From disabled activists to older people and their families: Understanding the role of directly-funded home care in Canada

Authors: C.Kelly, L. Dansereau, K. Aubrecht, A. Grenier & A. Williams

From disabled activists to older people and their families

In the late 1980s and early 1990s in Ontario, Canada, echoing actions in other parts of the world, disabled advocates and their allies demanded, developed, piloted, and evaluated a directly-funded (DF) home care program. DF home care is when people receive cash to arrange their own services. It is also referred to as self-managed, self-directed, family-managed care and direct payments. Following other Independent Living advocates, the Ontario group wanted a program designed by disabled people, for disabled people. Independent Living argues that disabled people are the experts in their bodies and know what type of supports they need to lead a full life. Furthermore, existing services were (and continue to be) inadequate for many reasons, including services delivered at inconvenient times, workers refusing to do specific tasks, and care tied to buildings rather than to individuals. The existing services positioned disabled people as passive patients in need of help. Activists, predominately with physical disabilities, insisted "we are not sick" and "we do not need care" (as it is commonly conceptualized) (Kelly, 2016). Through DF home care, they demonstrated their ability to participate actively in all aspects of society. Taking control of their services not only enabled flexibility to receive support when, how and where they needed it, but also sent a cultural message about the role of disabled people in society.

Disability activism has evolved substantially since this time in Canada (Hande, 2018), making gains in accessibility legislation (Beer, 2010), the cultural and arts realms (Kelly & Orsini, 2016), and important work to bridge and interweave with other social justice movements in the form of disability justice (Mingus, 2011; Taylor et al., 2016). Access to attendant care, and in particular an Independent Living personal assistance model (Nishida, 2017), remains a foundational background support that is essential for supporting individuals and activists.

DRAFT

From disabled activists to older people and their families

We introduce our study with this legacy because Independent Living, in one form or another shapes many of the DF program histories in Canada.[1] DF home care, however, has far outgrown its roots as a program predominately geared at people with physical disabilities who have the intellectual and social capital to manage their care. In Canada, only two programs require individuals to actually 'self-manage' (Kelly, Jamal, Aubrecht, & Grenier, Revision requested), and many programs allow the funds to go to home care agencies (rather than a 'hire your neighbor' approach) – a shift that may dramatically alter the outcomes of DF. Older people and their families, including older people with dementia, are increasingly accessing DF forms of home care in Canada.

This paper presents findings from a qualitative case study of the Self and Family Managed care program in the province of Manitoba, Canada. The case study is part of a larger research project that asks: how does DF shape the experiences, working conditions, and policy landscape of Canadian home care, and what are the theoretical implications? In this paper, we document, describe and consider the implications of the shifting the framework from a self-managed program that serves people with physical disabilities, to a more 'mainstream' program that serves a variety of individuals. This axis, from self-to family, disabled activist to older clients, emerged as a cluster of themes from our qualitative study. Below, we situate our study in amid similar international DF studies, present the context of the case study, share the methods, and present four themes– the impetus for getting on the program, demographics of the clients, the use of home care agencies, and ability/interest in administrative responsibility. Taken together, these themes suggest there are two general profiles (with exceptions) using DF in Manitoba: self-managers with physical disabilities, and family-managers with an older family

[1] Ontario is unique for having an Independent Living centre actually administer the program.

member, often with dementia. Beyond a demographic difference, we argue these two profiles use the program in very different ways, and have different outcomes related to their program use.

Literature Review

This study contributes to research on the conceptual, political, and practical implications of extending Independent Living attendant service models to a broader population base. Studies in this area of research emphasize two main concerns, one, if the social and health benefits of Independent Living are sustained under family management, and importantly, if older clients actually have the same goals as younger disabled people.

Askheim et al (2013) conducted a comparative survey study exploring the expansion of DF home care in Norway after the existing program removed the requirement for self-management in 2006. The study found after this change, the program served a more heterogeneous population, with more people with brain injuries, intellectual disabilities and sensory impairments, although 80% of clients still had mobility impairments. The study found the broadening client base reduced the difference between personal assistance and traditional home-based services, although increased satisfaction remained. They found a reduced user influence on the home care arrangement and expressed concerns about how user control can be implemented by family members/guardians. This study helps demonstrate the limitations of applying “user control” as one of the stated goals and mechanisms for satisfaction.

