team to successfully discern the multiple and varied factors that should be considered when measuring ADPs in this region.

**Orientation within Health Care System.** The lower average ratings of Phase 2 survey items under the orientation within health care system sub-category was a surprising finding given

the Phase 1 interviews. The possible top-down influences of the orientation of ADPs within the health care system on other sub-categories could explain the lower average ratings for this sub-category. That is, the trickle-down effect of ADPs' orientation within health care system may have made survey items further along the stream more prominent or urgent to address.

The moderate ratings of challenges pertaining to scope and standardization were another unexpected finding given the descriptions of Phase 1 participants. The careful nuances of ADP standardization described by Phase 1 participants, such as avoiding "cookie cutter" programs when creating ADP standards, suggested this would be a prioritized challenge. This finding also contrasts the ADP literature which recognizes that the lack of a clarified scope for ADP services has been challenging (British Columbia Association of Community Care, 1997 as cited in Ritchie, 2003; Dabelko, 2004). Extant literature also speaks to the importance of a clear understanding and communication of the scope of ADP purposes so that clients and caregivers understand services (Hopp et al., 2020). Past efforts of the sub-regions to create standards and clarify scope (documented in grey literature that cannot be referenced here for anonymity) also suggested that this would be a greater area of focus. However, it is possible that participants felt that past projects and progress in these areas have made these items less prominent or urgent to address in comparison to areas that have not been addressed.

Finally, it is not surprising that transportation was acknowledged by Phase 1 interview participants, specifically as a challenge, and highly rated by survey participants, considering this study's findings that the out-of-home nature of ADP services is important. The high ratings of transportation challenges identified align with other ADP research (Anderson et al., 2012), particularly studies conducted with ADPs located in rural areas (Sanders et al., 2009). The findings of this study support differences in urban or rural locations can be either enabling if



urban and/or centrally located or challenging if rural or farther away from town or city cores. Study participants also discussed the importance of transportation being suitable for their clients, specifically people living with dementia. Together, these findings suggest that both the location of ADPs and the ability of existing transportation to support ADP clients are important factors for ADP directors to consider when thinking about how to meet their purposes.

**Ability to Support Clients and Caregivers.** Challenges pertaining to participants' ability to support clients and caregivers were discussed at length by Phase 1 participants and highly rated in Phase 2. The prominence and urgency of these survey items reflect the literature demonstrating that the acuity of clients is increasing and, as a result, making it more difficult for current mixed or social models of ADPs to meet the needs of clients (Anderson et al., 2012). As previously discussed, the acuity of clients, particularly those living with dementia, may also be influencing the needs of caregivers and the potential for caregivers to experience burnout due to the level of support caregivers are providing for people with higher acuity (Health Care Council of Canada, 2012; Schulz & Sherwood, 2009).

As described by Phase 1 participants, the complexity of client care and support needs are also influencing length of stay in ADPs and preventing clients from experiencing ADP services as participants perceived they should. Participants' recognition that earlier referral to ADPs could help directors with the preventive, upstream purposes of their work aligns with existing ADP literature (Ellen et al., 2017; Fields et al., 2014; Orellana et al., 2020b). For example, Dabelko (2004) recommended a potential two-model approach based on projected length of stay, with a short-term and long-term model depending on client needs and interests. It is possible that Dabelko's (2004) suggested model regarding projected length of stay aligns with the existing ADP models that participants used to describe their services (i.e., social, medical, mixed).

Therefore, it may be appropriate for ADP directors to consider, in partnership with their funder, how potential needs for medical models can be addressed without jeopardizing the preventive, social, or mixed models that some ADPs use.

Within this sub-category, participants also discussed and rated their ability to make ADPs inclusive and welcoming to diverse populations as an urgent challenge to address. Participants recognized that people living in their community were more diverse than the individuals who attended their ADPs but expressed they were not sure how to overcome this challenge due to structural constraints. The published ADP literature is also largely lacking in its attention to cultural, ethnic, and racial groups which provides little evidence for participants to reference when attempting to address this potential gap in their services (Dabelko, 2004; Ellen et al., 2017; Hopp et al., 2020). However, Hopp et al.'s (2020) study with Arab American stakeholders in metropolitan Detroit may offer some future steps for ADP directors of this health region. Hopp et al. (2020) concluded that ADPs need to be aware of the terms they might be using to describe their services, as terms such as "multicultural" may not resonate with various cultural, ethnic, or racial groups. As such, careful attention should be paid to language to ensure various groups relate to messaging and to confirm that ADPs are recognizing the diversity that exists within cultural, ethnic, and racial groups (Hopp et al., 2020). Dabelko (2004) also recommend ADPs regularly inventory their services and programs to verify they are responsive to their evolving communities.

**Perceptions of ADPs.** The high rating of perceptions that ADPs are not part of the health care system speaks to this sub-category's connections to the orientation within the health care system sub-category. The perceptions of ADPs regarding their status as a health care service may stem from the well-established primacy of acute medical services over home and community

care services (Chappell & Hollander, 2013; Lefebvre et al., 2020). The mixed model of providing ADP services suggest that most participants saw their ADPs as offering both medical and social supports, which might complicate their placement in a biomedically oriented system.

Participant's elaboration of the perceptions and stigma held by specific ADP stakeholders also may also be connected to ageism. Interview participants referenced both community members and health care professionals as holding perceptions that ADPs are just for "old people." Although many ADPs provide services for primarily older adults, chronologically younger people have conditions and experience life events that can be supported by ADP services (Anderson et al., 2014). With people experiencing the onset of some chronic conditions, such as the effects of stroke, earlier than in the past (Heart & Stroke, 2017), it becomes important for ADP directors to consider how they are, or can be, adjusting their programs to meet the needs of these relatively younger individuals, if they have not already.

(Mis)perceptions that ADPs are only for older people may also prevent people who would be considered "older" (i.e., aged 65 years or older) from accessing ADPs if they have internalized ageism that encourages them to distance themselves from other older people or health services associated with aging (Levy, 2009; Meisner & Levy, 2016; Sarkisian et al., 2002; Swift et al., 2017). The ADP literature has also documented instances of ageism in ADPs, primarily through infantilization of clients (Salari, 2006). Community members may be distancing themselves from this service to avoid exposing themselves to age stereotypes and/or ageism. It would be beneficial to explore the age appropriateness of ADPs in this health region, especially as age demographics of ADPs are variable and changing.

### ***Enablers***

Although challenges were a larger focus in Phase 1 interviews than enablers, the enabler

survey items tended to receive higher ratings than challenge survey items in Phase 2, with many enablers exceeding 9.0. The higher ratings of enablers could be due to a lower quantity of enablers, but their importance to ADP purposes was more concentrated; whereas challenges had a higher quantity, but their importance to ADP purposes was dispersed. Overall, there were four interrelated sub-categories that were uniquely enablers, which included approach to services; client and caregiver involvement; collaboration and partnerships; and referrals. These sub-categories are integrated and discussed in detail below. An overview of average ratings of enabler sub-categories can be found in Table 16.

Table 16. *Average Mean Ratings of Enablers Sub-Categories*

<b>Sub-Category</b>	<b>Strength of Support</b>	<b>Degree of Promotion</b>
Approach to Services and Operations	8.8	9.0
Client and Caregiver Involvement	8.3	8.9
Collaboration and Partnerships	7.8	8.0
Referrals	7.3	7.6

**Approach to Services & Client and Caregiver Involvement.** Both the approach to services as well as client and caregiver involvement sub-categories are interrelated key findings of this study. Findings demonstrate the importance of these sub-categories to enabling the pursuit of ADP purposes, particularly the highest rated ADP purpose to ‘provide person-centered services for all clients and caregivers.’ The attention to client and caregiver strengths, values, and preferences when approaching service delivery, and providing services that are flexible to these factors, is consistent with definitions of person-centered care (American Geriatrics Society [AGS] Expert Panel on Person-Centered Care, 2016). The involvement of clients and caregivers in the design and delivery of services also addresses the collaboration between health care professionals and individuals accessing services required of person-centered services (AGS Expert Panel on Person-Centered Care, 2016). These findings lend support to person-centered

care approaches being not only appropriate for home and community care settings (Moore et al., 2017), but a highly relevant facilitator of their purposes. The detailed discussions and high ratings related to providing person-centered services also reflect shifts within ADPs and the broader health care system to valuing the experiences and perspectives of people accessing services (Dabelko, 2004; Premier's Council on Improving Healthcare and Ending Hallway Medicine, 2019).

ADP directors have more control over the implementation of these two sub-categories than other ADP stakeholders, as they are responsible for determining the overall approach to providing ADP services and the degree to which clients and caregivers are involved with staff and services. While the legacy LHINs/Ontario Health set quality improvement parameters that pertain to service approaches and client and caregiver involvement, the design and implementation of these two enablers is decided by directors (Health Quality Ontario, 2013; Ministry of Health and Long-Term Care & Health Quality Ontario, 2014). Participants substantiated their power over these enablers when describing their responsibilities in Phases 1 and 2, as well as when a few survey participants elaborated on their "focused" actions and the "time and energy" they spend when implementing these enablers. It is notable that these highly rated enablers pertained to areas ADP directors can directly influence.

**Collaboration and Partnerships & Referrals.** Similar to the previous two sub-categories, both the collaboration and partnerships as well as referrals sub-categories are interrelated with respect to key findings of this study. Specifically, these sub-categories demonstrate the importance of strong connections within and outside of ADPs. The positive impacts participants shared about collaboration within their ADP sub-region networks and at the larger health region level were clear enablers. Supportive communication between ADP directors

at sub-region and regionwide levels connect with existing literature related to capacity building of ADPs (Sanders et al., 2009). The collaborations participants already engaged in not only supported their ADP purposes, but these could also be harnessed to support follow up with the findings of this study. The task force recommended in the comparison between current and desired purposes section of this chapter is one example of how this interest in internal connections could be useful. The importance of the support from and interest in collaborating with other ADPs could also be heightened by the COVID-19 pandemic (Sadarangani et al., 2021), which created a context in which ADP directors relied on each other in the absence of guidelines and directives from Ontario's Ministry of Health.

The importance of collaborating with other health care and support services, sometimes in the form of formal referrals, was also discussed and highly rated in this study. Participants recognized their own willingness to collaborate with other health care and support services was a facilitator of their ADP purposes. Further, the introduction of the Ontario Health Teams model appeared to be an enabler of these types of collaborations, which aligns with the intentions of Ontario's health care system restructuring (Ontario Health Teams, 2021). However, while Ontario Health Teams felt promising for some participants, these and other participants also expressed concerns with service continuity as the health care system transitions to Ontario Health and Ontario Health Teams.

### ***Both Enabling and Challenging Factors***

Although participants described much of the content within sub-categories as distinctly enabling or challenging, a few sub-categories existed as both enablers and challenges depending on context. Therefore, it is appropriate to consider these factors together and to compare these findings to the extant literature. Sub-categories that participants discussed as both enablers and

challenges included funding and resources; organizational affiliations and governance; built or physical environment; staff; and advocacy and awareness. Attention to the distinctions of sub-category items as enabling or challenging is presented for each sub-category below. The average ratings of these sub-categories from both their enabler and challenge categories can be found in Table 17.

Table 17. *Average Mean Ratings of Enabler and Challenge Sub-Categories*

Sub-Category	Enabler		Challenge	
	Strength of Support	Degree of Promotion	Prominence	Urgency to Address
Funding and Resources	7.0	6.7	6.5	6.9
Organizational Affiliations and Governance	7.7	7.6	5.8	5.8
Built or Physical Environment	7.4	7.8	6.5	7.5
Staff	8.7	9.0	5.4	6.3
Advocacy and Awareness	7.4	8.3	7.6	8.2

**Funding and Resources.** Participants' ratings of the funding and resources survey items demonstrated that this sub-category could be enabling or challenging depending on the context. Specifically, participants highlighted that when funding and resources were sustainably available, they felt their ADP purposes were supported. In contrast, when funding and resources were limited, they found their pursuit of ADP purposes to be challenged. The funding and resources sub-category is one of the factors where, although Phase 1 and 2 findings were both enablers and challenges, the findings were predominantly challenging. This is supported by the Phase 2 results as this sub-category had the lowest average ratings of enablers.

Participants recognized the financial support of the Ministry of Health, especially in comparison to the United States, but also established the inadequacy of this funding to meet current, let alone desired, ADP purposes. The lack of base funding was the most prominent and urgent funding and resources challenge. This finding reflects how government funding is a main source of financial support for Canadian ADPs (Weeks, 1998). It is also consistent with North

American literature that suggests government reimbursements of ADP services are typically insufficient (Anderson et al., 2012; Sanders et al., 2009). Due to government funding not covering all the costs to meet ADP purposes, ADPs require co-payments (or fees) from clients and caregivers. The challenge of being a community support service that charges client fees was rated moderately by participants in Phase 2 and was rarely discussed by Phase 1 participants. The lack of attention to client copayments contrasts Weeks' (1998) speculation that Canadian ADP clients and caregivers might find co-payments challenging because they are not accustomed to paying for health services. Weeks' (1998) suggestion is interesting considering the challenges the current study's participants shared with perceptions that ADPs are not part of the health care system. It is possible that the presence of co-payments contributes to these perceptions. It is also conceivable that because ADP directors are not responsible for paying co-payments, this challenge is not as salient to them. Other ADP stakeholders, namely clients and caregivers, may have rated this challenge differently as they are responsible for paying fees.

Given Phase 1 discussions and ADP literature (Anderson et al., 2012; Sanders et al., 2009), it is surprising to see the relatively moderate ratings of the funding and resources challenges in the Phase 2 survey when compared to the other sub-categories. This could be due to the variety of the funding and resource survey items which included broader health care system, staff, and client items. Participants may also be accustomed to operating their ADP(s) with a limited "shoestring" budget and resigned about the potential for changes to funding and resources to occur. It is also possible that the different organizational affiliations of participants influenced the ratings of these items. As discussed in the next sub-category, affiliations with an umbrella organization were enabling due, in part, to the increased access to resources. The high



number of participants affiliated with an organization may be masking the findings of standalone ADPs or smaller affiliate organizations.

**Organizational Affiliations and Governance.** Many participants described their organizational status (i.e., standalone, under a larger organizational umbrella) as both enabling and challenging to meeting their ADP purposes with regards to access to resources and decision making. The benefits of being affiliated with an organization were rated more highly than the challenges by this study's participants. The positive influence of being connected to an umbrella organization for meeting ADP purposes was also discussed by ADP administrators in Sanders et al.'s (2009) study. The ratings for organizational affiliations as enablers were also higher than the ratings for standalone status. Together, these findings suggest that being part of a parent organization could be an optimal model for ADPs.

However, the type of parent organization or organizational affiliation may influence the degree of support or promotion that ADP directors experience when pursuing their ADP purposes. Potential enabling factors of affiliations with long-term care mentioned by Phase 1 participants were not reflected in the ratings of this survey item in Phase 2, and, for many participants, this survey item was not applicable to their ADP. When it was applicable, it appeared to have a low supportive influence on participants' pursuit of ADP purposes. In contrast, while many participants found connections with businesses to be not applicable, when they were present, they were a relatively high enabler. The influence of organizational affiliations on the ability of ADPs to pursue their purposes should be explored further to determine if there is an optimal organizational status for the operation of ADPs (Ellen et al., 2017). Researchers conducting studies with ADPs should also provide organizational status in the study context to support the exploration of this potentially differentiating factor of ADPs.

**Built or Physical Environment.** The high ratings of the attractive and welcoming physical space of ADPs as an enabler to ADP purposes was an unanticipated but key finding. As previously mentioned, there is limited research regarding the physical environments of ADPs and this research focuses on ADPs serving people with dementia. As such, this ADP literature generally attends to the functional and supportive aspects of the environment (e.g., secure facilities, multiple rooms for activities, etc.), rather than the visual attractiveness of ADP locations (Brown, 2012). However, this key finding is consistent with research regarding other environments associated with older adults' health and well-being. For example, the settings of LTC facilities and Older Adult Centres appear to be important to the experience of older people in these physical environments (Fleming & Purandare, 2010; Hostetler, 2011; Hrybyk et al., 2012; Older Adults Centres' Association of Ontario, 2016; Roth et al., 2016; Swift et al., 2017). Some of the existing supports include modernized external and internal environments and being situated in purposefully built environments (Older Adults Centres' Association of Ontario, 2016; Roth et al., 2016). The high ratings of the limited capacity and unsuitable location of ADPs as challenges to meeting ADP purposes are also reflected in the ADP literature (Anderson et al., 2012), as well as research on other service settings for older adults (Older Adults Centres' Association of Ontario, 2016; Roth et al., 2016). For example, Brown's (2012) findings that most ADPs in Nova Scotia are operated in environments smaller than the recommended size demonstrates the limited physical capacity to meet the demand of clients. The outdated and repurposed quality of many Older Adult Centres and some LTC facilities have also been noted as challenges for these services for older people (Older Adults Centres' Association of Ontario, 2016; Roth et al., 2016).

