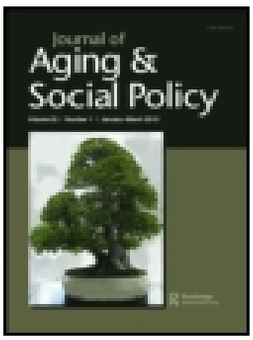

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Emergent Issues in Directly-Funded Care: Canadian Perspectives

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ABSTRACT

Direct Funding (DF) provides individuals with a budget to arrange their own home care instead of receiving publicly arranged services. DF programs have evolved in a number of countries since the 1970s. In Canada, while small-scale DF programs have existed since the early 1970s, the research on these programs remains limited. Responding to gaps identified by an umbrella review and using a health equity framework, this research extends the knowledge base on DF programs from a Canadian perspective through an environmental scan. The research asks: What are the features of DF programs across Canada? What are the emerging issues related to program design and policy development? The study employed a qualitative environmental scan design, gathering data through questionnaires and semi-structured interviews (n = 23). The findings include a summary table describing features of 20 programs and two interview themes: a lack of information on DF workers and concerns about the growing role of home care agencies. This study has the potential to contribute to long-term health equity monitoring research. The findings suggest that as DF expands in Canada, promoting hiring from personal networks may address inequities in rural access to home care services and improve social outcomes for linguistic, cultural, and sexual minorities. However, the findings underscore a need to monitor access to DF programs by people of lower-socioeconomic backgrounds in Canada and discourage policy design that requires independent self-management, which disadvantages people with compromised decision-making capacities.

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Direct funding; consumer-directed care; self-managed care; Canada; home care

Introduction

Direct Funding[1] (DF) provides individuals with a budget to arrange their own home care instead of receiving publicly arranged services. DF programs have existed in multiple countries since the 1970s (Da Roit & Le Bihan, 2010; Ottmann et al., 2009; Ranci et al., 2019). DF programs grained

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significant traction in the 1990s when various parliamentary acts came into force in the UK and the US launched the large scale Cash and Counseling demonstration project (Ottmann et al., 2009). In Canada, while small-scale DF programs have existed since the early 1970s, the research on these programs remains limited. This article is concerned with understanding DF in Canada as a means of contributing to a widening international knowledge base about direct funding home care programs.

This article provides contextual information on DF care programs in Canada followed by an umbrella review (Grant & Booth, 2009) of systematic and synthesis review studies. The study is framed with the concept of health equity and used qualitative environmental scan methods to address two research questions: what are the features of DF programs across Canada, and, what are the emerging issues related to program design and policy development? The findings include a summary table describing features of 20 programs and two interview themes: a lack of information on DF workers, and the growing role of third-party agencies in DF service delivery. The discussion considers potential equity implications related to economic status; ethnic, cultural, and sexual minority identities; rurality; and cognitive impairment.

DF in the context of Canadian home care

Home care is excluded from the Canada Health Act (1985). As such, the national regulations, standards, and universal principles that govern the rest of Canadian health care do not apply to home care. Despite this, home care is funded by ministries of health and governed by health organizations in the provinces and territories, leaving it outside of social service structures. The language of social care is often used by Canadian scholars to situate their work; yet, unlike other countries there is no official "social care" sector in Canada, but rather a complex, fractured system that is not quite health nor social services.

Home care and other care services are under 13 separate provincial and territorial jurisdictions, with some exceptions related to Indigenous populations and veterans. The provincial/territorial governance model results in great variation in terms of eligibility, funding and delivery models in different parts of the country, and this variation is exacerbated outside of urban centers (Canadian Healthcare Association, 2009). Uneven service availability across and within provinces is one of the most pressing issues facing care services in Canada (Canadian Medical Association, 2010).