Cramm & Nieboer (2017)’s longitudinal, quantitative study of frail older people living in community settings in the Netherlands found involving community health nurses may improve the self-management abilities and quality of life. While not specifically on DF home care, this study shows that the self-management aspect may be/become onerous for some individuals and

DRAFT

decrease the potential health and social outcomes of DF home care. This study also indirectly demonstrates that self-management is not a predetermined state to be tested, but a skill that can be supported and developed. Even among younger disabled people, recent research outlines the amount of 'work' required to be a self-manager (Katzman & Kinsella, 2018) that includes accepting a degree of risk (Junne & Huber, 2014).

A small qualitative, grey literature study conducted in Scotland found uptake of DF home care by people with dementia and their carers was low and requires additional support to ensure there is an appropriate person to manage the payment when there is no power or attorney or guardianship (Kinnaird & Fearnley, 2010; Petch, 2010).

Brennan et al (2017) conducted a qualitative study in Iceland, Norway and Sweden that that found state commitment to service access as a human right is at odds with decentralized provision of those services. That is, national bodies make commitments to programming autonomously from regional implementation. This study particularly sheds light on issues of unequal access to services among regions, varying interpretations and implementation, lack of civil society engagement at local level, restrictions of liberty of movement, and financial pressures on local governments. Indeed, similar issues are faced in Canada when national and federal bodies make home care commitments that are delivered on a regional basis.

Woolham et al (2016) study directly explores if there are differences in outcomes for people using DF home care over the age of 75 versus younger clients in England. This study represents an important challenge to widespread consensus in research communities that DF home care is better for clients, and to broad policy commitments to expand personalization. The study used questionnaires and found that while older people like the flexibility and control provided by DF, the goal of life transformation and independence is incongruent with their life

DRAFT

stage and goals. The existing scholarship in this area demonstrates the need for research that further unpacks which elements of DF home care policy are crucial for the improved satisfaction and potential health benefits. That is, how crucial is self-management, or receiving funds, or directly hiring attendants from the community? Demographics and life stage may be key to achieving the outcomes. That is DF may work 'best' for some groups (i.e., younger, physically disabled people) and not as well for others. It is thus important to consider the implications of a program that may only be able to serve certain groups of people.

Context

Home care, like most health and social programming falls under provincial jurisdiction in Canada, with some exceptions related to Indigenous communities and veterans. As such, there is great variation in home care, and DF home care, across the country. Our research team conducted an inventory of DF programs across the country, identifying a program in each of the ten provinces and no programs in the territories (Kelly et al., Revision requested). We found that DF home care in Canada is presently a niche policy option in eight of ten provinces serving less than 8% of home care users, with the exception of the province of Newfoundland (~40%) and New Brunswick (~20%). The programs are mostly administered by government or non-profit organizations. The majority of the programs do not require self-management, as the client can have help managing their funds (with the exceptions of Ontario and Nova Scotia). There are two policy features with great divergence across the country –whether or not users can hire family members and if clients must use a 'hire your neighbor' approach or can hire home care agencies.

The case study for this project is located in the province of Manitoba. The Manitoba Self and Family Managed care program started in 1991 and served 980 clients at the time of data collection in 2018. This represents only 2.6% of home care users. The program is administered

by government health authorities and operates alongside a large scale public home care provider. A client or family manager can manage the funds. The funds can be used to hire home care agencies, and approximately 40% of clients do this. Family members can only be hired on an exceptional basis.

(Theory – Independent Living/Disability Studies)

Methods

We conducted a qualitative case study of DF home care in Manitoba following an environmental scan of all DF programs in Canada (see Kelly, Jamal, Aubrecht & Grenier, submitted). The case study has three main sources of data: an online demographic survey of DF workers (n=93), key informant interviews representing various stakeholder groups (n=13, representing 7 stakeholders), and in-depth, semi-structured interviews with workers (15 urban/8 rural), older clients and their families (16 urban/8 rural). Some family managers were supporting more than one person, making a total of 28 older clients included in this study.

Participants were recruited through direct mailouts, radio ads, social media postings, word of mouth and posters. Interviews were conducted in-person as much as possible and were conducted by 1-2 trained research staff. Data was analyzed by two coders using Dedoose software using reiterative thematic analysis. For more in-depth information on the research rationale, instruments, recruitment, analysis, and participant profiles, see Kelly, Hande, Dansereau, Aubrecht, Martin-Matthews, and Williams (submitted). The study was approved by Health Research Ethics Board at the University of Manitoba (reference number: HS20640), the Winnipeg Regional Health Authority (reference number: RAAC 2017-022), and by letters/email of support at the remaining four Regional Health Authorities in Manitoba.

DRAFT

Findings

We have four main themes that help demonstrate the two key profiles using DF home care in Manitoba: the impetus for getting on SFMC, demographics, use of home care agencies, and expertise/interest in administration.

