Direct Funding and the Depoliticization of Home Care Systems: Popular Rhetoric and Policy Directions in Ontario

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Abstract

Home care systems have undergone major transformation in the last twenty years, manifesting as a volatile series of policy changes in Ontario, Canada. This includes increasing attention to direct funding (DF) home care where individuals receive cash transfers to arrange their own services. Through a textual analysis of 101 media and grey literature sources about DF home care in Ontario published between 2011 and 2018, we find three interrelated, yet sometimes conflicting, discourses in public circulation. DF is represented as: (1) a 'fix' to the challenges of mainstream home care; (2) a form of marketization; and (3) as social transformation. We argue that these discourses reflect a neoliberal policy climate that depoliticizes and instrumentalizes DF in ways that obscure how continual policy adjustments actually contribute to frustrating experiences with home care. The contradictory claims about DF home care in the public domain often untether DF from its social justice history and from the careful implementation needed for it to be an empowering and equitable home care model. We suggest that DF home care should not be approached primarily as an individual fix to systemic problems with home care nor as a strategy for cost saving. Rather, DF should be one component of a broad spectrum of social care policies that fully acknowledge both the social justice history of the program and the complex interdependencies of home care users, workers and informal caregivers.

Keywords: aging; Canada; disability; self-managed care

Résumé

Les systèmes de soins à domicile ont connu une importante transformation au cours des vingt dernières années, engendrant une série de changements politiques en Ontario (Canada), dont une attention croissante au financement direct (FD) des soins à domicile où les individus reçoivent des fonds pour gérer leurs propres services. En analysant 101 textes des médias et de la littérature grise au sujet du FD des soins à domicile, nous trouvons trois discours en libre circulation qui sont étroitement liés mais parfois contradictoires. Le FD est présenté comme étant (1) une « solution » aux défis que posent les soins à domiciles traditionnels, (2) une forme de marchéisation et (3) une transformation sociale. Nous soutenons que ces discours sont le reflet d'un milieu politique néo-libérale qui dépolitise et instrumentalise le FD de manière à masquer la façon dont l'ajustement continu des politiques concourt réellement aux expériences frustrantes liées aux soins à domicile. Les affirmations contradictoires au sujet du FD des soins à domicile du domaine public détachent souvent le FD de son histoire de justice sociale et de la mise en œuvre minutieuse nécessaire pour qu'il devienne un modèle de soins à domicile responsabilisant et équitable. Nous proposons que le FD des soins à domicile ne soit pas abordé comme une solution individuelle aux problèmes systémiques liés aux soins à domicile ou comme une stratégie visant à réduire les coûts, mais plutôt comme faisant partie d'un large éventail de politiques d'assistance sociale qui reconnaît pleinement l'histoire de justice sociale du programme ainsi que l'interdépendance complexe entre les usagers des soins à domiciles, les travailleurs et les aidants naturels.

Mots clés: vieillissement; Canada; invalidité; soins autogérés

Introduction

Canadian home care systems are often described as being "in crisis" in light of aging populations, escalating waitlists, increasing health care spending, and shortages of health care workers which have intensified in recent years, particularly during the current pandemic. Users and workers experience home care as fragmented, inadequate and inconsistent. While there is widespread recognition that significant change is necessary, home care system transformation has been ungainly over the last twenty years—characterized in Ontario by a volatile series of policy adjustments related to care workers and service delivery. These changes include increasing attention to direct funding (DF) home care, a relatively niche home care model where individuals receive cash transfers to arrange their own services.[1] In many contexts, DF as a policy mechanism is linked to improved autonomy and increased satisfaction with services (Low, Yap, & Brodaty, 2011). Yet, it is also an example of neoliberal downshifting of care from state provision to individual health management and contributes to precarious forms of care work through creating casual positions without security or benefits – and these challenges must be carefully considered as this approach to home care continues to expand.

Through a textual analysis of 101 media and grey literature sources about DF home care in Ontario published between 2011 and 2018, we find three interrelated, yet sometimes conflicting, discourses in public circulation. DF is represented as: (1) a 'fix' or important alternative to mainstream home care; (2) a form of marketization; and (3) a mechanism for broad social transformation. We argue that these competing discourses reflect a neoliberal policy climate that depoliticizes and instrumentalizes DF in ways that obscure how continual policy adjustments contribute to frustrating experiences with home care. Through contradictory claims in the public domain, DF home care is often untethered from its social justice history and from the careful implementation needed for it to be an empowering and equitable home care model. We suggest that DF home care should not be approached primarily as an individual fix to systemic problems with home care nor as a strategy for cost saving. Rather, DF should be one component of a broad spectrum of social care policies that fully acknowledge both the social justice history of the program and the complex interdependencies of home care users, workers and informal caregivers. We discuss the three discursive themes in more detail after providing a review of Ontario's home care and DF context, our theoretical framework (neoliberal policy making) and our research methods. We discuss how these themes reflect how DF policy for older people is depoliticized by neoliberalism and austerity as well as the potential for "repoliticizing" DF as part of more fundamental home care transformations that are rooted in the history of independent living activism.

