# Health Reform Observer -Observatoire des Réformes de Santé

Volume 8	Issue 1	Article 4	
----------	---------	-----------	--

# Advancing Direct Payment Reforms in Ontario and Scotland

Sarah CARBONE, University of Toronto, Toronto, Ontario, Canada Sara Allin, University of Toronto, Toronto, Ontario, Canada

 $28\ \mathrm{May}\ 2020$ 

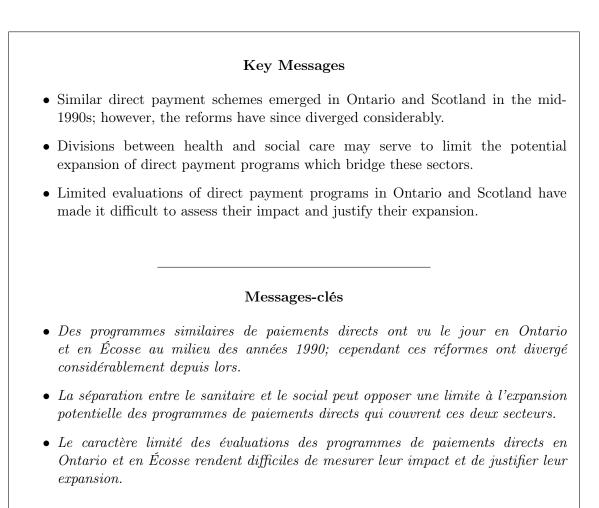
A Comparative Health Reform Analysis

RECOMMENDED CITATION: Carbone S, Allin S. 2020. Advancing Direct Payment Reforms in Ontario and Scotland. *Health Reform Observer - Observatoire des Réformes de Santé* 8 (1): Article 4. DOI: https://doi.org/10.13162/hro-ors.v8i1.4154

#### Abstract

Over the last several decades, there has been an increased interest in cash-for-care programs internationally. Important among these reforms has been the emergence of direct payments (DPs), which are cash payments given directly to individuals so that they can purchase their own community care services. In the mid-1990s, both Ontario and Scotland implemented early direct payment programs with the explicit goals of providing greater choice and control over social services to adults with disabilities. Since then, however, the programs have diverged considerably. In Scotland, negative public perceptions resulted in DPs conversion into a program option embedded within the Self-Directed Support program. In Ontario, DPs have never been required by law and have instead expanded through multiple distinct programs funded through different government ministries. This paper compares the evolution of DPs in these two jurisdictions in order to better understand the actors and mechanisms that contributed to this divergence. Using the 3-I framework, we explore the ideas, interests and institutions that have shaped these reforms into their current structures. Our analysis offers several insights for other jurisdictions considering expanding direct payment reforms. These include recognizing: 1) policy conversion as a tool for managing negative perceptions of a reform, 2) policy levers for encouraging compliance among administering authorities,  $\mathcal{P}$  divisions between health and social care as limiting possible expansion of the reform, and 4) program evaluations as justification for the reform's expansion.

Les programmes de chèques services suscitent un intérêt croissant dans le monde depuis quelques décennies. Au nombre de ces réformes, une tendance importante a été l'émergence de paiements directs, qui sont des paiements en espèces versés directement aux bénéficiaires pour qu'ils achètent eux-mêmes leurs services de soins communautaires. Au milieu des années 1990. l'Ontario et l'Écosse ont tous deux mis en place de tels programmes de manière pionnière, avec comme but explicite d'offrir plus de choix et de contrôle sur les services sociaux aux adultes handicapés. Depuis, cependant, ces deux programmes ont divergé considérablement. En Écosse, une réaction négative de l'opinion publique à conduit à transformer les paiements directs en une option au sein du programme Self-Directed Support (soutien auto-administré). En Ontario, les paiements directs n'ont jamais été mis en place légalement et se sont développés à travers divers programmes financés par des ministères différents. Cet article compare l'évolution des paiements directs dans ces deux entités politiques afin de mieux comprendre les acteurs et les mécanismes ayant contribué à cette divergence. Suivant le concept 3-I, nous explorons les idées, les intérêts et les institutions ayant façonné ces réformes dans leur état actuel. Notre analyse fournit des indications aux autres entités tentées par des réformes de paiements directs, entre autres : 1) la conversion de politique comme un outil de gestion des perceptions négatives d'une réforme, 2) les leviers politiques pour améliorer l'adhésion des autorités administrative, 3) les limites potentiellement apportées à la réforme par la séparation entre le sanitaire et le social et 4) les évaluations de programmes comme une justification de l'expansion de la réforme.



ACKNOWLEDGEMENT: We would like to thank Dr. Ellen Stewart, a Chancellor's Fellow in Social Studies of Health and Medicine at the University of Edinburgh, for sharing her insights into the Scottish context, and for reviewing earlier versions of this manuscript.

# 1 BRIEF DESCRIPTION OF THE HEALTH POLICY REFORM

The last several decades have observed an international trend toward offering health and social care users greater control over their services through the administration of cash-for-care programs (Arksey and Baxter 2012; McNeill and Wilson 2017). Now available in the majority of high-income countries, these programs have taken on a variety of forms and names, including: individual or personal budgets, self-managed care, direct payments (DPs), and direct funding. Although the schemes differ in their composition and ideolog-ical underpinnings (Pearson and Ridley 2017), they are based on the premise that giving individuals personal budgets can empower them by expanding their degree of choice and control over services (Alakeson 2010).

Important among these reforms has been the emergence of DPs. Direct payments are cash payments that individuals requiring community care can use to purchase social services and support based on their specific needs (Ridley et al. 2011). The payments, which now exist in a number of countries either as stand-alone programs or program options embedded within broader regimes, are expected to produce a range of social, economic, and health benefits. However, evaluations of DPs and other cash-for-care schemes have demonstrated mixed results. While some studies have found improved access, satisfaction with care, and reduced or stable system costs associated with DPs (Alakeson 2010; Cook et al. 2019), others have found no change in health outcomes between those who receive DPs and those whose budgets are managed by a third party (Woolham et al. 2017). Furthermore, some authors have commented that there is insufficient evidence that choice over services is the mechanism by which care experiences are improved and are critical of the legal and administrative burden that increased choice can have on service users (Murphy and Kelly 2019). Despite this, DPs and other cash-for-care schemes remain an appealing option in many contexts due to their potential to impact system costs through a more efficient use of resources by having care determined by those who are most familiar with care needs (i.e., service users) (Leadbeater, Bartlett, Gallagher 2008). This aim to improve efficiency has become particularly critical as many nations seek to contain health care spending as population longevity and medical complexity increase.