All provinces extend principles of universal access to the medical aspects of home care; that is, there are no co-payments for services provided at home by medical professionals such as nurses. There are income-tested co-payments for personal care and home support (with maximums) in all provinces except Ontario, Manitoba, and the three northern territories (Canadian Home Care Association, 2013). Eligibility for home care services centers around functional

levels of impairment (often deficit based), using standardized assessment tools such as the Resident Assessment Instrument-Home Care (RAI-HC) tool (Canadian Home Care Association, 2013). All provinces have some degree of publicly-funded home care, in some cases services are even organized and delivered by government providers (e.g., the provinces of Manitoba and Saskatchewan). In the public-provider examples, a large portion of home care workers are government employees and are unionized. In all provinces, there are varying degrees of service provision contracted through third party agencies (both nonprofit and for-profit, all non-governmental) that supplement public home care or form the majority of provision (Canadian Healthcare Association, 2009; Keefe et al., 2011). To further complicate the Canadian landscape, individuals may use personal funds or insurance settlements to contract home care agencies in lieu of or to "top-up" what is provided by the public system.

DF care programs are an anomaly in all provinces, operating *alongside* these systems. DF programs gained more sustained attention in the late 1980s and early 1990s when provinces began experimenting with the model in response to disability and parent advocacy groups who were frustrated with mainstream services. Not all DF programs fall under ministries of health as there are also care services for people with intellectual disabilities largely funded through ministries of social and community services. In Canada, care services are a fragmented system that straddles health and social spheres, and historically struggles for policy attention in a climate that favors primary health care interventions.

Literature on DF home care internationally and in Canada

The growth of the DF policy mechanism has warranted systematic and synthesis reviews of DF studies (FitzGerald Murphy & Kelly, 2019; Low et al., 2011; Manthorpe et al., 2011; Ottmann et al., 2013; Ottmann et al., 2009). As such an *umbrella review* (Grant & Booth, 2009) combined with a thematic qualitative analysis is appropriate. Umbrella reviews are "overarching reviews" that compile "evidence from multiple reviews" (Grant & Booth, 2009, p. 95). The following section outlines the three thematic gaps that emerged from the reviews (See Table 1).

Gap 1: Need to focus on outcomes other than enhanced choice

FitzGerald Murphy and Kelly (2019) conducted a qualitative metasynthesis review of international scholarship on DF from Australia, the United Kingdom, and the US that found this literature overwhelmingly focused on providing "more choice" as a key indicator of program success. While choice may be a desirable outcome for some, it is often overemphasized in studies of DF, and does not always include a consideration of the conditions

Table 1. Qualitative umbrella review.

Source	Time and locations	Number of sources	Review type	Key conclusions	Thematic gaps
FitzGerald Murphy & Kelly (2019)	2009-2017 AU, UK and US	225→47 Includes table of sources	Critical narrative	• Majority of studies on DF focus on choice over specific health and social outcomes • More choice does not mean better care	• Overemphasis on choice
Ottmann et al. (2013)	2013 US and UK	277→17 Includes table of sources	Systematic narrative review	• Some older people express low interest in DF • High levels of satisfaction, but this reporting does not account for ecological factors • Need to consider diverse policy contexts	• Overemphasis on choice • Lack of focus on political contexts
Low et al. (2011)	1994-2009 No exclusions	164→35 Includes table of sources	Systematic review * *of home care, not just DF*	• DF care has lowest quality evidence • DF is linked to increased satisfaction, but has little effect on clinical outcomes • Included studies were conducted in vastly different health and social care systems	• Overemphasis on choice • Lack of focus on political contexts
Manthorpe et al. (2011)	?-2010 UK	161	Review to facilitate DF uptake in Scotland	• Significant agreement about perceived barriers and facilitators to DF uptake • Studies reviewed did not take place in the context of the current recession • "Light touch" DF oversight may enhance risks	• Lack of focus on political contexts
Ottmann et al. (2009)	1992-2008 US, UK & AU	228→41 Includes table of sources	Literature review	• DF programs may not resonate with the preferences of older people • DF linked to increased satisfaction, and similar or better outcomes compared to agency services, • DF programs are cost-neutral	• Overemphasis on choice

needed to support *informed and meaningful choices*. Ethnographer and philosopher Mol (2006) observes how the "logic of choice" in contemporary healthcare settings may undermine practices that lead to positive experiences of care. More choice does not necessarily confer better health and social outcomes and may even place particular social groups at a disadvantage. In the case of older clientele, more "choice" is not necessarily the most valued outcome of using DF home care since it may also involve an increased complexity of system navigation. Ottmann et al. (2009) emphasize that the cash transfer element of DF "may not provide the kind of choice that resonates with the preferences of many older people" (Ottmann et al., 2009, p. 1). As these programs continue to evolve in Canada, it is important to consider other health and social outcomes, such as ability to choose workers, access to specific ethnic foods, and so on, which are elements of DF programs that operate aside from (or perhaps in addition to) enhancing choice. To address this issue, this study focuses on health equity rather than enhanced choice.