Together, these enablers and challenges suggest that research into optimal ADP design and location as an “emerging place type” could be beneficial to ensure the physical environments of ADPs support their purposes, rather than contradict them (Moore, 2002; Moore et al., 2006). There is potential for interdisciplinary collaborations with experts in architecture and interior design to explore findings regarding ADP environments further and support future construction of and on ADP buildings. However, previous researchers have noted various challenges to these collaborations including constraints to conducting research in health care settings, the inattention to the influence of physical aspect of health care environments, and limited architectural researchers with which to collaborate (Devlin & Arneill, 2003). The expansion of environmental gerontology and research in health care settings, including ADPs (Brown, 2012; Franko, 2014), is promising to overcome these previous challenges and amplify documented enablers.

Co-location with long-term care was one of the few survey items that was shared between the enablers and challenges Phase 2 survey sections. The findings demonstrated that this factor was neither highly enabling nor highly challenging for most study participants. The potentially neutral or equally supportive and challenging status of co-location with LTC is consistent with Ritchie’s (2003) discussion of the benefits (i.e., easier transitions) and constraints (i.e., stigma) of LTC co-location. This survey item was also rated as not applicable by many Phase 2 participants and not addressed by many Phase 1 participants. This finding could demonstrate that many ADPs have already shifted locations from LTC facilities to address the stigma that is attached with these locations (Weeks, 1998). This was the case for one interview participant, who claimed that the benefits of a standalone location outweighed the benefits of being co-located.

**Staff.** In contrast to the previous factors which have either mainly consisted of challenges or been mixed, the staff sub-category largely pertained to enablers of pursuing ADP purposes.

The survey items in the enablers staff sub-category were consistently rated as high in Phase 2 and enthusiastically discussed by Phase 1 participants. The enabling factors of familiar and trusting professional relationships between staff, clients, and caregivers and among staff, as well as staff dedication to working with clients and caregivers are all consistent with the strengths identified by the ADP administrators of Sanders et al.'s (2009) study and the clients, caregivers, and nurses of Ritchie's (2003) study. Current findings also demonstrated that it is important to employ staff with professional backgrounds that reflect and can achieve their ADP purposes. Given that there exist a variety of ADP purposes, it is logical that ADPs would excel in their purposes with staff from a variety of professional backgrounds (Leitsch et al., 2001; Ritchie, 2003). However, participants described employing staff with various professional backgrounds as challenging. The ability of ADP directors to provide education and training to staff with wide ranging professional backgrounds was also described as a challenge.

The strength of staff as an enabler of ADPs suggests that frontline ADP staff are vital to meeting the purposes of ADPs and should be recognized for the key roles they play. Many Phase 1 participants described being unable to financially reimburse staff equitably for their work given constraints with funding and resources, which is consistent with the broader ADP literature (Anderson et al., 2012; Sanders et al., 2009) and commentaries regarding home and community care funding in Ontario (Ontario Community Support Association, 2021). Although Phase 2 participants did not rate low staff wages as a prominent or urgent challenge, this could be due to other mechanisms that make low staff wages not applicable, such as a unionized environment. If more funding and resources are allocated to ADP directors, it will likely be challenging to determine where funds and resources should be assigned. In any discussions of funding and resource advocacy, it might be beneficial for ADP directors to discuss where additional funds

and resources would be best allocated in the context of pursuing their current, and desired, ADP purposes.

**Advocacy and Awareness.** The advocacy and awareness sub-category contained items that were both highly challenging and highly enabling. Participants shared that they found client and caregiver testimonials as supportive to advocacy and awareness, but also recognized that these anecdotal types of data were difficult to translate into evidence that is valued by stakeholders in decision making positions. The lack of Ontario or Canadian research regarding ADP services was both a prominent and urgent challenge described by participants. Phase 1 participants shared that the awareness of their ADP purposes is often informed by literature conducted in a United States context, which limits its applicability to the context of this health region. Together, these findings support calls for increased research with ADPs (Orellana et al., 2020b; Tarrant, 2010).

The awareness of ADP purposes at an individual level was also described as challenging by participants, particularly among community members, potential clients, caregivers, and health care professionals. The low awareness of ADPs is consistent with other ADP research (Fields et al., 2014; Ritchie, 2003), which also discusses how the inability to articulate ADP purposes prevents a clear awareness of ADPs from spreading. Researchers have suggested marketing and promoting ADP services as a solution (Ritchie, 2003); however, study participants identified this strategy as a challenge given the limited funds, resources, and knowledge about communications.

In contrast, participants highly rated the enabling factors of the collective advocacy taking place at the sub-region and larger health region level. In the future, participants could build on this enabler by strengthening the advocacy elements of their network(s) and possibly expanding it to include other provincial or national health regions. The potential task force

formed to address and refine the findings of this study could also serve as a starting point for an advocacy organization. Having a provincial or national organization dedicated specifically to ADPs would address the lack of such an association in Canada. The research co-produced or informed by the National Adult Day Services Association in the United States suggests that having an organization specific to ADPs might be beneficial to ADPs operating in Canada (Orellana et al., 2020b; Tarrant, 2010).

### **Future Research**

As identified throughout this chapter, key findings highlighted several potential areas that could benefit from future research. To begin, ADP directors could be re-engaged to clarify and refine the interpretations and initial conclusions made regarding ADP purposes, enablers, and challenges. This re-engagement will be particularly important to ensure that any knowledge translation tools and activities that are produced from these findings are co-created and reflect their perspectives.

It is important to note that ADP directors are also not the only stakeholder of ADPs. Findings suggest it would be valuable to explore these research questions with other ADP stakeholders. Clients and caregivers are one stakeholder group whose perspectives are vital to gain given the origin and purposes of ADPs to reflect their interests and needs. Study findings suggest that striving to gather data from a variety of ADP clients would be valuable, particularly in exploring the challenges ADP directors face in making their services diverse and inclusive. Frontline staff are another stakeholder group that should be involved. As with ADP directors, frontline staff perspectives are often absent from the ADP literature (Orellana et al., 2021). Further, as the stakeholder responsible for practically applying and following through on many of these ADP purposes, it will be important to gain their perspectives. Finally, ADP directors

spoke to the influence of government officials, health planners, and policy makers on ADP purposes and the enablers to and challenges of meeting these purposes. Gaining the perspectives of this stakeholder group could provide valuable insight into systems level perspectives and realistic actions to strengthen enablers and overcome challenges described by other ADP stakeholder groups.

In the development and refinement of ADP purposes, it will be important to consider suitable indicators and measures of the purposes to support future research into if and how ADPs meet the purposes stakeholders have defined. There is an interest from this stakeholder group to engage in future research to ensure that decisions are relevant to their contexts. Primary research or scans of grey literature from other health regions in Ontario or Canada may also be appropriate future studies. The results of this research may reveal actions taken elsewhere to clarify purposes and/or address enablers and challenges of these purposes that could be transferred to this health region.

### **Strengths**

As participants of the study acknowledged, this research addresses a gap in the ADP literature by exploring ADP director perspectives. Directors are a significant stakeholder due to their experiences with many other ADP stakeholders and their responsibilities of guiding ADPs. Participants provided valuable insight into the purposes of ADPs, as well as the current enablers and challenges to pursuing these purposes. This study is also one of few studies conducted in a Canadian context, addressing a gap in the ADP literature that focuses on the United States.

The integrated knowledge translation approach is another strength of this research. Involving knowledge users at the beginning and throughout most of the research cycle helped to increase the relevance of this study for knowledge users (Bowen & Graham, 2013; Nguyen et al.,

2020). This relevance was in terms of not only the eventual application of findings, but the content and design of study methods and instruments as well (e.g., use of language, interview methods, survey format). Finally, the future co-creation of knowledge translation products will be strengthened as knowledge users can leverage their understanding of the ADP context in this region to disseminate findings. The primary researcher can also ensure through co-creation that the content of knowledge translation products is consistent with participants' perspectives and respects their desired level of confidentiality and privacy.

This research also met mixed methods measures of quality (Creswell & Plano Clark, 2017; Hong et al., 2018; O'Cathain, 2010) through the rationale of creating an informed and refined description of ADP purposes, enablers, and challenges. How Phase 1 and Phase 2 were integrated was detailed throughout the thesis and the findings of this integration were considered and discussed in the Results and Discussion chapters (Creswell & Plano Clark, 2017; Hong et al., 2018). Importantly, divergences between the two phases were also discussed (Creswell & Plano Clark, 2017; Hong et al., 2018).

This study also met the quality criteria of both qualitative and quantitative descriptive methods. Rigor was achieved through the time in the field and the flexible and multifaceted tools used to understand the nuances and complexity of this phenomenon (Tracy, 2010). Credibility was established through many direct quotations and crystallization of interviews, survey responses, prolonged engagement with knowledge users, and discussions between the primary researcher and her supervisor during all phases of the research (Lincoln & Guba 1985 as cited in Krefting 1991; Tracy, 2010). Both integrated knowledge translation and a review of the literature demonstrated that this was a worthy topic to explore that makes a significant contribution both conceptually to the ADP literature and practically for knowledge users (Tracy, 2010). In terms of



quantitative description, this study clearly stated the data analysis plan, which aligned with the descriptive goals of the study, and focused on describing the distribution of Phase 2 ratings rather than determining causal relationships between items (Porta et al., 2014).

### **Limitations**

As with all research, this study should be considered within the context of its limitations. First, knowledge users were engaged in most of the research but were not formally involved in the data analysis process of Phases 1 and 2. Although indirect feedback on analysis of Phase 1 was provided via input on the Phase 2 survey instrument items, the primary researcher primarily analyzed the data to respect knowledge users' time and to meet the timelines of a master's thesis. The integrated knowledge translation process should be considered with this in mind.

This study also did not include all the current ADP directors from the larger health region. The inclusion of about half of the ADP directors from this region limits the transferability of these findings as it does not represent the views of all ADP directors in this region, particularly sub-region four that was represented by only two participants. There is also a possibility that self-selection or non-response bias was present. That is, ADP directors that chose to participate might not share similar perspectives as the ADP directors who did not participate. It is also possible that social desirability bias was present as participants may have strived to present themselves and/or their ADPs favourably. The primary researcher aimed to address these biases by building relationships with participants through attending large health region meetings and smaller sub-region network meetings and suggesting that she would be flexible to people's availability and willing to support participation where appropriate.

The aim of this study was not to generalize findings to other health regions; however, as demonstrated by situating this study's finding within the literature, it is likely that findings could

be applicable to other ADPs and contexts. A few important factors for individuals considering the transferability of this study include the demographics of participants (i.e., predominately white, female) and characteristics of the ADPs participants directed (i.e., most operated their ADPs under the umbrella of a larger organization, most provided services primarily for people living with dementia). Also, this study did not collect the age of the clients and caregivers who attended participants' ADPs. This information could have helped with potential transferability of findings and situating the findings within ADP literature.

Finally, while York's Office of Research Ethics was prompt in reviewing and approving the ethics proposal, the additional requirements to receive ethics statements from each ADP organization extended the initial time to apply for ethics and interview or survey participants. The additional time required for ADPs' organizational ethics was especially relevant for ADP directors who operated under the umbrella of larger organizations. These individuals were required to communicate with multiple levels of their organization to confirm their ethics process and receive the appropriate signatures. While the primary researcher attempted to streamline this process through drafting statements, it did require participants to engage in additional work that may have caused reluctance or a prolonged prelude to participate and resulted in one survey response not being included in Phase 2.

## **Conclusion**

Consistent with its aims, this study made progress with informing and refining the purposes of ADPs, and what factors enable and challenge these purposes, in a specific health region of Ontario using a collaborative research approach. Findings aligned with established purposes and calls to expand upon these purposes. The results of this study also extended these purposes by introducing novel purposes and nuances not yet addressed by existing literature.

Potential future areas of priority based on the findings of relative differences between current and desired purposes were also identified and connected to the several enablers and challenges discovered.

This research began the process of modernizing ADP purposes that have not been formally updated in Ontario for many years. The mobilization of this strategically positioned, yet often overlooked ADP stakeholder, is beneficial to other ADP stakeholders. The updated ADP purposes discovered through this research can be used to inform and optimize the policies, practices, procedures, and services of ADPs in this health region. A clearer understanding of the purposes of ADPs begins to situate this service in the broader continuum of health care and support services and, ultimately, contribute to strengthening the Ontario health care system's effectiveness in enhancing the experiences of service users, particularly older people. The continued mobilization of this and other ADP stakeholders is necessary to determine if the growing interest in ADPs is warranted, and what factors enable and challenge ADPs to sustainably meet this vision.

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## Appendix A: Interview Recruitment Email Script

Subject: Adult Day Program Phase 1 Research Opportunity – Interview Participants Needed

Hello,

I'm inviting you to take part in Phase 1 of a research study "Exploring the Purpose of Adult Day Programs from Directorial Staff Perspectives" being conducted by Deanna Vervaecke and Dr. Brad Meisner in the School of Kinesiology and Health Science at York University. We are conducting virtual interviews (i.e., Zoom or telephone) as part of this phase of the research study that will explore the purpose(s) of adult day programs, as well as the challenges to and enablers of achieving adult day program purpose(s), from the perspectives of adult day program directors.

The virtual interview takes approximately 45-60 minutes to complete and will be guided by a set of predefined questions. We are simply trying to capture perspectives of adult day programs from directors in the [anonymized health region]. Your responses to the questions will be anonymized and your information will be kept private and confidential, unless consented to otherwise.

If you are interested in knowing more about the project, or are willing to participate, please contact the research team by replying to this email. If you have any questions, please do not hesitate to ask.

Thank you,

Deanna Vervaecke, BSc (Hons.)  
Graduate Student, Master of Science  
School of Kinesiology & Health Science  
York University  
[vdeanna@yorku.ca](mailto:vdeanna@yorku.ca) | 519-754-8631

Brad Meisner, PhD  
Associate Professor  
School of Kinesiology & Health Science  
York University  
[meisnerb@yorku.ca](mailto:meisnerb@yorku.ca)

## Appendix B: Survey Recruitment Email Script

Subject: Adult Day Program Phase 2 Research Opportunity – Survey Participants Needed

Hello,

I'm inviting you to take part in Phase 2 of a research study "Exploring the Purpose of Adult Day Programs from Directorial Staff Perspectives" being conducted by Deanna Vervaecke and Dr. Brad Meisner in the School of Kinesiology and Health Science at York University. We are conducting surveys as part of this research study that explores the purpose(s) of adult day programs, as well as the challenges to and enablers of achieving adult day program purpose(s), from the perspectives of adult day program directors.

The survey consists of answering a few questions regarding the adult day program(s) you direct, and rating proposed adult day program purposes, challenges, and facilitators using criteria outlined in the survey. The estimated time of completion will be no more than 30-45 minutes. With this phase, we are trying to capture your perspectives of the interview responses for adult day programs in the [anonymized health region]. Your responses to the questions will be anonymized and your information will be kept private and confidential.

If you are interested in knowing more about this phase of the research project, or are willing to participate, please contact the research team by replying to this email. If you have any questions, please do not hesitate to ask.

Thank you,

Deanna Vervaecke, BSc (Hons.)  
Graduate Student, Master of Science  
School of Kinesiology & Health Science  
York University  
vdeanna@yorku.ca | 519-754-8631

Brad Meisner, PhD  
Associate Professor  
School of Kinesiology & Health Science  
York University  
meisnerb@yorku.ca

## Appendix C: Consent Form – Interview

### Informed Consent Form – Information Page

**Study Name:** Exploring the Purpose of Adult Day Programs from Directorial Staff Perspectives

**Researchers:** Brad Meisner, PhD ([meisnerb@yorku.ca](mailto:meisnerb@yorku.ca)) and Deanna Vervaecke, BSc (Hons.) ([vdeanna@yorku.ca](mailto:vdeanna@yorku.ca))

**Purpose of the Research:** To explore the purpose(s) of adult day programs, as well as the challenges to and enablers of for achieving these purpose(s), from the perspectives of adult day program directors.