Impetus for getting on SFMC

Self-managers and family-managers had different reasons for getting on DF home care that are characterized in two sub-themes: choice and flexibility, and independence versus avoiding institutional care.

Choice and flexibility

All participants were generally unsatisfied home care services as delivered by the regional health authority, and participants universally prefer the flexibility of arranging personalized services and schedules which allowed clients to receive what all participants believed to be better quality care and support. In addition, the impetus for switching to SFMC was the ability to arrange for a broader scope services. For example, Sarah is an 89 year client who was receiving government supplied home care but needed assistance caring for her pet.

> *Sarah: Well, I was at home care first. And then I have a little dog and when I fell and injured my back I needed someone to walk the dog and it was finding someone, and this firm offered to walk the dog. So I changed from RHA home care to SFMC and this firm that I now use, because they were willing to walk my dog for me.*

DRAFT

From disabled activists to older people and their families

For most, however, the broadened scope of work in the SFMC program allowed workers to attend appointments and social events, act as driver, go shopping, and perform almost any task required in the home.

The ability to choose their own worker was important among all participants regardless of age or management profile. Choice of person means that the client is comfortable with the person providing care, is confident in their skills, and that workers be reliable and willing to do whatever is needed. Some clients had additional individual preferences based on gender, ethnicity, language skills, or having a previously established familiarity. Family managers provided many instances of preference for workers with formal certification, and were much more likely to emphasize the importance of choice based on characteristics such as gender, ethnicity and language fluency.

A few participants overtly enjoyed interacting with people from a variety of ethnicities, as expressed by Lisa, a family manager for her 99-year-old father with mild dementia.

> *Lisa: Oh, yes, there are immigrants, like there are, there's a black worker, there's a couple of our Indigenous people. Younger ones, middle-aged ones and some near retirement and some who have been home care workers, some who have worked in personal care homes. Yes, it's quite a range actually. And actually he finds them interesting.*

The idea that it is interesting to learn about different cultures is echoed by Clarice, a spousal manager for her 75 year old husband with moderate dementia:

> *Clarice: I find other countries and other ways of living interesting, so we talk about that quite a bit.*

DRAFT

From disabled activists to older people and their families

However, the majority of clients had preferences and predispositions for a particular gender or cultural background that made them feel comfortable, particularly with the intimate nature of personal care. While some had no preference, gender was often more important for female clients, particularly older women in the family managed profile who tended to feel nervous around men. In contrast, male clients were also likely to prefer care delivered by women as ‘natural’ caregivers while a only a few preferred care provided by their own gender. A requirement for specific genders is more evident in the family-managed profile than the self-managed profile.

A few of clients were interested cultural matching, or having a worker from a similar cultural background, but this was only evident among clients that themselves come from a minority cultural or ethnic group. The importance of cultural matching is most evident in self-managers and spousal family managers, but weakens when the family manager is an adult child and does not share the same preferences as the client. The following excerpt comes from an older couple in the family-managed profile who, although they live apart, jointly manage his care related to early-stage Parkinson’s, and both participated in the interview. The couple share a somewhat similar culture (she is from the West Indies and he originated from India) and they explain that Samir was uncomfortable with having to accept just ‘anyone’ providing intimate care so they switched to SFMC.

> *Samir: I didn't like it. I didn't like a stranger coming in.*
>
> *Interviewer: Was it a different person every time?*
>
> *Samir: No, it was the same guy … but I wasn't used to somebody seeing me.*
>
> *Anora: Yeah, it's an intimate situation, the shower …We knew a health care aide in my family, and [the SFMC program] accepted him being not Samir’s*

DRAFT

family. And my relative was willing to do it and had a relationship with Samir. So, Samir was comfortable with having somebody he knew here.

Samir preferred someone he already knew, someone who was male, and perhaps it added to his comfort that his care was provided by someone with a similar cultural background

A more overt desire for cultural matching was expressed by Mike, an Indigenous self-manager with a biography that included attending residential schools and experiencing decades of structural and direct racism. He was strongly insistent that it was important to him find workers from within his own culture.

Interviewer: What are the advantages of having the ability to manage for yourself?

Mike: Well, to have my own people employed, like, Aboriginal First Nations culture. The comfort zone, it's supposed to take me back to my healing and who I am.

The importance of cultural matching such as in the above examples appears to be strongly shaped by patterns of historical oppression and the client's own ethnic identity.