Gap 2: Lack of focus on political contexts

The second gap identified by systematic and synthesis reviews on DF home care is that existing studies typically do not focus on specific social, political, and economic contexts. Low et al. (2011, p. 10) comment, "the health and social care systems in which the evaluations [included in the review] were conducted differ significantly – for instance, the UK, Canada and Australia offer universal health and social care […] Successful programs would need to be skillfully adapted for other settings." Another review makes a similar argument: "None of the research scrutinized for this review took place in the context of the current recession," suggesting the results of the evaluation may change in light of shifting economic contexts (Manthorpe et al., 2011). Taking up the call identified in these reviews, this study attends to the shifting policy context in Canada at both provincial and national scales.

Gap 3: Lack of synthesized information on Canadian programs

Most significantly, Canada is excluded from most international literature reviews, scoping reviews, and edited collections exploring DF in multinational contexts. There is existing, but limited, gray literature on individual programs in Canada; in particular, attendant service programs geared at adults with physical disabilities and informed by Independent Living philosophies operating in Ontario and British Columbia (Stainton et al., 2013; Yoshida et al., 2000). In 2006, Health Canada commissioned a national report on self-managed care programs, which describes publicly funded DF programs in Canada based on a literature review, website review, and key

informant interviews (Spalding et al., 2006). As such, there is no current information that is easily accessible on the number, nature, or features of DF programs in Canada; this study directly addresses this gap.

Conceptual framework

This study is framed with the concept of health equity. A health equity approach asks policy makers and researchers to identify and address features of service design and delivery that may result in unequal access and disparate health and social outcomes for different groups of people. Health inequities are experienced by socially and geographically defined groups of people and can be caused by the ways social and health services are organized (Marmot & Allen, 2014). Braveman's (2003) health equity framework advocates for "monitoring" style research, or "repeated study of a question over time" that results in "primarily descriptive" information that can document broad trends when synthesized with other research findings. While this study is not part of a large-scale monitoring project, the use of a health equity lens can contribute to the knowledge base on DF care programs.

There are emerging concerns from other countries that DF home care may exacerbate health inequities when scaled up, and mitigating potential health equities should be considered in program design (Carey et al., 2019, 2017; Schmidt, 2017). DF home care programs may be prone to health inequities due to the emphasis on individual responsibility. Prior to this study, it was known that at least one program in Canada required the client to independently "self-direct" (Kelly, 2016). If there are more programs in Canada that have this requirement, there would be implications for people living with dementia and people with intellectual disabilities, and/or other factors that make it difficult for people to take on the role of self-manager (e.g., social isolation). This is a topic that has been discussed in international literature but has not been considered in Canadian contexts.

As Canada generally operates with principles of universal provision, this study is attuned to potential examples of the "Matthew effect" – that is, when universal systems inadvertently privilege those who are already privileged (Merton, 1968). Specifically, DF home care may exacerbate or perhaps address health inequities related to rurality, may not be as accessible to people of lower socioeconomic backgrounds, and may have impacts on worker health (in comparison to traditional home care settings), but may improve home care experiences for linguistic, cultural, and sexual minorities if clients are able to hire workers of similar or sympathetic backgrounds. This project generates descriptive information related to these elements that may or may not turn into trends over time (Braveman, 2003).

Table 2. 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

Methods

This study employed a qualitative environmental scan similar to the approach of Sciegaj et al. (2016) and Spalding et al. (2006). Environmental scans gather basic descriptive information to help inform decision making (Graham et al., 2008). Kelly and Jamal developed program inclusion criteria (Table 2), and research assistants used what Choo (2001) defines as "basic searching strategies" to identify 20 programs in Canada. After identifying the programs, policy insights were collected through interviews and descriptive information was collected through structured questionnaires.

