Directly-Funded Care Programs in Canada

October 2020

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Ethics Approval

The study was approved by the Health Research Ethics Board (reference number: HS20640) at the University of Manitoba.

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Kelly, C., Jamal, A., Aubrecht, K., & Grenier, A. (2020). Emergent issues in directly-funded care: Canadian perspectives. *Journal of Aging & Social Policy*. **doi:10.1080/08959420.2020.1745736**

Suggested Citation

Kelly, C., Dansereau, L., Balkaran, K., Tingey, E., Aubrecht, K., Hande, M.J., & Williams, A. (2020). *Directly-Funded Care Programs in Canada*. Centre on Aging, University of Manitoba, Winnipeg, Manitoba. **https://doi.org/10.34991/847b-5q61**

Publishing Information

Centre on Aging, University of Manitoba
338 Isbister Building–183 Dafoe Road
Winnipeg, Manitoba, Canada R3T 2N2

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Executive Summary

This report documents Directly-Funded care programs in Canada. Directly-funded (DF) care refers to when caregivers or individuals are given funds or budgeted hours to arrange their own home care services. DF programs serve adults with physical disabilities and cognitive disabilities (including dementia), adults and children with intellectual disabilities, and older adults who require assistance with the activities of daily living.

We conducted an environmental scan that included information from the public domain, questionnaires, and key informant interviews. The scan identified 20 DF care programs in Canada at the time of data collection (2017–18). We found three main types of DF programs. **Home care programs** provide support with the activities of daily living and are typically funded through provincial ministries of health. **Individualized funding programs** serve people with intellectual disabilities, are typically funded through provincial social service ministries, and allow for a broader use of funds for community involvement. Finally, **respite programs** provide brief periods of relief for unpaid caregivers. Some programs have more than one aim.

Our report describes 20 DF home care programs across Canada and summarizes key features. Across the provinces, we found only a small proportion of home care clients using a DF option except for Newfoundland and Labrador. We also found different policy responses in each jurisdiction related to whether clients can hire family members and whether clients can contract third party agencies to provide services rather than hiring workers directly. Most of the programs allow the either client or another person (often a family member) to manage DF care services.

We make seven key recommendations for the development and evolution of DF care programs in Canada:

1. Allow for the hiring of family members who do not co-reside

2. Provide more administrative support for care managers

3. Standardize pay for care workers across all continuing care settings in each province

4. Create a regular check-in and/or reporting procedure where clients and workers can discuss workplace issues, interpersonal concerns, as well as potential abuse and mistreatment

5. Limit client needs reassessments

6. Develop tools for family members to assess the quality and appropriateness of home care agencies

7. Encourage agencies and government service providers to adopt some of the practices that DF clients cite as providing higher satisfaction

DF programs are an important component of the continuing care sector in Canada, and we encourage efforts to expand and develop programs across all settings. We caution, however, that providing funds to families and clients to arrange their own services does not guarantee increased client and worker satisfaction nor does it guarantee increased care quality. Indeed, careful planning and attention to issues of equity, access, caregiver burden, abuse, working conditions, and other elements common to all continuing care settings are important to ensure DF care best supports families, clients, and workers.

Introduction

Demand for home care is increasing throughout Canada and elsewhere due to a convergence of factors. Most notably, our population is aging, people are living longer, and sometimes age brings increased needs for support with the activities of daily living. We also have a growing number of individuals living with disabilities and chronic care needs (Statistics Canada, 2018). At the same time, there is a cultural and health shift away from residential care, stemming back to deinstitutionalization movements led by people living with intellectual, psychosocial, and physical disabilities. When asked, the vast majority of people would prefer to stay in their own homes as long as possible if care needs were to arise (Peterson & Quinn, 2017).

COVID-19 has revealed the failings (at worst) and shortcomings (at best) of medicalized congregate living. Contemporary critiques of residential care are built on diverse histories of deinstitutionalization that has not been fully actioned. The current moment is more receptive to the critiques of care embedded in these histories, bolstering the growing demand for home care and other alternatives to residential care. Yet, home care systems in Canada are strained. There is a higher demand than there is capacity (Accreditation Canada & Canadian Home Care Association, 2015; Donner et al., 2015; Health Association Nova Scotia, 2014; Ontario Ministry of Finance, 2014). We have human resourcing issues in terms of high worker turnover (Ferguson, 2020; Zeytinoglu et al., 2009), and there may be further recruitment challenges in the wake of COVID-19. Furthermore, there are complaints about consistency and specific practices of current home care services. Home care was uniquely specified in the renegotiation of the federal health transfer as a priority area for the Canadian health care system.

In the United Kingdom, United States, and Australia (Cortis et al., 2018; Laragy & Vasiliadis, 2020; San Antonio et al., 2010; Slasberg & Beresford, 2015), as well as some European countries (Ranci et al., 2019), directly-funded care programs are a policy mechanism that potentially responds to some of the strains and issues facing the home care sector. **Directly-funded (DF) care** refers to when caregivers or individuals who require assistance with the activities of daily living are given funds or budgeted hours to arrange their own home care services. In Canada, these types of programs are growing exponentially and are a valuable alternative or supplement to the home care sector. This report documents DF care programs in Canada.

Terminology

In Canada and globally, DF programs are referred to by several terms, including self-managed or family-managed care, self-directed care, consumer-directed care, cash-for-care, personal budgets, individualized funding, and direct payments. Depending on the context, these terms sometimes have a broader meaning in that they may refer to programs that use a patient-centred or person-first approach to care planning, but do not necessarily involve the budgeting of funds. In Canada, DF care involves a needs assessment, often by a health care or social services professional. The needs assessment results are allocated as a budget of hours, a dollar amount, or a combination. The client, unpaid caregiver, or other legal third party then recruits, hires, and trains workers from the community, or purchases services from home care agencies. We elect to use the term directly-funded to refer to situations where clients are responsible for a budget or monetary transfer, which we distinguish from person-centred planning and research that focuses on the patient self-management of specific health conditions.

Influence of Independent Living

It would be remiss to present a report on DF programs in Canada without discussing the influence of the Independent Living (IL) movement. The IL movement is a branch of the disability rights movement that began in the United States in the 1970s at the University of California, Berkeley. Influenced by other civil rights movements at the time, people with disabilities demanded inclusion in society and asserted their right to make decisions about their lives. IL runs in parallel with deinstitutionalization and community-living movements led by people with intellectual disabilities, people with psychiatric diagnoses, and their allies. Together, these movements advocate for the inclusion of people with disabilities throughout our institutions and social structures and, importantly, for them to live in the same communities as nondisabled people. IL advocates that people with disabilities should have control over the services that are directed at them. To this end, some proponents argue that people with disabilities should be given the funds reserved for social and health services and direct the design of the services around their lives.

Early versions the IL model still echo in contemporary DF care programs and there are many examples of people with disabilities advocating for and designing these programs in Canadian and international contexts (Disability Rights UK, 2012; Lord, 2010). Programs more heavily influenced by IL would be characterized as encouraging the client to independently self-manage the funds that support their care, to act as an employer by hiring people from their local networks and communities, and to train their own workers or hire workers trained in disability rights, Independent Living, and empowerment rather than hiring workers with 'typical' health care training. In IL, people with disabilities are the experts of their bodies and needs, and are qualified to train individuals to support them;

sometimes, disability activists find the medicalized approach of care worker training programs can result in patronizing approaches to providing help (Longmore, 2003; Thomas, 2007). DF care has been welcomed by governments across the political spectrum, albeit for different rationales. DF programs have diversified and been adapted for different client populations over time and across jurisdictions, yet, there remains a strong contingent of younger, physically disabled people who benefit greatly from DF care models and continue to draw on the advocacy of the IL movement.

From the 1960s onwards and often in parallel to the IL movement, people with intellectual disabilities and their allies have worked towards inclusive education, deinstitutionalization, and community living (Abbas & Voronka, 2014; Community Living Ontario, 2009). There are accounts of families and allies organizing in many different contexts (Community Living Society, 2020; Community Living Thunder Bay, 2020; Lord, 2008). Parent advocacy for deinstitutionalization is complicated and contradictory at times (Burghardt, 2015; Carey & Gu, 2014), but ultimately has moved towards less medicalized and more inclusive approaches to supporting people living with intellectual disabilities. One innovation associated with this advocacy is the use of microboards. A microboard is a group of five or more people who formally establish a non-profit society along with the person living with an intellectual disability to help that individual in all aspects of their life, including monitoring finances and support services (Holder, 2020). Innovations in home-based care delivery, such as DF programs and microboards, are shaped and linked to advocacy and activist work led by people with disabilities and their supporters.