Ontario and Scotland share several similarities which make them strong comparators, including: similar health system regulation and financing, conceptualizations of health and social care, and efforts to bridge the divide between these sectors. Direct payment reforms emerged in both jurisdictions in the mid-1990s, yet they have since diverged considerably. Over the last decade, DPs in Scotland have become embedded within a broader program of Self-Directed Support (SDS), whereas in Ontario DPs remain available only through a collection of public programs. Consequently, both the scale and reach of DPs have shifted in the jurisdictions, with DPs becoming available to all social care users in Scotland, whereas in Ontario the majority of potential users remain ineligible. This paper explores the evolution of DP programs in Ontario and Scotland in order to better understand the actors and mechanisms that contributed to this divergence in policy. Comparing how DPs evolved in each context may provide insight into the utility and feasibility of expanding upon DP programs in similar jurisdictions in the future.

# 2 HISTORY AND CONTEXT

#### 2.1 Justification of jurisdictions

Ontario and Scotland are strong comparator jurisdictions due to the many similarities in their health and social care systems. Both Scotland and Ontario have state regulated and financed health systems with a degree of private service provision. Both jurisdictions are also accountable to a broader set of governing principles set by central governments and receive transfer payments from these governments for their compliance. Despite this, they each have autonomy over the majority of health decision-making in their jurisdictions and spend just over 40% of their total program budget on health care (Auditor General 2017a; FAOO 2018). Both jurisdictions distinguish between health and social care, though they have made some effort to integrate these two aspects of care over time. In Scotland, social care refers to "all forms of personal and practical support for children, young people and adults who need extra support" (Scottish Government n.d.). This includes various types of help, including care homes, support for unpaid carers, and free personal and nursing care. These services are administered through local authorities (i.e., local government) in Scotland, whereas health services are administered through local health authorities (i.e., Health Boards). In Ontario, although it is not a commonly used term, we consider social care to comprise various home and community care services that are not delivered by health professionals. These include personal care services, homemaking services, and community support programs (Ontario Government 2019). These services are funded and administered through multiple government ministries, like the Ministry of Community and Social Services (MCSS), and the Ministry of Health and Long-Term Care (MOHLTC). For the purpose of this paper, we consider social care as all personal care and/or support with the activities of daily living for people with disabilities (National Health Service 2018). Efforts to bridge the divide between health and social care in both jurisdictions will be further discussed throughout this paper, as they have implications for the evolution of DPs which cut across both boundaries. Importantly for this paper, the inception of DP programs was also similar in both jurisdictions, emerging in the mid-1990s for adults with disabilities who could selfmanage their services.

#### 2.2 Direct payments in Ontario

Direct payment programs in Ontario grew through the Independent Living movement which originated in the 1970s in the United States and spread to Canada in the 1980s (Yoshida *et* 

al. 2015). According to Yoshida and colleagues (2015, 184), a variety of "pre-existing conditions and critical factors [...] created a social and political climate" for the implementation of DPs. These included the combination of existing social movements with similar ideologies, precedents to DPs in Ontario, prior experience in the governance of attendant services, and changes in the direction of the government. As a result of these conditions, the *Ministry* of Community and Social Services Act was amended in 1993 to enable direct funding<sup>1</sup> and in 1994 the Ontario Ministry of Health<sup>2</sup> approved funding for the Self-Managed Attendant Services Direct Funding pilot (Direct Funding Ontario n.d.(a)). This pilot represented an early effort to implement DPs in Ontario, and enabled adults with physical disabilities to become employers of their own personal attendants who would provide basic care (e.g., assist with dressing or undressing, meal preparation, personal hygiene, etc.) (Direct Funding Ontario n.d.(b)). A total of \$4.4 million was originally allocated to the pilot, in order to fund 102 participants, and in 1998 under the provincial Conservative government, the program became permanent with a budget of \$18.7 million to serve 700 participants (Direct Funding Ontario n.d.(a)). The program continues to exist today, administered through the Centre for Independent Living in Toronto. Funding support for the program has, until recently, been provided through the MOHLTC; however, the newly elected Conservative government has moved to separate the Ministry of Health from the Ministry of Long-Term Care. This transition is in its early stages, and its impact on the program remains unclear.

Since their emergence in Ontario, efforts to extend DPs to other populations with functional limitations have achieved mixed successes. Since its inception as a pilot in 1994 the Direct Funding program has persisted. However, it has grown marginally in size and currently operates on a total budget of \$45 million to serve approximately 1,000 adults with physical disabilities (Izenberg, Buchanan, Lurette 2018). In 2006 the Passport program was launched, extending DPs as an option to adults with developmental disabilities and their families (Government of Ontario 2017a). By 2014, the program supported more than 13,000 people and additional investment was recently announced to extend the program to 42,000 more people by 2020 (Ministry of Children, Community, and Social Services 2018; Government of Ontario 2018). Direct payments have also become available through the Ontario Autism Program, where parents can access "childhood budgets" to directly purchase services and supports (Ontario Government 2020). Most recently, in 2017 the then Liberal government established a new crown agency called Self-Directed Personal Support Services Ontario (SDPSSO) to extend DPs to a broader population and establish a central pool of personal support workers; however, the newly elected Conservative government quickly dissolved the agency.

<sup>&</sup>lt;sup>1</sup>Direct funding is the language used in Ontario to describe DPs.

 $<sup>^{2}</sup>$ The Ministry of Health was renamed in 1999 to the Ministry of Health and Long-Term Care (MOHLTC) and then back to the Ministry of Health in 2019.

#### 2.3 Direct payments in Scotland

Direct payments emerged as a potential policy reform in the United Kingdom (UK) in the 1980s. Various organizations including the British Council of Disabled People and the Spinal Injuries Association supported the reform and collaborated to create a Direct Payments campaign in 1989 targeting potential political supporters (Evans and Hasler 1996). After years of campaigning, the *Community Care (Direct Payments) Act* received royal assent in 1996. This legislation enabled local authorities to provide DPs to adults between the ages of 18 and 65 who were in need of community care services (The Health Foundation 1996). Shortly after its enactment, in 2000, DPs were extended to adults over the age of 65, 16- and 17-year-old youth, and parents of disabled children. As enabling legislation, this reform gave local authorities the option of allocating DPs or maintaining existing modes of service provision (Pearson 2004), and as a result of this flexibility and other factors, uptake of DPs in Scotland was relatively slow. The first major evaluation of DPs in Scotland showed that just over one third of local authorities offered DPs to a total of 143 participants across the country in the late-1990s (Pearson 2004; Witcher *et al.* 2000).