Interview and structured questionnaire protocol

Key informants are defined as "a select (nonrandom) group of experts who are most knowledgeable of the organization or issue" (Parsons, 2008). In-depth interviews with policy makers result in high quality information on complex issues by drawing on expert knowledge of the policy process (Marshall, 1996). For this study, 1–2 key informants per program (n = 23) were identified by locating contacts listed on program information pages, phoning employee directories, or sending e-mail inquiries. The key informants were directly involved in the policy development and/or administration of the identified program. Four programs had two informants (identified as A and B in quotes), and two programs had the same informant.

There were two research instruments: a structured questionnaire and a semi-structured interview guide. The questionnaire was designed to standardize descriptive information about the programs, including program history, program age, number of clients served, eligibility, and other details. Prior to the interview, research staff emailed a partially-filled questionnaire (based on information found in the public domain) to the key informants to confirm and fill-in missing information. The compiled information was emailed to the participants up to four times for confirmation prior to making it publicly available by way of a webinar presentation. Semi-structured interviews took place over the phone, with the exception of the two local programs. The interviews were 45–90 minutes in duration and were conducted

between August 2017-April 2018. The interview guide explored issues such as hiring family members, program history, and surrounding advocacy or critiques from stakeholder groups. To include the French-speaking province of Quebec, study instruments were professionally translated and French-speaking graduate research assistant collected data in that province.

During the informed consent process, participants were informed of the risk of identification in light of their public roles as key informants. Participants were offered gift cards to acknowledge their contributions; many informants declined because of rules of their employers. The interviews were digitally recorded and transcribed by a professional transcription service using intelligent verbatim style. The study was approved by the Health Research Ethics Board (reference number: HS20640) at the University of Manitoba.

Data analysis

Dedoose qualitative data analysis software was used for the thematic analysis (Bourgeault et al., 2010). The team employed open and axial coding techniques (Miles & Huberman, 1994). Open coding involves reading through transcripts and tagging excerpts into themes, patterns, or discordant comments. The interview guide provided a starting point for identifying key topics, but other themes arose due to the semi-structured nature of the interviews. Axial coding is when researchers make connections, identify relationships, or make "big picture" observations across open codes (Miles & Huberman, 1994). The coding was iterative, with two coders and regular meetings where both open and axial codes were discussed.

Findings

Table 3 contains a summary of all care programs in Canada using DF mechanisms. Nineteen of the 20 programs operate at a provincial level (column A). The programs are categorized as one or more of three types (column C). The first type, home care, involves assistance with the activities of daily living; seven DF programs can be categorized in this way. The second type, individualized funding, refers to help with the activities of daily living *plus* a broader array of activities that support social inclusion (e.g., day programs). Individualized funding programs are geared at people with intellectual disabilities; there are six individualized funding programs. Finally, respite programs are used to relieve a caregiver who is supporting a client; two DF programs are specifically designed for respite. Five programs explicitly fall under more than one category.

Column F highlights the percent of the total home care client population that is served by DF in the jurisdiction of the program; it was only possible to

Table 3. Descriptions of directly funded home care programs in Canada.

		Type			Background & Eligibility						Who Can Manage Care				
Jurisdiction	Program Name	Respite	Indivualized Funding	Home Care	Inception	Number of Clients	Approximate % of Home Care Users	Age Eligibility	Means-Tested Eligibility	Average Monthly Funding	User	Family	Legal Rep or 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		–	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 Disability Support Program		•		–	90	–	19-64	•	–	•		•	Yes	Yes*
NL	Self-Managed Home Support Services &Paid Family Caregiving Option	•	•	•	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		–	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.

provide numbers for home care programs. In most programs, DF represents a minor proportion of all home care clients. Only one program, in the province of Newfoundland and Labrador, serves a substantial proportion (40%) of the client population; New Brunswick's program serves 20% of the client population and all other programs serve less than 10% of home care clients. Two programs require the client to completely self-manage, while the remainder allow for a family member, informal, or formal support person to assist with administration (column J).

Table 3 highlights a core issue that arose in the interviews, to be discussed further; that is, whether clients are permitted to use the funds to hire third party agencies to deliver services or if they can only directly hire individuals in their communities (column K). Fourteen programs allow for agency hires, and six have a direct hire-only rule. Programs have a variety of policies regarding hiring family members (column L). Three programs allow family hires and seven programs only allow distant family hires (e.g., non-immediate family members, members who do not reside with the client). Five programs only allow family hires on a case-by-case basis and five do not allow family members to be hired at all.