Home Care and Direct Funding in Ontario

In Canada, most health and social services are organized and delivered on a provincial and territorial basis. There is "not one single health care system in Canada, but multiple systems, one for each province and territory" (England, Eakin, Gastaldo, & McKeever, 2007, p. 176).

Under the *Canada Health Act*, provinces and territories are not obligated to provide publicly funded home care. As such, each jurisdiction has its own history and approach to home care provision. Ontario introduced publicly funded home care in 1970. Since this time, Ontario has had a storied history of home care policy, with successive governments making and unmaking far-reaching policy decisions. One of the most notable decisions was the introduction of Community Care Access Centres (CCACs) by the Conservative government in 1997 (England et al., 2007). CCACs were introduced to expand home care provision and minimize bureaucracy and administrative costs by introducing "managed competition" where home care providers competed for government contracts to deliver services. According to England et al. (2007), this change followed the logic of neoliberal restructuring by introducing policy interventions from other global north countries. This increased private service delivery and, ironically, government intervention in the form of financial auditing and top-down bureaucratic management. Following a scathing report released by the Auditor General of Ontario in 2015, the CCACs were dismantled due to high administrative costs (Auditor General of Ontario, 2015). Local Health Integration Networks (LHINs) then took over the responsibilities of the CCACs, though it is not yet clear if the LHINs have corrected the failings of the CCACs. A draft of a new health bill in early 2019 indicated that the Ford government may replace the LHIN model with a central provincial agency (Crawley & Boisvert, 2019). Similar policy doings and undoings in the realm of personal support workers, including decisions related to regulation, monitoring, education and wages, also characterize the home care policy climate in Ontario (Kelly & Bourgeault, 2015a, 2015b). This volatility has often created a sense of general confusion and pessimism about home care policy reform in the public domain.

What we term "mainstream" home care in Ontario is currently coordinated by government agencies (e.g., LHINs) and is delivered by a complex patchwork of public and private agencies that match care workers with home care users. Amid this landscape, DF is a niche, publicly funded home care option that operates *alongside* "mainstream" home care. DF was introduced in Ontario in 1994. The Self-Managed Attendant Services program is administered by the publicly funded non-profit organization the Centre for Independent Living Toronto. In 2018, 980 people received DF through the Centre for Independent Living Toronto (Kelly, Hande, Dansereau, Martin-Matthews, & Williams, 2020) compared to the 560,000 total who received home care in Ontario (Purbhoo & Dhalla, 2017). This particular DF program is generally intended for people with physical disabilities. While some may enter old age while on the program long term, it is not targeted at older people. The DF model emerged from politicized legacies of disability activism, namely the Independent Living and Community Living movements (Kelly & FitzGerald Murphy, 2018) which challenge ableism, emphasize choice, and facilitate empowerment through control of services and social inclusion (Centre for Independent Living in Toronto, n.d.). The Centre for Independent Living Toronto has carefully built and expanded their services over the past 25 years and DF users are often passionate advocates of the program because of its potential to reformulate more just relations of care and to better meet the needs of disabled people (Kelly, 2016; Yoshida, Willi, Parker, & Locker, 2004). However,

unions, which represent approximately 25% of Ontario's mainstream home care workers (Canadian Union of Public Employees Ontario, 2016) have been highly critical of the growth of DF, suggesting that it is a form of privatization. At times, this has created tensions between organized labour and disability rights activists (Cranford, 2005).

DF policy in Ontario has undergone a number of shifts since the program's inception. Following the launch of a pilot in 1994 and an official program in 1998, Self-Managed Attendant Services expanded its client base twice due to funding injections in 2011 and 2014. In 2011, government administration of the program was transferred from the ill-fated CCACs to the LHINs (Centre for Independent Living in Toronto, n.d.). In 2014, after years of advocacy from a number of sectors, the Ontario government announced immediate plans for a new DF program targeted at older people. This option never materialized. Similarly, in 2017, a public agency was briefly introduced to organize a dramatic expansion of DF in Ontario. This agency was dissolved less than a year later and replaced with a DF program called Family-Managed Home Care that serves specific client cohorts and, notably, is not geared towards older people. The new Family-Managed Program includes four eligible client groups: "children with complex medical needs; adults with acquired brain injuries (ABI); eligible home-schooled children; [and] clients in extraordinary circumstances" (Ministry of Health and Long-Term Care, 2018; North East Local Health Integration Network, n.d.)

Theoretical Context: Neoliberal Policy Making

The Ontario home care policy landscape has been shaped by the logics of neoliberalism and austerity that have been deepening in most welfare states in the global north since the 1990s (Bezanson and Luxton, 2006). The characteristics and impacts of neoliberalization have been discussed extensively by care theorists. In 2002, Mary Daly noted a social care policy trend in European welfare states of creating a "care mix" that include partnerships with the private sector (Daly, 2002, p. 260). Care theorist Olena Hankivsky (2004) noted how increasingly globalized economies have challenged Canada's ability to develop effective federal policies and led to a trend of the state downloading care provision onto provinces, non-profits, and private agencies which were already dealing with dwindling resources.