In 2013 the Social Care (Self-Directed Support) Act legally required all local authorities to offer youth and adults with social care needs four choices over how they received social care, including: 1) DPs; 2) individual service funds; 3) council arranged services; or 4) a mix of the options. Despite this legislation, expansion of DPs has still been slow with inconsistent uptake of SDS among local authorities in Scotland (Eccles and Cunningham 2018). Today, the Act continues to be the primary mode of administering DPs in Scotland, with a total expenditure of more than £539 million per year to serve more than 80,000 citizens (Scottish Government 2017a) of whom less than 5% received DPs in 2017 (Auditor General 2017a). Between 2011 and 2018, the Scottish Government invested approximately £70 million GBP toward SDS implementation (Auditor General 2017b).

## **3** GOALS OF THE REFORM

#### 3.1 Stated

Increased flexibility, choice, and control are often cited as the most important drivers of DPs and other cash-for-care reforms (Arksey and Kemp 2008). In Scotland, DPs are currently offered through the national SDS scheme, which was implemented to "... ensure that social care is controlled by the supported person to the extent that they wish; is personalised to their own outcomes...; and respects the person's right to participate in society" (Scottish Government 2018). In Ontario, increased choice and flexibility are among the core objectives of both the Direct Funding and Passport programs (Direct Funding Ontario n.d.(b); Developmental Services Ontario 2014). Efforts to expand upon DPs in Ontario through the SDPSSO also advanced these values, even though the agency never fully came to fruition

(Government of Ontario 2017b).

#### 3.2 Implicit

Underlying the stated objectives of DP reforms in both jurisdictions are more implicit goals of shifting power relations and containing system costs. In Scotland, there have been several references to DPs and SDS as a means of shifting power away from service providers and toward consumers (Arksey and Kemp 2008; Health and Social Care Alliance Scotland 2017). This shift can be achieved through the reform by giving users more flexibility in selecting their providers, ultimately driving improved quality of care (Rummery *et al.* 2012). Efforts to expand upon DPs in Ontario have also demonstrated a desire to shift power relations within the province. While the Direct Funding and Passport programs can similarly be seen as consumer-focused reforms, the creation of the SDPSSO was also intended to better manage the home care labour market (Dansereau, Hande, Kelly 2019). In addition to planning to expand DPs, the SDPSSO also intended to employ a pool of personal support workers from which users could draw. Had the agency been established, the provincial government would have become responsible for over 40% of home care services in the province, severely restricting the market for existing home care agencies (Picard 2018).

The potential cost-efficiency of DPs has also been a major driver of the policies' promotion in both jurisdictions. As Pearson and Ridley (2017) note, "the successive dismissals of direct payment legislation on the statute throughout the 1990s were only brought to an end when the council of Disabled People commissioned research, which in promoting the merits of direct payments also showed them to be up to 40 per cent cheaper than directly provided services" (citing Zarb and Nadash 1994). In Ontario, early evaluations of the Direct Funding program also pointed to its potential cost-effectiveness, serving to assuage government concerns (Yoshida *et al.* 2015). These discourses have persisted as DPs have evolved in each jurisdiction even in the absence of comprehensive evaluations of their cost-efficiency.

# 4 FACTORS THAT INFLUENCED THE POLICY DECISIONS AND EVOLUTION OF THE PROGRAMS

In this section we focus on the dominant ideas, institutions and interests (National Collaborating Centre for Healthy Public Policy 2014) that influenced the policy decisions and evolution of the policy programs in the two jurisdictions.

#### 4.1 Ideas

Changes in the structure and delivery of DPs in Scotland were brought about as a result of multiple coinciding ideas. When DPs were first enabled in 1996 through the Community Care (Direct Payments) Act, local authorities across Scotland were slow to integrate them into care (Pearson 2004). Across the country, there was suspicion that DPs were indicative of future cuts to services, and concerns that DPs would force individuals to direct their own care when their preference was to have the services organized through an agency (The New Mental Health 2015). These concerns may have stemmed in part from lingering dissatisfaction toward the internal market in health care and marketization of welfare that had been established in Scotland in the mid-1990s (Riddell 2006; Pearson 2004). In the early 2000s there was also a growing narrative throughout the country that DPs were failing to deliver upon their stated objective of offering better choice, flexibility, and control to users (Ridley *et al.* 2011) and that the health care system could not continue as it had before (Eccles and Cunningham 2018). As a result, attention turned toward a new conceptualization of "personalization" as a solution to address concerns over existing DP structures.

The personalization agenda was instrumental in the transformation of Scotland's DP program into the broader regime of SDS. Personalization refers to the idea that services are tailored to the needs and preferences of users, who are central in their design and delivery (Kendall and Cameron 2014; Manthorpe et al. 2011). The concept of personalization was already a government priority in the UK; however, Scotland's strategic use of the term "self-directed support" was in part to distinguish itself and its policy ambitions from those in England that were more focused on consumerism and increased competition (Manthorpe et al. 2015). As such, personalization represented an opportunity to truly offer choice and flexibility to users, which DPs had seemingly failed to deliver. Notions of personalization were also already embedded in earlier Scottish social policy, through the concepts of partnership, collaboration, and co-production (Pearson, Watson, Manji 2018). In 2006, the personalization agenda became even more pronounced when the UN adopted the Convention on the Rights of Persons with Disabilities (Pearson, Watson, Manji 2018). Similarly, Scotland's *Changing Lives* report (Scottish Government 2006) demonstrated a clear commitment to personalization moving forward (Pearson, Watson, Manji 2018). In combination, these ideas on personalization formed the foundation of the Self-Directed Support Act (2013), requiring local authorities to offer four choices over how social care and support would be administered, one of which was DPs. Growing from the foundation of DPs, this Act represented an attempt to further advance the objective of delivering greater choice and control to service users.