Two dominant thematic issues emerged in the interviews: a lack of information on the workers and the increasing role of agency providers in DF home care.

Issue 1: Lack of information on DF workers

Worker issues were discussed frequently in the interviews, yet there is very little to no information available on care workers employed under DF in Canada. Gathering information on care workers has been noted as a problem in other contexts (Saks & Allsop, 2007) and this issue may be exacerbated under DF programs. When asked about the demographics, education, and other information related to workers, there were limited responses, with many key informants clearly saying that they do not collect this information. Example responses include:

> "We don't do any data gathering or analysis in relation to that." (KI01a)

> "It's not something we collect information on." (KI06)

> "I really don't have much information on that, no." (KI07a)

> "We don't collect any of that information." (KI16)

Nineteen of 20 programs did not collect information on workers employed under DF. This lack of information about the workers raises challenges for program evaluation and assessment.

Arm's-length administration

Many key informants explained that the lack of information about workers is a part of the "arms-length" monitoring approach of DF programs. For example:

> Self-management of care is essentially the hallmark of [our program]. It allows individuals independence and fosters independence in terms of decision-making […] It's also good from an administrative point of view obviously, because the department doesn't want to get into a situation of being the employer for care-givers. (KI07b)

The above example most demonstrates the two aims of many DF programs – to enable independence among users while relieving pressure on care systems by limiting government roles. Another example: "we will not pay the [worker directly] because we cannot be seen as being the employer." (K106) and "So we will support in an arm's length way" (K106). Another key informant directly connects the lack of information on workers with not assuming liability:

> In our contracts it is explicitly indicated that those who enter into an agreement are solely responsible for hiring and managing their own staff. So therefore we don't capture any of that information because that's not something we are essentially responsible for. (KI10)

Variability in wages

The key informants discussed concerns about the variability in wages paid to workers. The majority of the programs offer guidelines around wages but do not monitor how much workers are being paid. For example, when asked, "is there a set wage for workers?" a key informant responded:

> The wage is the responsibility of the manager [to determine], so we fund an hourly rate based on a formula that is inclusive of all of the requirements of being an employer […] The manager is then responsible to work within that frame. The actual hourly rate that they pay, they choose to make that decision. (KI16)

Similarly, KI05 states, "It's not policed that people are actually paying the exact rate that they're funded at. But, that's the idea, to stay within those regional rates." Yet, KI06 highlights the tension in this approach:

> [Wages are] really up to the family. […] We try to talk about what going rates are, what minimum wage might be, what they want to consider. We will try to give them some advice. Now, families certainly can stretch their dollar an awful lot. The less you pay somebody, the more you can stretch your money.

Generally, program administrators assess client needs and allocate a dollar amount based on those needs, but after that point, clients can largely do what they want with the funds, within employment and labor rules. Another key informant explains the tension:

> Just because the hourly rate is X they don't need to pay their staff, that they're actually able to pay them less and then take the difference to cover the overhead. Which, as you can imagine, there can be some tension there on the expectation that the majority of the money is going to direct care versus the cost of running a business. (KI11a)

Newfoundland and Labrador, Alberta (Family Managed Services), and Quebec address the issue of wage variability by a more "hands-on" monitoring style. The province of Newfoundland and Labrador pays workers directly (i.e., the client submits a log of hours and the health authority pays the workers), while Quebec and Alberta require clients to use a payroll service. The Direct Allocation program in Quebec has a centralized payroll system (in French, "Centre de traitement du Chèque emploi-service") that was established in response to clients underpaying workers. This payroll system means the province gathers some information on workers. The Laurentian region's Integrated Health and Social Services Center reported that 2,850 DF clients, who fall into a variety of categories from intellectual impairment to palliative care, employ 6,194 workers in this region. While these numbers may not be generalizable to the rest of Quebec or Canada, they may point to an approximate ratio of two workers to every one client – revealing a starting point for conducting further research. Alberta's Family Managed Services requires clients to contract private payroll service companies and therefore information on workers is not centralized.

In summary, key informants report that there is very limited information available on the people employed under DF programs in Canada, in part due to a hands-off approach that protects governments from the liability – one of the advantages of DF as a policy mechanism. Unfortunately, the hands-off nature has the unintended consequence of a variability in wages paid to the workers, something that is a concern to key informants in this study. Three programs – in Newfoundland, Quebec, and Alberta (Family Managed Services) – have taken a more hands-on approach to address the issue of wage variation.