Populations Served by DF

DF programs serve a number of different populations. Historically, DF programs served younger adults with physical disabilities with the social and cognitive capacity to self-manage their own care and workers. Some DF programs are designed to serve children and adults with intellectual disabilities; in such cases, the individuals often have assistance from an unpaid support person in managing their services and program funds, such as a family member, friend, or legal third party representative. Over time, DF programs have been increasingly accessed by older adults living with multiple chronic conditions that include physical and cognitive impairments, many of whom rely on an unpaid caregiver to manage their funds and care. Finally, some DF programs are specifically designed to provide respite to unpaid caregivers.

Types of Programs

Our study identified three main types of programs, although there is overlap and some fall into more than one category. First, there are DF **home care** programs, which are designed to help people with the activities of daily living, including dressing, bathing, eating, and meal preparation. DF home care programs are found in all ten Canadian provinces, with one additional federal program for veterans and their families. Some programs require a certain type of support activity to access funding; for example, clients may only be eligible for help around the house if they also require assistance with personal care. Most home care programs are funded through provincial ministries of health. The second type of DF program, **individualized funding**, is geared towards people with intellectual disabilities, usually adults but sometimes also adapted to children.

DF individualized funding programs are found in all provinces except Quebec and Nova Scotia. They are often broader in scope than home care programs, providing financial support that can be used to enable social participation (e.g., purchase a gym membership, bus pass) in addition to personal care. Individualized funding programs are typically run and funded through provincial, social, or family service departments. Finally, we identified DF **respite** programs, which are designed to provide relief to unpaid caregivers. While many of the home care and individualized funding DF programs support caregivers, whether intentionally or inadvertently, there are two programs in Ontario exclusively dedicated to providing respite for caregivers. As we describe the programs in our findings section, these three terms will be used to help identify the primary aim of the programs.

Methods

Prior to our study, a national inventory of DF programs was commissioned by Health Canada (Spalding et al., 2006), and the National Resource Center for Participant-Directed Services at Boston College launched an inventory of American programs in 2010 (Sciegaj et al., 2014). Our study provides an update to the 2006 Health Canada report and follows a similar approach, using qualitative environmental scan methods (Graham et al., 2008). Our research team developed a set of inclusion criteria, as detailed in Table 1.

Table 1: Inclusion Criteria for DF Program Inventory

1. Funds are allocated to clients by a government or government-funded agency
2. Funds can go to clients or their families (sometimes through reimbursement)
3. Program must serve people over 16 years old, but may also serve children
4. Clients/families use funds to choose and direct services themselves
5. Clients/families hire workers as individuals or hire agency staff
6. Funds are used for home care, which must include personal care, and may also include household maintenance or care of dependents
7. Funds are used for continuing care, not acute care
8. Program must currently be in operation

Source: Kelly, Jamal, Aubrecht, and Grenier, 2020.

Through basic search techniques (Choo, 2001) we identified 20 programs across Canada. After our data collection was complete, we were informed that Ontario had launched a new DF program for families of very specific groups—children with complex medical needs, adults with acquired brain injuries, eligible home-schooled children, and clients in "extraordinary circumstances." This program is not included in our study (Home and Community Care, 2017). As each program was identified, research assistants began filling in a structured questionnaire for each program using publicly accessible information (Appendix 1). The questionnaire was designed to collect standardized and descriptive information about each program. It was rarely possible to complete the entire questionnaire with information available collected through the environmental scan. Research assistants then sought out a key informant contact for the program in question through email addresses and phone numbers included on program websites and/or government directories.

Only people working in, administering, or overseeing one of the DF programs in this study were eligible to be a key informant. The formal consent process informed participants of the increased risk of identification due to their public roles as policy makers. All key informants were asked to correct and complete the partially filled questionnaire; the member-checking process with key informants was repeated up to four times over the course of the study, and we also consulted with them as necessary as data were condensed into tables and summarized for other outputs.

We identified one or two key informants per program (n=23); four programs had two informants and two programs had the same informant. In addition to assisting with the structured questionnaires, key informants participated in semi-structured in-depth interviews over the phone, with one in-person interview related to a program local to the research location. Interviews aimed to discuss program history, thoughts and opinions, and regional issues. The interviews took place between August 2017 and April 2018, each was 45–90 minutes long, and all were recorded and professionally transcribed. In order to include Quebec, the study instruments were professionally translated into French and a French-speaking research assistant was hired for data collection. After data collection for Quebec, the completed questionnaire and transcription were professionally translated into English. The study was approved by the Health Research Ethics Board (reference number: HS20640) at the University of Manitoba. All information in this report comes from publicly available documents with additional details and clarification provided by key informants.

Limitations

The data presented below is based on the time of data collection. To ensure accuracy, we cross referenced the information with publicly available information and confirmed with key informants up to four times as the information was processed into tables and figures. Some key informants gave general confirmations and estimates while others confirmed with exact numbers. Many of the programs operate regionally, through health authorities but the key informants were often from provincial governments. Provincial governments are responsible for policy directives but not necessarily the daily operation of the programs, and thus there were some elements of the programs to which the key informants could not specifically speak.

Descriptions of Programs in Canada

1. Federal

In Canada, health and social services are under provincial jurisdiction with only a few population groups under federal jurisdiction, such as First Nations people living on-reserve, people in the armed forces or national police, and security services. Our environmental scan identified one federal DF program.

1.1. Veterans Independence Program

The Veterans Independence Program (VIP) is a federal home care program founded in 1981 and administered and funded through Veterans Affairs Canada. VIP is a needs-based, proactive, self-managed program focused on helping clients maintain their independence. The program originated due to the concern that long-term care facilities were the only options for a growing population of World War One and World War Two veterans (KI-07). VIP provides care for veterans, primary caregivers of veterans, and survivors of a war service veteran who was eligible but did not receive VIP at the time of death or admittance to a health care facility. Notably, VIP is a secondary provider of funding, topping up services provided by various provincial home care programs (KI-07). Some of the services funded by the VIP program are those rarely included in provincial programs, such as grounds maintenance and transportation.

In 2016, the VIP program served 90,854 clients across the country (89.4 percent male) and allocated an average monthly funding amount of $3,855 to each client. Clients can be of any age but must have served overseas for at least 365 days and be approved for disability benefits, war veterans' allowance, and/or prisoner of war compensation. Funding is used to cover assistance with housekeeping, grounds maintenance, personal care, nutrition, ambulatory health care, transportation, and health support services. Clients, legal representatives, or other third parties (such as family members) manage the care, and clients are encouraged to hire home care agencies to provide the services (KI-07). With some exceptions, clients cannot hire family members.

2. British Columbia

2.1. Choices for Supports in Independent Living

Initiated in 1994, the Choices for Supports in Independent Living program provides flexible self-directed home care for clients with chronic health conditions The program is supported and promoted by disability organizations including Spinal Cord Injury BC and the Individualized Funding Resource Centre. The program served 956 clients in 2015–16, with 80 percent under the age of 65. This program is administered through regional health authorities and funded by the British Columbia Ministry of Health. Eligible individuals must be over 19 years old, have one or more chronic conditions limiting independent function, need care at home after hospitalization or in lieu of hospitalization, or require end-of-life care. Clients must be capable of self-management, have a legal representative, or establish a formal Client Support Group (KI-11).

In 2015–16, the average monthly funding per client was $7,360. The funds must be used to hire workers directly; the funds may not be used to hire family members or to purchase agency services. There are no educational requirements for workers and wages are set by the client or their representative (KI-11). Monthly financial and administrative documents are sent to case managers, who may also be consulted by clients about concerns regarding care quality, abuse, or disputes over funding (KI-11). There are no other procedures for reporting abuse or registering complaints, and no avenues for workers to report labour issues (KI-11). The program does not collect information on worker demographics or quality of care (KI-11).

2.2. Individualized Funding, Community Living BC

The Individualized Funding program is administered and funded through Community Living BC, a crown agency under the Ministry of Social Development and Poverty Reduction (KI-01). Crown agencies are owned by government departments but operate independently at 'arms-length' from other government programs. The use of a crown agency to administer the program is unique and is the only example of this practice that we found in our study. The Individualized Funding program began when community advocacy groups called for an individualized care option for people with developmental disabilities (KI-01). In March 2016, the program served a total of 3,028 adults over the age of 18, including 2,800 clients living with developmental disabilities (diagnosed prior to the age of 18) and 228 individuals with a diagnosis of Fetal Alcohol Spectrum Disorder or Autism Spectrum Disorder. Clients may have help managing the program from a legal representative called an agent; family members or guardians frequently act as agents. Alternatively, clients may establish a microboard to help

the individual direct their finances and support services. Vela Canada, a non-profit agency contracted by Community Living BC, works with potential clients to provide information on programs, funding, microboards, and government policy (KI-01).