In contrast with Scotland, concerns over the implementation and expansion of DPs were not as pronounced in Ontario. As Dansereau, Hande and Kelly (2019) point out, Ontario's health minister believed that DPs were a "good" policy, justifying its potential expansion to other user groups like older adults. In the late-1990s, the MCSS released a policy called *Making Services Work for People* in response to frequent complaints from individuals and families about the quality and clarity of services offered in the province (Passport 2018). This policy statement did not appear to lead to any program changes until 2006 when DPs were extended through the MCSS to adults with developmental disabilities.

The early expansion of DPs to new DP programs may have also been facilitated by

the strong underlying neoliberal ideology assumed in the original configuration of Direct Funding Ontario, which placed clear responsibility on the service user, rather than the government. Ideas relating to the limited role and responsibility of government over service delivery and potential for cost savings likely served to align DPs with broader government agendas during a period of austerity (Hande and Kelly 2015). In contrast, the SDPSSO proposed to expand the role of government in service delivery by employing a pool of personal support workers in addition to offering DPs. This may have been a result of the challenges many individuals and families faced in trying to find qualified personal support workers in a stressed labour pool (Care Watch 2017). As such, the proposed SDPSSO represented an attempt to meet the growing expectations of users and their families while also gaining more public control over the home care market.

#### 4.2 Institutions

Institutional divisions between health and social care sectors have had implications for DP reforms in both jurisdictions. In both Ontario and Scotland, there has been a strong legislative and institutional division between health and social care provision. There have also been efforts to bridge this divide in both jurisdictions, either by legislating their integration (as in Scotland) or merging administration and accountability through a combined ministry (as in Ontario). These efforts have had an impact on the DP reforms which have spanned both sectors.

In Scotland, the division between health and social care originated in the design of the National Health Service (NHS) in the UK, whereby all health services were provided on a universal basis free-at-the-point-of-use, and social care fell under different legislation, with different financing mechanisms, a separate budget, and a needs-based, means-tested program. In Scotland, this means-test was abolished over a decade ago, yet until recently social care remained funded and administered separately from the NHS. In an effort to bridge this divide, the *Public Bodies (Joint Working) Act* was released in 2014, requiring NHS Boards and local authorities to develop a plan to integrate resources and planning. This Act resulted in the creation of 31 integration authorities responsible for managing the integrated care services and budgets (Hendry *et al.* 2016). This requirement for integration appeared to have had the effect of stalling the implementation of SDS among local authorities by diverting organizational capacity to the new initiative (Auditor General 2017b; Pearson, Watson, Manji 2018).

The Ontario government has been similarly divided on health and social care. This relates to the fact that social care is excluded from the *Canada Health Act*, and the dominant medical focus of the health system which has been difficult to rebalance (Peckham *et al.* 2018). This is important to consider in light of the expansion of DPs in Ontario, which have been funded and administered through both social- and health-oriented ministries over time. Since its initial inception, administration of the Direct Funding program in Ontario has shuffled through multiple ministerial placements. Funding for the program originated

through the MCSS before being briefly transferred to the Ministry of Long-Term Care, and then finally to the MOHLTC. This administrative reorganizing coincided with changes and reductions to the federal transfer payments to the provinces (Kelly 2016). In particular, the combining of two federal transfer programs (the Established Programs Financing and the Canada Assistance Plan) into the single Canada Health and Social Transfer was managed in most provinces by sustaining funding for health care services, often at the expense of social programs for vulnerable populations (Kelly 2016; McIntosh 2004). This prioritization of health-related initiatives was maintained when the transfer program was split into the Canada Health Transfer and Canada Social Transfer in 2004 (Kelly 2016). This institutional context made it more "... pragmatic for Independent Living to endorse a health care model at times to gain access to funding increases" (Kelly 2016, 137).

In 2005, the provincial government also moved to regionalize health services with the establishment of Local Health Integration Networks (LHINs), whose responsibility was to streamline health services. After several years, administration of the Direct Funding Program was transferred to the LHINs in 2012, further strengthening the program's alignment with health over social care (Kelly 2016). These institutional developments have had important implications for the evolution of DP reforms in Ontario, as they have served to dichotomize the services that could fall into either the health or social care realms and privilege those aligned with health care (Baranek, Williams, Deber 2004; Daly 2007). While the Direct Funding program (which serves adults with physical disabilities) was funded by the MOHLTC, the Passport program (which serves adults with developmental disabilities) is funded separately through the MCSS. As Kelly (2016, 137) notes, this institutional divide has forced people with both physical and developmental disabilities to "bridge multiple systems and occupy diminishing policy spaces."

#### 4.3 Interests

Several stakeholder groups have had an instrumental role in the transition of DPs into SDS in Scotland. As previously described, DPs emerged in Scotland in part due to the campaigning of various disability rights organizations. These organizations have maintained involvement in the development of SDS over time. For example, Scottish Autism has been working closely with local authorities in order to ensure that SDS meets the unique needs of their population (Scottish Autism n.d.). These efforts are consistent with the increasing public demand for health and social care designed to meet the needs of the population, a key driver in the advancement of SDS (Open Learn 2013). However, while DPs were largely advanced from the bottom-up, the SDS scheme has shown a gradual shift toward a more top-down, or government-based agenda (Pearson, Watson, Manji 2018). Faced with the changing demands and growing rights of the population, multiple successive governments have used SDS as a means to shift the balance of care toward the community and drive their own interests. The role of the Convention of Scottish Local Authorities (COSLA) has been central in this strategy. With the release of the SDS Act, COSLA transitioned from a networking body into a strong negotiating power, representing local authorities in negotiations with the government over the implementation and evaluation of the reform. Alongside the Scottish Government, COSLA has advocated for transitioning to an SDS approach, and has been fully committed to its implementation (Scottish Government 2010).

Similar to Scotland, support for the expansion of DPs in Ontario has largely been driven by the changing demands of the population, various interest groups, and the government. Both the Passport program and SDPSSO were brought about in large part due to the general public and various interest groups like disability and seniors advocacy groups, unions and professional health associations (Dansereau, Hande, Kelly 2019; Passport 2018). These include organizations like Home Care Ontario which have supported self-directed care for many years provided that it offers users free choice over their care providers (Home Care Ontario 2015). In the case of Direct Funding Ontario specifically, the Centre for Independent Living in Toronto has also been an important stakeholder in maintaining DPs and has been instrumental in securing additional funding to continue to run the program. This has included negotiating renewed contracts to ensure the continuation of the Direct Funding program after the Ministry of Health introduced plans to move administration of the program to the LHINS (Direct Funding Ontario n.d.(a)).