**What You Will Be Asked to Do in the Research:** This phase of the study will require approximately 45-60 minutes of your time to complete an audio recorded one-on-one interview either over Zoom or over telephone. Virtual interviews will take place at a quiet and private location of your choice.

**Use of Audio/Video-Conferencing Software:** This study will use Zoom, an externally-hosted cloud-based service, to collect data. Recordings (audio/video) will be saved in a password-protected file to research team members' local computer, not the cloud-based service. However, when information is transmitted over the internet, privacy cannot be guaranteed. There is always a risk that your responses may be intercepted by a third party (e.g., government agencies, hackers). Further, while York University researchers will not collect or use IP address or other information which could link you to your computer or electronic devices without informing you, there is a small risk with any platform, such as Zoom, that information collected on external servers fall outside the control of the research team. The researchers acknowledge that the host of the online products (Zoom communication technology) may automatically collect participant data without their knowledge (i.e., IP addresses). Although this information may be provided or made accessible to the researchers, it will not be used or saved without participants' consent on the researchers' system. Further, because this project employs e-based collection techniques, data may be subject to access by third parties as a result of various security legislation now in place in many countries and thus the confidentiality and privacy of data cannot be guaranteed during web-based transmission. If you are concerned about these issues, we would be happy to make alternative arrangements (where possible) for you to participate, perhaps via telephone. Please contact Deanna Vervaecke ([vdeanna@yorku.ca](mailto:vdeanna@yorku.ca)) or Brad Meisner ([meisnerb@yorku.ca](mailto:meisnerb@yorku.ca)) for further information.

**Risks and Discomforts:** The risks associated with this study are expected to be minimal. Many participants regularly engage in conversations regarding the research questions with other health service partners. However, the potential for risk remains. There is potential for economic risk to the adult day program(s) you direct. For example, interview data may refer to those who provide funding to adult day programs, either positively or negatively. Whether positive or negative, the findings may impact funding. There is also potential for professional or social risk. For example, findings may alter the perceptions of the adult day program(s) you direct by others in health and social services that lead to changes to relationships and administration. Also, as stated above, through using Zoom via the internet, privacy cannot be guaranteed if the meeting is intercepted by a third party.

These risks will be managed for participants by preserving privacy and confidentiality of individual participants through data management (e.g., anonymizing interview transcripts, safely securing paper and electronic data, etc.) and the larger sample of participants. Results that pertain to topics or details relating to potential social, professional, and/or economic risk will only be reported at the group-level



and will not be labeled. The researchers will also work collaboratively with participants to design and disseminate knowledge translation resources (e.g., fact sheets) to ensure content truly reflects their perspectives and the level of information they would like to share. Finally, you are free to skip any question during the interview and/or leave the interview at any time. You can also contact Brad Meisner by e-mail at [meisnerb@yorku.ca](mailto:meisnerb@yorku.ca) to ask questions, request an alternative interviewer, or withdraw from the study. To decrease the likelihood of a third-party interception, the Zoom meeting will require a password to enter.

**Benefits of the Research and Benefits to You:** You may benefit from participating in this research study by gaining experience with community-based research and research methods firsthand. It is also an opportunity to reflect upon your experiences with adult day programs. You may also find it cathartic to voice your experiences throughout the research process. Additionally, you will be able to use findings to communicate the purpose(s) of, challenges to, and enablers of adult day programs with stakeholders. Finally, this research will contribute to the literature in many ways, including increasing understanding of adult day programs in a Canadian context, further exploring the purpose of adult day programs, answering a call to explore the characteristics of adult day programs and those who direct them, and reporting on collaboration with a key adult day program stakeholder (i.e., directors).

**Voluntary Participation and Withdrawal From the Study:** Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision to not participate will not influence the nature of the ongoing relationship you may have with the researchers and colleagues either now, or in the future. If you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

**Confidentiality:** All information you supply during the research will be held in confidence and be kept private. Unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Only the research team will have access to this information. No third parties will be informed of your choice to participate. When collecting the data, we will ensure that the rooms are private where others will not see or hear you. We will use a pseudonym (not your name) in our written and computerized records so that the information we have about you does not contain your name. When emails are sent to you, there will be no identifiable return address or subject lines that disclose study participation. All electronic records, including audio recordings, will be kept secure in a password-protected file on the researcher's personal password-protected computer or on a York University secure firewalled server. All hard copy data will be safely stored in a locked facility for seven years and only research staff will have access to this information. After this period has ended, the data will be destroyed using a paper shredder and deletion of electronic data, including audio recordings, via overwriting and reformatting of external drives. Confidentiality will be provided to the fullest extent possible by law.

**Future Research Use:** The data collected in this research project may be used – in an anonymized form – by members of the research team in subsequent research investigations exploring similar lines of inquiry. Any secondary use of anonymized data by the research team will be treated with the same degree of confidentiality and anonymity as in the original research project.

**Questions About the Research?** If you have questions about the research in general or about your role in the study, please feel free to contact Deanna Vervaecke by email at [vdeanna@yorku.ca](mailto:vdeanna@yorku.ca) or by telephone at 519-754-8631 or Dr. Brad Meisner by e-mail at [meisnerb@yorku.ca](mailto:meisnerb@yorku.ca). This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's

Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University by telephone at 416-736-5914 or by e-mail at [ore@yorku.ca](mailto:ore@yorku.ca).

## Informed Consent Form – Signature Page

**Study Name:** Exploring the Purpose of Adult Day Programs from Directorial Staff Perspectives

**Researchers:** Brad Meisner, PhD ([meisnerb@yorku.ca](mailto:meisnerb@yorku.ca)) and Deanna Vervaecke, BSc (Hons.) ([vdeanna@yorku.ca](mailto:vdeanna@yorku.ca))

### Legal Rights and Signatures:

I \_\_\_\_\_, consent to participate in this research study. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

**Signature** \_\_\_\_\_  
Participant

**Date** \_\_\_\_\_

**Signature** \_\_\_\_\_  
Researcher/Principal Investigator

**Date** \_\_\_\_\_

### Additional consent:

#### 1. Audio recording

- I consent to the audio recording of my interview(s).

**Signature** \_\_\_\_\_  
Participant Name:

**Date** \_\_\_\_\_

#### 2. Permission to use direct, unattributed quotations

- I consent to the use of my de-identified quotations in the publications arising from this research.

**Signature** \_\_\_\_\_  
Participant Name:

**Date** \_\_\_\_\_

#### 3. Consent to waive anonymity

- I consent to the use of my name in the publications arising from this research.

**Signature** \_\_\_\_\_  
Participant Name:

**Date** \_\_\_\_\_

### Appendix D: Interview Guide

1. Can you briefly tell me about yourself and how you came to be a director at an adult day program?
2. Can you briefly tell me about the adult day program(s) you direct?
3. How would you describe the current purpose, or purposes, of your adult day program?
4. Can you tell me about a service or program that you offer at the adult day program(s) you direct that you think demonstrates or fulfills this/these purpose(s)?
5. Do you think that the Ontario Community Support Association's adult day program purposes align with your perceptions of adult day program purpose(s)? Why or why not?
  - OCSA definition: "A support service which provides supervised individualized programming in a group setting for adults *to assist in achieving and maintaining their maximum level of functioning, to prevent premature and inappropriate institutionalization, and to provide respite and information for caregivers*" (Ontario Community Support Association, 1999, p. 29, emphasis added).
6. Do you think your current purposes and/or OCSA's purposes differ from what adult day program purposes should be? If yes, how so?
7. Can you tell me about any enablers that currently support your adult day programs' purpose(s)?
8. Can you tell me about any challenges that currently impede your adult day programs' purpose(s)?
9. Is there anything that you would like to add or clarify that has not already been covered?
10. Do you have any questions for me?

## Appendix E: Survey Instructions Email Script

Subject: Adult Day Program Phase 2 Research Opportunity

Hello,

Thank you for your interest in participating in Phase 2 of the research study “Exploring the Purpose of Adult Day Programs from Directorial Staff Perspectives”.

I have attached three documents to this email: “Survey Consent Form”, “Phase 2 Survey Instructions”, and “Phase 2 Survey Reporting”.

Please open and read the “Survey Consent Form” first. If you have any questions about the research, please contact me or Dr. Brad Meisner before proceeding with the survey. You always have the right to decline or withdraw your consent to participate in the research. If you decline to consent, I would like to thank you for your time and kindly ask you to respond to this email, or contact Dr. Brad Meisner at [meisnerb@yorku.ca](mailto:meisnerb@yorku.ca), to inform the research team of your decision. Declining to consent does not carry a penalty. Alternatively, if you decide to consent to participate in this phase of the survey, please sign and save the consent form and proceed to opening the “Phase 2 Survey Instructions” and “Phase 2 Survey Reporting” documents.

The “Phase 2 Survey Instructions” document provides direction on how to report your perspectives for sections three to five of the survey. The “Phase 2 Survey Reporting” document is where your feedback should be recorded. Once you have completed the “Phase 2 Survey Reporting” document you can save it and respond to this email with it, and the completed “Survey Consent Form”, attached.

I am aware that completing this survey asks you to make space in your busy schedule. Out of acknowledgement of this, we have designed the survey so that it can be completed as you have time (i.e., it doesn't need to be completed all at once). I am also more than happy to work with you to make finishing the survey as seamless as possible.

If you have any questions at any time, please do not hesitate to contact me at [vdeanna@yorku.ca](mailto:vdeanna@yorku.ca) or 519-754-8631, or Dr. Brad Meisner at [meisnerb@yorku.ca](mailto:meisnerb@yorku.ca).

Thank you,  
Deanna Vervaecke, BSc (Hons.)  
Graduate Student, Master of Science  
School of Kinesiology & Health Science  
York University  
[vdeanna@yorku.ca](mailto:vdeanna@yorku.ca) | 519-754-8631

Brad Meisner, PhD

Associate Professor  
School of Kinesiology & Health Science  
York University  
[meisnerb@yorku.ca](mailto:meisnerb@yorku.ca)

## Appendix F: Consent Form – Survey

### Informed Consent Form – Information Page

**Study Name:** Exploring the Purpose of Adult Day Programs from Directorial Staff Perspectives

**Researchers:** Brad Meisner, PhD ([meisnerb@yorku.ca](mailto:meisnerb@yorku.ca)) and Deanna Vervaecke, BSc (Hons.) ([vdeanna@yorku.ca](mailto:vdeanna@yorku.ca))

**Purpose of the Research:** To explore the purpose(s) of adult day programs, as well as the challenges to and enablers of achieving these purpose(s), from the perspectives of adult day program directors.

**What You Will Be Asked to Do in the Research:** This phase of the study will require approximately 30-45 minutes of your time to complete a survey via email. You will be asked to respond to questions about yourself as an adult day program director and the adult day program(s) you direct. You will also be asked to rate purpose(s), challenges, and enablers according to provided criteria.

**Risks and Discomforts:** The risks associated with this study are expected to be minimal and equivalent to the risks described in the first consent form completed prior to the interviews. Many participants regularly engage in conversations regarding the research questions with other health service partners. However, the potential for risk remains. There is potential for economic risk to the adult day program(s) you direct. For example, the survey data may refer to those who provide funding to adult day programs, either positively or negatively. Whether positive or negative, the findings may impact funding. There is also potential for professional or social risk. For example, findings may alter the perceptions of the adult day program(s) you direct by others in health and social services that lead to changes to relationships and administration.

These risks will be managed for each participant by preserving privacy and confidentiality of individual participants through data management (e.g., anonymizing survey responses, safely securing paper and electronic data, etc.) and the larger sample of participants. Results that pertain to topics or details relating to potential social, professional, and/or economic risk will only be reported at the group-level and will not be labeled. The researchers will also work collaboratively with participants to design and disseminate knowledge translation resources (e.g., fact sheets) to ensure content truly reflects their perspectives and the level of information they would like to share. You can also contact Brad Meisner by e-mail at [meisnerb@yorku.ca](mailto:meisnerb@yorku.ca) to ask questions or withdraw from the study.

**Benefits of the Research and Benefits to You:** As with the risks, benefits to this phase of the research are equivalent to previous phases. You may benefit from participating in this research study by gaining experience with community-based research and research methods firsthand. It is also an opportunity to reflect upon your

experiences with adult day programs. You may also find it cathartic to voice your perspectives throughout the research process. Additionally, you will be able to use findings to communicate the purpose(s) of adult day programs with stakeholders and prioritize actions as a larger network, as well as sub-sections (such as geographical sub-regions and models of adult day programs), using the findings regarding ratings of challenges and enablers. Finally, this research will contribute to the literature in many ways, including increasing understanding of adult day programs in a Canadian context, further exploring the purpose of adult day programs, answering a call to explore the characteristics of adult day programs and those who direct them, and reporting on the collaboration with a key adult day program stakeholder (i.e., directors).

**Voluntary Participation and Withdrawal From the Study:** Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision to not participate will not influence the nature the ongoing relationship you may have with the researchers and colleagues either now, or in the future. If you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

**Confidentiality:** All information you supply during the research will be held in confidence and be kept private. Unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Only the research team will have access to this information. No third parties will be informed of your choice to participate. When emails are sent to you, there will be no identifiable return address or subject lines that disclose study participation. All electronic records will be kept secure in a password-protected file on the researcher's personal password-protected computer or on a York University secure firewalled server. All hard copy data will be safely stored in a locked facility for seven years and only research staff will have access to this information. After this period has ended, the data will be destroyed using a paper shredder and deletion of electronic data via overwriting and reformatting of external drives. Confidentiality will be provided to the fullest extent possible by law.

**Future Research Use:** The data collected in this research project may be used – in an anonymized form – by members of the research team in subsequent research investigations exploring similar lines of inquiry. Such projects will still undergo ethics review by the HPRC, our institutional REB. Any secondary use of anonymized data by the research team will be treated with the same degree of confidentiality and anonymity as in the original research project.

**Questions About the Research?** If you have questions about the research in general or about your role in the study, please feel free to contact Deanna Vervaecke at [vdeanna@yorku.ca](mailto:vdeanna@yorku.ca) or Dr. Brad Meisner by e-mail at [meisnerb@yorku.ca](mailto:meisnerb@yorku.ca). This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy



Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University by telephone at 416-736-5914 or by e-mail at [ore@yorku.ca](mailto:ore@yorku.ca).

## Informed Consent Form – Signature Page

**Study Name:** Exploring the Purpose of Adult Day Programs from Directorial Staff Perspectives

**Researchers:** Brad Meisner, PhD ([meisnerb@yorku.ca](mailto:meisnerb@yorku.ca)) and Deanna Vervaecke, BSc (Hons.) ([vdeanna@yorku.ca](mailto:vdeanna@yorku.ca))

### Legal Rights and Signatures:

I \_\_\_\_\_, consent to participate in this research study. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

**Signature** \_\_\_\_\_  
Participant

**Date** \_\_\_\_\_

**Signature** \_\_\_\_\_  
Researcher/Principal Investigator

**Date** \_\_\_\_\_

### Additional consent:

#### 1. Consent to waive anonymity

I, \_\_\_\_\_, consent to the use of my name in the publications arising from this research.

**Signature** \_\_\_\_\_  
Participant Name

**Date** \_\_\_\_\_

**Appendix G: Phase 2 Survey Reporting and Survey Rating**

**1. Demographic Questions**

a) What is your current age? (please specify): \_\_\_\_\_

b) What is your gender?

- Female  Male
- Genderqueer  Transgender
- Other (please specify): \_\_\_\_\_

c) What is your ethnicity or cultural background? Note: A person’s ethnicity describes their belonging to a group of a larger population that shares their ancestry, colour, language, or religion.

- African  Latino or Hispanic
- Caribbean  Middle Eastern
- Caucasian  South Asian
- East Asian  Southeast Asian
- Indigenous  West Asian
- Other (please specify): \_\_\_\_\_

d) Please provide your highest level of education and additional relevant certificates and qualifications.

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e) What is your title at the ADP(s) you direct?

- Adult Day Service coordinator  Manager
- CEO  Program coordinator
- Community support services manager  Supervisor
- Executive Director  Other (please specify): \_\_\_\_\_

f) Please briefly describe your duties and responsibilities as the director of your ADP(s).