Issue 2: Role of home care agencies

The second major theme that emerged in the interviews is the ambiguous role of home care agencies in the delivery of DF in Canada. In most provinces and other countries, DF programs were initially designed to enable the *direct hire* of care workers, that is, where clients hire someone from their communities or social networks. All programs in Canada allow for this option. Surprisingly, a notable proportion of people currently using DF across Canada are using the funds allocated to them to contract care agencies in order to minimize the administrative requirements, reduce liability and to build in a "safety net" if a worker is sick. Although more research is needed,

this is likely a function of not having a public database of providers, and/or client assumptions that agencies pose lower risks than working with an individual.

In 14 of 20 DF programs in Canada, clients are permitted to use the "direct funds" to contract agency services (column K in Table 3). This variability in policy design is an indication of a lack of consensus across Canada about how DF programs should operate. A key informant helps to summarize this shift in the policy mechanism:

> The program, as much as it's changed from being a self-managed model with the young disabled population to now a self *and* family model with an older population, the shift has also occurred where fewer people are hiring their neighbor or their friend, and more people are using private agencies to be able to fill the care responsibilities of service. (KI16)

Three main concerns arose in the interviews in relation to the use of agencies for DF home care programs: the cost to the client, potential conflicts of interest of agency providers, and if the some of the benefits of the DF model are linked to hiring workers directly from the community.

Cost to the client

To use agencies, clients and their families must often contribute personal funds to the cost of care *in addition to* any required program co-payments, as DF programs will not cover the higher hourly rates or administrative overhead. One informant provides context for this:

> They can hire whomever they want. It is their responsibility. Now we are only able to pay a certain amount, so an hourly rate is 22 CAD an hour and a certain agreement holder [client] wants to hire someone who costs 30 CAD or 40 CAD an hour, that's fine, they can go and pay that difference themselves. (KI10)

One key informant explains that cost is the reason why their program only allows for the use of agencies in emergency situations:

> Individuals can use the funding to purchase from a private organization on the short-term emergency back-up basis. It's really intended for them to hire their own staff. If people are hiring a private organization […] their purchasing power really gets reduced. (KI09)

Issues of cost extend beyond the "per hour" rate charged to clients to specific agency policies that may increase the overall cost to the client, such as minimum call times. On key informant comments on the equity implications of agency-use:

> It can become costly. As a result of that cost, not all folks can then come to the program. Not all folks are going to be able to direct hire because they're not able to find or recruit staff, or they don't have that skillset to do it. At the same time they don't have the financial means to go out and pay an agency and fund that balance.

> At times it can lead to a sense that you need to have means in order to be on the program – that's not the design of the program, but that's an outcome at times because folks are using agencies. (KI16)

Key informants from both programs that allow for agency use and those that do not permit it are concerned about the cost to the client and the potential for uneven access to care based on one's ability to pay above and beyond program co-payments.

Conflicts of interest

Key informants also raised concerns that the third-party agencies may have conflicts of interest in relation to DF programs by promoting the programs for their own financial gain, independent of program goals or client needs. A key informant explains:

> We're seeing problems with that because we haven't taken control of the narrative. And I'll give you an example of what I mean by that, is these private supportive living environments, they're private companies. Many of them have taken it upon themselves to advertise self-managed care on their private websites, and they can describe whatever they want about it. They could provide inaccurate information. (KI10)

Agency advertising of DF becomes especially troubling when knowledge about DF programs may not always be well-communicated by provincial governments and regional health authorities, nor understood by the care coordinators tasked with administering them.