In contrast, the reasons for wanting choice of ethnicity among clients from Canada's dominant (white-anglo) culture is firmly based in racism and prejudice, and this pattern was most evident in the family-managed profile. For example, Margaret is a spousal manager organizing care for her husband, both originating from the UK, and she is overt about their cultural preferences:

Margaret: We've actually chosen not to have a certain category of worker, not because we're prejudiced or racist. …There are some significant cultural

DRAFT

> *differences which change the approach to work, the speed of work, the willingness to work in different cultures … I mean for example, if you look at the work ethic, this might sound horrible. It's a reality. If you looked at the work ethic for example of a Filipino girl who was choosing to work in the healthcare field compared to a gal from Ethiopia, you would see a significant difference of how they move, how quickly they catch on, their eagerness to work and yadda yadda. There are significant cultural differences.*

Stereotypes of various ethnicities, both positive and negative, infuse the talk of many of family managers, but for others an important aspect of their ability to choose their own worker was based on communication and language fluency rather than ethnicity or race. For example, Doug explains that his 86 year old mother has dementia and has lost some of her own ability to communicate effectively, and this is only made worse when there is a language barrier.

> *Doug: We've had some healthcare aides that are new Canadians and mom can't understand them. They speak English, of course, they're going through the process, but their accents are a little strong. We had a person like that and we said, "We love you as a person but mom has to understand you."*

A concern about ethnicity involves the recognition that there may be significant cultural differences regarding behavior and normative expectations of how to provide care and support. For example, Craig, whose wife has advanced dementia, enjoys learning new recipes from his workers who are all newcomers to Canada. However, there is a cultural barriers with one of his workers against participating in swimming, which he perceives as valuable exercise and important for his wife's wellbeing. He anticipates the issue may cause scheduling issue in the future.

DRAFT

From disabled activists to older people and their families

> *Craig: One worker comes from a faith community that really does not allow wearing bathing suits, or going to the beach, or being in a public place where you see half-naked people. I mean if I want her to take my wife swimming ….*

This excerpt also intersects with ability for clients within the SFMC program to be supported through a broader scope of services. It is unlikely that Craig's wife would have workers take her out swimming if she were not in the SFMC program.

While female clients were somewhat more likely to prefer female workers, gender was less of an issue than ethnicity. Participants from an historically repressed background themselves were more likely to try to hire workers from their own ethnic background, however, ethnicity otherwise was only an issue among people expressing racism and ethnic stereotypes. Spousal family managers and older clients in general were somewhat more likely to make choices based on prejudice, however, the vast majority of participants were comfortable with multiple ethnicities. Nevertheless, for many the issue of language fluency and capacity to communicate effectively was highly relevant in their choice of worker. Family-managers are much more likely to look for workers with formal training than are self-managers. Above all, the most important thing to both self- and family-managers is the quality of the relationships between the client and the worker.

Independence versus avoiding institutional care

There is a fundamental difference between the two profiles in the reason for accessing home care services. Self-managers tend to have long term (often life long) chronic disability or illness but are otherwise a youthful and productive individual. Family-managers are the spouses or adult children of older adults who are experiencing disability and illness that is resulting a loss of independence and an increasing need for support over time. The home care system actively

encourages younger people to become self-managers. Maureen is a self-manager with Multiple Sclerosis who was on public home care but switched to SFMC over 20 years ago.

> *Maureen: My coordinator urged me to be a self-manager so that's how I started.*

In contrast, the majority of family managers heard about the SFMC program through personal networks, caregiver support groups, or private home care agencies that they were already hiring. It is relatively rare for older clients and their family members to be told about the SFMC program by their home care coordinator.

Among self-managers the impetus for using the SFMC program is to maintain as much independence and autonomy as possible. This means that workers are not always welcome to voice their opinions about what should or should not be done regarding how the client manages their life:

> *Maureen: My first worker that I had, she found the job very challenging. Her previous position had been to be in charge and now here I was telling her what to do so one day she said, that's it, I quit! … and they have to respect my other workers and respect my privacy.*
>
> *Mike: I'm not one to depend on anybody. I'm a veteran. I'm independent. I am strong-willed. You can kill me or point a bullet at me, I ain't going down. I don't care who you are. That's the way I am. Very straight. Very bold. Very strong. And, I hate people that try to butter me up and play games.*

The requirement of autonomy on the part of the person receiving services is far less evident in the family-managed profile, and is almost entirely absent among older clients with dementia. Instead, the goal of family managers is to keep the client in their own home and out of

institutional care, and to maximize care quality and quality of life. Many family managers simply felt it was their duty to do everything they could to avoid having their loved-one be admitted into care home by providing the most personalized (best possible) home care. Right or wrong, many participants held a very dim view of the quality of care provided in residential care settings, as exemplified by Shoshana who, along with her brother is co-manager for their 95-year-old mother with dementia who is living in a retirement residence.