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## 2. Adult Day Program Questions

- a) In what legacy LHIN region are the ADP(s) you direct?
- |  |  |
|--|--|
| <input type="checkbox"/> [Anonymized Region 1] | <input type="checkbox"/> [Anonymized Region 3] |
| <input type="checkbox"/> [Anonymized Region 2] | <input type="checkbox"/> [Anonymized Region 4] |
- b) If the ADP(s) you direct are in the [Anonymized Region 1], please select the sub-region(s) in which they are located (you can select more than one).
- |  |  |
|--|--|
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
- c) If the ADP(s) you direct are in the [Anonymized Region 2], please select the sub-region(s) in which they are located (you can select more than one).
- |  |  |
|--|--|
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
| <input type="checkbox"/> [Anonymized Sub-region] |  |
- d) If the ADP(s) you direct are in the [Anonymized Region 3], please select the sub-region(s) in which they are located (you can select more than one).
- |  |  |
|--|--|
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
- e) If the ADP(s) you direct are in the [Anonymized Region 4], please select the sub-region(s) in which they are located (you can select more than one).
- |  |  |
|--|--|
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
| <input type="checkbox"/> [Anonymized Sub-region] | <input type="checkbox"/> [Anonymized Sub-region] |
- f) How many ADP locations do you direct?
- |                            |                             |
|----------------------------|-----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 5  |
| <input type="checkbox"/> 2 | <input type="checkbox"/> 6  |
| <input type="checkbox"/> 3 | <input type="checkbox"/> 7  |
| <input type="checkbox"/> 4 | <input type="checkbox"/> 8+ |
- g) What type(s) of ADP(s) are you funded to direct? You can select more than one answer. If you direct ADPs at more than one location, please note how many locations fall into each category.
- |   |   |
|---|---|
| <input type="checkbox"/> Acquired Brain Injury, number: _____ | <input type="checkbox"/> Integrated/Blended/Supportive, number: _____ |
| <input type="checkbox"/> Aphasia, number: _____               | <input type="checkbox"/> Stroke, number: _____                        |
| <input type="checkbox"/> Dementia/Specialized, number: _____  | <input type="checkbox"/> Other, please indicate: _____                |
- h) To help us understand your client populations, please provide an **average** of the number of clients that attend your ADP(s) **each year** before COVID-19. If you direct ADPs at more than one location, please provide clients served each year for each ADP location.
- 
- i) To help us understand your client populations, please provide an **average** of the number of clients that attend your ADP(s) **each day** before COVID-19. If you direct ADPs at more than one location, please provide clients served each day for each ADP location.
-



**3. Rating Adult Day Program Purpose(s)**

Please reference the *purpose* scales and directions provided in the “Phase 2 Survey Instructions” document to complete this section.

<b>Purposes</b>	<b>Rating 3.a) current</b>	<b>Rating 3.b) desired</b>
<i>Example: Purpose</i>	<i>e.g., NA</i>	<i>e.g., 8</i>
Provide person-centered services for all clients and caregivers		
Provide services that consider a holistic concept of health (e.g., physical, cognitive, emotional)		
Provide services that address and support client overall functioning		
Maintain client abilities		
Maintain and promote or improve client abilities (where appropriate)		
Provide clients with purposeful, dynamic engagement and therapeutic recreational opportunities		
Enable meaningful social connections within and among clients and caregivers that create a sense of community and belonging		
Enable social connections between staff and clients and caregivers that create a sense of community and belonging		
Provide clients with meals to meet nutritional and social needs		
Provide and encourage client and caregiver independence and choice		
Provide caregivers and clients with out-of-home respite		
Provide caregivers with resources, education, and support		
Empower caregivers to advocate for their person		
Connect clients and caregivers with services and resources		
Provide care coordination and system navigation for clients and caregivers		
Advocate for clients and caregivers		
Provide physical environments that support purposeful engagement and recreational opportunities		
Provide safe and secure environments that meet the interests, needs, and diversity of clients		
Provide services that reflect the current community and client population interests and needs		
Keep people living in the community to prevent or delay relocation to care facilities (e.g., long-term care, retirement homes, hospital), if that is what they want		
Provide services that support the overall functioning of the health system		
<b>Other</b>		
Please specify:		

Additional Comments:

--

#### 4. Rating Adult Day Program Enablers

Please reference the **enablers** scales and directions provided in the “Phase 2 Survey Instructions” document to complete this section.

Enablers	Rating 4.a) support	Rating 4.b) promote
<b>Funding and Resources</b>		
Receiving ministry/government funding		
Having opportunities to apply for grants to complement funding from the ministry/government		
Having a LHIN-funded navigator/case manager embedded within your ADP(s)		
Having access to technology and digital health resources		
Having the ability to meet ADP purposes without sufficient funding		
<b>Organizational Affiliations and Governance</b>		
Falling under the umbrella of an organization that provides additional services that can support clients and caregivers (e.g., in-home respite, overnight respite)		
Falling under the umbrella of an organization that results in greater access to resources		
Having an organizational hierarchy or structure that supports you to operate at a systems level (e.g., sitting on regional planning tables)		
Having an affiliation with long-term care		
Being a stand alone or smaller organization which supports efficient, responsive, and autonomous decision making		
Having connections with businesses that provide your ADP(s) with resource support (e.g., low rent)		
<b>Collaboration and Partnerships</b>		
Collaborating within ADP sub-region networks		
Collaborating at the [anonymized large health region ADP network]		
Feeling a lack of competition between ADP providers		
Ontario Health Teams bringing different sectors and services closer together in collaboration and awareness of each other		
Having a willingness to collaborate and work with other health care and support services (e.g., BSO)		
Collaborating with local community supports (e.g., municipalities, cultural organizations)		
Partnering with post-secondary institutions for student placements		
Partnering with research organizations to measure ADP outcomes (e.g., ICES)		
Having good working relationships and involvement with legacy LHIN/Ontario Health representatives		



Referrals		
Receiving a good amount and depth of client information from legacy LHIN referrals (e.g., narratives)		
Receiving suitable referrals due to care coordinators' familiarity with local ADPs		
Having an increasing number of caregivers, clients, and health care professionals <i>actively</i> seeking out ADPs as new services to support themselves or people they care for		
Built or Physical Environment		
Operating in physical environments that are appropriately designed for ADP(s) (e.g., room designs that support recreational programming and client care)		
Operating ADP(s) in physically attractive or welcoming environments		
Being co-located with long-term care		
Operating ADP(s) out of standalone location(s)		
Being centrally located in your community		
Providing ADP services in a small community		
Approach to Services		
Providing services from a strengths-based or restorative approach (i.e., focusing on client strengths, adapting activities to client abilities rather than doing activities <i>for</i> the client)		
Using the dementiAbility framework (including with clients not living with dementia)		
Empowering staff to provide creative and responsive/flexible recreational opportunities		
Providing structured services (e.g., consistent schedule for activities, exercise, meals)		
Having assessment processes that support grouping clients based on interests, needs, and qualities		
Having an organizational culture of supporting and "working with" staff		
Having an organizational culture, processes, and programs that support diversity and inclusion		
Working to address systems of oppression in ADP settings (e.g., anti-racism strategies)		
Staff		
Your experience working with ADPs or Community Support Services		
Having an inter/multidisciplinary staff		
Employing staff with a recreational background		
Employing staff with a medical or clinical background (e.g., nurses)		
Employing staff with a personal support background (e.g., PSW)		
Having staff members share responsibilities (e.g., everyone can provide personal care support)		
Having a staff member dedicated to caregiver support		
Providing consistent staff training and education, for all roles (including your own)		

Having staff communication systems that foster collaboration, support, and information sharing		
Building familiar and trusting professional relationships with and among staff		
Having dedicated staff with a genuine interest in working in this field and with ADP client populations		
Staff drawing on close professional relationship and knowledge of client interests and needs		
Staff using knowledge of existing community and health resources		
<b>Client and Caregiver Involvement</b>		
Seeking and receiving consistent client and caregiver feedback to inform services		
Encouraging active client involvement in program design and delivery		
Having familiar and trusting professional relationships with clients and caregivers		
Having clients and caregivers that proactively plan for transitions		
<b>Advocacy and Awareness</b>		
Having connections with OCSA		
Being a member of Ontario Health Teams and COVID-19 planning tables		
Participating in (or benefiting from) collective advocacy at ADP sub-region and [anonymized large health region ADP network]		
Tracking and/or having access to data that can be used to advocate for resources and ADPs		
Attending age friendly events and fairs		
Receiving and documenting client and caregiver stories and testimonials		
Receiving and documenting staff stories and testimonials		
<b>Other</b>		
Please specify:		

Additional Comments:

## 5. Rating Adult Day Program Challenges

Please reference the **challenges** scales and directions provided in the “Phase 2 Survey Instructions” document to complete this section.

Challenges	Rating 5.a) prominent	Rating 5.b) urgent
<b>Orientation within Health Care System</b>		
Operating within a system that focuses on and values clinical or medical needs rather than taking a holistic perspective (i.e., a perspective that considers all domains of health)		
Having concern for service continuity as the health care system transitions to Ontario Health and Ontario Health Teams		
Client fear of long-term care waitlists encouraging them to enter long-term care and exit ADPs prematurely		
Lacking two-way communication with other health care providers (e.g., primary care, long-term care)		
Competing with long-term care for resources and recognition		
Competing with home care for resources and recognition		
Ministry/government involvement (i.e., wanting ministry/government guidance and collaboration, but also wanting to retain flexibility in decision making)		
Experiencing staff turnover at higher system levels (e.g., LHIN/Ontario Health) and its implications (e.g., delayed projects, continuously providing education about ADPs)		
Determining and following through on ADP scope in the health care continuum (i.e., where and when your ADP responsibilities for clients and caregivers begin and end)		
Staff understanding ADP scope in the health care continuum		
Providing standardized ADP services across regions		
Having consistent access to safe and accessible transportation to and from ADPs		
Determining ADP purposes to prioritize (e.g., prioritizing clients or prioritizing caregivers)		
Experiencing external pressure to focus on services outside of core ADP purposes		
Feeling concern that your own ADP(s) are moving away from a social model (i.e., focus on social interaction and therapeutic recreation) to a medical model (i.e., focus on clinical personal care and overall functioning)		
Feeling outside pressure to move towards providing a medical model of ADPs		
Seeing an increasing need for ADPs that follow a more medically based model		
<b>Funding and Resources</b>		
Receiving funding from a variety of sources (e.g., Ministry of Health, United Way, etc.)		

Meeting legislation and funder expectations of ADPs that don't align with your understanding of ADP purposes		
Having strict and inflexible funding requirements		
Experiencing limited opportunity to pursue pilot programs that could turn into programs (e.g., low or no funding, brief timelines)		
Experiencing a lack of base funding increases		
Increasing client fees to offset lack of base funding increases		
Being one of few Community Support Services that charges client fees		
Funding/resources preventing admission and retention of higher need or more complex clients		
Having an insufficient number of staff (and access to more staff) due to funding		
Providing low staff wages due to funding		
Increasing demand for ADPs with lack of infrastructure to support ADPs and client populations		
Competing with other ADPs for limited resources (e.g., funding, grant opportunities)		
Experiencing assumptions and pressure to conform to idea that ADPs "make it work on a shoestring budget"		
Having the ability to (and receiving praise for) meeting ADP purposes without sufficient funding		
Experiencing a lack of time in your role at your ADP(s)		
Experiencing a lack of geriatric speciality services in your region (e.g., geriatricians)		
Overall lack of resources in the health care system		
<b>Organizational Affiliations and Governance</b>		
Being under the umbrella of an organization which decreases autonomy and slows progress		
Different organizational affiliations (i.e., umbrella organizations, standalone) creating differences and sometimes inequities in resources		
Different organizational affiliations preventing or complicating progress towards ADP standardization		
Experiencing regional differences in the operation of ADPs based on legacy LHIN/Ontario Health leadership		
Having multiple and varied roles and responsibilities (e.g., payroll, staff scheduling, regional planning)		
<b>Built or Physical Environment</b>		
Finding and/or retrofitting environments that are suitable for ADP services		
Physical space constraints limiting ability to serve more clients and caregivers		
Providing ADP services (including new virtual services) in rural area(s)		
Being co-located with long-term care		

<b>Staff</b>		
Providing consistent staff education/training (e.g., paying for courses, backfilling)		
Aligning and maintaining staff education/training with changing client needs		
Staff perceptions of suitable ADP clients not aligning with the current ADP model		
Staff assumptions of client abilities and interests (e.g., activities they would be interested in)		
Staff doing "for" or limiting client independence		
Staff expectations of roles/responsibilities based on professional background, rather than ADP models		
Hiring and retaining an inter/multidisciplinary staff model		
Hiring staff that reflect the diversity of the community		
Ensuring staff are building professional relationships		
<b>Ability to Support Clients and Caregivers</b>		
Reaching and supporting diverse client populations (e.g., race/ethnicity, sexuality, ages)		
Making ADPs inclusive and welcoming to diverse populations		
Supporting diverse interests, needs, and qualities of clients in one program		
Supporting complexity and level of care/support needs of current client populations		
Supporting level of caregiver needs and burnout		
Managing transition planning with clients and caregivers		
<b>Perceptions of ADPs</b>		
Perceptions and/or stigma of ADP services and their implications (e.g., low or no referrals) among health care professionals		
Perceptions and/or stigma of ADP services and their implications (e.g., preventing attendance) among community members and potential clients and caregivers		
Caregivers having a perceived responsibility to support older family members without accessing health care and support services		
Perceptions that ADPs are not part of (or not a valued part of) the health care system		
Perceptions that ADPs are becoming too standard or generic		
Current clients' perceptions of people suitable to attend ADPs		
Perceptions of ADPs preventing clients and caregivers from advocating for ADPs		
<b>Advocacy and Awareness</b>		
Marketing and promoting ADP services		
Community members and potential clients and caregivers having limited understanding and awareness of ADP services		

Health care professionals having limited understanding and awareness of ADP services		
Lack of Ontario/Canadian research on ADP services		
Experiencing low advocacy power of and for ADPs		
<b>Measuring ADP Outcome Metrics</b>		
Existing indicators are outdated or unable to capture differences across ADPs and client populations		
Creating meaningful/suitable indicators that capture all elements of ADPs		
Metrics of ADP success being difficult to define and measure (e.g., quality of life, inherent change of some conditions, absence of standard milestones)		
Translating current types of ADP evidence (e.g., client testimonials) into formats that funders value		
Feeling concern that adjusting indicators to be more meaningful or suitable will impact funding		
Varied organizational affiliations creating different systems of tracking/data collection		
Having limited staff capacity and time to track meaningful data/use available assessments		
Lack of best practices or standards for ADPs		
<b>Other</b>		
Please specify:		

Additional Comments:

Please print or bring this document up on another computer monitor as you work through the survey.

**3. Rating Adult Day Program Purposes**

Please reference the scales provided below to rate the possible adult day program **purposes** (found on page 4 of the “Phase 2 Survey Reporting” document) according to two (2) criteria:

- a. **how relevant** they are to the **current operation** of the adult day program(s) you direct.
- b. **how relevant** they are to **your desired operation** of the adult day program(s) you direct.

Please use the “Other” row to add and rate purpose(s) not found in the list. Please use the “Additional Comments” box to provide additional input. **Please use NA (not applicable) when a purpose does not apply to your experiences.**

3. a)

**Current operation:** Not at all relevant Moderately relevant Highly relevant

Not Applicable	0	1	2	3	4	5	6	7	8	9	10
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3. b)

**Desired operation:** Not at all relevant Moderately relevant Highly relevant

Not Applicable	0	1	2	3	4	5	6	7	8	9	10
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**4. Rating Adult Day Program Enablers**

Please reference the scales provided below to rate the possible adult day program **enablers** (found on page 6 of the “Phase 2 Survey Reporting” document) according to two (2) criteria:

- a. **how strongly they support** the purpose of the adult day program(s) you direct.
- b. the **degree to which they promote** the purpose of the adult day program(s) you direct.