These neoliberal trends have had profound effects on social care policy for both older and disabled people. Researchers have argued that neoliberalism reinforces ageist (Hastings and Rogowski, 2015) and ableist (Goodley, Lawthom, & Runswick-Cole, 2014) ideologies in social care policy in the UK. According to Hoppania (2018), neoliberalism also makes social care policy less democratic. Analyzing the advanced neoliberalization of care policies for older people in Finland, Hoppania (2018) argues that:

> Neoliberalism happens covertly, and mostly outside of the traditional democratic arenas and the remit of elected politicians. It takes the form of restructuring the parameters within which any and all social policy is shaped, so that the neoliberal models emerge as the only possible and feasible ways to respond to the situation of care for older people, and other issues. (p. 7)

With this lens one might trace how popular discourse around DF and home care policies more generally have become increasingly and intentionally *depoliticized*. This is not to say that DF policy mechanisms are no longer political, but rather that the politics of DF are narrowed (Hoppania, 2018) and relocated (Standring, 2018). Wood and Flinders (2014) refine the concept of depoliticization by identifying three key forms—governmental, societal, and discursive. In the case of DF, we are witnessing an example of all three forms. Governmental depoliticization involves transferring state services to arm's-length or technocratic bodies. The brief decision to delegate DF home care provision to a central public agency typified governmental depoliticization. Societal depoliticization involves social issues being transferred from the public to the private sphere, focusing on "the existence of choice, capacity deliberation and the shift toward individualized responses to collective social challenge" (Wood & Flinders, 2014, p. 165). Over the last 30 years, DF discourse has shifted from its explicit connection to Independent Living philosophies and history, to an emphasis on cost savings, efficiencies and competitive management that has enabled DF to gain and maintain traction in the public domain. Discursive depoliticization involves issues being transferred "from the private realm to the 'realm of necessity'" (Wood & Flinders, 2014, p. 165). Discourses of crisis accelerate these types of shifts (Standring, 2018). Similarly, recent shifts towards DF expansion are often accompanied by references to crises of health care spending and Canada's aging population. Yet, numerous political theorists (Standring, 2018; Wood & Flinders, 2014) have noted that these crises are not inevitable or natural but rather socially and politically constructed. Discourses of crisis are thus important frames through which austere "small government" policy directions appear as necessary responses to exogenous phenomena rather than being internally related to a state's changing political economy. Moreover, these discursive frames often render explicit political challenges and alternatives to these policy directions unfeasible or outside of their scope.

The depoliticization of home care models and approaches thus significantly narrows the scope of changing policy even as new policy interventions give the impression that something significant is being done to address "the crisis of home care". Hoppania (2018) also notes that policy making in the late neoliberal period is often characterized by drawn out policy development (sometimes involving widespread public consultations) that creates the "illusion of consensus" (Wood & Flinders, 2014, p. 162) but ultimately does not address the core challenges of unsatisfactory home care conditions, worker retention, scarce public resources and inequalities in care relations. Depoliticization has also narrowed the perceived possibilities for alternative models for home care in Canada and foreclosed many opportunities for building solidarity between home care workers, users and unpaid caregivers. We explore some strategies of repoliticization to counter these DF policy making trends in our conclusion.

We now turn to a review of our research methods and our analysis of popular media discourse around DF policy shifts in relation to extending home care for older people in Ontario.

Methods

As part of a larger project on DF home care in Canada, we examined discourses surrounding DF home care in Ontario through a textual analysis of material found in the public domain. According to Alan McKee, "Textual analysis is a way for researchers to gather information about how other human beings make sense of the world" (2003, p. 1). By exploring themes in textual sources, researchers can not only discern patterns in what people talk about and how they talk about it but can also glean the interpretations that most likely rest behind the texts. In the context of Ontario, textual analysis can help us trace patterns in government policies and rhetoric as well as public response, all of which can give us clues to the social and political dynamics surrounding social care policies in general and DF specifically.

Jason Bainbridge outlines a number of tools for conducting textual analysis, including classifying texts as "open" or "closed." Open texts are intended to have multiple meanings as in the case of a complex poem, novel or other creative work. Closed texts use certain techniques such as captions, commentary, metaphor, and metonymy to "limit space for the reader to generate a variety of interpretations" (2011, p. 228). The authors of closed texts provide clues to how they would like the content to be interpreted. The sources in our analysis can be largely considered closed texts in that they are meant to be read and interpreted in specific ways.

However, Murphy and Dingwall argue that all texts are "the *product* of people's work. They are never literal descriptions of reality" (2003, p. 74, emphasis in original). Thus, our analysis also sought to identify implicit meanings that rest below the surface. The latter element distinguishes our analysis as a "discourse analysis," where texts are analyzed for "how language is used to accomplish personal, social, and political projects" (Starks & Brown Trinidad, 2007, p. 1372). To explore implicit meanings, we sought to identify "structured absences" (that which conveys meaning because it has been left out) (Bainbridge, 2011, p. 230). For example, the perspectives of older people are often absent in articles about DF home care. We also looked for exnomination which occurs when dominant ideas become so obvious they seem like common sense (Bainbridge, 2011, p. 230). For example, based on the sources we collected it becomes an unquestioned fact that home care is in crisis. Close attention to the context of texts also enabled the discovery of implicit meaning.