> *Shoshana: [the SFMC program] is a lot of work, but to keep a parent in their home when they want to be in their home, and the home is safe, is just such a superior quality of life … that's where the great saving is with the home care or the family managed, to keep our parents in our home, they're staying healthier because they're not getting pneumonia and they're not picking up the infections that you would get in a group setting.*

Shoshana sees it as her duty to do the best she can to keep her mother out of a care home. Further she believes that it is a cost-savings to the system as a whole. This sense of duty is highest among co-resident family-managers. Co-residency brings on an added nuance to the role of family manager; they not only perform the function of care administrators, they are also full time caregivers. In particular, when the spouse is the care manger, they are also a life partner, connected by social convention, history and strong emotional ties. Prior to entry into the SFMC program, all spousal managers were attempting to provide full care by themselves, and home care was often seen not only as a way of supporting their loved one, but also as a support for themselves.

<u>Demographics</u>

DRAFT

From disabled activists to older people and their families

In our study, there is a distinct demographic difference between the client profiles of self-manager and family-manager. Self-managers are younger, live alone, and draw on relatively limited financial and social (family) resources. Self-managers are equally likely to be male or female. Family-managed clients are typically 75 years or older, may live alone or with the family manager, and the family manager and client are somewhat more likely to be a female. Men and women both manage for their spouses, however it is more likely that a parent will be managed by a daughter than a son. Family managed clients must have social resources (to allow them to rely on someone to act as a family manager) and they also tend to be on the higher end of the socio-economic scale. We found quite a few examples of the client or manager in the family-managed profile paying out-of-pocket for care, purchasing more hours of care than they have been assessed through the SFMC program and/or ‘topping up’ the wages of workers:

> *Shoshanna: As a family we were very pleased just to subsidize the hourly wage to be competitive. It is difficult, so you have to have money to be able to subsidize.*
>
> *Richard: This agency is a business, you know. … They [charge] $26 an hour, I pay for part of it and the program pays for part of it.*
>
> *Deborah: … we supplemented, which we still do with family income, our personal income, to pay the staff*
>
> *John: [The cost of her care] is over the limit of what the SFMC program pays for, so funds are paid from the program and additional funds are paid privately.*

DRAFT

From disabled activists to older people and their families

> *Doug: The home care people at the hospital were not very happy with me taking my dad home early, because they couldn't provide services. And I just said, well too bad. If you can't provide the service I'll buy the service.*

Notably, three-quarters (16 out of 21) of the family-managed participants reported paying out-of-pocket, and the majority of those hired workers through private agencies. In contrast, self-managers do not have access to funds to 'top up' the hourly wage of their workers. (find quote from CU15)

Further, they can struggle with the costs of managing the paperwork of self-management. Maureen is a self-manager who is a disability activist and involved in a disability peer support group and worker training program. Having been a part of the SFMC program for over 20 years, she has a great deal of expert knowledge. In her interview she commented that she and other self-managers have been advocating for an increase in the SFMC administration allowance, which is a fixed amount to cover administration costs related to paperwork, such a photocopying, envelopes, stamps and so on.

> *Maureen: The majority of family managers don't use [the administration allowance]. It's easier for them to pay it from their pocket than to do the record keeping. I'm on a very strict income. I don't have the finances to pay for it.*

Self-managers who cannot afford to 'supplement' have no options. Mike, an Indigenous veteran receiving additional funds through the national veteran's home care program and dealing with a number of complex health issues, believes that he is barely getting by with the hours he had been assessed for support, but does not have the financial capacity to do anything about it.

> *Interviewer: If it was up to you, how many hours do you think you would need to feel better supported that you could keep healing?*

DRAFT

From disabled activists to older people and their families

> *Mike: At least double this. More home care for more days because I find myself struggling by myself. I buried two wives. I buried two brothers. I took on the military in this country and I have a hard time. Mobility issues, walking, trust issues. Everything you would think of, my day is not ordinary. It's not pleasant and it's hard every day to come up with a solution, or at least survive the day … No wonder I can't heal. No wonder I get so angry and, loud because that system is not fair. I can call them racist, 'cause, they're ignorant of how I live and who my people are.*
>
> *…*
>
> *Interviewer: So right now you've got ten hours a week …*
>
> *Mike: That's all I get from the health authority. The rest has to come now in that transition from Veterans Affairs to the health authority. I'm still cut in half and facing an uphill battle in my healing. I used to get $1055 biweekly, now it's $500. It affects my health. It affects my diet. It affects everything in my circle and it pisses me off.*

The frequency of 'topping up' suggests both a gap in the program model as well as an advantage for those of higher socio economic background.