## 5 HOW THE REFORMS WERE ACHIEVED

In this section we briefly describe the policy levers and instruments used in Scotland and Ontario in order to shape and advance the DP reforms.

In Scotland, regulatory, economic and organizational levers were used to transform DPs into SDS. The expansion of DPs into SDS in Scotland is represented through a clear progression of government legislation. Since 1996 when DPs were first enabled through the *Community Care (Direct Payments) Act*, multiple successive reports and legislation followed, embedding DPs into the health care strategy of the country. Particularly important was the 2002 *Community Care and Health Act* which helped to cement DPs in Scottish legislation by requiring all local authorities to offer them to eligible clients. Using the concept of path dependence, this legislation may have served to limit future policy options against the exclusion of DPs because they had become embedded in the law. As a result, the legacy of this policy has endured and DPs have consistently been included in subsequent policies in the country.

As local authorities and frontline social care workers would ultimately be responsible for the implementation of SDS, their commitment was critical to the advancement of the policy option. Local authorities who were test sites (i.e., pilot sites) for SDS were offered a sum of money for transitional funding so that service provision could be preserved while users tried new funding arrangements (Manthorpe *et al.* 2015). Further, to encourage local authorities' support with SDS, DPs were presented as only one way of achieving the reform's goals. As such there were never enough DP users to warrant any restructuring of services (Riddell *et al.* 2006). This meant that the local authorities were not required to make any major changes in their approach to delivering services in order to comply with the Act. This may have served to reduce resistance among this interest group; however, as a consequence of the flexibility that was afforded to local authorities, the reform was taken up inconsistently across regions resulting in a piecemeal delivery of SDS options and low uptake of DPs specifically (Eccles and Cunningham 2018). This inconsistency has also been attributed to the limited budgets of local authorities for social care services, which may have impacted the restructuring of services (Auditor General 2017b). Further, despite the flexibility afforded to local authorities in the implementation of SDS, frontline social care workers have continually expressed strong concerns about SDS being linked with cuts in social care budgets rather than a true effort to improve users' choice and control (Pearson and Ridley 2017).

In Ontario, organizational levers have been the primary means of advancing DP reforms. In contrast with Scotland where DPs are embedded in law, no such legislation exists in Ontario. Throughout the province, DPs have been advanced in a decentralized fashion, with the government dividing the responsibility for delivering DPs among multiple distinct ministries and organizations. Although the Direct Funding program is run by a single organization, the Passport program is run separately and administered through 11 Passport agencies assigned to specific geographic regions (Ministry of Children, Community and Social Services 2019). The SDPSSO would have also been administered through a third, once again separate, agency. This individualized governance assigned to each agency and reinforced by the institutional division of health and social care has meant that they were given more control and flexibility over administering the programs in their own ways without infringing on the other existing services. However, despite being a separate DP agency, the SDPSSO also represented broader organizational changes to the home care market. By planning to employ a central pool of personal support workers in addition to extending DPs to a broader population, the agency threatened to undermine and compete with existing service providers who took legal action to prevent it from operating (Picard 2018; Dansereau, Hande, Kelly 2019 citing Christie 2018). This intended restructuring of services restricted the expansion of DPs, even though the interest groups opposing the proposed agency may have supported expanding DPs in a different context.

Economic levers have also been used to control the expansion of DPs in Ontario. The Direct Funding program began as a pilot program with a modest budget to serve a small portion of potential clients. Over time, this funding has been increased; however, it continues to limit the number of people who can access DPs. Across the various DP programs in Ontario, there are extensive lists of eligible clients waiting to join the programs (Izenberg, Buchanan, Lurette 2018; Government of Ontario 2017a). Consequently, funding for these programs has served to restrict the spread of the reform.

# 6 EVALUATION

Evaluations of SDS in Scotland have given a mixed impression of whether the program has successfully delivered upon its stated goal to provide clients with greater choice and control over their services. Although no national targets were set for local authorities when the SDS strategy was first announced, they became a dominant regulatory feature throughout its implementation. Between 2007 and 2017, the Scottish government undertook significant reforms to establish what is known as the "Scottish Approach" (i.e., a strategic state in Scotland) (Elliott 2020). This approach broadly refers to the articulation of a long-term vision for the country. This shift toward a strategic state resulted in the production of national outcomes, targets and indicators, to which local government were now expected to contribute (Elliott 2020). In 2015, nine national health and well-being outcomes and 23 integration indicators were announced (Scottish Government 2017b; Scottish Government 2015), many of which related to the objectives of SDS. For example, one of the health and social care integration indicators reports the "percentage of adults supported at home who agree that they had a say in how their help, care or support are provided" (Scottish Government 2017c). These indicators, which must be reported on an annual basis by the integration authorities, represent government efforts to hold authorities accountable to the country's long-term vision. However, recent reports by the Scottish government suggest that these routine data collections are insufficient for monitoring and evaluating SDS specifically, in part because they draw data from a population of both health and social care users (Scottish Government 2019a).

Early reports suggested that for clients who were offered the SDS options, the program was delivering upon its promises of greater choice and control (Rummery et al. 2012). Overall, user experiences with SDS appear to have been positive; however, one study found that the ongoing austerity of local government has resulted in a reduction of choice and control for some DP users (Manji 2018). This is reflected in the fact that several of the participants experienced reductions in their care packages following the implementation of SDS in their areas (Manji 2018)<sup>3</sup>. Other reports have also indicated that there was a lack of evidence that all local authorities had successfully implemented SDS (Auditor General 2017b) despite the new legislation and integration indicators. A recent report by the Scottish Government (2019b) showed that local authorities have differed in the ways they interpret and deliver the SDS options. This led them to conclude that the options have not offered a similar extent of choice and control in different places. Consistent with this finding, by 2017 only 70% of eligible social care clients were believed to be receiving the SDS options (Scottish Government 2018). Further, although the number of people receiving DPs doubled between 2010 and 2016, they still represented less than five percent of the population receiving non-residential social care services (Auditor General 2017b). These realities have led some researchers to conclude that overall SDS has resulted in little change

 $<sup>^{3}</sup>$ It is important to note that the population included in this study was very small and consisted of only 13 SDS users.

to the way that social care is delivered in Scotland (Pearson, Watson, Manji 2018). This apparent uneven implementation of the SDS options by local authorities will likely need to be addressed in order to maximize the reform's potential to offer the greater choice and control it promises.