Please use the “Other” row to add and rate enabler(s) not found in the list. Please use the “Additional Comments” box to provide additional input. **Please use NA (not applicable) when an enabler does not apply to your experiences.**

4.a)

**Strength of support:** No support Moderate support Extreme support

Not Applicable	0	1	2	3	4	5	6	7	8	9	10
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4. b)

**Degree promotes:** No promotion Moderate promotion Extreme promotion

Not Applicable	0	1	2	3	4	5	6	7	8	9	10
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**5. Rating Adult Day Program Challenges**

Please reference the scales provided below to rate the possible adult day program **challenges** (found on page 9 of the “Phase 2 Survey Reporting” document) according to two (2) criteria:

- a. how **prominent** they are for the adult day program(s) you direct.
- b. how **urgent they are to address** for the adult day program(s) you direct.

Please use the “Other” row to add and rate challenge(s) not found in the list. Please use the “Additional Comments” box to provide additional input. **Please use NA (not applicable) when a challenge does not apply to your experiences.**

5. a)

<b>Prominence:</b>	Not at all prominent			Somewhat prominent				Extremely prominent			
Not Applicable	0	1	2	3	4	5	6	7	8	9	10

5. b)

<b>Urgency:</b>	Not at all urgent			Somewhat urgent				Extremely urgent			
Not Applicable	0	1	2	3	4	5	6	7	8	9	10



### Appendix H: Organizational Ethics Approval

I, \_\_\_\_\_ (name) \_\_\_\_\_, am the authority within \_\_\_\_\_ (Name of Organization) who can confirm that Dr. Brad Meisner and Deanna Vervaecke are not required to pursue external research ethics approval for the project titled, *Exploring the Purpose of Adult Day Programs from Directorial Staff Perspectives*, through this organization in addition to the approval granted by York University.

**X**

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Date:

## Appendix I: MobilizeYU Certificate

MobilizeYU

CERTIFICATE OF COMPLETION



*Innovation York hereby certifies that*

**DEANNA VERVAECKE**

*has successfully completed the*

**MobilizeYU 2020 PROGRAM**

(June-August 2020)

Sarah Howe  
Assistant Vice-President,  
Innovation & Research Partnerships,  
York University

innovation  
york | YORK  
UNIVERSITÉ  
UNIVERSITY

### Appendix J: Phase 1 Quotations – Part 1

Table 3. Phase 1 Interview Participant ADP Purposes Quotations

Sub-category	Identifier	Quotation (IP#)
Purposes	T3.Q1	They [clients] can come and be actively and purposefully engaged in activities. Not just to fill their time, but things that they would like to do, where they still feel like they can contribute. I think that's what we see as the purpose of adult day. (IP2)
Purposes	T3.Q2	The caregiver access to information. I think just being comfortable to talk about what they're really going through with our program coordinators, seeing the changes with the client, good days and bad days, and us being able to offer information. (IP2)
Purposes	T3.Q3	Just trying to support the caregivers and help them understand what they're experiencing, what they're going to experience, but more importantly, giving them more confidence and tools on how to best advocate for the person that they're caring for. (IP4)
Purposes	T3.Q4	It's our people that are more vulnerable that get lost in the system. So it's a lot of advocacy. (IP3)
Purposes	T3.Q5	Respite and information for caregivers is a very key piece, and sometimes it's respite for the individual away from their caregiver. So it goes both ways. (IP15)
Purposes	T3.Q6	You don't always feel like you're getting that full break when you can't leave your home. [Caregivers] can go home and just nap or do whatever they need to do. Those are the days they would plan to go out with their friends, or meet up with family, or go to important medical appointments. (IP13)
Purposes	T3.Q7	That's really what we're trying to do is give them the opportunity to connect with peers, to connect with other people and know that they're not alone in their experiences. To have those caregivers recognize there's other people in a similar boat too. (IP2)
Purposes	T3.Q8	I don't want to say clients are friends, but it's more of that kind of relationship as opposed to, "you have a patient." (IP1)
Purposes	T3.Q9	It [the ADP] has become a piece of the person like it's their community. And the purpose is to have that community for the clients. (IP8)
Purposes	T3.Q10	A lot of times our clients really look forward to that mealtime, that lunch time get together. They socialize when they're eating their lunch ... They're getting their nutritional needs met, where they feel like they want to eat, as opposed to eating alone. (IP17)
Purposes	T3.Q11	Many people think of maximum level of functioning of being able to eat, dress yourself, have a shower independently, but it's not just those pieces, it's fulfilling the spiritual component. (IP15)

Purposes	T3.Q12	Day programs need to be person-centered. So, what [ADP organization] can offer may be very different than what [another ADP organization], for example, may be able to offer. And I think just letting people know that we're not all the same in what we're able to provide but ultimately, we're all still striving for the same end goal. (IP4)
Purposes	T3.Q13	Giving them an environment where they can feel safe and that they're not going to be judged because that's, for people with dementia, they're so used to being judged by medical professionals, by friends, by family, and here they can be exactly whoever they want to be. (IP1)
Purposes	T3.Q14	When people come in, they understand the environment that they're in. Even people with mid-level cognition challenges, they come in and they understand if there's a bunch of tables and there's activities on tables. (IP2)
Purposes	T3.Q15	From a system perspective in that slice in time, you're able to gather a lot of really vital and key pieces of information, but you're also able to do a lot of preventative elements in terms of health promotion, awareness, support, and that's critical. I think when you look at all the pieces together, of how people journey through life and how they access certain parts of support, the day program allows the system a chance to breathe but gather very, very critical and important pieces of information. (IP15)

### Appendix J: Phase 1 Quotations – Part 2

Table 4. *Phase 1 Interview Participant ADP Enablers Quotations*

<b>Sub-category</b>	<b>Identifier</b>	<b>Quotation (IP#)</b>
Enablers	T4.Q1	We are lucky in Ontario that our government does see day services as a really strong investment because in the US, people are paying over \$100, unless there's a subsidy, and then they might pay \$60 a day to attend. (IP1)
Enablers	T4.Q2	We're fortunate because we have a very large budget, we can operate this many programs and be supported by services from the region. (IP2)
Enablers	T4.Q3	This is a perfect example, and it has happened, where we've had a client, it's an elderly woman, for example, living at home, children are checking in, she has a volunteer visitor who comes in every week to visit with that client. The volunteer visitor is actually in the home, they see what's happening. They can say, "Hey I've noticed some decline." So then, they would report that to the coordinator, the coordinator would follow up with the family, the family would be like, "Oh wait a minute, maybe I need a day program." (IP14)
Enablers	T4.Q4	We can be very nimble. We can make decisions very quickly. We can be very responsive to our clients and their responses to their surveys about what they want or what they need. We can add services and change services much more easily. It's not without cause and without process, but we still are able to do it a little bit more nimbly. (IP5)
Enablers	T4.Q5	They [property owners] are being a good corporate citizen by giving us a significant break on our rent. Because they realize we provide a very important service to the community. (IP6)
Enablers	T4.Q6	Network wise, locally, it is so valuable to be connected to other day partners. (IP15)
Enablers	T4.Q7	When you get all these different people, and we learn. That's such a gift to learn from different organizations in different areas. And I think we need to have the perspective to gain knowledge from others and their experiences. That only makes our own practice richer and more diverse. (IP1)
Enablers	T4.Q8	When care coordinators know that you're supporting somebody then they make a connection, so there's that, "Oh, there's a match that somebody will feel more comfortable." (IP5)
Enablers	T4.Q9	When we're getting the information from the LHIN it is a full complete assessment. We get access to a wide variety of history and it just helps us. (IP15)
Enablers	T4.Q10	We're seeing a lot more people as a result of families seeking us out. But there's the therapists in the hospital and the whole health care sector that's looking for an answer too. (IP9)

Enablers	T4.Q11	If you just have lightweight chairs and tables, you don't limit what you're able to do. We can slide the tables over and we can set up golf. We can do bowling. We can do any kind of active game in a small space. (IP2)
Enablers	T4.Q12	The outsides of the door frames on the washrooms are painted a separate colour, that helps the clients distinguish where the bathrooms are. Even the coloring through here, in terms of wall color is set for people with dementia. (IP12)
Enablers	T4.Q13	I think one thing that bodes well for us is our physical environment. It's very nice. It's modern and it doesn't under value us. It makes people feel good about themselves. They want to come because it's a great program, but it's a nice building too. (IP9)
Enablers	T4.Q14	Some [clients] will even get here themselves. Because we are located right in the hub of [town]. There's a lot of subdivisions here, senior homes. A lot of them [clients], I can think of four right now, that they just walk here. (IP17)
Enablers	T4.Q15	A restorative care approach is so important. Families say they're amazed. When we do creative work, when we do artwork, it's all got to have a functional, restorative approach. I think that that is one thing that makes us very successful. People don't just sit in chairs, they don't just listen to music or watch a TV. (IP12)
Enablers	T4.Q16	When we're introducing new people to the program, if we have a framework to say, "hey, here's what we do." If they have trouble getting up in the morning, but exercises start at 11 then as long as they get here by 10:30 they won't miss joining in on that exercise class. There are some things that routine can really benefit. (IP2)
Enablers	T4.Q17	Obviously, there's got to be an idea. There's got to be a plan. You don't want people [staff] coming in and having absolutely no thought process on what they're going to do. But they have to have the ability and the empowerment to change it based on what they're actually faced with. (IP4)
Enablers	T4.Q18	Taking an individual view and perspective and doing those individual needs assessments when somebody comes in, as well as regularly and annually in more of a formal way to make sure that they have the appropriate package in place, whatever their goal is. (IP11)
Enablers	T4.Q19	The culture of the organization. It's where we meet the goals that we have. And trying to work with the staff. Opposed to against the staff. Appreciating the staff for the jobs that they do. And actually showing that appreciation. (IP8)
Enablers	T4.Q20	We're designated a positive space for LGBTQ+ individuals. We do cultural competency training for our staff, but we also build these things into our interview practices to find out, is this person going to match our organization's values? One of our big values is inclusivity. We accept everybody for

		who they are and where they're coming from, regardless of age, income status, orientation, religion. (IP6)
Enablers	T4.Q21	I think the fact that we have such a diverse team is really important. We have social work, recreation specialists, recreation assistants, PSWs [Personal Support Workers], RPNs [Registered Practical Nurses], and of course admin and management. Everybody has their own lens that they see things through and that is a strength. We are stronger as an organization, and as a service provider when we have a kaleidoscope of perspectives. (IP1)
Enablers	T4.Q22	We can do a lot with a little because we had to in terms of creativity and resource and "let's just get it done." (IP3)
Enablers	T4.Q23	It's everybody's job. We're all there to support our clients in every aspect of care. There isn't that, "Oh let me just get the PSW [Personal Support Worker] to help you with that" because everybody has the skill set and the qualifications to do that. (IP5)
Enablers	T4.Q24	I definitely think for us as well, having a key role that is dedicated to the family support. That is vital. I think that's what helps that link of, "We saw this at the program today, how are they actually coping at home?" And that's what helps kind of do that preventative, upstream work a little bit, but also coaches and supports people to navigate or when to start looking for additional supports. (IP15)
Enablers	T4.Q25	That huddle in the morning, getting down to who's coming today, how are we setting up to make them successful today, what is it that they need, has the coordinator got any recent information about maybe changes with them from caregivers. What's the plan for today so that we're all on board and that I'm not doing something that's getting in the way of what somebody else is doing. (IP2)
Enablers	T4.Q26	One of the things that I like to have is cohesiveness and collaboration. I find that when staff are able to depend on each other and they're open about providing suggestions and asking for solutions they work better together. And they know where the strengths and weaknesses are on their team. (IP8)
Enablers	T4.Q27	A very passionate group. Turnover's very low. People who come into this kind of work seem to be very much drawn to it, the working closely one on one with people. (IP10)
Enablers	T4.Q28	My staff learn so much about these people, so we're able to program for them effectively. (IP4)
Enablers	T4.Q29	Some younger people that come into the program, they want to do some challenging activities, and even people that are older, that maybe never had a chance to learn a musical instrument or whatever. If they want to, and if we've got the capacity to do so, then we do it. (IP9)
Enablers	T4.Q30	When you know and understand the person and develop the relationship, you have the ability, as well to circumvent unnecessary emergency department visits. Sometimes people need to go because medically, you need that support. But sometimes you're able to catch things that would prevent the

		hospital visit, which could then prevent somebody potentially becoming ALC [alternative level of care], deconditioning and then only knowing what would happen. (IP15)
Enablers	T4.Q31	There are some families that have got their five homes picked. They know once mom can't help herself in the bathroom, they're done. Those families are really good because they know their limits. They know when they can and can't continue at this [ADP]. (IP14)
Enablers	T4.Q31	OCSA [Ontario Community Support Association] later came up and became that advocacy organization to support all of our services which we really appreciate, and we are a member of. (IP5)
Enablers	T4.Q33	That's why I created that [regional network] so that we could be at least as providers a unified group hopefully for a whole region, and it's a big region. In my mind, the more voices we have at a table, the stronger we can be to advocate. (IP1)
Enablers	T4.Q34	We've been very successful over the 13 years that I've been there of enhancing the program. When I got there [city] was four days, [town] was three. We're now six days in [city] and four days in [town]. To add a day is a significant thing. Quite a bit of funding too. So that way it's going well. We've increased our staffing ratio with the support of the LHIN. We got nursing with the support of the LHIN by advocating and showing good data about our successes and they've been very supportive. (IP10)



### Appendix J: Phase 1 Quotations – Part 3

Table 5. Phase 1 Interview Participant ADP Challenges Quotations

Sub-category	Identifier	Quotation (IP#)
Challenges	T5.Q1	I think one of the big challenges with adult day is, you've got these independent sites with small staff teams. And the core of what we're trying to do is rec social programming and engage seniors and keep them as active and connected with their peer groups, give those caregivers a break. That's the core of it, but we often get involved in so many other aspects of clients' lives because you get to know them, and the staff recognize things. And so a bit of that, I don't know what the proper term is, but a bit of that scope creep where you're starting to do things that are maybe a little more social work focused or a little more case management focused. (IP2)
Challenges	T5.Q2	Sometimes the legislative pieces just get so complicated. All those enhanced pieces, "What are you doing for enhanced? What are you doing for this? That?" We never have any time to focus on the core. ... Why do we feel the need to be doing all the extra things and only showcasing the extra things, because, honestly, the meat and potatoes of what we do is the thing that's so valuable to our clients and our caregivers. It's the things that can change their lives. (IP2)
Challenges	T5.Q3	Right now, I think I'm going to weigh more on almost the caregiver respite end of it. (IP9)
Challenges	T5.Q4	I refuse to have us go into a medical model. I don't think that's the way to go, but it's... We're being pressured as part of the system to take these very complex individuals. (IP1)
Challenges	T5.Q5	We see people coming to our program much, much more progressed than they did, maybe 10, 15 years ago. So their ability to stay with us in the program is harder. It's shorter because they can't participate in that group setting or the environment's not safe, or it's overstimulating for them. So we're at a loss of how to continue to support them, because we haven't had the chance to develop that strong relationship with them or really, really get to know them to create that emotional connection. (IP15)
Challenges	T5.Q6	There's all kinds of fear laden in LTC placements which is really unfortunate because I think it's making that waitlist not an actual waitlist for people that need services. It's causing more of a problem within the system. If people didn't have that sense of urgency, they wouldn't get on the list. (IP5)
Challenges	T5.Q7	Oftentimes, we know when they come in if they're on a waitlist for long term care. We have to kind of mentally prepare ourselves. They may not even make their first day. (IP6)
Challenges	T5.Q8	It's just a little frustrating that we're not seen as an equal player as long-term care even though we're actually dealing with the same population. (IP1)