<u>Agency vs 'hire your neighbour'</u>

Historically, DF home care advocates for a 'hire your neighbour' approach where workers with or without any formal training are hired from local communities and networks. There is an option in the Manitoba program (but not in all programs in Canada) to use the funds to hire non-profit or for-profit home care agencies, which operate alongside public home care provision. The self-managers are not interested in hiring care through private agencies.

DRAFT

From disabled activists to older people and their families

> *Mike: make sure you interview and, recommend and get the right employees with the right training behind them. One good person like that, is going to make a lot of difference in the care of the subject, you know. I think, that's where I didn't have a pull for somebody to come to me with. These agencies are like, they're not… (pause) Interviewer: That's not the way to go?*
>
> *Mike: No*

Family managers are far more apt to hire an agency, or combine agency workers with direct hire workers, than to act solely as direct employers. One of the issues for family managers is simply finding and hiring people, and this issue is often cited as the reason for working with a private agency.

> *Miriam: You know there's a limit to my capacity to reach out and just find other people like that on a one-by-one-by-one basis*
>
> *Mary-Anne: I say to people you know you don't have to hire your own people, you just have to hire the agency and they hire the people.*

While some managers hire people through on-line classifieds, others prefer to find workers through social networks and word of mouth, and some rely on the social networks of their workers.

Self-managers are far more likely to express an interest in training their own worker. If they are interested in hiring people with formal training they look for people with a PACE certificate rather than a care aide certificate. PACE (Personal Attendant Community Education) is training provided through a non-profit disability agency (ILRC) for disability support workers. One of our participants acted as a community educator for the PACE program, and found most of her workers that way. (Get quote from CU15)

DRAFT

From disabled activists to older people and their families

Family managers impetus to hire agencies relates to the theme discussed later regarding expertise and interest and expertise.

> *Olivia: If you're hiring family or a friend across the street, that's when it does get, I'm sure, get complicated. But with a company like this, they pay all the benefits and they look after all of that. So all I have to do is report back on the money that I've spent.*

In many ways, the use of home care agencies relieves and prevents administrative burden on the clients and family members. It is important to note however, that the use of agencies is not without a cost. Agency workers are typically paid less than directly-hired workers, and families do not have a way of evaluating which agencies are 'better' than others.

Agencies cater to the preferences (prejudices) of clients in ways that the public system does not.,

Clients can ask for "only women" or "no gay people" or "only Christians" or whatever criteria they may want, and private agencies will cater to their wishes. The public system tries to be cooperative toward personal preferences in care, such as sending only women when requested, however there are limits to how selective people can be within the public system as there are labour laws that address discrimination based on gender, sexuality, religion or race. The private system allows people to be far more selective, and far more discriminating.

In Winnipeg, the Filipino community has a strong presence in front-line care, and at least one private agency is exclusively staffed by people from the Philippines. This over-representation may be partially explained by ethnic stereotypes that privilege the Philippines as a caring and kind culture that values hard work, as expressed by Marianne who manages care for her 91 year old mother:

DRAFT

From disabled activists to older people and their families

> *Marianne: Personally I'd only ever hire Filipinos.*
>
> *Interviewer: Alright, you feel like they have a better kind of caring ethic?*
>
> *Respondent: Yeah, and their work ethic is just insane.*

For other family managers, people from the Philippines are not only ‘wonderful’, some are also highly trained and hold professional certifications. For example, Steven, a spousal manager for his wife with dementia explains that he prefers Filipino staff, and doesn’t mind turnover and new workers as long as they are formally educated. Foreign credentials such as these are not recognized in Canada, however the credentials signify to Steven that the worker holds experience and skill that he can trust.

> *Steven: Interestingly I've said to my contact at the care agency, I said I don’t care who you send just make sure they're Filipino.*
>
> *Interviewer: Oh, you prefer they're Filipino?*
>
> *Steven: Oh, they're just wonderful people. Anyway, so okay so they send me somebody else. And it can be a trained nurse in the Philippines that hasn’t got the certification recognized here and, you know, so they've got all kinds of experience. There was even one who was a doctor from the Philippines. There was one that came a couple of weeks ago and she was teaching nursing over in the Philippines and now she's doing some homecare work here … you know, they have experience, they're warm-hearted, they are good communicators.*

Steven’s excerpt also exemplifies our finding that family managers are far more likely to prefer workers with formal education than are self-managers. Indeed, several indicated that all of their workers were required to have at minimum a health care aide certificate.