The program issues funds to the client or their agent, with an average monthly funding of $2,800 in 2017. Funds may be used to purchase services for clients needing in-home support, community inclusion services to encourage community engagement, and respite care for families. Agents are permitted to purchase services from private home care agencies, however hiring family members, partners, or out-of-province services is prohibited. There is no requirement for workers to have experience or educational credentials, however all workers must pass a criminal record check (KI-01). There are no formal avenues to report abuse or care quality concerns. The program does not gather information on worker demographics and Community Living BC does not communicate directly with the workers (KI-01).

3. Alberta

3.1. Family Managed Services

The province of Alberta introduced the Family Managed Services program in 2005 to serve adults aged 18 or older living with developmental disabilities. This individualized funding program served approximately 4,500 clients in 2017 and is administered by the Ministry of Community and Social Services. We could not access specific demographic information on program clients, however, our key informant indicated that most of the clients are between the ages of 18 and 30, many are living with physical

disabilities in addition to intellectual disabilities, and the program serves more men than women (KI-05). On entering the program, clients designate a fund administrator, either themselves or an individual from their personal network; the fund administrator is typically a family member or legal guardian. Fund administrators must act as employers and hire workers directly.

The average monthly funding per client is confidential (KI-05). The program is funded by Alberta's Ministry of Community and Social Services. Funding may be used for in-home services, support related to employment and community assistance (such as therapy and behavioural supports), and administrative costs. Fund administrators are required to take training on employment standards, abuse protocols, and payroll responsibilities and are then responsible for planning, hiring staff, monitoring quality, managing payroll, and record keeping. Fund administrators are also required to ensure that workers have abuse protocol training plus specialized instruction as necessary. Fund administrators are not permitted to hire a relative of the client, not even extended family members.

3.2.   Self-Managed Care

The Self-Managed Care program is a home care program that was introduced in 1991 to enhance choice and flexibility primarily among adults with physical disabilities, although people of any age are eligible for the program following clinical assessment. The program served 1,700 clients at the time of data collection. In 2018, Self-Managed Care represented about 1.3 percent of all

home care users. The program is funded by the Alberta Ministry of Health and the average monthly funding for the program is $3,277. Clients or a legal representative may hire workers and act as a direct employer, contract with an agency, or a combination. There are no specific educational requirements for workers. The province does not track information on whether agreement holders hire directly from their networks or contract with home care agencies but based on her experience our key informant believed that agency use is fairly common (KI-10).

Home care case managers assist clients and families in understanding their responsibilities, and health authorities offer educational sessions to new clients, but our key informant indicated that there was 'lots of room for improvement' in terms of supporting people using Self-Managed Care (K-10). Clients or families open a dedicated bank account into which provincial funds are deposited and submit quarterly financial reports that are audited periodically at the discretion of the local health authority. There is no oversight of hours worked aside from self-reports or agency communication with the health authority, and there is no day-to-day provincial oversight of service delivery. The program does not collect information on workers, there is no systematic oversight of the work environment, and there is no formal avenue for complaints or reporting abuse (KI-10).

4. Saskatchewan

4.1. Community Living Self-Directed Funding

Community-based organizations representing individuals with intellectual disabilities in Saskatchewan advocated for a self-directed individualized funding program for years (KI-15). In 2014, the Demonstration Project was approved for testing and remains in operation. The program is administered through the community-based organization Saskatchewan Association for Community Living and is funded by the Saskatchewan Ministry of Social Services. The program represented seven clients at the time of data collection. Community Living Self-Directed Funding is designed for people over the age of 18 living with an intellectual disability. To be eligible for the program, a client must have a legal representative (family member or support network) who is responsible for acting as an employer and managing program funds.

In 2017, the average monthly funding was $6,250 per person (KI-15). Funds are issued to the client representatives who then may hire workers directly, purchase private agency services, or pay for programming delivered through government recognized community-based organizations (KI-15). There are no specific educational requirements for workers hired and wages must be in accordance with labour standards and regulations (KI-15). Case managers with the health authority participate in (unspecified) periodic team meetings with the individual and their support networks (KI-15). Worker complaints and issues are resolved by the client or their representative through the client's support networks; there are no formal avenues to report abuse or

misconduct (KI-15). The program does not collect information on the workers or monitor the quality of care.

4.2. Individualized Funding for Home Care

The Individualized Funding for Home Care program is administered and funded through the Saskatchewan Ministry of Social Services and began in 2002 in response to the advocacy of community groups representing individuals with physical disabilities (KI-09). The program served 130 clients in 2016–17, representing less than 1 percent of all home care clients. Of note, this is a home care program that uses the term individualized funding differently than we defined at the outset of the report. This program is not geared towards people with intellectual disabilities, instead, clients of any age must have a medical condition that requires long-term supportive care needs. Twenty percent of clients are under 19 years old, 63 percent are between the ages of 19 and 65, and 8 percent are aged 66 or older (information was not available for 9 percent of clients). A family member or legal representative may manage funds for the client, and 52 percent of clients are represented by a legal guardian, including all of the clients under the age of 18.

Funds may be used to hire personal support worker services but family members, out-of-province workers, services provided by a person/organization that owns, leases or rents the client's residence, or self-employed workers hired on a contract basis are not eligible. There are no educational requirements for workers and wages must comply with labour laws and Canadian Revenue Agency policies (KI-09). The program is funded by Saskatchewan's Ministry of Health. In 2017, the average funding

per client was $3,975 per month. Monthly reports are sent to the appropriate health region detailing money distribution, management, and employee timesheets. Clients who have concerns about the quality of care may consult with case managers or care coordinators from the health region (KI-09). There are no formal avenues for workers to report labour issues or concerns regarding abuse or misconduct. The program does not collect information about workers employed through the program (KI-09).

5. Manitoba

5.1. In the Company of Friends

In the Company of Friends is an individualized funding program established in response to a grassroots movement to empower people living with intellectual disabilities (KI-02). The program was piloted in 1993 and became permanent the following year, serving 66 clients in 2017. The program is funded through the Department of Family Services and administered through the non-profit organization Living in Friendship Everyday.

To be eligible for the program, clients must be at least 18 years old and must have a social support network referred to as a microboard who are committed to providing long-term guidance and support. The microboard is a requirement, rather than an option, which is a unique feature of this program. As of August 2018, the average funding per client was $9,300 per month. Funds may be used to pay wages for support workers, to train staff, and for equipment costs. One member of the microboard is designated to assume the responsibilities of an employer and

submit quarterly reports. The program does not permit clients to hire family members as workers; any support from family members is considered volunteer-based assistance from a support network and from "an individual who cares about the circumstances in a client's life" (KI-02).

5.2.   Manitoba Self and Family Managed Care Program

Manitoba's Self and Family Managed Care program is a home care program that was established in 1991 based on the advocacy work of the Independent Living Resource Centre (ILRC), a non-profit community organization with a focus on providing support to individuals with disabilities to participate in community life (KI-16). The program appears to be expanding, growing from about 500 clients in 2015 to 980 clients at the time of data collection, with about 20 percent of clients living in rural areas. The program is funded through Manitoba Health, Seniors and Active Living and administered through the regional health authorities, with funding also going to the ILRC to educate and assist self-managers and families in managing funds and recruiting and training staff (KI-16). The ILRC is registered with the province as a home care agency but does not provide personal care services; rather, the agency operates a six-week attendant training program, organizes manager support groups and other support services, and runs a low-cost program to support people in the financial aspects of acting as an employer and managing program funds.

About 25 percent of clients act as self-managers and are typically younger adults with disabilities, while 75 percent of clients are older adults with home care services organized by a 'family manager', who may be any individual willing to take on the role of care manager on behalf of the client. Prospective clients must be

a resident of the province, registered with Manitoba Health, and assessed as needing home care. The official policy indicates that clients must have used government-delivered home care services for at least one year prior to being eligible for the self-managed option, however our key informant indicated that this policy appears to be relaxing in recent years as demand has increased (KI-16). There is no specific age eligibility to join this program.

The average monthly funding per person in 2018 was approximately $3,800, however individual amounts vary widely by assessed needs based on hours, which are designated as household maintenance (funded at a rate of $13.58 per hour) and personal care (funded at a rate of $19.81 per hour). The program also funds worker transportation (costs of bus fare or mileage for up to 10 km), worker recruitment (up to $25 per hire) and training (up to eight additional hours per hire), and $150 per year for administration costs. Clients are reassessed annually, or as requested by the client or family member when there is a change in health that may require more assistance. Funds may be used to hire workers directly, or purchase personal care services through a private agency, and to cover some administrative costs such as bookkeeping. Care managers may hire family members with special approval.