The data for this study was drawn from 101 news media and grey literature sources referring to DF in Ontario published online between January 2011 and March 2018. This time span was chosen in response to an announcement in the 2014 provincial budget that the government would develop a more widely available DF home care option. We elected to include media and grey literature sources in order to gauge public perceptions of DF during this time period. Jamal performed date-limited web searches using combinations of the following search terms: home care, direct funding, self-directed care, self-managed care, individualized funding, attendant services, personal support worker, senior, older adult, CCAC, LHIN and Ontario. Jamal manually searched reference lists of sources for additional material. Eighty-eight sources were initially imported into EndNote. Sources included press releases, online news articles,

discussion papers, and government documents (see Table 1). Jamal used NVivo 11 to perform initial open coding and created the first draft of a codebook, then refined the coding structure and reviewed all coded materials to confirm that the refined codes still fit the data. Coded excerpts were exported from NVivo into Microsoft Word and Hande and Jamal reviewed the excerpts to look for themes, in consultation with Kelly. All authors met on a regular basis to discuss analysis. Hande later performed an updated web search, finding and coding 13 additional sources.

Table 1
Summary of Sources

Text/author type	**Number of sources**	**Examples**
Ontario government	36	Annual budgets, press releases, websites, reports
Media pieces	24	Articles
Disability and other organisations engaged in advocacy	18	Reports, pre-budget submissions, websites
Home care service providers	10	Blog posts, websites, press releases
Individuals	5	Blog posts, discussion forum posts
Unions	4	Press releases
Educational institutions	2	Conference programs
Legal organisations	2	Reports on legal issues related to DF
Total number of sources	**101**	

Findings

Between 2011-2018, DF home care drew attention from community groups, policy makers, unions, insurance companies, and private home care agencies. The number of public domain sources we found per year referring to DF in Ontario rose from three in 2011 to 25 in 2015, dropped to nine in 2017 and was on the rise again in 2018. The texts included in our analysis framed DF in three main ways: as a fix to the existing challenges of mainstream home care; as marketization; and as social transformation. We discuss each of these framings in turn, drawing on our sources to demonstrate who is interested in this policy debate and how they position DF in relation to pressing social and political issues.

DF as a 'fix' to the challenges of mainstream home care

Mainstream public home care systems are widely criticized for failing to provide meaningful quality support. Research finds that DF is widely preferred by users than is mainstream home care (Ottmann, Allen, & Feldman, 2013), as it provides control over scheduling, choice over workers, and a more flexible scope of duties for the workers. Consequently, demand for DF home care alternatives, with their promise of independence,

flexibility, "choice" and "control", has been recently growing across Canada. Policy makers and community groups who authored texts in our analysis assert that the DF model might "fix" home care by offering an alternative for those who struggle with the limitations of mainstream service delivery. According to these sources, the "fix" requires restructuring current policies to increase access to DF, for example by increasing funding, improving program advertising, and revising assessment processes to fully capture the needs and wants of users. DF is also proposed as a fix to chronic challenges such as the comparatively limited scope of duties and inflexibility of mainstream home care workers, dwindling public resources for a growing demand for home care provision, and relatedly, informal caregiver burnout.

Our analysis found that the most common arguments for expanding or enhancing DF relate to the limits of control and independence (26 sources) and flexibility (15 sources) in the mainstream home care system. Journalist Laurie Monsebraaten recounts several clients' accounts of the unique benefits of DF; most importantly, she found that instead of relying on home care agencies to select and schedule workers, DF users can hire their own workers to do tasks they decide are important, thereby "put[ting] people with disabilities in the driver's seat". The flexibility of DF means that "there are 'no agency policies and procedures to interfere with the assistance you need or how it happens…. [attendants] can take you to appointments, help you get your mail, use the phone, organize your files, whatever your daily needs might be'" (Monsebraaten, 2016). Flexibility also means that users can hire workers who share or respect their cultural practices or marginalized identities instead of being assigned workers. Users say that, unlike mainstream home care, the flexibility of DF better enables them to work, pay taxes and thus "give back to society" (Lea, 2015; Van Brenk, 2014).

DF may be particularly important for rural clients as home care agencies do not operate in all communities, forcing some people who require assistance to move into long-term care facilities that are often far away from family and communities (Sinha, 2012). DF is also framed as a way to enhance the relationship between home care users and their informal caregivers and as a fix for caregiver burnout. Similar to mainstream home care, when clients remain in their communities it is easier for informal caregivers to be better integrated into an individual's care plan (23 sources) and DF allows family caregivers to get reliable "breaks" when they need them. DF allows home care users to maintain their own caregiving roles (3 sources), preventing the institutionalization of users' parents or apprehension of their children (Monsebraaten, 2016).