DRAFT

From disabled activists to older people and their families

Care managers who hire people directly appear to be more interested in experience and personality. Family managers look for ‘caring’ people who are patient, tolerant and compassionate, while self-managers look for people that will do as they are asked without arguing. For example, Guy, a spousal family manager caring for his wife, looks for

> *Guy: we don’t need a very specialized training person, we don’t need someone with four years of university for example to fulfill the job requirement. It could be a person with a high school education … I do advertise that I would like somebody with caregiver experience, that would at least weed out the people that don’t have I guess the character to work in a role like that, like patience or whatever.*
>
> *Miriam: Well they have to tolerate, I don't know, grumpiness. They have to tolerate that, you know …your filters kind of get a little less. You feel free to speak your mind as you age.*
>
> *Doug: When I hire healthcare aides, I look for ladies with children … I think they have patience. You know how a child can be petulant? Mom can be petulant. And if they’re dealing with their own kids, then they can deal with mom.*

Self-manager

> *Interviewer: When you're looking out for new workers, are there certain things that you're looking for that are really important to you that they have skills or characteristics?*
>
> *Maureen: They have to be crazy like me.*

Expertise and interest in administration and management

DRAFT

From disabled activists to older people and their families

In general, family managers are less experienced at 'managing' care; in our sample family managers had a median of 2 years of experience as a care manager, in contrast to self-managers with a median of 15 years of experience. Family managers are more likely to hire agencies, as noted in the previous theme, because they are less willing, or less able, to do the extra work required to act as a direct employers.

There are difficulties and challenges inherent in acting as an employer, however those that directly hire have often decided that "the benefits outweigh the problems". Maureen, a self-manager, describes some of issues of employing workers directly related to having to hire, fire, coordinate schedules, arrange for back-up workers and so on.

> *Maureen: I had problems along the way. I've had people I've had to fire. It's always difficult. And then people phone in sick so I always had to find someone else and things like that. But the benefits outweigh the problems.*

Experienced self-managers complain less about the paperwork required by the RHA to receive SFMC funds, but tend to grumble more than family-managers about the paperwork required by the CRA, particularly regarding disability tax credits.

Those who directly hire may have their employees conduct administrative tasks. Family-managers or self-managers may use staff to train other employees, while family managers are more likely use staff for help with scheduling, and self-managers are more likely to have staff help with paperwork such as payroll, taxes and so on.

> *Deborah (family manager caring for her 82 year old mother with dementia): My regular fulltime girl has sort of risen to sort of supervisor role and she lays*

out the schedule and then I do the payroll from the schedule. And she's the one that's helped me get all the staff.

DRAFT

Table 1. Age, gender and relationship of self- and family-managers and clients

	Self Managers	Family Managers	Family-managed clients
Interviews (N=24)	3	21	25 [a]
Interview participants	3	20 [b]	7 [c]
Age range	59-79	---	68-102
Gender	Female 2 Male 1	Female 14 Male 7	Female 17 Male 8
Relationship	self		17 parent 7 spouse/partner 1 other family

a. Four family managers were caring for two people, either both parents or a spouse and a parent
b. One interview was with the client not the family manager
c. Four interviews included the family manager and client, one the family manager and two clients, and one the client but not the family manager

Table 2. Self-managed and family-managed care profiles

	Client as self-manager	**Client with family manager**
Living arrangement	Typically living independently	Client co-resident with family manager, living in a retirement residence, or living independently
Life-stage	Client any age, typically younger, single and with no children	Client aged 70 and older, typically married or widowed with adult children
Relationship between client and care manager	Self	Typically adult child or spouse, occasionally friend or other family member
Managing for how many	Self (one person)	One or more; such as both parents, may act as manager concurrently or serially
Resource level	Any, but more likely to be moderate or lower income (on disability support for example)	Any, but more likely to be affluent and/or well-educated
Geography	Typically urban	Any
Health stability	Relatively stable (homeostasis)	Trajectory of increasing need and repeated hospitalization

DRAFT

From disabled activists to older people and their families

Expertise in managerial position	Exceptionally high expertise with many years of experience in role	Expertise widely variable, typically months to a few years experience in role
Manager having other priorities	Low to moderate	Moderate to many, including work, self-care, and responsibility for other family members (such as children or grandchildren)
Stress related to managerial position	Low to moderate	Moderate to high
Hiring mechanism	Direct – hire your neighbour	Direct or agency hire
Impetus for accessing program	Independence and autonomy	Choice, quality of life and avoiding institutionalization

DRAFT

Discussion

Our findings emphasize the shifting frame of DF, which began by serving younger adult self-managers but increasingly works with family-managers in the service of older adults. The stories of workers and users portray DF home care as favorable in contrast to regular home care. In rural settings, the DF model appears to work well for users with strong community ties that enable them to hire their own workers.