6. Ontario

6.1. Caregiver Support Project

The Caregiver Support Project, initiated in 2011, is a project administered by the Alzheimer's Society of Toronto and it served 874 Toronto-area clients in 2015–16. The program is funded by the local health authority as well as by private donations. The Caregiver Support Project provides grants to unpaid caregivers to relieve distress involved in providing support to individuals living with any kind of disability or medical need. This is a small program; the average monthly funding at the time of data collection was $117. The caregiver must be referred to the program through a seniors' service organization and is required to meet with a coordinator to discuss their needs. The caregiver proposes how they will use the grant, which must be directly related to care activities or care-related expenses. Caregivers are required to submit receipts to show appropriate use of funds; no additional paperwork is required. The majority of grant monies pay for respite care services, to purchase incontinence supplies, and to pay for day-program fees for the care receiver (KI-03). A unique aspect of this program is the ability to fund an array of non-traditional items needed to ensure the health and well-being of the caregiver in a holistic sense, such as purchasing health club memberships, a winter coat, or covering the cost of taxi rides to medical appointments (KI-03). Almost all clients are adult children caring for a parent, about 75 percent are female and 25 percent male, and about 80 percent are supporting an older adult living with cognitive impairments or dementia.

6.2. Passport

Ontario's Passport program is an individualized funding program and funded by the Ministry of Community and Social Service (presently the Ministry of Children, Community and Social Services). Established in 2005, the program served 24,000 clients in 2016–17. The impetus for the program was to provide support for people 18 years of age or older diagnosed with a developmental disability as they transition away from the school system (KI-17). Clients are assessed through local offices of Development Services Ontario and are referred to the program based on that assessment. The average monthly funding per person is approximately $833. The funds are allocated towards community participation expenses, such as recreation programs, employment support, and transportation. The funds can also be used for hiring support workers, caregiver respite, administration costs (to a maximum of 10 percent of funding), and person-directed planning costs (to a maximum of $2,500). Passport provides flexibility for clients to choose activities in the community that interest them, rather than the fixed activities typically organized by agencies (KI-17).

Clients, legal representatives, family members, or other persons providing informal support are eligible to manage program funds. For support services, clients may hire directly, hire an agency, or a combination. Those who hire directly must comply with tax, labour and other laws, and all spending must be reported through monthly submission of receipts and invoices. Anyone over the age of 18, including family members, may be hired with the exception of the primary caregiver and the spouse of the client.

6.3.   Self-Managed Attendant Services

In Ontario the Self-Managed Attendant Services program, piloted in 1994 and established as a permanent program in 1998, is colloquially called the Direct Funding program. This home care program is funded through the Ontario Ministry of Health and Long-Term Care and is administered by the Centre for Independent Living in Toronto (CILT), which is a non-profit cross-disability organization and part of the global disability rights movement. CILT is run by people with disabilities and pursues a vision of "social and economic equity for people with disabilities as seen through the lens of Independent Living principles" (Centre for Independent Living in Toronto, 2018). The Self-Managed Attendant Services program is the only program run by an Independent Living advocacy group; however, Independent Living organizations have been directly involved in the development of DF home care programs in other provinces (such as Manitoba) and throughout the world.

The program served 912 people in September 2017 (approximately 0.4 percent of the province's home care clients), but our key informant mentioned that it had grown to almost 980 clients by October and they were working to accommodate a waiting list of about 450 applicants. To be eligible, clients must be over the age of 16, live with a diagnosed disability, live independently, and be able to complete the written application form. Clients are required to self-direct their care and manage their own funds; in 2017 the majority were between the ages of 45 and 65, and about 60 percent were male. Applications are reviewed by a panel of peers organized through CILT to assess client suitability. The peer-assessment process is based on the Independent Living principle that people

with disabilities are the experts in their own bodies and needs; it is a unique element of this program and is in contrast to needs-assessment processes by health and social services professionals seen in other programs. This process also enhances peer-mentoring for new clients who may be taking on self-direction for the first time.

The program is funded by the Ministry of Health and Long-Term Care. As of 2017, the average monthly funding per client was $4,035. The funds cannot be used to hire immediate family members or significant others and clients are required to act as employers and hire workers directly. The funds can be used to hire the services of home care agencies only in emergency circumstances; otherwise, clients must find and hire workers from their networks and communities. Clients submit quarterly financial reports and are reassessed for funding hours only at their own request. The program does not collect any information about workers.

6.4. Wesway Family Directed Respite Services

Wesway Family Directed Respite Services, established in 1973, is one of the oldest respite programs in Canada. The program originated from the Wayside and Wesley United Churches in the Thunder Bay area, with each church running and funding respite programs for families of children with physical and/or developmental disabilities (KI-06). In 1987, the program expanded services to younger adults with developmental disabilities and older adults in need of home support (KI-06). Clients must be co-resident with a family caregiver. The program served 327 caregivers in 2016–17; 106 caring for children, 39 caring for younger adults, and 183 caring for older adults.

Uniquely, this program is funded by multiple government ministries: Children and Youth Services; Community and Social Services; and Health, and is additionally supported through private fundraising. Average funding varies across demographic groups; in 2016–17 the average monthly funding was $510 for children, $725 for younger adults, and $560 for older adults. Coordinators advise families on how to develop contracts, apply for subsidies, and set appropriate wages; there are no restrictions on who may be hired, and workers are typically a family member, neighbour, or friend (KI-06). Younger adult clients with disabilities and their caregivers undergo an annual 'quality assurance measurement audit' to ensure appropriate care is being provided, and adult clients are given abuse training to learn how to identify instances of abusive behaviour (KI-06). Children and older adults do not receive this training; however, when abuse is reported or suspected the program will investigate.

7. Quebec

7.1.   L'allocation Directe – Chèque Emploi-Service

In Quebec, professional home care and non-professional support services are both delivered by public employees; private agencies play a limited role. The province first established L'allocation Directe in 1978 to increase the social participation of people with disabilities, and in 1998 the program was modified and named the Chèque Emploi-Service with the goals of increasing choice and flexibility, alleviating carer burden, reducing administrative burden for authorities and users, and increasing the protection of women workers. The program represented 10,219 clients at

the time of data collection. The program is funded by the Quebec Ministry of Health and Social Services and provides an average monthly funding of $503. People of any age are eligible for the program following clinical assessment and the development of a care plan. Clients, their family members, and legal representatives are eligible to manage care. In 2018, the program represented 7.8 percent of all provincial home care users. Clients may hire directly, purchase services from a home care agency, or a combination, and there are no specific educational requirements for workers. If hired directly, clients register their workers with their health authority. Our key informant believed that 90 percent of workers are hired directly but could not provide supporting documentation. There were 10,386 workers employed in the Chèque Emploi-Service program in 2015–16, almost all of whom were women in part time positions.

Each regional authority educates clients and their families in understanding their responsibilities, and there are additional support organizations in some regions to help clients find workers. Program funds are deposited into client accounts held by the Caisse Populaire Desjardins, a large credit union that serves as a processing centre for the program by handling payroll for workers. A key impetus for the 1998 redesign of the program was concern that workers were not being paid fairly and funds were being misused (KI-12), and the processing centre addresses these issues while also collecting information on workers' identities, hours worked, and whether support is personal care or home making. Clients submit a bi-weekly time sheet to the processing centre, which handles accounting and generates worker paycheques. The health authority periodically assesses timesheets to compare the care plan to support delivery (KI-12), however it is unclear how often or to what depth reviews occur. Care quality and clinical outcomes are not reported.

8. New Brunswick

8.1. Long Term Care Services for Seniors

Founded in 1978, Long Term Care Services for Seniors served 1,060 clients at the time of data collection. The program is administered through the Social Development Regional Offices and funded by the Government of New Brunswick.

This arrangement is unique; while individualized funding programs are often funded and administered through social service ministries, the other DF home care programs in this study are funded by ministries of health. To be eligible for Long Term Care Services, clients must be older adults (65 and over) and have care needs requiring additional support for the client or caregiver. Primarily, the services focus on assistance with the activities of daily living. The program emphasizes a 'home first policy' (KI-19) that aims to keep older adults at home for as long as possible.

In many ways this program is not exclusively a DF program and our research team debated whether or not to include it in this report. This program includes a range of options beyond at-home assistance. Further, the financial aspect works differently than other programs. The majority of clients elect to hire third party agencies and the program will transfer funds directly to the agency rather than to the client (KI-19). A very small percentage of clients choose to receive funds to privately hire workers (KI-19). While it may appear as though New Brunswick has a high proportion of home care clients using a DF option, in practice it is more accurately a high proportion of clients who chose from a list of approved agencies. This program also includes a financial assessment and clients can be deemed ineligible on financial grounds and would then have to access care privately (KI-19).

In terms of how the program operates, clients are either self-represented or represented by a family member. Other legal representatives cannot manage care for the client. Case managers and social workers may discuss and educate clients on potential options available in the program (KI-19). On average, clients receive $1,250 in monthly funds. Distant family members can be hired, but immediate family members such as siblings, parents, children, or grandchildren are excluded (KI-19). Formal avenues for reporting abuse, misconduct, or quality of care do not seem to be available. The program does not gather information on workers.