		There's been a lot more focus the last few years on more the home care side of it, the PSW [Personal Support Worker]. Day program's not prominent. (IP3)
Challenges	T5.Q9	I don't think long term care really knows we exist. And I think that for the majority of even our regional group, they would not have any idea what long term care gets. I pass it along because I see the emails and I hear it on our morning meeting. And I shake my head. And I say why can't we get a little bit of that? So I think that the competition or the big sister, little sister thing kind of comes more from adult day program to long term care. I don't think they give us a thought truthfully. (IP12)
Challenges	T5.Q10	We're going by, prior to COVID, old best practice standards that go back from 20 years ago, with the staff client ratio recommendations. We're still being funded for those, but the needs and the care needs of our clients from personal care support, behaviour support, to caregiver support has really changed. It's really changed. (IP3)
Challenges	T5.Q11	I would love to be able to take on some more complex type clients, but we just don't have the financial resources to increase staffing. (IP4)
Challenges	T5.Q12	We have had some people say, "why aren't you open from 6am to 8pm? Not everybody who works, works 9am to 3pm." We realize that there could be some value in being able to operate off the traditional business hour model, but until we're given the means to do so, it's hard. (IP6)
Challenges	T5.Q13	Honestly the wages for day program staff in general are, they're crappy. And there's nothing I can do about that. And I don't like it. (IP4)
Challenges	T5.Q14	The way my peers on the ADP network can move so quickly, that does break my heart a little because I think people would assume the opposite, that we have a large staff team, we have a lot of programs, that you'd be able to mobilize that and do it quicker. But in this unionized environment, with this larger organization, that's probably one of my biggest challenges is that it takes so long. (IP2)
Challenges	T5.Q15	That's always the fear. If somebody else comes in, are clients going to be guaranteed the same level of quality, price, whatever of service? How do we work with families to ensure a smooth transition? (IP6)
Challenges	T5.Q16	Different LHINs might have different expectations. So you have a group in [Region 1] that are all doing it this way. And the group in the old [Region 3] that's doing it this way. (IP10)
Challenges	T5.Q17	Trying to find reasonable, rentable spaces for something like our day programs can also sometimes be a bit of a challenge. I would just love to be able to have the opportunity to have space and be able to use funding to set it up properly from the beginning, instead of trying to adapt a space as best as we can to fit for the clients that we're serving. (IP4)

Challenges	T5.Q18	What that does to their [clients'] self esteem and their feeling of "why am I here?" So, if a client is telling themselves the story, "My daughter's dumping me here because she's going to make me live here in six months or three months" and then we're walking you through the hallways of long-term care. We're just helping you tell that story. (IP2)
Challenges	T5.Q19	We would bake and they'd let people dump a few things in. Well, why can't they stir? Why can't they put everything into the muffin tins? "Because it's messy and it takes too much time." What the heck are we in hurry for? The whole point of us being here is that I don't care if it takes you an hour to do one tray of muffins, if a couple of ladies felt like they actually baked a tray of muffins. That's the whole point. (IP2)
Challenges	T5.Q20	We try to hire to better serve our community, to better reflect the makeup of our community. But we also know that there's a PSW [Personal Support Worker] shortage across the province, as a whole, and our positions are part time and don't offer benefits. So, it's very hard to attract staff when we need to. It is also a challenge in that you have to complete a post secondary certificate to become a PSW. So that has to be somebody who wants to be one and can afford to go. (IP6)
Challenges	T5.Q21	Even the initial challenge of meeting individual needs within a group setting, it's a complicated statement if you actually just back that up and think about it. If I've got 12 people here, I'd like for my team to be able to find some commonality amongst those people that are there, so that the group programming speaks to something. But if you have 40 people in an adult day program and they all have a different interest, how do you pick what the common program is? So if you take that, just on the cognitive side in the first place, and then you mix into that different physical needs and all of those things, it's a real mixed bag for staff to try and figure out what to do. (IP2)
Challenges	T5.Q22	And some families don't plan. They're just like "I'm keeping mom home. I'm not taking her to any homes." So then, when the client has a fall or the caregiver dies, which are things that you can't foresee, that family goes into a tailspin. And we can't take that client seven days a week. So, then that family is in crisis. (IP14)
Challenges	T5.Q23	In our community, we're still very white. We're very WASP [White Anglo-Saxon Protestant] here. We have gotten some more visible diversity, but where are those people? We know they're there in the community, but they're not walking through our doors. (IP1)
Challenges	T5.Q24	There's a stereotype as to what day programs provide and people think it's just for old people. And it's not. They don't realize that there's actually a lot of benefit for people attending a day program. (IP1)
Challenges	T5.Q25	One of our clients who knew about our program because when she was working she was aware of our program. When she asked for a referral to our program, the response that she got from the

		referral source was, “Oh, you don’t want to go there. You’re too young to go to something like that.” She said she demanded for the referral because she knew that once she got there she’d love it, but that’s kind of the discriminatory thing that we get when people are uneducated and they don’t have a good understanding of what we do. (IP9)
Challenges	T5.Q26	I think the identification of organizations that we’re a valued service is a work in progress. We are part of the [Region 1] Ontario Health Team. What I can tell you though is I had to knock on the door three or four times to even get in the door. I think there’s a feeling, I don’t think, I know there’s a feeling that our services are kind of this mom-and-pop social club. (IP10)
Challenges	T5.Q27	They feel like they’re abandoning in some cases, “I’m pushing my duties as a caregiver as a child or a spouse. I have failed.” (IP6)
Challenges	T5.Q28	They either think that the functioning is too high for their client or it’s too low. So it’s the two extremes. (IP2)
Challenges	T5.Q29	I can’t always say that day programs are a sexy cause that people want their name attached to. (IP6)
Challenges	T5.Q30	We’re still kind of an enigma to everybody and they don’t really grasp the benefits that we can have or impact that we can have on the whole system either, like the health care system and the community support services system. (IP9)
Challenges	T5.Q31	I think the problem is, there’s not a lot of Canadian based information. When the LHIN was looking at the liberal dementia strategy for provinces, they were looking at day programs, but they were relying on a lot of the State’s information. (IP3)
Challenges	T5.Q32	It was very hard to find parameters around best practices, what a day program should look like, how many square feet you should have per person, what types of furniture, activities, that kind of thing. I couldn’t find anything. (IP7)
Challenges	T5.Q33	It’s like really, how do you measure quality of life? Because quality of life is different things to different people. That’s the age-old question we grapple with in trying to prove that we are valid. (IP9)
Challenges	T5.Q34	Everybody has their own forms and applications. They use their own client management software systems, so nobody really knows if you’re comparing apples to oranges when a lot of these decisions are being made. The data that I can get from what I use may not be as wholesome or fulsome as what somebody else using a different system can provide. (IP6)
Challenges	T5.Q35	If you decrease your targets, you’re at risk of decreasing your funding. (IP9)
Challenges	T5.Q36	You need somebody to focus on doing that. You can’t do that kind of stuff effectively off the side of your desk. You need good data collection. You need to know your outcome measurements. You need all of that kind of stuff in order for it to be meaningful. Otherwise, it’s just an exercise in

		futility that someone's just putting stuff down because they have to come up with some kind of measurement in the end. (IP9)
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### Appendix K: Phase 2 Survey Rating Results – Part 1

Table 8. *Ratings of Purposes Survey Items' Relevance to Current ADP Purposes*

<b>Purposes</b>	<b><i>n</i> = 15</b>		<b>Mean</b>	<b>Median</b>	<b>Mode</b>	<b>Min – Max</b>
	<b>Missing</b>	<b>NA</b>	<b>(SD)</b>			
Provide person-centered services for all clients and caregivers	2		8.8(1.4)	9.0	10	5 – 10
Provide clients with purposeful, dynamic engagement and therapeutic recreational opportunities	2		8.8(1.4)	9.0	10	6 – 10
Maintain and promote or improve client abilities (where appropriate)	2	2	8.5(1.4)	8.0	8	6 – 10
Provide services that consider a holistic concept of health (e.g., physical, cognitive, emotional)	2		8.5(1.6)	8.0	8	5 – 10
Enable meaningful social connections within and among clients and caregivers that create a sense of community and belonging	2		8.5(1.5)	8.0	8	5 – 10
Provide services that support the overall functioning of the system	2		8.5(1.4)	8.0	8	6 – 10
Maintain client abilities	2	1	8.4(1.4)	8.0	8	6 – 10
Advocate for clients and caregivers	2	1	8.4(1.9)	9.0	10	5 – 10
Provide and encourage client and caregiver independence and choice	2		8.4(1.3)	8.0	8	6 – 10
Connect clients and caregivers with services and resources	2		8.4(1.9)	10.0	10	6 – 10
Keep people living in the community to prevent or delay relocation to care facilities (e.g., long-term care, retirement homes, hospital), if that is what they want	2		8.4(1.6)	8.0	8	5 – 10
Enable social connections between staff and clients and caregivers that create a sense of community and belonging	2		8.3(1.4)	8.0	8	5 – 10
Provide physical environments that support purposeful engagement and recreational opportunities	2		8.2(2.3)	8.0	10	2 – 10
Provide care coordination and system navigation for clients and caregivers	2	1	8.2(1.6)	8.0	10	6 – 10
Provide services that address and support client overall functioning	2		8.2(1.9)	8.0	10	4 – 10
Provide clients with meals to meet nutritional and social needs	2		8.2(1.6)	8.0	10	6 – 10
Provide caregivers and clients with out-of-home respite	2		8.2(2.2)	8.0	8	2 – 10
Provide safe and secure environments that meet the interests, needs, and diversity of clients	2		8.1(2.2)	8.0	8	2 – 10

Empower caregivers to advocate for their person	2	8.0(2.0)	8.0	10	5 – 10
Provide services that reflect the current community and client population interests and needs	2	8.0(1.8)	8.0	8	4 – 10
Provide caregivers with resources, education, and support	2	7.5(2.5)	7.0	10	3 – 10

NA: Not Applicable; SD: Standard Deviation

Table 9. *Ratings of Purposes Survey Items' Relevance to Desired ADP Purposes*

<b>Purposes</b>	<b>n = 15</b>		<b>Mean (SD)</b>	<b>Median</b>	<b>Mode</b>	<b>Min - Max</b>
	<b>Missing</b>	<b>NA</b>				
Provide person-centered services for all clients and caregivers	1		9.8(0.6)	10.0	10	8 – 10
Enable social connections between staff and clients and caregivers that create a sense of community and belonging	1		9.8(0.6)	10.0	10	8 – 10
Enable meaningful social connections within and among clients and caregivers that create a sense of community and belonging	1		9.7(0.6)	10.0	10	8 – 10
Provide clients with meals to meet nutritional and social needs	1		9.7(0.6)	10.0	10	8 – 10
Provide physical environments that support purposeful engagement and recreational opportunities	1		9.7(0.8)	10.0	10	7 – 10
Maintain and promote or improve client abilities (where appropriate)	1	2	9.7(0.8)	10.0	10	8 – 10
Provide services that address and support client overall functioning	1		9.6(0.7)	10.0	10	8 – 10
Provide caregivers and clients with out-of-home respite	1		9.6(0.7)	10.0	10	8 – 10
Provide safe and secure environments that meet the interests, needs, and diversity of clients	1		9.6(1.1)	10.0	10	6 – 10
Provide clients with purposeful, dynamic engagement and therapeutic recreational opportunities	1		9.6(1.1)	10.0	10	6 – 10
Provide services that reflect the current community and client population interests and needs	1		9.6(1.1)	10.0	10	6 – 10
Provide services that consider a holistic concept of health (e.g., physical, cognitive, emotional)	1		9.5(0.9)	10.0	10	7 – 10
Provide services that support the overall functioning of the system	1		9.5(1.1)	10.0	10	6 – 10
Provide caregivers with resources, education, and support	1		9.4(0.9)	10.0	10	7 – 10
Maintain client abilities	1	1	9.4(1.0)	10.0	10	8 – 10
Provide care coordination and system navigation for clients and caregivers	1	1	9.4(1.0)	10.0	10	7 – 10
Empower caregivers to advocate for their person	1		9.4(1.0)	10.0	10	7 – 10
Connect clients and caregivers with services and resources	1		9.4(1.1)	10.0	10	7 – 10
Keep people living in the community to prevent or delay relocation to care facilities (e.g., long-term care, retirement homes, hospital), if that is what they want	1		9.3(1.6)	10.0	10	5 – 10



Advocate for clients and caregivers	1	1	9.1(1.7)	10.0	10	5 – 10
Provide and encourage client and caregiver independence and choice	1		8.8(2.7)	10.0	10	0 – 10

NA: Not Applicable; SD: Standard Deviation

**Appendix K: Phase 2 Survey Rating Results – Part 2**

Table 10. *Ratings of Enabler Survey Items' Strength of Support for ADP Purposes*

<b>Enablers</b>	<b>n = 15</b>		<b>Mean</b>			
	<b>Missing</b>	<b>NA</b>	<b>(SD)</b>	<b>Median</b>	<b>Mode</b>	<b>Min - Max</b>
<b><i>Funding and Resources</i></b>			<b>7.0</b>			
Receiving ministry/government funding	1		8.6(1.8)	9.5	10	5 – 10
Having opportunities to apply for grants to complement funding from the ministry/government	1	1	7.5(2.2)	8.0	8	2 – 10
Having access to technology and digital health resources	1	1	7.5(2.3)	8.0	10	3 – 10
Having a LHIN-funded navigator/case manager embedded within your ADP(s)	1	5	6.0(3.6)	7.0	9	0 – 9
Having the ability to meet ADP purposes without sufficient funding	1	2	5.3(3.5)	5.5	3	0 – 10
<b><i>Organizational Affiliations and Governance</i></b>			<b>7.7</b>			
Falling under the umbrella of an organization that results in greater access to resources	1	2	8.9(1.5)	9.5	10	5 – 10
Having an organizational hierarchy or structure that supports you to operate at a systems level (e.g., sitting on regional planning tables)	2	1	8.7(1.6)	9.0	10	5 – 10
Being a stand alone or smaller organization which supports efficient, responsive, and autonomous decision making	1	3	8.5(2.9)	10.0	10	0 – 10
Having connections with businesses that provide your ADP(s) with resource support (e.g., low rent)	1	5	8.0(1.9)	8.0	10	5 – 10
Falling under the umbrella of an organization that provides additional services that can support clients and caregivers (e.g., in-home respite, overnight respite)	1	1	7.9(3.7)	10.0	10	0 – 10
Having an affiliation with long-term care	2	4	4.1(4.3)	3.0	0	0 – 10
<b><i>Collaboration and Partnerships</i></b>			<b>7.8</b>			
Collaborating within ADP sub-region networks	1		8.8(1.4)	9.0	10	6 – 10
Feeling a lack of competition between ADP providers	1	4	8.7(1.6)	9.5	10	6 – 10
Having a willingness to collaborate and work with other health care and support services (e.g., BSO)	1		8.0(2.4)	8.5	10	2 – 10

Ontario Health Teams bringing different sectors and services closer together in collaboration and awareness of each other	2	1	7.9(1.5)	8.0	7	5 – 10
Having good working relationships and involvement with legacy LHIN/Ontario Health representatives	1		7.7(2.3)	8.0	8	2 – 10
Collaborating at the [large health region network]	1	1	7.5(2.9)	8.0	10	0 – 10
Partnering with post-secondary institutions for student placements	1		7.4(2.4)	8.0	6	2 – 10
Partnering with research organizations to measure ADP outcomes (e.g., ICES)	1	4	7.3(2.1)	6.5	6	5 – 10
Collaborating with local community supports (e.g., municipalities, cultural organizations)	1		7.3(2.2)	7.0	6	3 – 10
<b>Referrals</b>			<b>7.3</b>			
Receiving a good amount and depth of client information from legacy LHIN referrals (e.g., narratives)			7.3(3.0)	8.0	10	2 – 10
Receiving suitable referrals due to care coordinators' familiarity with local ADPs			7.3(2.0)	7.0	7	3 – 10
Having an increasing number of caregivers, clients, and health care professionals <i>actively</i> seeking out ADPs as new services to support themselves or people they care for			7.3(2.0)	7.0	7	2 – 10
<b>Built or Physical Environment</b>			<b>7.4</b>			
Operating ADP(s) in physically attractive or welcoming environments			8.6(1.4)	8.0	10	6 – 10
Operating in physical environments that are appropriately designed for ADP(s) (e.g., room designs that support recreational programming and client care)			8.2(1.8)	8.0	10	5 – 10
Providing ADP services in a small community		4	8.1(3.2)	10.0	10	0 – 10
Being centrally located in your community			7.7(2.3)	8.0	10	3 – 10
Operating ADP(s) out of standalone location(s)		4	7.4(3.1)	8.0	10	0 – 10
Being co-located with long-term care		5	4.2(3.9)	3.0	0	0 – 10
<b>Approach to Services and Operations</b>			<b>8.8</b>			
Providing structured services (e.g., consistent schedule for activities, exercise, meals)			9.5(0.8)	10.0	10	7 – 10