Many of the sources we analyzed were authored by young disability activists and advocates since, historically, DF is more often used by younger disabled people than by those in the older age group. However, DF is increasingly being framed as a "fix" for Canada's aging population. For example, advocates like Gail Acton, director of a non-profit home care agency, note that DF is an essential mechanism for responding to "changing societal norms regarding seniors' expectations to live and age independently in their homes" (Acton, n.d., p. 27).

A number of Ontario government, non-profit and media sources also describe DF as a potential fix for an overstretched home care system. These sources position DF as a way of

easing the administrative and financial burden of mainstream home care models on the state. Home care is universally acknowledged as more cost efficient than facility-based long-term care and this reiterated by a number of our sources. For example, a community advocacy group notes:

> Inappropriate settings [e.g., nursing homes] are a substantial drain on the health care system. By investing in more appropriate, community-based supports, patient flow pressures are eased, resulting in short-term cost savings. The better health outcomes for consumers to attendant services results in substantial savings over the longer-term. (Ontario Attendant Services Advisory Committee, 2013, p. 3)

In a media release announcing the expansion of DF in Ontario, Deb Matthews, then Minister of Health and Long-Term Care, explains that DF brings mutually beneficial goals of health spending efficiencies and client choice:

> Many people with disabilities want to manage their own care because it provides them with greater choice. Direct funding also results in better value for our health dollars, because it relieves pressure on our health care system and frees up resources to provide care for others. (Ministry of Health and Long-Term Care, 2014)

Calls to better maximize the value of health dollars or stretch government funding are widespread among our sources, particularly in response to the general consensus that models such as the CCACs (discussed above) are largely inefficient and costly. Gail Acton recommends drastically minimizing government spending by cutting administrative funding in favour of unpaid administrators (DF clients and their families), thereby maximizing results and increasing the value of public health dollars:

> Bureaucracy, administrative costs, overpaid consultants, and duplication and mismanagement of services have gobbled up 80% of every dollar spent, leaving only 20% of the dollars available to the user of home care, hospitals, clinics, community care and nursing homes. The goals of the provincial party in power must be to reverse the 80/20 rule of government spending, and put 80% of home health care dollars into the hands of the consumers of service. (Acton, n.d., p. 2)

Interestingly, although international research suggests that DF programs are cost-neutral in comparison to mainstream home care (Ottmann, Laragy, & Haddon, 2009; Slasberg, Beresford, & Schofield, 2012; Stainton, Asgarova, & Feduck, 2013) and that an increase in DF does not correspond with fewer stays in long-term care (Chappell, Dlitt, Hollander, Miller, & McWilliam, 2004), public domain sources consistently assert that DF saves money.[2] Ontario government reports also suggest that DF is key to helping "stretch" public funding by drawing more heavily on unpaid community and family supports. DF seems to fit in well with broader health policy strategies of "Creating incentives to encourage more people to volunteer their time and services as unpaid caregivers (for example, facilitating the use of high school students as volunteers, encouraging corporate caregiver support programs)" (Donner et al., 2015, p. 30), thereby reducing strain on the mainstream home care system.

DF as marketization

Historically, DF has garnered support from across the political spectrum, drawing on distinct narratives of individual empowerment and a "cost cutting" rationale. However, our public domain scan revealed that, increasingly, advocates for disabled and older people are joined by private interests in demanding DF as a mainstream solution that follows a private market, rather than a public welfare, logic of service delivery. Media articles calling for DF expansion make frequent references to crises or daunting projections of elevated home care costs (Donner et al., 2015) and aging populations (Blomqvist & Busby, 2014). Public-private mixes or "multi-pronged" home care solutions, which have reportedly worked in other countries, are often proposed as remedies for reducing government spending by forging more partnerships between informal caregivers and public and private sector home care services (Blomqvist & Busby, 2014, n.p.; 2015). Åke Blomqvist and Colin Busby, both affiliates of the C.D. Howe Institute[3], are the most vocal proponents of these approaches. In a 2014 *National Post* article they present data suggesting that the public cost of long-term care services will triple in the next 40 years to $71 billion CAD. The government, they say, simply cannot "shoulder the burden" alone. Instead, they would like to see Canada model its long-term and home care solutions along the lines of France's "unique public-private long-term care financing structure" (Blomqvist & Busby, 2014) which would incorporate graduated DF based on income while allowing private insurance companies to supplement public cash benefits.