8.2.   Self-Managed Disability Support Program

New Brunswick's Self-Managed Disability Support program is an individualized funding program administered through the Department of Social Development supporting 90 clients at the time of data collection. The Disability Support program offers two models of service delivery; the first allows clients to self-manage their case plan, while the second allows the client to request the support of a social worker. Clients who opt for the self-managed model will meet with the department to develop a case plan through determining their strengths and unmet needs. Afterwards, the client manages their services to address their needs. Clients, legal representatives, or other third parties may manage care. The program allows for the hiring of agency workers and family members that do not live in the same residence as the client. The average monthly funding for this program was unavailable.

Prospective clients can apply to the program by contacting the social development office and filling out an application, which can be filled out by the prospective client, with support from a staff member from the social development office as need, or by an 'independent facilitator,' an individual who acts as an advisor and helps clients develop a long-term care plan. Clients must be between the ages of 19 and 64, reside in New Brunswick, have a long-term disability, and require disability-related support to address unmet needs. Once a person turns 65 years old, they are transferred to the Long Term Care program (KI-19). Additionally, a financial assessment is conducted to determine the client's contribution towards the cost of supports.

There are several eligible expenses under this program, including hiring a home support worker, respite for informal caregivers, assistance in and outside the home, support for community involvement, personal living skills training, disability-specific transportation, assistive devices not covered under other programs, and residential facility services. If the funds are used for residential facility services, those clients would not be using a DF option as it is more commonly understood in other provinces and countries. Clients are responsible for ensuring that skills of the workers are meeting their requirements.

9. Nova Scotia

9.1. Self-Managed Care Program

Established in 1994, Nova Scotia's Self-Managed Care is a home care program funded by the Nova Scotia Department of Health and Wellness and administered by the provincial health authority, serving 216 clients in 2016–17. The program was established due to the growing needs of a population living with conditions such as quadriplegia, paraplegia, and/or neuromuscular disorders such as multiple sclerosis (KI-14). Clients must be at least 19 years old and have a chronic or stable condition that requires ongoing support for the routine activities of daily living, as assessed by a program case coordinator. Clients must be capable of making their own personal care decisions (this capacity is presumed unless determined otherwise), and either self-direct their own services or clients may appoint a personal advocate (unpaid) to become their care manager; the client or care manager acts as a direct employer of workers and is responsible for service planning and financial management. Reflecting the high rural population in Nova Scotia, 73 percent of clients live in rural areas. In 2016–17, 59 percent of clients were female and 41 percent male, with an overall average age of 58 years old. The average monthly funding for the program is $3,100 per client. Funding must be used to hire workers directly but cannot be used to purchase services from home care agencies, nor hire health professionals or workers acting as private contractors. We could not determine the proportion of clients self-managing or with appointed care managers, and the program does not collect any data on workers.

9.2. Supportive Care Program

Nova Scotia's Supportive Care Program was established in 2008 and funded 528 clients in 2016–17. The program was established to provide home care services for individuals living with dementia but may be characterized as predominantly a respite program, with about 98 percent of clients using the program for respite (KI-14). The program is administered through the regional health department and funded by the provincial Ministry of Health. Clients may be of any age but must have a diagnosis of progressive cognitive impairment and require support for daily living; the vast majority are over 65 years old, 63 percent are female, and 61 percent live in the Halifax Regional Municipality. The program requires a substitute decision maker or power of attorney to manage care and program funds (KI-14).

Care managers receive a monthly allowance of $500 for direct care and home support services, with an additional annual funding of $495 earmarked specifically for snow removal services. Managers must provide quarterly financial reports and unspent funds must be returned. Care managers may hire a home support agency but are encouraged to hire directly as the money generally goes further and can cover approximately 40 hours of care per month (KI-14). The program is premised on a supportive approach for adults living with cognitive impairment, allowing for greater consistency in provision of care than is possible through 'regular' home care services, and clients can receive services from people they know and trust (KI-14). The Supportive Care Program is available as an additional service for clients already receiving 'traditional' provincial home care services, although many use it as a substitute for those services to reduce stress for the care-receiver related to inconsistent or changing staff (KI-14). Uniquely, the Supportive Care Program allows care managers to hire family members with any relationship to the client, including spouses.

10. Prince Edward Island

10.1. Home Care and/or Disability Support Program

Prince Edward Island's Home Care and/or Disability Support program is an individualized funding program that served 1,414 clients in 2017. At the time of data collection, the program was undergoing a major transformation; it is unknown how many of the features reported here have remained throughout the transformation. The program was established in 2001 in response to demand from the community for services addressing the needs of individuals living with physical and/or intellectual disabilities (KI-13). Administered through the provincial Department of Family and Human Services, the program is funded through a combination of provincial and federal financing via the provincial Department of Family and Human Services and Social Development Canada. Clients must be under the age of 65 and have a physical or intellectual disability that requires support for the activities of daily living. The program is person-centred, working with the individual and/or their caregiver to develop a support plan based on unmet needs. The person managing the funds is designated as a Support Coordinator, and may be the individual receiving services, a family member, or other third party such as the client contact person within the Department of Family and Human Services.

The average monthly funding per client is $833 dollars ($10,000 per year), with a maximum funding ceiling broken down into four categories depending on assessed level of function ranging from a maximum of $3,100 per month for 'very low functioning' clients to $400 per month for 'high functioning' clients. With additional eligibility criteria related to the precise funding stream, program monies may be used for technical aids, community support

(including vocational and work-related support), family support programs (including respite), and financial planning. Clients and program staff collaborate to determine the frequency of financial reporting and support plans are reviewed annually. The program is highly individualized and does not capture information related to hours of service received or workers hired.

11. Newfoundland and Labrador

11.1. Self-Managed Home Support Services and Provincial Home Support Services Program

In Newfoundland, professional home care services are delivered by public employees and all non-professional support services are contracted out to the private sector. The self-managed option was established in 1998 to promote independence and choice, to supplement informal supports, and to increase access for people living in remote and rural areas underserved by private home care agencies. The program represented 3,680 clients at the time of data collection. In 2018, the self-managed program served about 40 percent of all home care users (KI-14). People of any age are eligible for the program following clinical assessment. The program is funded by the Department of Health and Community Services with an average monthly funding of $1,500 per client. Funds must be managed by clients and/or their families, which is subsidized based on a sliding scale formula; clients are responsible for the cost of the unsubsidized portion of the services recommended in the care plan. Information from the care plan is shared with clients and service providers in one health region, but in the other three regions clients are told only their approved hours, amount of subsidy, and co-pay responsibilities (Deloitte Inc., 2018). Clients or a substitute decision maker may employ individuals,

purchase services through a provincially approved agency, or a combination. Our key informant suggested that most workers are hired individually because clients often live in locations without agency services but could not provide supporting documentation. There are no educational requirements for workers; the majority of DF workers hold no formal education beyond high school, and 25 percent have less than a high school diploma (Government of Newfoundland and Labrador, 2019).

Subsidies for workers hired directly are deposited into a client bank account and the client may hire a bookkeeper. Payroll information, including worker identities, is submitted to the health authority on a bi-weekly basis. When contracting with a private home care agency, the agency submits a bill to the health authority and the client, subsidies go from the health authority directly to the agency, and remaining charges are the responsibility of the client. Financial audits occur once in the first year and then at the discretion of the health region. Clients or agencies also submit monthly progress reports to the local health authority, which are required to be kept 'on file' by clients, but there is no systematic monitoring of the quality and type of services delivered (KI-14).

Summary of Directly-Funded Programs in Canada

Table 2 summarizes the key features of DF care programs in Canada. Our discussion includes observations about patterns and emerging issues in DF care programs.