Available information on the Direct Funding and Passport programs in Ontario portray similar challenges to those in Scotland. Although few reports on the programs are publicly available, DPs administered through the Direct Funding program were associated with greater empowerment and confidence in self-managing care by clients (Lord 2012). Similar evaluations of the Passport program are unavailable; however, gaps in coverage continue to persist for both the Direct Funding and Passport programs, as evidenced by extensive lists of clients waiting to join them. Similar to Scotland, these reports suggest that DPs in Ontario have the potential to improve the delivery of social care services; however, they are inaccessible to many eligible clients. Evaluations of the economic performance (such as cost-effectiveness analysis and budget impact assessments) of the programs are also lacking in both jurisdictions.

# 7 ANALYTIC COMPARISON

As this analysis demonstrates, ideas may help to explain why DP reforms seemed to diverge between Ontario and Scotland over time. In Scotland, ideas played a critical role in framing DPs as a "problem" (Eccles and Cunningham 2018). In particular, negative perceptions towards DPs' abilities to deliver enhanced user choice and control in Scotland led to them being reformed through SDS, a comparable policy option with a nuanced ideological underpinning. This is indicative of policy conversion, a phenomenon whereby new goals are adopted to alter the way a policy operates within society (Béland 2010). This conversion allowed DPs to persist as one option for social care users, with proponents advocating for their potential to support personalization. This type of policy conversion might be a useful tool in other jurisdictions struggling to maintain support for DPs, as an ideological shift can serve to subtly reorient a policy's objectives to align with current interests. Similar negative perceptions towards DPs were not as apparent in Ontario. DPs appeared to have support from both government and social care agencies, and there were limited critiques of the Direct Funding program. These realities may have made it more feasible to expand DPs in their existing form in Ontario; however, this expansion has still been slow.

The institutional division between health and social care and efforts to bridge this divide have also had important implications for the evolution of DPs in the jurisdictions. In Scotland, DPs have consistently fallen within the boundaries of social care, and government efforts to integrate health and social care may have actually hindered the implementation of SDS by diverting resources. In Ontario, the Direct Funding program began as social care reform in the MCSS and then was transferred to the MOHLTC. This transfer exacerbated a gap in services for people with developmental disabilities, prompting a need for the creation of the Passport program funded through the MCSS.

Lastly, interests played an important role in how DP reforms came onto the governments' agendas and impacted the ways in which the governments drove those agendas forward. Consistent between Ontario and Scotland, the general populations and key interest groups were integral in the advancement of DPs. Perhaps even more important were the governments' objectives in driving ahead neoliberal and personalization ideas during a period of austerity. This is particularly apparent in Ontario's efforts to implement the SDPSSO which was met with significant resistance from both providers and community agencies. However, although not integral to the advancement of DPs as a policy option, the interests of the organizations responsible for administering DPs had a major influence on how the reforms were pushed forward. In both jurisdictions, the DP reforms were shaped in a decentralized fashion, to be administered through local authorities in Scotland, and multiple distinct organizations in Ontario. This method ascribed high levels of autonomy to the organizations delivering DPs which may have reduced their resistance to the reform. However, despite supportive legislation and interest groups in Scotland arguing for DPs, the government has also needed to use a variety of regulatory levers to encourage local authorities to comply with the SDS Act, whereas in Ontario the organizations were more autonomous and required less regulation, perhaps due to the lack of overt legislation.

Ultimately, this analysis offers a number of lessons to jurisdictions considering expanding upon DP programs in the future. First, in jurisdictions where existing DP programs have negative reputations, policy conversion may be an effective means of continuing to expand them; however, in a rebranded format. As was the case in Scotland, the shift of DPs to SDS served to distance the reform from negative outcomes and policy legacies. This subtle change allowed the program to persist; however, it did not result in a widespread change in uptake, as evidenced by the few social care users who choose the DP option. Second, legislation alone is insufficient for ensuring compliance with a policy reform. In Scotland, successive legislation embedded SDS into the national strategy of the country; however, uptake of the policy reform varied considerably between regions. Consequently, organizational and regulatory levers have been needed to encourage greater consistency among the local authorities. Third, institutional divisions between health and social care can have a critical impact on DP reforms. In both jurisdictions, in attempts to better integrate health and social care we see a privileging of health services that serves to further limit potential expansion of DPs. Other jurisdictions with similar divisions may struggle to expand upon DP reforms. Finally, the limited use of measurement and evaluation in both Ontario and Scotland makes it difficult to assess the impacts of these programs on care recipients and families, and on the health and care systems more broadly. Limited evaluation may also raise challenges in justifying and expanding upon the programs over time.

#### 8 REFERENCES

- Alakeson V. 2010. International developments in self-directed care. Issues in International Health Policy 78: 1-11.
- Arksey H, Baxter K. 2012. Exploring the temporal aspects of direct payments. British Journal of Social Work 42(1): 147-164. https://doi.org/10.1093/bjsw/bcr039
- Arksey H, Kemp PA. 2008. Dimensions of choice: a narrative review of cash-for-care schemes. Department of Social Policy and Social Work, University of York, Social Policy Research Unit Working Paper, DHP2250. http://citeseerx.ist.psu.edu/viewdoc/ download?doi=10.1.1.498.4008&rep=rep1&type=pdf
- Auditor General. 2017a. NHS In Scotland 2017. Audit Scotland, 26 October. http://www.audit-scotland.gov.uk/report/nhs-in-scotland-2017
- Auditor General. 2017b. Self-directed support: 2017 progress report. Audit Scotland, 24 August. http://www.audit-scotland.gov.uk/report/self-directed-support-2017-progressreport
- Baranek PM, Williams PA, Deber RB. 2004. Almost home: reforming home and community care in Ontario. Toronto: University of Toronto Press.
- Béland D. 2010. Policy change and health care research. Journal of Health Politics, Policy and Law 35(4): 615-641. https://doi.org/10.1215/03616878-2010-019
- Care Watch. 2017. NEW self-directed personal support services Ontario (SDPSSO), scheduled to start in 2018. 12 November. https://carewatchontariodotcom.files.wordpress. com/2017/11/bg\_sdpsso\_commentary\_201711121.pdf
- Community Care and Health (Scotland) Act (2002 asp 5). Government of the United Kingdom. http://www.legislation.gov.uk/asp/2002/5/introduction
- Community Care (Direct Payments) Act (1996 c.30). Government of the United Kingdom. https://www.legislation.gov.uk/ukpga/1996/30/introduction
- Cook JA, Shore S, Burke-Miller J, Jonikas JA, Hamilton M, Ruckdeschel B, Norris W, Markowitz AF, Ferrera M, Bhaumik D. 2019. Mental health self-directed care financing: efficacy in improving outcomes and controlling costs for adults with serious mental illness. *Psychiatric Services* 70(3): 191-201. https://doi.org/10.1176/appi.ps.201800337
- Daly T. 2007. Out of place: mediating health and social care in Ontario's long-term care sector. *Canadian Journal on Aging* 26(Suppl 1): 63-75.
- Dansereau L, Hande MJ, Kelly C. 2019. Establishing a crown agency amid multiple service providers: self-directed personal support services Ontario (SDPSSO). *Health Reform* Observer - Observatoire des Réformes de Santé 7(1): 1-11. https://doi.org/10.13162/ hro-ors.v7i1.3685