The expansion of DF is linked to rhetoric around the opportunity for private home care agencies, consultants, companions, and other navigation services to fill so called emerging consumer markets for individualized care services. Though DF users in Ontario are currently not permitted to use their public funding to contract private agencies, both the private and non-profit home care sectors have been growing since the 1990s and stand to benefit from relaxed restrictions on how this funding can be used. Companies like AlayaCare are shaping public discussion around increased demand for DF by advancing market strategies like deregulated variable pricing and developing software platforms to help agencies administer user budgets and optimize worker routes (Schauer, 2017). Our public domain scan discovered that organized labour was highly critical of these policy framings and market strategies. Two of the three main unions that represent a significant proportion of health and home care workers in Ontario argued that efforts to expand DF beyond the relatively niche group of current users is a form of marketization. Canadian Union of Public Employees (CUPE) Ontario has suggested that DF is a form of "contracting out" public sector work, with deleterious effects on both users and workers. In response to the development of the Passport Program, a form of direct funding for people with developmental disabilities, the Ontario Public Service Employees Union (OPSEU) president worried that DF would marketize essential services and open "vulnerable people" to exploitation by allowing private agencies to skim profits from public funding (National Union of Public and General Employees, 2015). Union representatives have voiced concerns that the visions of individualizing and minimizing state interference inherent in DF do not address problems of social inequality or ensure more equitable access to care. Heather Duff, a unionized CCAC

worker, states: "This will compromise care quality, lead to a further erosion of the home care system and put the burden on already stressed families to find, interview and hire their own care. Essentially they would become employers" (Canadian Union of Public Employees Ontario, 2015). Moreover, union advocates argue that DF takes the onus off government to expand social services, safety nets and programming. CUPE Ontario argues that Ontario's home care system needs to be changed, but attempts to mainstream DF are "the wrong approach to system change." Instead, CUPE Ontario has called on "the province to improve home and community care by creating a unified and public home care system, ending contracting out and improving care quality by stabilising the workforce through more full time personal support worker positions" (Canadian Union of Public Employees Ontario, 2015).

These competing discourses reflect the contradictions of DF expansions and point towards desires for broader changes to Ontario's home care systems. Our next section examines how DF is discussed as integral to visions of and proposals for systemic change.

DF as system transformation

Recent calls for home care "overhauls" and large scale "system transformations" have left some policy makers and advocacy groups considering DF as more than a fix or one part of a "multi-pronged solution," but rather as a key feature of a new vision for home care funding and delivery. The transformative dimensions of DF were mentioned in many of the source texts we examined.

A formative evaluation of a DF program for informal caregivers describes DF as a transformative model not only for home care users and workers but also for caregivers. It warns that implementing DF on a large scale will require "[pushing] beyond conventional thinking and action" (Williams, Peckham, Rudoler, Tam, & Watkins, 2013, p. v). DF's capacity to shift care relations between users and workers is frequently highlighted in public domain sources. One news piece on DF asserts that the direct employer-employee relationship means that users and workers "respect each other and care about each other more" (Monsebraaten, 2016), which can result in longer term commitments from workers (Lea, 2015), something that is much sought after in a sector where turnover is high. The Law Commission of Ontario has underscored the transformative capacities of DF for people with multiple disabilities and echoed users by saying that DF "has the capacity to fundamentally transform the relationship between users and providers of attendant services, increasing the respect with which the attendant services users are treated, and providing an additional safeguard against abuse" (2012, p. 148). Other texts emphasize that DF can give "power back to people who should have had that power in the first place" (Deb Matthews, quoted in Meyer, 2014) and that it reflects "good societies [that] include everyone and respect choice" (Everyday Ordinary Lives Group, 2012, p. 1).

Despite the promises of DF-related solutions, the value of "mainstreaming" – where DF is offered to all or a significant proportion of home care users – is up for debate. International DF scholars (for example, Slasberg, Beresford, & Schofield, 2014) have argued that DF will always be a niche solution, with benefits only experienced by clients with very specific profiles. In

Canada, the Law Commission of Ontario cautions that DF only works for people who "choose" or "desire" it. They admit that for many individuals "agency-sourced attendant services will better meet their needs" (2011, p. 145). Nevertheless, DF mainstreaming appears to be well underway in other neoliberal countries in the global north, such as the United Kingdom. In Ontario, advocates and policy makers have been suggesting that many more people can take advantage of DF than are currently doing so. Commenting on a small expansion (of 300 people) of the Self-Managed Attendant Services program in 2014, former program manager Leisa DeBono commented: "There are more than 700 people doing it across the province. It can't be that hard" (Migneault, 2014).

This 2014 expansion was extremely modest compared to numbers recently proposed. In October 2017, the Ontario government suddenly announced the creation of a new public agency called Self-Directed Personal Support Services Ontario (SDPSSO) with a mandate to provide DF home care for people requiring more than 14 hours of care per week. SDPSSO was proposed to help recruit, screen and employ personal support workers (PSWs), who would likely be unionized through SEIU (Crawley, 2017; Picard, 2018). SDPSSO would work with Ontario's Local Health Integration Networks to "receive client referrals and follow the plan of service; manage client intake and match with PSWs; and [facilitate] client scheduling of services" (Ontario Society of Occupational Therapists, n.d.).

Underscoring the volatility of home care policy in Ontario, the SDPSSO plan did not survive a change in provincial governance in 2018. Nevertheless, during its short implementation from late 2017 to early 2018, there was a flurry of news media about the agency. Home care users and providers were alarmed about the secrecy and rapid roll out of the new program (Picard, 2018). A lawsuit was launched by home care provider organizations (Crawley, 2018). Leaked government documents revealed that the SDPSSO was projected to provide up to 40% of home care services by 2021 (Picard, 2018). This suggests that, whether feasible or not, DF was imagined as a mainstream model. Although this dramatic solution apparently took home care providers by surprise, the steady increase in mentions of the positive potential of DF in Ontario government texts (Ministry of Health and Long Term Care, 2015a, 2015b, 2017; Select Committee on Developmental Services, 2014) as well as in the 2014 announcement about a new DF program for older people suggests that this move had been in the works for several years.