Providing services from a strengths-based or restorative approach (i.e., focusing on client strengths, adapting activities to client abilities rather than doing activities for the client)	1	9.4(0.9)	10.0	10	8 – 10
Empowering staff to provide creative and responsive/flexible recreational opportunities		9.1(1.1)	10.0	10	7 – 10
Having an organizational culture, processes, and programs that support diversity and inclusion	1	8.9(1.1)	9.0	9	7 – 10
Having an organizational culture of supporting and “working with” staff		8.9(1.2)	9.0	10	7 – 10
Having assessment processes that support grouping clients based on interests, needs, and qualities	1	8.7(1.7)	9.0	10	4 – 10
Using the dementiaAbility framework (including with clients not living with dementia)	3	8.4(1.5)	8.5	10	6 – 10
Working to address systems of oppression in ADP settings (e.g., anti-racism strategies)	1	7.5(2.9)	8.5	10	0 – 10
<b>Staff</b>		<b>8.7</b>			
Having staff communication systems that foster collaboration, support, and information sharing		9.2(1.0)	10.0	10	7 – 10
Building familiar and trusting professional relationships with and among staff		9.1(1.2)	10.0	10	7 – 10
Your experience working with ADPs or Community Support Services	1	9.1(1.1)	10.0	10	7 – 10
Staff drawing on close professional relationship and knowledge of client interests and needs		9.1(1.3)	10.0	10	6 – 10
Having dedicated staff with a genuine interest in working in this field and with ADP client populations		9.0(1.3)	10.0	10	6 – 10
Employing staff with a recreational background		8.8(1.7)	10.0	10	5 – 10
Having an inter/multidisciplinary staff		8.7(1.9)	10.0	10	3 – 10
Having staff members share responsibilities (e.g., everyone can provide personal care support)		8.7(1.5)	9.0	10	6 – 10
Providing consistent staff training and education, for all roles (including your own)		8.5(2.0)	10.0	10	4 – 10
Staff using knowledge of existing community and health resources		8.3(2.0)	8.0	10	4 – 10

Having a staff member dedicated to caregiver support	2	8.3(1.7)	8.0	10	5 – 10
Employing staff with a medical or clinical background (e.g., nurses)	4	8.3(2.8)	10.0	10	2 – 10
Employing staff with a personal support background (e.g., PSW)	1	7.9(3.0)	9.5	10	1 – 10
<b><i>Client and Caregiver Involvement</i></b>		<b>8.3</b>			
Having familiar and trusting professional relationships with clients and caregivers		9.1(1.1)	9.0	10	6 – 10
Seeking and receiving consistent client and caregiver feedback to inform services		8.5(1.5)	8.0	8	5 – 10
Encouraging active client involvement in program design and delivery		8.1(1.7)	8.0	10	5 – 10
Having clients and caregivers that proactively plan for transitions		7.4(2.7)	8.0	10	0 – 10
<b><i>Advocacy and Awareness</i></b>		<b>7.4</b>			
Tracking and/or having access to data that can be used to advocate for resources and ADPs	1	8.4(1.3)	8.0	8	3 – 10
Participating in (or benefiting from) collective advocacy at ADP sub-region and [larger health region] networks	1	8.0(2.0)	8.0	10	0 – 10
Attending age friendly events and fairs	2	7.5(2.7)	8.0	7	3 – 10
Being a member of Ontario Health Teams and COVID-19 planning tables	1	7.4(2.8)	8.0	8	6 – 10
Receiving and documenting client and caregiver stories and testimonials		7.3(2.4)	8.0	10	0 – 10
Having connections with OCSA	2	7.1(2.5)	8.0	8	2 – 10
Receiving and documenting staff stories and testimonials	1	5.9(3.1)	7.0	7	0 – 10

NA: Not Applicable; SD: Standard Deviation

Table 11. *Ratings of Enabler Survey Items' Degree of Promotion for ADP Purposes*

<b>Enablers</b>	<b><i>n</i> = 15</b>		<b>Mean</b>			
	<b>Missing</b>	<b>NA</b>	<b>(SD)</b>	<b>Median</b>	<b>Mode</b>	<b>Min - Max</b>
<b><i>Funding and Resources</i></b>			<b>6.7</b>			
Having access to technology and digital health resources	2	2	7.6(2.2)	8.0	8	5 – 10
Receiving ministry/government funding	1		7.6(2.1)	7.5	10	2 – 10
Having opportunities to apply for grants to complement funding from the ministry/government	1	2	6.7(2.2)	7.0	5	0 – 9
Having a LHIN-funded navigator/case manager embedded within your ADP(s)	1	5	6.0(3.5)	8.0	9	3 – 10
Having the ability to meet ADP purposes without sufficient funding	2	3	5.5(3.5)	7.0	8	0 – 10
<b><i>Organizational Affiliations and Governance</i></b>			<b>7.6</b>			
Falling under the umbrella of an organization that results in greater access to resources	2	2	9.0(1.5)	10.0	10	0 – 10
Having an organizational hierarchy or structure that supports you to operate at a systems level (e.g., sitting on regional planning tables)	2	2	8.5(1.8)	9.0	10	5 – 10
Being a stand alone or smaller organization which supports efficient, responsive, and autonomous decision making	1	3	8.2(3.3)	10.0	10	5 – 10
Having connections with businesses that provide your ADP(s) with resource support (e.g., low rent)	1	6	8.0(2.0)	8.0	10	0 – 10
Falling under the umbrella of an organization that provides additional services that can support clients and caregivers (e.g., in-home respite, overnight respite)	1	1	7.8(3.7)	10.0	10	0 – 10
Having an affiliation with long-term care	1	5	4.3(3.9)	3.0	0	5 – 10
<b><i>Collaboration and Partnerships</i></b>			<b>8.0</b>			
Collaborating within ADP sub-region networks	1		8.9(1.5)	9.0	10	5 – 10
Collaborating at the [large health region network]	1	1	8.3(1.9)	9.0	10	5 – 10
Feeling a lack of competition between ADP providers	1	5	8.2(2.3)	9.0	10	4 – 10
Partnering with research organizations to measure ADP outcomes (e.g., ICES)	1	5	8.2(2.0)	9.0	9	5 – 10
Ontario Health Teams bringing different sectors and services closer together in collaboration and awareness of each other	2	1	8.1(1.8)	8.5	8	2 – 10

Having a willingness to collaborate and work with other health care and support services (e.g., BSO)	1	1	7.8(2.5)	9.0	9	2 – 10
Having good working relationships and involvement with legacy LHIN/Ontario Health representatives	1	1	7.7(2.6)	8.0	10	2 – 10
Collaborating with local community supports (e.g., municipalities, cultural organizations)	1		7.6(2.3)	8.0	8	5 – 10
Partnering with post-secondary institutions for student placements	1		7.2(2.5)	8.0	8	2 – 10
<b><i>Referrals</i></b>			<b>7.6</b>			
Receiving suitable referrals due to care coordinators' familiarity with local ADPs			7.9(1.8)	8.0	8	2 – 10
Having an increasing number of caregivers, clients, and health care professionals actively seeking out ADPs as new services to support themselves or people they care for			7.5(2.7)	8.0	10	4 – 10
Receiving a good amount and depth of client information from legacy LHIN referrals (e.g., narratives)		1	7.4(3.1)	9.0	9	2 – 10
<b><i>Built or Physical Environment</i></b>			<b>7.8</b>			
Operating in physical environments that are appropriately designed for ADP(s) (e.g., room designs that support recreational programming and client care)		1	8.8(1.6)	10.0	10	6 – 10
Operating ADP(s) in physically attractive or welcoming environments		2	8.8(1.2)	9.0	10	7 – 10
Being centrally located in your community	1	1	8.7(1.8)	9.0	10	0 – 10
Providing ADP services in a small community		4	8.3(3.2)	10.0	10	0 – 10
Operating ADP(s) out of standalone location(s)		4	7.2(3.8)	9.0	10	4 – 10
Being co-located with long-term care		5	5.0(3.5)	5.0	0	0 – 10
<b><i>Approach to Services and Operations</i></b>			<b>9.0</b>			
Empowering staff to provide creative and responsive/flexible recreational opportunities			9.6(0.7)	10.0	10	8 – 10
Providing structured services (e.g., consistent schedule for activities, exercise, meals)			9.5(0.8)	10.0	10	5 – 10
Having an organizational culture, processes, and programs that support diversity and inclusion		1	9.4(0.8)	10.0	10	8 – 10

Providing services from a strengths-based or restorative approach (i.e., focusing on client strengths, adapting activities to client abilities rather than doing activities for the client)	1	9.4(0.9)	10.0	10	7 – 10
Having an organizational culture of supporting and “working with” staff		9.0(2.1)	10.0	10	1 – 10
Using the dementiaAbility framework (including with clients not living with dementia)	3	8.8(1.5)	9.0	10	2 – 10
Having assessment processes that support grouping clients based on interests, needs, and qualities	1	8.8(2.4)	10.0	10	8 – 10
Working to address systems of oppression in ADP settings (e.g., anti-racism strategies)	1	7.8(3.4)	9.5	10	0 – 10
<b>Staff</b>		<b>9.0</b>			
Having dedicated staff with a genuine interest in working in this field and with ADP client populations		9.5(0.8)	10.0	10	5 – 10
Staff drawing on close professional relationship and knowledge of client interests and needs		9.5(0.8)	10.0	10	5 – 10
Having a staff member dedicated to caregiver support	2	9.5(1.0)	10.0	10	1 – 10
Building familiar and trusting professional relationships with and among staff		9.3(1.4)	10.0	10	2 – 10
Your experience working with ADPs or Community Support Services	1	9.1(1.5)	10.0	10	2 – 10
Providing consistent staff training and education, for all roles (including your own)		9.1(1.7)	10.0	10	5 – 10
Having staff communication systems that foster collaboration, support, and information sharing		9.1(1.4)	10.0	10	7 – 10
Having an inter/multidisciplinary staff		8.8(1.7)	10.0	10	5 – 10
Employing staff with a personal support background (e.g., PSW)	1	8.8(2.5)	10.0	10	6 – 10
Having staff members share responsibilities (e.g., everyone can provide personal care support)		8.7(1.7)	10.0	10	5 – 10
Staff using knowledge of existing community and health resources		8.7(2.0)	10.0	10	8 – 10
Employing staff with a medical or clinical background (e.g., nurses)	4	8.6(2.5)	10.0	10	8 – 10
Employing staff with a recreational background		8.5(2.4)	9.0	10	4 – 10
<b>Client and Caregiver Involvement</b>		<b>8.9</b>			



Having familiar and trusting professional relationships with clients and caregivers		9.7(0.5)	10.0	10	6 – 10
Seeking and receiving consistent client and caregiver feedback to inform services		8.9(1.5)	10.0	10	6 – 10
Encouraging active client involvement in program design and delivery		8.7(1.5)	9.0	10	9 – 10
Having clients and caregivers that proactively plan for transitions		8.1(2.9)	10.0	10	0 – 10
<b><i>Advocacy and Awareness</i></b>		<b>8.3</b>			
Receiving and documenting client and caregiver stories and testimonials		9.1(1.6)	10.0	10	0 – 10
Tracking and/or having access to data that can be used to advocate for resources and ADPs	1	8.9(1.7)	10.0	10	0 – 10
Attending age friendly events and fairs	2	8.5(2.4)	10.0	10	0 – 10
Participating in (or benefiting from) collective advocacy at ADP sub-region and [health region] networks	1	8.4(2.7)	9.5	10	4 – 10
Being a member of Ontario Health Teams and COVID-19 planning tables	1	8.2(2.7)	9.0	10	2 – 10
Having connections with OCSA	2	7.8(3.0)	9.0	10	4 – 10
Receiving and documenting staff stories and testimonials	1	7.3(3.5)	8.5	10	0 – 10

NA: Not Applicable; SD: Standard Deviation

### Appendix K: Phase 2 Survey Rating Results – Part 3

Table 12. *Ratings of Challenge Survey Items' Prominence for ADP Purposes*

<b>Challenges</b>	<b><i>n</i> = 15 Missing</b>	<b>NA</b>	<b>Mean (SD)</b>	<b>Median</b>	<b>Mode</b>	<b>Min - Max</b>
<b><i>Orientation within Health Care System</i></b>			<b>6.4</b>			
Having consistent access to safe and accessible transportation to and from ADPs		1	7.6(2.6)	10.0	8	1 – 10
Competing with long-term care for recognition and resources			7.6(2.5)	7.5	7	1 – 10
Having concern for service continuity as the health care system transitions to Ontario Health and Ontario Health Teams			7.5(2.1)	8.0	8	2 – 10
Experiencing staff turnover at higher system levels (e.g., LHIN/Ontario Health) and its implications (e.g., delayed projects, continuously providing education about ADPs)		1	7.1(2.6)	7.5	7	2 – 10
Competing with home care for recognition and resources			6.9(3.0)	7.5	10	1 – 10
Determining ADP purposes to prioritize (e.g., prioritizing clients or prioritizing caregivers)		2	6.9(2.7)	7.0	5	2 – 10
Ministry/government involvement (i.e., wanting ministry/government guidance and collaboration, but also wanting to retain flexibility in decision making)			6.7(2.4)	7.0	8	3 – 10
Seeing an increasing need for ADPs that follow a more medically based model			6.5(2.8)	8.0	8	1 – 10
Lacking two-way communication with other health care providers (e.g., primary care, long-term care)			6.5(2.9)	7.0	7	1 – 10
Determining and following through on ADP scope in the health care continuum (i.e., where and when your ADP responsibilities for clients and caregivers begin and end)		1	6.4(2.4)	6.0	5	2 – 10
Operating within a system that focuses on and values clinical or medical needs rather than taking a holistic perspective (i.e., a perspective that considers all domains of health)			6.2(2.7)	7.0	7	1 – 10
Staff understanding ADP scope in the health care continuum			6.1(2.2)	6.0	8	2 – 10

Client fear of long-term care waitlists encouraging them to enter long-term care and exit ADPs prematurely	1	5.6(3.0)	6.5	7	0 – 10
Providing standardized ADP services across regions	1	5.6(3.2)	7.0	7	0 – 10
Experiencing external pressure to focus on services outside of core ADP purposes	2	5.4(2.7)	6.0	5	0 – 10
Feeling concern that your own ADP(s) are moving away from a social model (i.e., focus on social interaction and therapeutic recreation) to a medical model (i.e., focus on clinical personal care and overall functioning)	1	5.0(3.3)	5.0	8	0 – 9
Feeling outside pressure to move towards providing a medical model of ADPs	1	4.6(3.4)	5.0	0	0 – 9
<b>Funding and Resources</b>		<b>6.5</b>			
Experiencing a lack of base funding increases	1	8.7(3.0)	10.0	10	0 – 10
Experiencing assumptions and pressure to conform to idea that ADPs “make it work on a shoestring budget”	1	7.5(3.6)	10.0	10	0 – 10
Having the ability to (and receiving praise for) meeting ADP purposes without sufficient funding		7.4(2.9)	8.0	7	0 – 10
Experiencing a lack of time in your role at your ADP(s)		6.9(2.7)	8.0	8	0 – 10
Overall lack of resources in the health care system		6.7(2.8)	7.0	8	0 – 10
Increasing demand for ADPs with lack of infrastructure to support ADPs and client populations		6.6(2.9)	7.0	10	1 – 10
Increasing client fees to offset lack of base funding increases	1	6.6(3.6)	7.5	10	0 – 10
Having an insufficient number of staff (and access to more staff) due to funding		6.5(3.6)	8.0	10	0 – 10
Funding/resources preventing admission and retention of higher need or more complex clients	1	6.4(3.1)	7.5	8	0 – 10
Providing low staff wages due to funding	2	6.4(3.5)	7.0	10	1 – 10
Experiencing limited opportunity to pursue pilot programs that could turn into programs (e.g., low or no funding, brief timelines)	3	6.3(2.8)	6.5	2	2 – 10
Experiencing a lack of geriatric speciality services in your region (e.g., geriatricians)	1	6.1(3.6)	7.5	8	0 – 10