- Developmental Services Ontario. 2014. Passport program: guidelines for adults with a developmental disability and their caregivers. https://www.mcss.gov.on.ca/documents/ en/mcss/publications/developmental/passport/Passport Program Guidelines-en.pdf
- Direct Funding Ontario. n.d.(a). History of direct funding. https://www.dfontario.ca/ info/history.html
- Direct Funding Ontario. n.d.(b). Self-managed attendant services in Ontario. https://www.dfontario.ca
- Eccles A, Cunningham I. 2018. The enablers and barriers to voluntary sector organisations providing personalised support through delivery of self directed support, part two: the experience of SDS implementation in local authorities. http://www.ccpscotland.org/pp/wp-content/uploads/sites/3/2018/08/pp-research-report-2018.pdf
- Elliott IC. 2020. The implementation of a strategic state in a small country setting—the case of the 'Scottish Approach'. *Public Money & Management* 1-9. https://doi.org/10.1080/09540962.2020.1714206
- Evans J, Hasler F. 1996. Direct payments campaign in the U.K. Independent Living Institute, June. https://www.independentliving.org/docs2/enildirectpayment.html
- FAOO (Financial Accountability Office of Ontario). 2018. Ontario health sector—an updated assessment of Ontario health spending. Financial Accountability Office of Ontario, 14 March. https://www.fao-on.org/en/Blog/Publications/health-sector-march-18#2.%20Introduction
- Government of Ontario. 2017a. 13,000 adults with developmental disabilities receiving support. Ontario Newsroom, 14 February. https://news.ontario.ca/mcys/en/2017/02/13000-adults-with-developmental-disabilities-receiving-support.html
- Government of Ontario. 2017b. Aging with confidence: Ontario's action plan for seniors. November. https://www.ontario.ca/page/aging-confidence-ontario-action-planseniors
- Government of Ontario. 2018. 2018 Ontario budget. http://budget.ontario.ca/2018/ budget2018-en.pdf
- Hande MJ, Kelly C. 2015. Organizing survival and resistance in austere times: shifting disability activism and care politics in Ontario, Canada. *Disability and Society* 30(7): 961-975. https://doi.org/10.1080/09687599.2015.1069731
- Health and Social Care Alliance Scotland (the Alliance). 2017. Personal experiences of self-directed support. Research Report. http://www.knowledge.scot.nhs.uk/media/ 12473998/alliance%20sds%20report.pdf
- Hendry A, Taylor A, Mercer S, Knight P. 2016. Improving outcomes through transformational health and social care integration—the Scottish experience. *Healthcare Quarterly* 19(2): 73-79. https://doi.org/10.12927/hcq.2016.24703

- Home Care Ontario. 2015. Self-directed care: balancing individual autonomy and value based home care. https://www.homecareontario.ca/docs/default-source/position-papers/self-directed-care-statement---august-2015-home-care-ontario.pdf?sfvrsn=4
- Izenberg D, Buchanan F, Lurette C. 2018. Direct funding means freedom for many people with disabilities. Is it accessible enough? *Healthy Debate*, 2 August. https: //healthydebate.ca/2018/08/topic/direct-funding
- Kelly C. 2016. *Disability politics and care: the challenge of direct funding*. Vancouver: UBC Press.
- Kendall S, Cameron A. 2014. Personalisation of adult social care: self-directed support and the choice and control agenda. British Journal of Learning Disabilities 42: 264-271. https://doi.org/10.1111/bld.12069
- Leadbeater C, Bartlett J, Gallagher N. 2008. Making it personal. *Demos.* 1-107. http://www.partnerships.org.au/Making%20It%20Personal.pdf
- Lord J. 2012. An evaluation of the expansion to the direct funding program. Toronto: Centre for Independent Living in Toronto.
- Manji K. 2018. 'It was clear from the start that [SDS] was about a cost cutting agenda': exploring disabled people's early experiences of the introduction of self-directed support in Scotland. Disability and Society 33(9):1391-1411. https://doi.org/10.1080/ 09687599.2018.1498767
- Manthorpe J, Hindes J, Martineau S, Cornes M, Ridley J, Spandler H, Rosengard A, Hunter S, Little S, Gray B. 2011. Self-directed support: a review of the barriers and facilitators. Scottish Government Social Research. https://clok.uclan.ac.uk/7034/1/7034\_Ridley. pdf
- Manthorpe J, Martineau S, Ridley J, Cornes M, Rosengard A, Hunter S. 2015. Embarking on self-directed support in Scotland: a focused scoping review of the literature. *European Journal of Social Work* 18(1): 36-50. https://doi.org/10.1080/13691457.2014. 885883
- McIntosh T. 2004. Intergovernmental relations, social policy and federal transfers after Romanow. *Canadian Public Administration* 47(1): 27-51. https://doi.org/10.1111/j. 1754-7121.2004.tb01969.x
- McNeill S, Wilson G. 2017. Use of direct payments in providing care and support to children with disabilities: opportunities and concerns. British Journal of Social Work 47:1 903-1922. https://doi.org/10.1093/bjsw/bcw159
- Ministry of Children, Community and Social Services, Government of Ontario. 2018. Transforming developmental services in Ontario. 27 July. https://mcss.gov.on.ca/en/mcss/programs/developmental/improving/index.aspx