Benefits of direct hire

Numerous comments suggest that hiring workers directly from a client's personal network and local community may be integral for achieving the positive benefits associated with DF care programs. The following quotes indicate that the benefits of DF such as better quality of care, improved rural access and greater flexibility in the tasks workers do are linked to the direct-hire element. One key informant comments, "The benefits [of DF] would be that families can have more flexibility in their services. They can hire the folks that they would like to hire" (KI05). Another key informant explains:

> Those agreement holders, the advantage to them is that they get to hire their own staff. They get to choose who goes into their environment to provide them with care. (KI10)

Another example:

> So the opportunities are for greater consistency in provision of care […] people are able to sometimes hire people who are maybe a next door neighbor or a student in the area that they know, has a good relationship with their loved one or a friend from the church or the local community center that they know. […] When you

> have the same person or the same two or three people coming through your home, you get to know the specifics of the person's environment, their little idiosyncrasies and just the specific things about them. (KI14)

This key informant links worker consistency and selecting workers based on prior relationships as avenues to high quality care. The informant highlights that DF enables a broader scope of practice for care workers who are not limited by agency, government, or union rules, another benefit that echoes through most of the interviews.

Canada's geography includes a number of rural and remote areas and the direct hire element may help meet the needs of rural clients. One example:

> Certainly the advantages are the availability of workers in remote areas, we have a very rural province as you're probably aware and so the workforce retention and recruitment issues are significant. So finding somebody and keeping somebody is often done better through self-managed. (KI04)

The ability to personally select and hire workers is one of the central features that distinguishes DF home care from other forms of service delivery. Some agencies are aware of this benefit and use "matching" processes to ensure workers and clients are well-suited to each other. However, one key informant wonders if the use of agencies inherently reduces the potential of DF, "[The use of agencies] would start being more similar to our current [home care] system" (KI11a), offering more of the same.

In summary, the use of agencies in DF programs raised concerns for the key informants about the potential (and actual) costs to clients, potential conflicts of interest for the agencies, and the concern that the direct hire element of DF may be integral to ensuring the positive benefits of the policy mechanism. Further, it seems to also flag potential issues of equitable access to DF services, in particular for individuals that may have limited financial resources.

Discussion

This study documents variation in DF programs in Canada, but there are some consistent policy features: almost all programs are under provincial jurisdiction, most programs are administered by a government or nonprofit organizations, programs largely serve a niche clientele among home care clients, and the majority of programs do not require the user to independently self-manage. The issues that remain divergent across the country are hiring family members and use of third-party agencies. There are three key policy implications of this study: worker issues need to be identified and dealt with more systematically; DF program design in Canada needs to respond to the expanding client base, which includes more older people than in previous years; and finally, the tensions about agency versus direct hire need to be

addressed. The findings highlight the importance of attending to the systemic inequities that shape how services are utilized, experienced and maintained by clients and their families.

This study found a lack of information about DF home care workers and their needs. There is a lack of information about *who* DF workers are and how this group of workers diverges and/or overlaps with the characteristics of other care workers. Information about workers is simply not collected by most programs, yet worker issues were a key concern raised in the interviews, as well as in international literature (Manthorpe et al., 2011). The structure of programs in Canada suggests that there may be an opportunity to gather information on the workers in the programs that provide administrative assistance or facilitate payroll because these iterations of DF take a slightly more "hands on" approach. Such findings align with the recommendations of Manthorpe et al. (2011), among others, who suggest that the current monitoring approach in the UK is too "light." This study confirms that DF home care workers are an under-researched group.

Attention to demographics of DF workers can help reveal if the claimed intention of cultural, linguistic, and other types of "matching" between worker and client is happening, or if it is only achievable for certain groups of people (San Antonio et al., 2010). It is difficult to discern if DF care workers are receiving the support they need to best carry out their work. It is unlikely that the health and wellbeing *of the workers* is protected in a system that cannot claim liability and typically does not provide benefits or job security. Taking "care" of workers is an essential aspect for ensuring DF programs function, and that clients will receive good care – an issue that requires further research in Canada.

Secondly, although many of the home care DF programs were initially designed for adults with physical disabilities to manage their own care in Canada, the key informants indicate there has been a gradual shift toward family-managed models. Family management enables broader uptake of programs, especially by older people and people with dementia, and should be promoted over an exclusively self-managed model. While many programs currently serve a wider population base (e.g., UK and Australia), the current landscape in Canada, like the US, is far from a scaled-up approach (Sciegaj et al., 2016).