Systems and health authorities need to recognize that there are important differences between the populations. We suggest that SMC and FMC could be differentiated rather than lumped together. Both family-managers and self-managers would benefit from additional support with the initial learning curve of care management and administration, understanding that the turnaround for family-managers is much higher than for self-managers. Rather than supporting individuals with gaining skills in administration, an option could be to create a formal body that connects workers with care managers, or that acts like an employment resource.

From disabled activists to older people and their families

Because of the strong involvement between family managers and private care agencies, we recommend much greater degree of oversight of the private industry through regulation and licensing, as well as means for formal referrals from home care assessors at the health authority.

Conclusion

We suggest Canadian DF home care functions well as a niche program that operates alongside public home care. DF policy should protect the independence of younger disabled users, but must also provide support for family carers, and consider greater oversight of DF workers.

DRAFT

References

Askheim, O. P., Andersen, J., Guldvik, I., & Johansen, V. (2013). Personal assistance: what happens to the arrangement when the number of users increases and new user groups are included? *Disability & Society, 28*(3), 353-366. doi:10.1080/09687599.2012.710013

Beer, C. (2010). *Charting a path forward: Report of the independent review of the Accessibility for Ontarians with Disabilities Act, 2005* Retrieved from http://www.mcss.gov.on.ca/en/mcss/publications/accessibility/charles_beer/tableOfContents.aspx

Brennan, C., Rice, J., Traustadóttir, R., & Anderberg, P. (2017). How can states ensure access to personal assistance when service delivery is decentralized? A multi-level analysis of Iceland, Norway and Sweden. *Scandinavian Journal of Disability Research, 19*(4), 334-346. doi:10.1080/15017419.2016.1261737

Cramm, J. M., & Nieboer, A. P. (2017). Self-management abilities and quality of life among frail community-dwelling individuals: the role of community nurses in the Netherlands. *Health & Social Care in the Community, 25*(2), 394-401. doi:10.1111/hsc.12318

Hande, M. J. (2018). Disability consciousness on the frontlines of urban struggle. *Antipode, 0*(0), 1-21.

Junne, J., & Huber, C. (2014). The risk of users' choice: exploring the case of direct payments in German social care. *Health, Risk & Society, 16*(7/8), 631-648. doi:10.1080/13698575.2014.973836

Katzman, E. R., & Kinsella, E. A. (2018). 'It's like having another job': The invisible work of self-managing attendant services. *Disability & Society*, 1-24. doi:10.1080/09687599.2018.1497949

Kelly, C. (2016). *Disability politics and care: The challenge of direct funding*. Vancouver, BC: UBC Press.

Kelly, C., Jamal, A., Aubrecht, K., & Grenier, A. (Revision requested). Canadian trends in direct funded home care. *Journal of aging & social policy*.

Kelly, C., & Orsini, M. (Eds.). (2016). *Mobilizing metaphor: Art, culture and disability activism in Canada*. Vancouver, BC: UBC Press.

Kinnaird, L., & Fearnley, K. (2010). *Let's get personal - personalisation and dementia*. Retrieved from Edinburgh, Scotland: https://www.alzscot.org/assets/0000/1820/Lets-get-personal.pdf

Mingus, M. (2011). Changing the Framework: Disability Justice. Retrieved from https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/

DRAFT

Nishida, A. (2017). Relating through differences: disability, affective relationality, and the U.S. public healthcare assemblage. *Subjectivity, 10*, 89-103. doi:10.1057/s41286-016-0018-2

Petch, A. (2010). Direct payments for people with dementia. *Community Care*(1833), 32-33.

Taylor, S., Hall, M., Lehman, J., Liebert, R., Nishida, A., & Stewart, J. (2016). Krips, cops and occupy: Reflections from Oscar Grant Plaza. In P. Block, D. Kasnitz, A. Nishida, & N. Pollard (Eds.), *Occupying disability: Critical approaches to community, justice and decolonizing disability* (pp. 15-30). New York: Springer.

Woolham, J., Daly, G., Sparks, T., Ritters, K., & Steils, N. (2016). Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment. *Ageing and Society, 37*(5), 961-984. doi:10.1017/S0144686X15001531

DRAFT