Table 2: Summative Overview of DF Care Programs in Canada

| Jurisdiction	Program Name	Type: Respite	Type: Indivualized Funding	Type: Home Care	Inception (Including Pilot Pgms)	Clients	Approximate % of Home Care Users	Age Eligibility	Means-Tested Eligibility	Average Monthly Funding	Who Can Manage Care: User	Who Can Manage Care: Family, Informal Support	Who Can Manage Care: Legal Representative, Other 3rd Party	Hire Agency Workers?	Hire Family Members?
AB	Family Managed Services (PDD)		●		2005	4,500	—	18+		—		●	●	Yes	No
AB	Self-Managed Care			●	1991	1,700	1.4%	None		$3,277	●		●	Yes	No*
BC	Choices for Supports in Independent Living			●	1994	956	2.3%	19+		$7,360	●		●	No	No
BC	Individualized Funding, Community Living BC	●	●		2005	4,068	—	19+		$2,800			●	Yes	No*
CA	Veterans Independence Program			●	1981	90,854	—	None	●	$3,855	●		●	Yes	No*
MB	In the Company of Friends		●		1993	66	—	18+		$9,300	Microboard			No	Yes*
MB	Self and Family Managed Care Program			●	1991	980	2.6%	None		$3,800	●	●		Yes	No*
NB	Long Term Care Services for Seniors	●		●	1978	1,060	20.0%	65+	●	$1,250	●	●		Yes	Yes*
NB	Self-Managed Support Disability Support Program		●		—	90	—	19-64	●	—	●		●	Yes	Yes*
NL	Self-Managed Home Support Services & Provincial Home Support Services Program	●	●	●	1988	3,680	40.0%	15+	●	$1,500	●	●		No	Yes*
NS	Self-Managed Care Program			●	1994	216	0.8%	19+	●	$3,100	●			No	No
NS	Supportive Care	●		●	2008	528	1.9%	65+		$500			●	Yes	Yes
ON	Caregiver Support Project	●			2011	874	—	None		$117	●	●		Yes	Yes
ON	Passport		●		2005	24,000	—	18+		$833	●	●	●	Yes	Yes*
ON	Self-Managed Attendant Services			●	1994	980	0.4%	16+		$4,035	●			No	No
ON	Wesway Family Directed Respite Services	●			1973	327	—	None		$375	●	●		Yes	Yes*
PE	Home Care and/or Disability Support Program		●		2001	1,414	—	64-		$833	●	●	●	Yes	Yes
QC	L'allocation Directe – Chèque Emploi-Service	●		●	<1997	10,219	7.8%	None		$503	●	●	●	Yes	No*
SK	Community Living Self Directed Funding		●		2014	7	—	18+		$6,250			●	Yes	Yes*
SK	Individualized Funding for Home Care			●	2002	154	0.3%	None		$3,959	●	●	●	No	No
A	B	C			D	E	F	G	H	I	J			K	L

No*: No with exceptions   Yes*: Yes with restrictions

Source: Kelly, Jamal, Aubrecht, and Grenier, 2020. The information is presented alphabetically for ease of reference.

Discussion: Policy Issues, Gaps, and Opportunities

There are 20 DF programs across Canada, representing one or more programs per provincial jurisdiction and one federal program for veterans (see Figure 1). The territories do not have DF programs. Some First Nations health authorities may also have DF programs, but were not included as part of this national scan. Except for Newfoundland and Labrador, Quebec, and Prince Edward Island, most provinces have two or more DF programs. Most DF programs across Canada are administered by a government or non-profit organization.
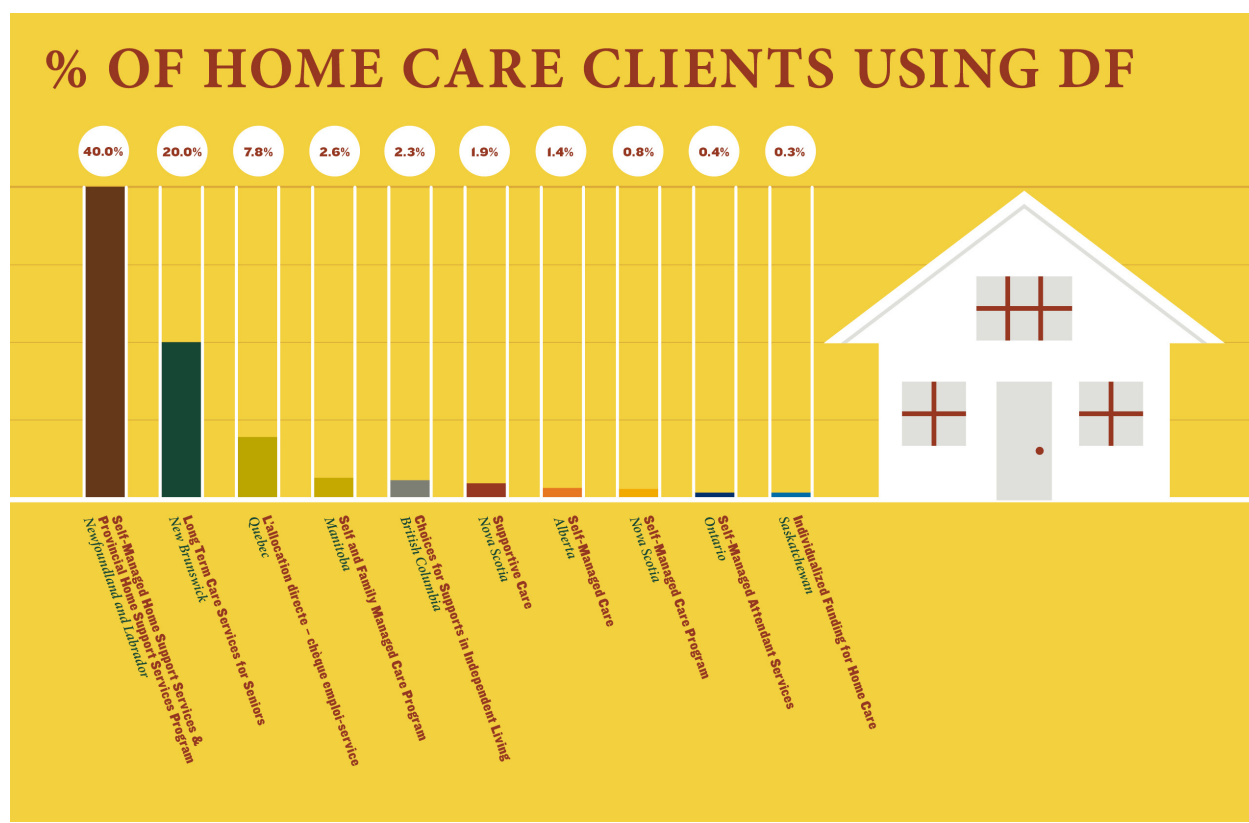
Figure 1: DF Care Programs across Canada
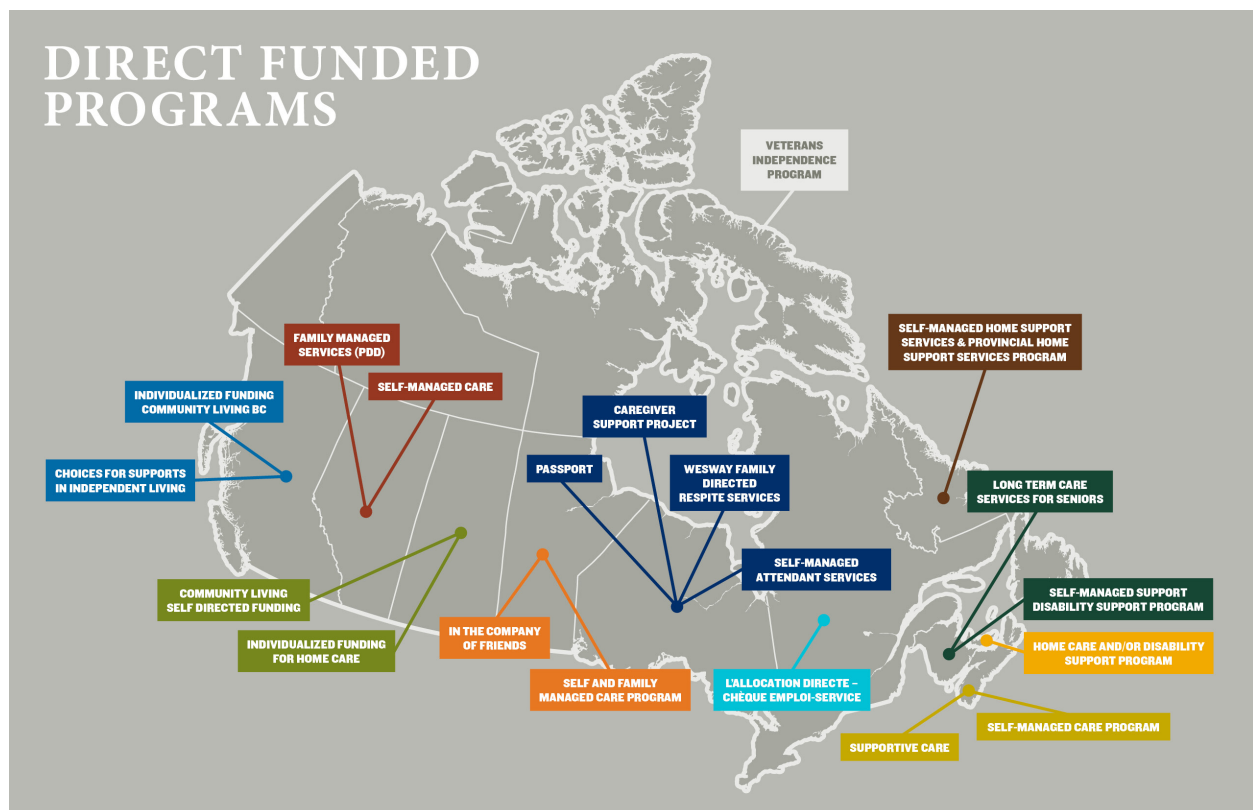
Proportion of Home Care

If we focus on the home care programs, it is noteworthy that DF programs serve less than 10 percent of home care clients in all but two provinces (Newfoundland and Labrador, and New Brunswick). Most DF programs are designed to target specific population groups, and this is reflected by the fact that DF programs serve less than 3 percent of home care clients in seven provinces. In contrast, 40 percent of home care clients in Newfoundland and Labrador are served by DF programs, as are 20 percent of home care clients in New Brunswick, while DF programs serve just under 10 percent of home care clients in Quebec. The program in Newfoundland and Labrador is large in part because it does not target a specific age category, care complexity, or patient-type, but has instead been designed to serve the large rural population in the province.