Media reports and details of the lawsuit suggest that the crown agency was developed in collaboration with SEIU which has unionized many DF workers in the United States (Dansereau, Hande, & Kelly, 2019). A 2016 public consultation submission by SEIU explains that the union's lobby for self-directed care in Ontario began in 2012 and that "for a self-directed care model to be sustainable and scalable it must consider impacts on the system, clients and the workforce" (SEIU Healthcare, 2016). SDPSSO thus appears to be a union compromise, a way of ensuring that workers will be regulated and unionized and that there will be a centralized, bureaucratic umbrella for home care.

This central employer, bureaucratic model had many home care users and providers concerned. Journalist Bob Hepburn described the polarized response to SDPSSO as follows:

> Proponents of the new agency say it is the best system for high-needs patients who are hardly in a position to go shopping for a personal support worker and for the workers themselves, who now often toil with part-time hours, split shifts and low pay. Critics are outraged, though, claiming [the Ontario government] is merely creating a costly government bureaucracy that duplicates work now performed both by for-profit companies and non-profit agencies. (Hepburn, 2017)

This critical response from home care users and providers is unsurprising given that they were not consulted about the proposed changes, despite the significant impact the changes would have on their day-to-day home care experiences.

Another journalist, André Picard, noted that each new policy "fix", like SDPSSO, "seems to make a bad situation even worse. It's time to let the good providers we have innovate and expand, not to burden patients with more red tape and shackles" (Picard, 2018). Picard's comment perhaps emphasizes the weariness and pessimism Ontarians feel about policy shifts that promise sweeping changes yet never address underlying structural problems or last long enough to be properly assessed. For many, the rapid creation and dissolution of SDPSSO no doubt exacerbates this weariness. Despite the SDPSSO's many opponents, Ontario's new DF policy directions do not seem to provide improved alternatives and continue to leave the growing demands and needs of older people unaddressed (Dansereau, Hande, & Kelly, 2019). Without developing effective structural challenges to the neoliberal status quo, meaningful collaboration with independent living experts, and a commitment to the more transformative independent living philosophy more generally, these efforts for DF as system transformation fall considerably short of their desired goals.

Discussion and Conclusion

Amidst these calls for system fixes, marketization and social transformation, we find DF conceptualized as instrumental, to varying degrees, to home care reforms. However, the relations between public discourses and home care policy shifts reflect many of the patterns of late neoliberal policy making (Bezanson & Luxton, 2006; Hoppania, 2018), including (1) rapid policy changes and transfers without meaningful public engagement or careful implementation and (2) depoliticizing policy change and social transformation in ways that significantly limit public perceptions of what DF can and cannot do. We noted the repeated framing of "crisis" in our sources as a means of discursive depoliticization to mobilize scarce public resources in an austere political economic climate. Yet, we argue, perpetually describing home care populations and their presumed needs as an impending crisis can obfuscate the ways in which continual policy adjustments themselves contribute to a sense of volatility and confusion. Public demands for lasting system transformation—from across the political spectrum—have been met with a relatively rapid succession of fleeting policy fixes. The trend of fixes seems to coincide with the expansion of DF at the same time as the creation of the CCACs. Creating a new DF program for

older people was another recent attempt at expansion, although the program did not materialize despite public interest. This volatility has made it difficult to adequately assess the advantages and disadvantages of new policies and social care arrangements. Heated, yet often contradictory, public demands for DF and home care transformation sometimes result in innovative, yet poorly planned, compromises to try to appeal to austere budget restrictions, popular demands for user choice and control and improved conditions for workers. The brief introduction of SDPSSO is an important example. Yet the public domain commentary reflected a lack of public consultation that raises questions about whether such an agency could have actually materialized as planned or accomplished its stated goals.

Amidst Ontario's rapid policy fixes and competing public discourses around home care system change, fundamental challenges in Ontario's home care landscape—such as eliminating lengthy waitlists, recruiting and retaining workers, and ensuring stable, adequate resources for home care—are depoliticized and as such remain largely unexplored within the public domain and inadequately addressed in the policy documents we reviewed. For instance, position papers discussing the expansion of DF options for older people in Ontario have correctly identified caregiver support as a key priority for users. Informal caregivers rarely receive financial compensation for their work (Chappell et al., 2004) and paid care workers continue to be a highly racialized and feminized workforce that receive the lowest pay out of all health care workers (Panagiotoglou, Fancey, Keefe, & Martin-Matthews, 2017; Rolf, 2016). While many of the texts we reviewed touted the benefits of DF home care for caregivers and workers, there is little evidence that significant new funds are being allocated to much needed supports like caregiver tax breaks or for benefits, higher wages and better working conditions for workers. The interdependent nature of care and the collective interests of workers, caregivers, and home care users remains largely outside public discussion and the policy process. For example, despite the central role that the Centre for Independent Living currently plays in the coordination and delivery of DF, our search uncovered only a couple of their authored documents, suggesting that they have become marginalized from such public policy debates. We note, however, that our inclusion/exclusion criteria prevented us from conducting a more extensive review of the Centre for Independent Living's archives documents related to this debate. While not the focus of our analysis, including such materials in our analysis might have revealed further tensions in Ontario's DF policy environment.