This study revealed a range of practices across the Canadian context. For example, Newfoundland and Labrador were conducting an extensive review at the time of the study. There were concerns about overspending and a lack of accountability, suggesting that frameworks for scaling up are not well established in Canada. Quebec and Newfoundland programs mitigated some of the administrative work of the program, either directly through paying workers or indirectly through requiring the use of payroll services. Indeed, some commentators in the UK have argued that DF works best for people who want to directly hire workers, instead of using agency services,

and who are "confident they have the skills and energy to manage their own support system" (Slasberg & Beresford, 2015, p. 482). As programs across Canada move to offer DF home care to a broader population, it is essential to consider the potential challenges of this approach and the kinds of capacities required of clients to access and benefit from the program.

A broader uptake of DF may not be able to deliver the same increased client satisfaction as a niche form of DF does and may actually generate health inequities. In the US, the evaluation of the Cash and Counseling Demonstration and Evaluation project found people receiving DF had better health outcomes and satisfaction compared to people receiving agency-based care (Carlson et al., 2007). Carlson et al.'s (2007) study implies that agency-based care may have poorer outcomes than a "hire-your-neighbor" approach, although it is not clear if expanding DF to a broader population that includes older people will have the same health and social benefits that are well established among a younger, disabled clientele (Harry et al., 2017). Key informants in this study see the expansion of DF programs in Canada associated with the increasing use of third party agencies, which in turn can cause access issues for those of low socio-economic status and/or limited social capital in the form of available informal support networks. As DF continues to expand in Canada, specific interventions and safeguards will be required to support access for rural clients and those of lower socio-economic status, whether or not they choose to use agencies.

This study demonstrates a tension about whether DF in Canada should be used only for directly hiring people from the community rather than through agency providers. More generally, this study identifies key areas for further inquiry related to the role of third-party agencies in the delivery of DF home care in Canada. This is not to say that agencies cannot deliver on the promises of DF, but rather that social, policy, and perhaps regulatory mechanisms are needed to help clients evaluate the services they are receiving from agencies, limit the cost of these essential services, and ensure equity in service delivery and positive client experiences.

Using agency providers raises a number of health equity questions in terms of access to services, especially for those of low socio-economic status. Not all people who require care will have the means to pay the additional costs associated with agency use. Some key informants described situations where DF is being used to offset costs for individuals who were planning to pay out-of-pocket for services. This is especially true in the case where individuals approach an agency to purchase services privately and then learn about DF options from the agency providers themselves. People of higher socioeconomic status are accessing DF in Canada and are highly satisfied with these programs. What remains to be seen is if the satisfaction is linked to program design or if it is because clients are supplementing their care budgets with personal funds, resulting in adequate hours and high quality care that would otherwise be

unavailable to those who cannot afford to "top-up" public provision. This issue reveals a gap in Canadian health care values (namely public administration and universality) and reiterates how home care continues to be seen as adjacent and supplementary to the medical system.

Limitations

The study has some limitations in terms of confirmability. Some programs develop policy at one level (e.g., provincial), while the daily administration was at the nonprofit or regional level. As there were 1–2 contacts per program, programs with this division could not fully answer some of the questions. Despite multiple opportunities for key informants to validate the compiled information, some of the responses were general (e.g., "we serve 'around' x number of clients"). The number of programs in Canada mean that it is not possible to provide detailed information about each program's eligibility criteria, history, and political history; however, the environmental scan of programs provides an overview of program features to add a Canadian perspective to international literature and a base for further research.

Conclusion

programs remain a growing part of the Canadian home care landscape and must be carefully designed to best serve older people and those who support them. While DF care programs can result in inequities in access to health and social services, they also have the potential to lead to high satisfaction for older and disabled people through thoughtful and contextually specific policy design. This study has the potential to contribute to long-term health equity monitoring research (Braveman, 2003). The findings isolate key areas for further research, namely exploring DF workers and the use of agencies. The findings suggest that as DF expands in Canada, hiring from personal networks may address inequities in rural access to home care services and improve social outcomes for linguistic, cultural, and sexual minorities. However, the findings also underscore a need to monitor access to DF programs by people of lower-socioeconomic backgrounds and discourage policy design that requires independent self-management, which disadvantages people with compromised decision-making capacities.

Notes

1. DF home care is described in different ways across jurisdictions: as self-managed care (Canada); self-directed care (Canada); direct payments (UK); consumer-directed care (Australia, US, although it does not always involve cash transfer); Cash and Cosunseling (US); and cash-for-care (European countries).

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