Figure 2: Proportion of Home Care Clients Using DF

% OF HOME CARE CLIENTS USING DF

| 40.0% | 20.0% | 7.8% | 2.6% | 2.3% | 1.9% | 1.4% | 0.8% | 0.4% | 0.3% |

- **Self-Managed Home Support Services & Provincial Home Support Services Program** — Newfoundland and Labrador
- **Long Term Care Services for Seniors** — New Brunswick
- **L'allocation directe – chèque emploi-service** — Quebec
- **Self and Family Managed Care Program** — Manitoba
- **Choices for Supports in Independent Living** — British Columbia
- **Supportive Care** — Nova Scotia
- **Self-Managed Care** — Alberta
- **Self-Managed Care Program** — Nova Scotia
- **Self-Managed Attendant Services** — Ontario
- **Individualized Funding for Home Care** — Saskatchewan

Family Hire

The majority of DF programs limit, restrict, or completely disallow care managers from hiring immediate family members as a care worker. Three programs allow family hires and seven programs allow only distant family hires (e.g., non-immediate family members, members who do not reside with the client). Five programs allow family hires on a case-by-case basis and five do not allow family members to be hired at all.

Figure 3: DF Care Programs and Hiring a Family Member

CAN FUNDS BE USED TO HIRE FAMILY MEMBERS AS SUPPORT WORKERS?

YES

✓	SUPPORTIVE CARE (NS)
✓	CAREGIVER SUPPORT PROJECT (ON)
✓	HOME CARE AND/OR DISABILITY SUPPORT PROGRAM (PE)

YES WITH RESTRICTIONS

✓	IN THE COMPANY OF FRIENDS (MB)
✓	LONG TERM CARE SERVICES FOR SENIORS (NB)
✓	SELF-MANAGED SUPPORT DISABILITY SUPPORT PROGRAM (NB)
✓	SELF-MANAGED HOME SUPPORT SERVICES & PROVINCIAL HOME SUPPORT SERVICES PROGRAM (NL)
✓	PASSPORT (ON)
✓	WESWAY FAMILY DIRECTED RESPITE SERVICES (ON)
✓	COMMUNITY LIVING SELF DIRECTED FUNDING (SK)

NO

✗	FAMILY MANAGED SERVICES (PDD) (AB)
✗	CHOICES FOR SUPPORTS IN INDEPENDENT LIVING (BC)
✗	SELF-MANAGED CARE PROGRAM (NS)
✗	SELF-MANAGED ATTENDANT SERVICES (ON)
✗	INDIVIDUALIZED FUNDING FOR HOME CARE (SK)

NO WITH EXCEPTIONS

✗	SELF-MANAGED CARE (AB)
✗	INDIVIDUALIZED FUNDING COMMUNITY LIVING BC (BC)
✗	VETERANS INDEPENDENCE PROGRAM (CA)
✗	SELF AND FAMILY MANAGED CARE PROGRAM (MB)
✗	L'ALLOCATION DIRECTE – CHÈQUE EMPLOI-SERVICE (QC)

Use of Home Care Agencies

The majority of DF programs in Canada permit care managers to hire the services of home care agencies (both non-profit and for-profit). As we discuss elsewhere (Kelly et al., 2020), it is not clear whether home care agencies deliver the benefits of DF care. A well cited study in the United States compared DF care (called Cash and Counselling) with agency-provided care, finding that DF care has better social and health outcomes (Carlson et al., 2007). However, these results are not directly transferable to the Canadian context, as many provinces have publicly provided services in addition to an open market approach. Historical and ongoing tensions regarding health system governance and organization, particularly the debate regarding privatization versus publicization, are directly relevant and highly visible within the DF context.

According to the key informants in this study, hiring an agency is often associated with out-of-pocket expenses for the clients and lower wages for the workers. As such, the use of agencies may raise equity issues for people of lower socioeconomic standing who may wish to access the program. Further, in other research led by our team, we found early evidence that increased satisfaction and positive benefits of DF care are associated with directly choosing and perhaps even hiring workers, which may not always be possible in agency settings (Kelly, Dansereau et al., Submitted).

Aside from the issues regarding hiring a private home care agency, the DF labour force is largely understudied, worker issues need to be identified, and already identified issues (such as lack of protections and precarity) should be dealt with more systematically. The policy issues highlight the importance of attending to systemic inequities that shape how funds are used and how services are experienced and managed by clients and their families.

Figure 4: DF Care Programs and Home Care Agencies

CAN FUNDS BE USED TO CONTRACT SERVICES THROUGH HOME CARE AGENCIES?

YES — AGENCIES CAN BE USED

- ✓ FAMILY MANAGED SERVICES (PDD) (AB)
- ✓ SELF-MANAGED CARE (AB)
- ✓ INDIVIDUALIZED FUNDING COMMUNITY LIVING BC (BC)
- ✓ VETERANS INDEPENDENCE PROGRAM (CA)
- ✓ SELF AND FAMILY MANAGED CARE PROGRAM (MB)
- ✓ LONG TERM CARE SERVICES FOR SENIORS (NB)
- ✓ SELF-MANAGED SUPPORT DISABILITY SUPPORT PROGRAM (NB)
- ✓ SUPPORTIVE CARE (NS)
- ✓ CAREGIVER SUPPORT PROJECT (ON)
- ✓ WESWAY FAMILY DIRECTED RESPITE SERVICES (ON)
- ✓ PASSPORT (ON)
- ✓ HOME CARE AND/OR DISABILITY SUPPORT PROGRAM (PE)
- ✓ L'ALLOCATION DIRECTE – CHÈQUE EMPLOI-SERVICE (QC)
- ✓ COMMUNITY LIVING SELF DIRECTED FUNDING (SK)

NO — DIRECT HIRE ONLY

- ✗ CHOICES FOR SUPPORTS IN INDEPENDENT LIVING (BC)
- ✗ IN THE COMPANY OF FRIENDS (MB)
- ✗ SELF-MANAGED HOME SUPPORT SERVICES & PROVINCIAL HOME SUPPORT SERVICES PROGRAM (NL)
- ✗ SELF-MANAGED CARE PROGRAM (NS)
- ✗ SELF-MANAGED ATTENDANT SERVICES (ON)
- ✗ INDIVIDUALIZED FUNDING FOR HOME CARE (SK)

Recommendations

DF care programs will continue to develop and expand in Canada as a policy mechanism that aligns with many social, health, and economic goals to honour people's wishes to age at home, or at least in their communities (Vasunilashorn et al., 2012). Based on our research and research elsewhere, we have seven recommendations for the development and evolution of DF care programs in Canada. These recommendations may need to be adapted to local needs and context.

1. Allow for the hiring of family members who do not co-reside

About 61 percent of older adults with dementia are living at home and require support (Canadian Institute for Health Information, 2020), and this demographic would benefit from receiving support from workers who are consistent and familiar. This recommendation is based on findings from literature in other countries (Ottmann et al., 2009), as well as from key informants in our study, especially from Nova Scotia's Supportive Care Program which is designed to support people living with dementia. It is important to restrict the hiring of co-residing family members to maximize the respite outcomes of DF programs for informal caregivers. It is generally acknowledged that caregiver support is insufficient in Canada, however there are other policy approaches that would better address this gap, such as formal recognition, tax credits, navigation services, assessment of caregiver need and, of course, increased availability of respite programs (Funk et al., 2019; Keefe, 2011; Sinha et al., 2018; Williams et al., 2011). Conversely, allowing for the hiring of family members who do not co-reside is a valuable way to promote holistic person-centred care, and perhaps attract different demographics to work supporting older and disabled people (Kokorelias et al., 2019; Toews, 2016). Specific programs may consider additional restrictions based on closeness of affiliation (e.g. spouse, children) to avoid potential conflicts of interest.