- Ministry of Children, Community and Social Services, Government of Ontario. 2019. Passport agencies: contact information. 22 January. https://www.mcss.gov.on.ca/ en/mcss/programs/developmental/serviceSupport/passport\_agencies.aspx
- Murphy MF, Kelly C. 2019. Questioning 'choice': a multinational metasynthesis of research on directly funded home-care programs for older people. *Health and Social Care in the Community* 27: e37-e56. https://doi.org/10.1111/hsc.12646
- National Collaborating Centre for Healthy Public Policy. 2014. Understanding policy developments and choices through the "3-I" framework: interests, ideas and institutions. Institut national de santé public Quebec. March. http://www.ncchpp.ca/docs/2014\_ProcPP\_3iFramework\_EN.pdf
- National Health Service. 2018. Introduction to care and support. August. https://www.nhs.uk/conditions/social-care-and-support-guide/introduction-to-care-and-support/
- Ontario Government. 2019. Home and community care. May. https://www.ontario.ca/page/homecare-seniors
- Ontario Government. 2020. Ontario Autism Program. January. https://www.ontario.ca/page/ontario-autism-program#section-4
- Open Learn. 2013. Foundations for self-directed support in Scotland. https://www.open. edu/openlearn/ocw/mod/oucontent/view.php?id=18707
- Passport. 2018. History. 29 October. http://passportfundinghnr.ca/en/history/
- Pearson C. 2004. Keeping the cash under control: what's the problem with direct payments in Scotland? *Disability and Society* 19(1): 1-14. https://doi.org/10.1080/0968759032000155596
- Pearson C, Ridley J. 2017. Is personalization the right plan at the wrong time? Re-thinking cash-for-care in an age of austerity. Social Policy and Administration 51(7): 1042-1059. https://doi.org/10.1111/spol.12216
- Pearson C, Watson N, Manji K. 2018. Changing the culture of social care in Scotland: has a shift to personalization brought about transformative change? Social Policy Administration 52: 662-676. https://doi.org/10.1111/spol.12352
- Peckham A, Morton-Chang F, Williams AP, Miller FA. 2018. Rebalancing health systems toward community-based care: the role of subsectoral politics. *Health Policy* 122(11): 1260-1265. https://doi.org/10.1016/j.healthpol.2018.09.014
- Picard A. 2018. Ontario is courting a home-care fiasco. Globe and Mail, 1 March. https://www.theglobeandmail.com/opinion/ontario-is-courting-a-home-carefiasco/article38175867/
- Public Bodies (Joint Working) (Scotland) Act (2014 asp 9). Government of the United Kingdom. https://www.legislation.gov.uk/asp/2014/9/contents

- Riddell S, Priestley M, Pearson C, Merce G, Barnes C, Jolly D, Williams V. 2006. Disabled people and direct payments: a UK comparative study. http://www.docs.hss.ed.ac.uk/ education/creid/Projects/10i Directpyts FinalRpt I.pdf
- Ridley J, Spandler H, Rosengard A, Little S, Cornes M, Manthorpe J, Hunter S, Kinder T, Gray B. 2011. Evaluation of self-directed support test sites in Scotland. Scottish Government Social Research.
- Rummery K, Bell D, Bowes A, Dawson A, Roberts E. 2012. Counting the cost of choice and control: evidence for the costs of self-directed support in Scotland. Scottish Government Social Research.
- Scottish Autism. n.d. Self-directed support. https://www.scottishautism.org/services-support/support-families/self-directed-support
- Scottish Government. n.d. Social care. https://www.gov.scot/policies/social-care/
- Scottish Government. 2006. Changing lives: report of the 21st Century Social Work Review. 7 February. https://www.gov.scot/publications/changing-lives-report-21stcentury-social-work-review/
- Scottish Government. 2010. Self-directed support: a national strategy for Scotland. October 2010. https://www2.gov.scot/resource/doc/329971/0106962.pdf
- Scottish Government. 2015. Core suite of integration indicators. 19 March. https://www2.gov.scot/Resource/0047/00473516.pdf
- Scottish Government. 2017a. Self-directed support, Scotland, 2016-17. 14 August. https://www.gov.scot/publications/self-directed-support-scotland-2016-17/pages/4/
- Scottish Government. 2017b. National health and wellbeing outcomes. 24 March. https://www2.gov.scot/Topics/Health/Policy/Health-Social-Care-Integration/ National-Health-WellbeingOutcomes
- Scottish Government. 2017c. Review of targets and indicators for health and social care in Scotland. https://www.gov.scot/publications/review-targets-indicators-health-socialcare-scotland/pages/29/
- Scottish Government. 2018. Transforming social care: Scotland's progress towards implementing self-directed support 2011-2018. 27 August. https: //www.gov.scot/publications/transforming-social-care-scotlands-progress-towardsimplementing-self-directed-support/
- Scottish Government. 2019a. Self-directed support implementation study 2018. Report 2: evidence assessment for self-directed support. April 2019. https://www.gov.scot/publications/self-directed-support-implementation-study-2018report-2-evidence-assessment/

- Scottish Government. 2019b. Self-directed support implementation study 2018. Report 3: self-directed support case studies. April 2019. https://www.gov.scot/publications/ self-directed-support-implementation-study-2018-report-3-case-studies/
- Social Care (Self-directed Support) (Scotland) Act (2013 asp 1). Scottish Parliament. https://www.legislation.gov.uk/asp/2013/1/contents
- The Health Foundation. 1996. The Community Care (Direct Payments) Act received royal assent on 4 July 1996. https://navigator.health.org.uk/content/community-care-direct-payments-act-1996-received-royal-assent-4-july-1996
- The New Mental Health. 2015. Personal budgets and mental health: Scotland isn't England. 18 December. http://thenewmentalhealth.org/?p=202
- Witcher S, Stalker K, Roadburg M, Jones C. 2000. Direct payments: the impact of choice and control for disabled people. Health and Community Care Research Findings. Edinburgh, Scotland. https://www2.gov.scot/Publications/2000/10/51fc94b4-02b4-48b1bf01-f1f307b9fd95
- Woolham J, Daly G, Sparks T, Ritters K, Steils N. 2017. 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 & Society 37: 961-984. https://doi.org/10.1017/S0144686X15001531
- Yoshida K, Willi V, Parker I, Locker D. 2015. The emergence of self-managed attendant services in Ontario: direct funding pilot project—an independent living model for Canadians requiring attendant services. In *Chronic care, health care systems and services integration*, Vol. 22, 1st Edition, ed. Kronenfeld JJ, 177-204. Bingley, UK: Emerald Publishing.