Receiving funding from a variety of sources (e.g., Ministry of Health, United Way, etc.)			5.9(3.4)	6.0	10	0 – 10
Competing with other ADPs for limited resources (e.g., funding, grant opportunities)	1		5.9(3.3)	7.5	8	0 – 10
Having strict and inflexible funding requirements			5.8(2.8)	5.0	5	1 – 10
Being one of few Community Support Services that charges client fees	2		5.6(4.0)	5.0	10	0 – 10
Meeting legislation and funder expectations of ADPs that don't align with your understanding of ADP purposes	1		5.0(2.9)	5.0	5	0 – 10
<b><i>Organizational Affiliations and Governance</i></b>			<b>5.8</b>			
Having multiple and varied roles and responsibilities (e.g., payroll, staff scheduling, regional planning)	1		7.7(2.8)	9.0	10	3 – 10
Experiencing regional differences in the operation of ADPs based on legacy LHIN/Ontario Health leadership	1		6.3(3.1)	8.0	8	0 – 9
Different organizational affiliations preventing or complicating progress towards ADP standardization	2		5.6(3.1)	7.0	7	0 – 10
Different organizational affiliations (i.e., umbrella organizations, standalone) creating differences and sometimes inequities in resources	1	3	5.5(2.5)	4.0	4	2 – 10
Being under the umbrella of an organization which decreases autonomy and slows progress	6		4.0(3.4)	4.0	0	0 – 8
<b><i>Built or Physical Environment</i></b>			<b>6.5</b>			
Physical space constraints limiting ability to serve more clients and caregivers			7.9(2.0)	8.0	10	5 – 10
Finding and/or retrofitting environments that are suitable for ADP services			7.2(2.6)	7.0	10	2 – 10
Providing ADP services (including new virtual services) in rural area(s)	1	2	7.2(3.2)	8.0	10	0 – 10
Being co-located with long-term care	6		3.9(4.2)	2.0	0	0 – 10
<b><i>Staff</i></b>			<b>5.4</b>			
Providing consistent staff education/training (e.g., paying for courses, backfilling)			7.1(2.7)	8.0	10	3 – 10
Aligning and maintaining staff education/training with changing client needs			6.6(2.9)	7.0	10	1 – 10

Hiring and retaining an inter/multidisciplinary staff model		6.3(3.0)	7.0	5	1 – 10
Ensuring staff are building professional relationships		6.0(3.1)	7.0	4	0 – 10
Staff assumptions of client abilities and interests (e.g., activities they would be interested in)		5.3(3.1)	5.0	2	0 – 10
Hiring staff that reflect the diversity of the community	1	5.1(3.2)	5.0	5	0 – 10
Staff perceptions of suitable ADP clients not aligning with the current ADP model		4.9(3.0)	5.0	5	0 – 10
Staff doing “for” or limiting client independence		4.0(2.8)	3.0	2	0 – 8
Staff expectations of roles/responsibilities based on professional background, rather than ADP models	1	3.4(2.4)	3.0	5	0 – 8
<b><i>Ability to Support Clients and Caregivers</i></b>		<b>6.8</b>			
Supporting level of caregiver needs and burnout		8.3(1.8)	8.0	10	4 – 10
Supporting complexity and level of care/support needs of current client populations		7.6(2.5)	8.0	9	2 – 10
Managing transition planning with clients and caregivers	1	7.1(1.9)	7.5	8	4 – 10
Making ADPs inclusive and welcoming to diverse populations	1	6.3(3.5)	7.5	8	0 – 10
Supporting diverse interests, needs, and qualities of clients in one program	1	6.1(3.3)	7.5	8	0 – 10
Reaching and supporting diverse client populations (e.g., race/ethnicity, sexuality, ages)	1	5.6(3.1)	6.5	8	0 – 10
<b><i>Perceptions of ADPs</i></b>		<b>6.2</b>			
Perceptions that ADPs are not part of (or not a valued part of) the health care system		7.8(1.4)	8.0	8	5 – 10
Caregivers having a perceived responsibility to support older family members without accessing health care and support services	1	7.2(2.0)	7.0	7	4 – 10
Perceptions and/or stigma of ADP services and their implications (e.g., low or no referrals) among health care professionals	1	6.1(1.9)	6.5	8	2 – 8
Current clients’ perceptions of people suitable to attend ADPs		6.1(2.7)	7.0	5	0 – 10
Perceptions and/or stigma of ADP services and their implications (e.g., preventing attendance) among community members and potential clients and caregivers	1	5.9(2.9)	6.0	6	0 – 10
Perceptions that ADPs are becoming too standard or generic	1	5.7(2.9)	6.0	8	0 – 10

Perceptions of ADPs preventing clients and caregivers from advocating for ADPs	2	4.8(3.3)	5.0	5	0 – 10
<b><i>Advocacy and Awareness</i></b>		<b>7.6</b>			
Lack of Ontario/Canadian research on ADP services	1	8.1(2.2)	8.5	10	4 – 10
Community members and potential clients and caregivers having limited understanding and awareness of ADP services		7.9(2.0)	8.0	10	3 – 10
Health care professionals having limited understanding and awareness of ADP services		7.7(1.9)	8.0	10	4 – 10
Experiencing low advocacy power of and for ADPs		7.4(2.0)	8.0	7	2 – 10
Marketing and promoting ADP services		7.0(2.7)	8.0	8	2 – 10
<b><i>Measuring ADP Outcome Metrics</i></b>		<b>7.1</b>			
Metrics of ADP success being difficult to define and measure (e.g., quality of life, inherent change of some conditions, absence of standard milestones)	1	8.1(2.2)	8.5	10	4 – 10
Having limited staff capacity and time to track meaningful data/use available assessments	1	7.8(2.2)	8.0	10	3 – 10
Existing indicators are outdated or unable to capture differences across ADPs and client populations		7.3(2.0)	7.0	6	4 – 10
Translating current types of ADP evidence (e.g., client testimonials) into formats that funders value	1	7.1(2.6)	8.0	8	1 – 10
Creating meaningful/suitable indicators that capture all elements of ADPs	1	7.0(2.8)	8.0	8	2 – 10
Varied organizational affiliations creating different systems of tracking/data collection	1	6.6(2.5)	7.0	7	2 – 10
Lack of best practices or standards for ADPs	1	6.4(2.1)	6.5	5	2 – 9
Feeling concern that adjusting indicators to be more meaningful or suitable will impact funding	1	6.3(3.1)	7.0	8	0 – 10

NA: Not Applicable; SD: Standard Deviation

Table 13. *Ratings of Challenge Survey Items' Urgency to Address for ADP Purposes*

<b>Challenges</b>	<b><i>n</i> = 15</b>	<b>Mean</b>	<b>Median</b>	<b>Mode</b>	<b>Min - Max</b>
	<b>Missing</b>	<b>(SD)</b>			
<b><i>Orientation within Health Care System</i></b>		<b>6.6</b>			
Having consistent access to safe and accessible transportation to and from ADPs	1	8.2(2.5)	9.0	10	2 – 10
Competing with long-term care for resources and recognition	1	8.1(2.7)	9.5	10	1 – 10
Having concern for service continuity as the health care system transitions to Ontario Health and Ontario Health Teams		7.6(2.4)	8.0	8	2 – 10
Experiencing staff turnover at higher system levels (e.g., LHIN/Ontario Health) and its implications (e.g., delayed projects, continuously providing education about ADPs)	1	7.4(2.6)	8.0	8	2 – 10
Competing with home care for resources and recognition	1	7.3(3.3)	9.5	10	1 – 10
Determining ADP purposes to prioritize (e.g., prioritizing clients or prioritizing caregivers)		7.2(3.1)	8.0	10	2 – 10
Seeing an increasing need for ADPs that follow a more medically based model		6.6(3.)	8.0	9	1 – 10
Client fear of long-term care waitlists encouraging them to enter long-term care and exit ADPs prematurely	1	6.5(3.5)	8.0	8	0 – 10
Ministry/government involvement (i.e., wanting ministry/government guidance and collaboration, but also wanting to retain flexibility in decision making)		6.4(2.8)	7.0	3	2 – 10
Determining and following through on ADP scope in the health care continuum (i.e., where and when your ADP responsibilities for clients and caregivers begin and end)	1	6.4(2.8)	5.5	5	2 – 10
Operating within a system that focuses on and values clinical or medical needs rather than taking a holistic perspective (i.e., a perspective that considers all domains of health)		6.3(3.6)	7.0	10	0 – 10
Lacking two-way communication with other health care providers (e.g., primary care, long-term care)		6.3(3.4)	7.0	10	1 – 10
Staff understanding ADP scope in the health care continuum		6.1(2.6)	5.0	5	2 – 10

Experiencing external pressure to focus on services outside of core ADP purposes		5.8(3.0)	6.0	5	0 – 10
Feeling concern that your own ADP(s) are moving away from a social model (i.e., focus on social interaction and therapeutic recreation) to a medical model (i.e., focus on clinical personal care and overall functioning)		5.7(3.9)	6.5	10	0 – 10
Providing standardized ADP services across regions	1	5.6(3.1)	6.5	7	0 – 10
Feeling outside pressure to move towards providing a medical model of ADPs		5.1(4.0)	5.5	0	0 – 10
<b><i>Funding and Resources</i></b>		<b>6.9</b>			
Experiencing a lack of base funding increases	1	8.6(3.3)	10.0	10	0 – 10
Experiencing assumptions and pressure to conform to idea that ADPs “make it work on a shoestring budget”	1	7.9(3.4)	10.0	10	0 – 10
Increasing demand for ADPs with lack of infrastructure to support ADPs and client populations		7.5(3.1)	9.0	10	1 – 10
Increasing client fees to offset lack of base funding increases	1	7.4(3.5)	9.5	10	0 – 10
Having the ability to (and receiving praise for) meeting ADP purposes without sufficient funding		7.3(3.2)	8.0	10	0 – 10
Experiencing a lack of time in your role at your ADP(s)		7.3(3.0)	8.0	10	0 – 10
Having an insufficient number of staff (and access to more staff) due to funding		7.1(3.7)	8.0	10	0 – 10
Overall lack of resources in the health care system		6.9(3.1)	8.0	10	0 – 10
Experiencing limited opportunity to pursue pilot programs that could turn into programs (e.g., low or no funding, brief timelines)	3	6.9(2.7)	7.5	10	2 – 10
Receiving funding from a variety of sources (e.g., Ministry of Health, United Way, etc.)		6.9(3.0)	8.0	10	0 – 10
Funding/resources preventing admission and retention of higher need or more complex clients	1	6.9(3.5)	8.0	10	0 – 10
Experiencing a lack of geriatric speciality services in your region (e.g., geriatricians)	1	6.7(3.8)	8.0	10	0 – 10
Having strict and inflexible funding requirements		6.4(3.0)	7.0	5	1 – 10
Providing low staff wages due to funding	2	6.4(3.8)	7.0	10	0 – 10



Competing with other ADPs for limited resources (e.g., funding, grant opportunities)		1	6.4(3.5)	7.5	8	0 – 10
Being one of few Community Support Services that charges client fees		2	6.3(4.0)	9.0	10	0 – 10
Meeting legislation and funder expectations of ADPs that don't align with your understanding of ADP purposes		1	5.2(3.3)	5.0	5	0 – 10
<b>Organizational Affiliations and Governance</b>			<b>5.8</b>			
Having multiple and varied roles and responsibilities (e.g., payroll, staff scheduling, regional planning)		1	7.1(3.3)	9.0	10	2 – 10
Experiencing regional differences in the operation of ADPs based on legacy LHIN/Ontario Health leadership		1	6.6(3.5)	8.0	8	0 – 10
Different organizational affiliations preventing or complicating progress towards ADP standardization		2	6.1(3.5)	7.0	8	0 – 10
Different organizational affiliations (i.e., umbrella organizations, standalone) creating differences and sometimes inequities in resources	1	3	5.4(3.4)	4.0	4	0 – 10
Being under the umbrella of an organization which decreases autonomy and slows progress		6	4.0(3.6)	3.0	0	0 – 10
<b>Built or Physical Environment</b>			<b>7.5</b>			
Physical space constraints limiting ability to serve more clients and caregivers			8.7(1.7)	10.0	10	5 – 10
Finding and/or retrofitting environments that are suitable for ADP services			8.3(2.2)	9.0	10	4 – 10
Providing ADP services (including new virtual services) in rural area(s)	1	2	7.9(3.2)	9.5	10	0 – 10
Being co-located with long-term care		6	5.0(3.9)	5.0	0	0 – 10
<b>Staff</b>			<b>6.3</b>			
Hiring staff that reflect the diversity of the community			7.4(2.7)	8.0	10	1 – 10
Providing consistent staff education/training (e.g., paying for courses, backfilling)			7.3(2.7)	8.0	10	3 – 10
Aligning and maintaining staff education/training with changing client needs			7.0(3.2)	8.0	10	1 – 10
Hiring and retaining an inter/multidisciplinary staff model			7.0(2.6)	7.0	10	1 – 10

Ensuring staff are building professional relationships		6.6(3.1)	7.0	10	1 – 10
Staff assumptions of client abilities and interests (e.g., activities they would be interested in)		5.9(3.3)	5.0	5	0 – 10
Staff perceptions of suitable ADP clients not aligning with the current ADP model		5.8(3.5)	5.0	5	0 – 10
Staff doing “for” clients or limiting client independence		5.4(3.5)	5.0	8	0 – 10
Staff expectations of roles/responsibilities based on professional background, rather than ADP models	1	4.3(3.4)	5.0	5	0 – 10
<b><i>Ability to Support Clients and Caregivers</i></b>		<b>8.0</b>			
Supporting level of caregiver needs and burnout		9.1(1.8)	10.0	10	3 – 10
Making ADPs inclusive and welcoming to diverse populations	1	8.0(2.7)	9.0	10	2 – 10
Managing transition planning with clients and caregivers		8.0(1.8)	8.0	8	4 – 10
Supporting complexity and level of care/support needs of current client populations		7.6(2.8)	9.0	10	2 – 10
Reaching and supporting diverse client populations (e.g., race/ethnicity, sexuality, ages)	1	7.6(2.7)	8.0	10	2 – 10
Supporting diverse interests, needs, and qualities of clients in one program	1	7.5(2.7)	8.0	8	2 – 10
<b><i>Perceptions of ADPs</i></b>		<b>7.3</b>			
Perceptions that ADPs are not part of (or not a valued part of) the health care system		8.8(1.3)	9.0	10	6 – 10
Caregivers having a perceived responsibility to support older family members without accessing health care and support services	1	8.4(1.8)	9.0	10	5 – 10
Perceptions and/or stigma of ADP services and their implications (e.g., preventing attendance) among community members and potential clients and caregivers	1	7.3(3.2)	8.0	10	0 – 10
Perceptions and/or stigma of ADP services and their implications (e.g., low or no referrals) among health care professionals	1	6.9(3.3)	7.5	7	0 – 10
Current clients’ perceptions of people suitable to attend ADPs		6.9(2.9)	7.0	7	0 – 10
Perceptions that ADPs are becoming too standard or generic	1	6.7(2.8)	8.0	8	2 – 10
Perceptions of ADPs preventing clients and caregivers from advocating for ADPs	2	6.2(3.9)	8.0	10	0 – 10

<b><i>Advocacy and Awareness</i></b>		<b>8.2</b>			
Lack of Ontario/Canadian research on ADP services	1	8.6(2.0)	10.0	10	5 – 10
Community members and potential clients and caregivers having limited understanding and awareness of ADP services		8.4(2.1)	9.0	10	3 – 10
Health care professionals having limited understanding and awareness of ADP services		8.3(1.9)	9.0	10	4 – 10
Experiencing low advocacy power of and for ADPs		8.2(2.3)	9.0	10	2 – 10
Marketing and promoting ADP services		7.8(3.0)	9.0	10	0 – 10
<b><i>Measuring ADP Outcome Metrics</i></b>		<b>7.5</b>			
Metrics of ADP success being difficult to define and measure (e.g., quality of life, inherent change of some conditions, absence of standard milestones)		8.2(2.3)	9.5	10	4 – 10
Existing indicators are outdated or unable to capture differences across ADPs and client populations		8.1(2.1)	9.0	10	4 – 10
Creating meaningful/suitable indicators that capture all elements of ADPs		7.9(2.6)	8.5	10	2 – 10
Having limited staff capacity and time to track meaningful data/use available assessments		7.8(2.7)	8.5	10	3 – 10
Translating current types of ADP evidence (e.g., client testimonials) into formats that funders value		7.7(2.1)	8.0	8	3 – 10
Feeling concern that adjusting indicators to be more meaningful or suitable will impact funding		6.9(3.4)	7.0	10	0 – 10
Lack of best practices or standards for ADPs		6.8(2.9)	7.0	9	2 – 10
Varied organizational affiliations creating different systems of tracking/data collection		6.7(3.0)	7.5	10	0 – 10

NA: Not Applicable; SD: Standard Deviation