2. Provide more administrative support for family and self-managers

Some programs (QC, NB, AB, for example) have a greater degree of involvement in administering DF through centralized payroll and other supports that reduce the administrative burden of managers organizing DF care. Family managers may be overwhelmed by the additional work of finding and hiring workers and managing finances, and self-managers do not find the payroll and paperwork elements to be particularly empowering (Kelly et al., 2020; Ottmann et al., 2009).

As such, we suggest that payroll services (centralized such as in Quebec, or through the commercial market such as in Alberta) be a requirement of DF programs, and that these external financial services be responsible for financial reporting. Professional financial oversight would ensure that workers are not underpaid, which according to the key informants interviewed for this study was a problem in Quebec prior to the use of the centralized payroll service. Part of the DF budget should be specifically designated to cover administration costs; this already happens in many of the programs although it is unclear whether such funding is always sufficient to cover the full cost of hiring an external payroll company. Further, if possible, in local contexts it may be beneficial for families and clients to have some input regarding the frequency of financial reports, as some families may prefer annual statements and others more regular submissions. We encourage efforts to limit paperwork and make administrative reporting easier, such as a potential mobile app mentioned by the key informant for Ontario's Passport program. Providing more support along with some flexibility in the administrative aspects of DF programs would improve user experiences.

3. Standardize pay for all care workers across continuing care settings in each province

Care workers should be paid the same whether they work in long-term residential care, home care, or DF care programs. We found a broad variation of pay for workers in our study, and it has been established elsewhere that in-home care work is underpaid in comparison to institutional-based work (Benoit & Hallgrimsdottir, 2011; Lilly, 2008). Better pay equity is important for attracting workers to DF care and for supporting increased government investment and resource allocation in the home care sector. Further, setting standardized pay will support clients who choose to use care agencies by helping to ensure the overhead charges and expenses do not reduce the pay of care workers. This recommendation may fit with larger advocacy efforts that aim to establish minimum living-wages in different provincial and territorial contexts.

4. Create a regular check-in and/or reporting procedure where clients and workers can discuss workplace issues, interpersonal concerns, as well as potential abuse and mistreatment

Throughout the study we found very little information on the workers employed through DF programs, especially those who are hired directly by clients. The ability to choose and hire workers is a benefit of DF care programs and should be encouraged; however, we strongly suggest that there is a need of formal avenues to support the vital workers who propel these programs. In a qualitative case study of the Manitoba Self and Family Managed care program, we found that workers may feel forced to accept unfair working conditions based on fear of losing their job or a sense of obligation based on emotional ties (Kelly, Hande et al., Submitted). We suggest a transparent and accessible reporting process for workers to turn to when they feel work

expectations are unfair or exploitative. This would give workers a point person for reporting issues of concern who is separate from the care manager, whose priority is the welfare of the care recipient. Directly hired worker might be contacted directly, privately, and at regular intervals and asked about their working conditions. Such an approach could also include resources if there are gaps in training identified by the client or the worker. The check-ins might happen at the time of hiring and once a year or upon request of the worker. Workers who are hired through an agency could be exempt from this process.

5. Limit needs reassessments

To maximize efficiency and cost-effectiveness and further reduce administrative burden on families and clients, we suggest client needs should only be reassessed if there is a self-identified change in condition and in cases where the client has intellectual disabilities or cognitive impairment including dementia, as a protective measure against negligence. The frequency of reassessment can also be a feature that is established through care planning based on the individual situation. We raise this issue because some younger DF care users, in particular, have very stable needs and may find the repeated reassessments time consuming and unnecessary.

6. Develop tools for family members to assess the quality and appropriateness of home care agencies

Older adults and people living with intellectual disabilities and cognitive impairments such as dementia may be more likely to use family-managed models of care and, further, to contract services through agencies rather than through hiring people directly from their informal networks (Kelly, Dansereau et al., Submitted). Family managers, like unpaid family caregivers in many settings, are often overwhelmed

by care responsibilities and program management (Adelman et al., 2014; Funk et al., 2019; Larkin et al., 2019; McCabe et al., 2016; Wolff et al., 2018). The policies and practices of home care agencies vary widely. As such, we suggest simple user-friendly tools to help family-caregivers choose an agency that suits the needs of their family member based on factors such as rate of pay for workers, ability to schedule workers, ability to choose workers, scope of practice of the worker, and additional fees.

7. Encourage agencies and government service providers to adopt some of the practices that DF clients cite as providing higher satisfaction

As agency use becomes more prevalent in the context of DF, it is important that home care agencies are made aware of the practices and values of DF care that lead to increased satisfaction with services, such as involving clients in their choice of worker, teaching workers about empowerment, giving an option for a shared-language worker, and client/family input into scheduling. Similarly, some of these principles should be considered for home care services delivered through health authorities.

Table 3: Summary of Recommendations

	Recommendation	Who the Recommendation Is For	Anticipated Benefits
1	Allow for the hiring of family members who do not co-reside	• Regional or provincial policy makers • Program administrators	• Better care for people living with cognitive impairments, such as dementia • Diversifying care worker labour force
2	Provide more administrative support for family and self-managers	• Program administrators	• Reduce caregiver strain • Reduce administrative burden for clients and their families • Encourage direct hiring • Improve working conditions
3	Standardize pay for care workers across all continuing care settings in each province	• Provincial policy makers	• Improve working conditions
4	Create a regular check-in and/or reporting procedure where clients and workers can discuss workplace issues, interpersonal concerns, as well as potential abuse and mistreatment	• Program administrators	• Help to monitor working conditions, especially for workers hired directly • Improve working conditions

	Recommendation	Who the Recommendation Is For	Anticipated Benefits
5	Limit client needs reassessments	• Program administrators	• Reduce client administrative burden • Save time and money for the health care system
6	Develop tools for family members to assess the quality and appropriateness of home care agencies	• Regional or provincial policy makers • Academic researchers	• Make agencies more accountable • Help families in choosing an agency that suits their needs
7	Encourage agencies and government service providers to adopt some of the practices that clients cite as providing higher satisfaction with DF care	• Home care agencies • Provincial home care programs	• Increase satisfaction for clients and their families

Areas for Future Research

Our study reveals a number of areas that require future research. There is a need for research that considers the role of agencies in the provision of DF care and home care more broadly. There is also a dearth of research and information on the demographics and experiences of DF care workers, especially those who are hired directly by clients and families. It is essential to uncover who DF care workers are, and if they represent similar or different demographics than those working in other continuing care sectors such as long-term residential care and publicly managed home care programs. We also suggest research that considers if DF care improves rural access to high quality services. Finally, as DF scales up and expands across Canada, it is essential to understand that the positive outcomes of DF programs are less well-established in a broad-based program. There is some evidence that broad-based DF programs may increase inequities on the basis of income and rural location in larger programs and, as such, health equity research related to DF care in Canada is needed (G. Carey et al., 2017; Schmidt, 2017).

Conclusion

DF care will remain an essential component of the continuing care sector in Canada and we encourage efforts to expand and develop programs in nascent settings. We caution, however, that the mechanism itself, providing funds to families and clients to arrange their own services, does not guarantee increased client and worker satisfaction. Indeed, careful planning and attention to issues of equity, access, caregiver burden, abuse, working conditions, and other elements common to all continuing care settings are important to ensure DF care best supports families, clients, and workers.

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Appendices

Appendix 1: Structured Questionnaire

Program statistics

1. How many people does your direct funded/self-managed care program serve?

2. What other home care programs do you offer?

3. How many people are served by the other (non-direct funded) home care programs?

4. What are the demographics of the people served by your [direct funding/self-managed] program in terms of the following factors? Please provide percentages or percentage estimates where available.

   a. age?

   b. gender?

   c. rural vs. urban?

   d. with dementia and/or some form of cognitive impairment?

   e. with legal substitute decision makers?

   f. Is there any other demographic information you have for clients? (e.g. ethnicity, education, income)

Program administration

5. How long has your [direct funded/self-managed] home care program been operating?

6. How is the program administered? (e.g., Through a non-profit organization? Through regional health authorities?)

7. Which ministry funds the program?

8. What is the average total cost of the program per person?

9. How does the cost per person compare to other home care arrangements?

Program eligibility

10. Who is eligible for your [direct funded/self-managed] program? Describe any restrictions on age, disability type or severity?

11. Do you have categories of clients in terms of needs and/or accountability requirements?

12. What is the application process for the program?

13. Does the program user have to be able to self-manage their care?

    a. If yes, what criteria is used to determine their capability?

    b. If no, can another person (friend or family member) manage their care?

Program details

14. What is the maximum number of hours (or funding amount) available to each person?

15. What is the average number of hours (or funding amount) used by each person in the program?

16. What can the funding be used for? Describe the main categories, and any restrictions.

17. Can program users hire family members?

18. What are the user's responsibilities? (e.g., payroll, hiring, training)

19. How often do you reassess clients?

20. How often do users have to complete reports?

Directly-Funded Care Programs in Canada