Hoppania argues that the participatory and democratic channels through which these pressing issues might be worked out are stifled and weakened by top down neoliberal restructuring. She explains:

> Currently, the hegemonic discourse around the governance of care frames [limited democratic channels] as givens, in such a way that it becomes very difficult to argue for any substantial, let alone transformative changes in the way care responsibilities and resources are distributed. This is a discourse which invokes bureaucratic logic and

> "apolitical" "musts" to avert criticism and sideline democratic decision making on these substantive questions. (2018, p. 16)

Despite the fact that DF has drawn support from across the political spectrum, the proposed DF fixes to the home care crisis and related marketization strategies are hardly value neutral. Most of the recommendations, policies and practices reviewed here call for dramatically shifting the responsibility of caregiving, system navigation, and administration onto individuals, families and private sector companies – a clear example of the societal depoliticization identified by Wood and Flinders (2014). We also note the restricted, instrumentalist narratives of DF in the public domain. It is almost imperative for DF advocates to frame the model in terms of cost savings or as a policy mechanism that can be transplanted into different social/political contexts rather than in terms of care models that require years of careful implementation, community control, stable funding, and commitments to social justice principles of self-determination and complex interdependencies. While the SDPSSO presented a challenge to the neoliberal status quo by providing more governmental oversight and protections for workers, this proposed restructuring represents more a depoliticized "fix" than a transformative solution called for by many home care users (see Dansereau, Hande, & Kelly, 2019 for further analysis). Specifically, SEIU's support of SDPSSO reproduces an economistic, as opposed to a political, approach to home care delivery, exemplifying what Wood and Flinders (2014) call governmental depoliticization. These competing discourses suggest a kind of "ideational drift" (Schmidt, 2011) where DF policy directions are contested terrain for subsuming community driven demands for self-directed care under a larger process of neoliberal health care restructuring in Canada.

While austerity and neoliberal restructuring often appear as the only option, possibilities remain for contesting and repoliticizing (Wood & Flinders, 2014) DF and home care policy making more generally, even if they are obscured in the popular discourse. This repoliticizing may be key for larger political transformations. Elsewhere, we have argued that DF care models must be continually interrogated and linked into community-based social justice movements to avoid co-optation (Hande & Kelly, 2015). Slasberg and Beresford (2015) and Sánchez Criado et al. (2016), discussing European examples, have both offered ways of "building on the strengths" of DF's social movement history to demand more than the status quo. Slasberg and Beresford (2015) have proposed that personal budgets, a form of DF home care in the United Kingdom, could be optimized if they were based on accurate assessments of the holistic needs of users rather than available resources and budgetary restraints. Making this change, they argue, requires a commitment to challenging the logic of austerity and resource-led care cultures that dominate social care policy, yet are rarely addressed directly. Sánchez Criado et al (2016) call for reinvigorating or even radicalising Independent Living politics, arguing that while DF in Spain has expanded under neoliberal governance, the Independent Living philosophies from whence DF models derive do not thrive in heavily bureaucratized and neoliberal contexts. They argue that these contexts conflate the user's agency in their care provision with consumerism in a predetermined marketplace. They argue that Independent Living philosophies have transformative potential when people have opportunities to experiment with their own

technologies and care arrangements through collective prototyping and "do-it-yourself" interventions. These interventions can be (re)politicized through community collectives that challenge medical paternalism, ageism, ableism, austerity and the neoliberalization of social care.

More broadly, social policy theorists, such as Daly (2002), make it clear that an economistic lens is too narrow given the far-reaching ramifications of social care policy. Instead the moral, social, and political aspects of care, while often sidelined, are integral to good policy and home care systems. DF programs alone are not a guarantee of positive outcomes but rather a crude instrument that more often than not improves the experience of home care. If Ontario moves forward with DF mainstreaming, it will be essential to develop DF options through participatory community-based channels that allocate sufficient resources and maintain the social justice spirit of original policies while also accommodating a wider array of potential users. This cannot happen within the narrow frame of austerity.

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Footnotes

[1] In other jurisdictions, DF is known as self-directed care (Canada); self-managed care (Canada); direct payments (UK); consumer-directed care (Australia, US, though it may not involve cash transfer); and cash-for-care.

[2] Chappell et al. (2004) do show, however, that DF, like other forms of home care, is cheaper than residential long-term care.

[3] Notably, the C.D. Howe Institute has been criticized for promoting neoliberal, right-wing policy strategies (see, for example, McQuaig, 2014).