RESEARCH ROUNDUP

Client-Directed Funding Models

AGEWELL

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Introduction

At APPTA, we strive to find relevant and timely research that has the potential to influence policy decision making for the aging population. One way of doing this is through our Research Roundup series. Our team devotes time to reading and prioritizing academic papers and grey literature, and investigates programming and products that foster innovation related to how we care for older adults. We then summarize that information for a quick and consumable product. These periodical documents will summarize evidence based on relevant policy topics that are discussed through our ongoing stakeholder engagement.

If there are particular topics of interest you would like us to investigate, please let us know by emailing Daniel Smiley, Research & Logistics Specialist, at daniel.smiley@dal.ca.

For this roundup, we are looking at *client-directed funding models*.

What is client-directed funding?

Direct Funding (DF) provides individuals with a budget to arrange their own home care instead of receiving publicly arranged services. DF programs have evolved in a number of countries since the 1970s. In Canada, while small-scale DF programs have existed since the early 1970s, the research on these programs remains limited[1].

In many developed contexts, home-care services have been overhauled with the intent of increasing control and flexibility for those using social and health services. This change is associated with providing funds directly to individuals, and sometimes their families and supports, to arrange at home-care assistance with the activities of daily living. Directly funded home-care programs are not value-neutral policy interventions, but can be complex and politicised tools for the enactment of care in contemporary times[2].

The argument in favour of Direct Funding is it gives individuals the ability to choose services that suit them best, enabling them to age in place longer and remain connected to their communities. However, this approach requires individuals to handle their own administration, and is sometimes not necessarily equitable in Canada for those with inadequate financial resources, social supports, and competence in the English language when navigating through services and applications.

1 https://www.tandfonline.com/doi/full/10.1080/08959420.2020.1745736)
2 https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-023-09048-9

Literature Review

Inequities in access to directly-funded home care in Canada: a privilege only afforded to some

Kelly, C.; Dansereau, L.; FitzGerald, M.; Lee, Y.; & Williams, A.	2023, Canada	Link to article

The goal of this research is to describe the role of agency providers in DF home care in Canada and consider potential equity implications for service access from the perspectives of clients and families. Framed with intersectionality, the study included online focus groups with families and clients (n = 56) in Alberta and Manitoba between June 2021-April 2022.

The article presents five thematic findings. First, the focus groups document high rates of satisfaction with the care regardless of whether the client uses agency providers. Second, agency providers mediate some of the administrative barriers and emotional strain of using DF home care, and this is especially important for family caregivers who are working or have additional care responsibilities. Third, there are out-of-pocket expenses reported by most participants, with agency clients describing administrative fees despite lower pay for the frontline care workers. Fourth, agencies are not generally effective for linguistic and/or cultural matching between workers and families. Finally, we find that DF care programs cannot compensate for a limited informal support network.

The researchers concluded that clients and families often intentionally choose DF home care after negative experiences with other public service options, yet the results suggest that in some Canadian contexts, DF home care is a privilege only afforded to some. Given the growing inequalities that exist in Canadian society, all public home care options must be open to all who need it, irrespective of ability to pay, degree of social support, or competence in the English language.

Choice and quality in home-based and community-based aged care: insights from two rapid evidence reviews

Hunter, N.J.; Wells, Y.; Clune, S.J.; Quintanilla, B.P.A.; & Johnstone, E.	2019, UK	Link to article

This literature review focused on drivers of choice and perceptions of service quality for older adults using consumer directed care programs. The review included 21 articles (most from Australia and the UK, with a few from Canada).

The literature highlighted that consumer choices of services are driven by a combination of: desire for flexibility in service provision; optimising mobility; need for personal assistance, security and safety, interaction, and social/leisure activities; and to target and address previously unmet needs. Similarly, consumer perspectives of quality include control and autonomy, interpersonal interactions, flexibility of choice, and safety and affordability.

The review suggests that future model development should take into account consumers' freedom to choose services in a flexible manner, and the value they place on interpersonal relationships and social interaction.

Literature Review (continued)

Emergent Issues in Directly-Funded Care: Canadian Perspectives

Kelly, C.; Jamal, A.; Aubrecht, K.; & Grenier, A.	2019, Canada	Link to article

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

Grey literature related to this study can be found here.

Self-managed aged home care in Australia – Insights from older people, family carers and service providers

Laragy, C. & Vasiliadis, S.D.	2021, Australia	Link to article

This paper presents findings from the evaluation of an Australian trial of self-managed home aged care. The primary aim of the evaluation was to examine whether self-management improved consumers' perceptions of their choice, control, and wellbeing. The secondary aim was to examine whether providers' prior experience with self-managed packages significantly influenced consumers' perceptions of choice, control, and wellbeing, thereby confounding trial effects. Various methods were used to collect data over nine months in 2018 and 2019. They gathered data from 60 online surveys and conducted 24 semi-structured telephone interviews with consumers, family carers, and consumers and carers jointly. Fourteen semi-structured telephone interviews were also conducted with CEOs and senior managers from each of the seven providers. Three providers had prior experience supporting self-management.

Participants reported improved wellbeing in interviews, however this was not reinforced statistically. Key desirable features of self-management included greater autonomy and control over spending, recruiting support staff and paying lower administration fees. There was no evidence of increased risks or fraud. The research limitations included a small sample size, convenience sampling with providers recruiting interview participants, no control group, and differences in trial implementation. The findings support the expansion of self-management opportunities and more comprehensive evaluations that use mixed methods.

Literature Review (continued)

Influences of service characteristics and older people's attributes on outcomes from direct payments

Davey, V.	2021, UK	Link to article

Background: In the UK, Direct payments (DPs) are cash-payments that eligible individuals can receive to purchase care services by themselves. Their advantages remain controversial. This controversy is partly due to their lack of historical visibility — DPs were deployed in stages, bundled with other policy instruments amidst increasing budgetary constraints. As a result, little unequivocal evidence is available about the effectiveness of DPs.

This study aims to address that evidence gap using data obtained during an early evaluation of DP's that took place between 2005 and 2007. They conducted semi-structured face-to-face interviews with 81 older people (and their proxies) that used DPs. Data on individual characteristics (dependency, unpaid care) and received services (types and amount of services) was also gathered. Multiple regression analyses were performed between measured outcome gains and individual and service characteristics.

They found that levels of met need compared very favorably to average social care outcomes in the domains of social participation, control over daily living and safety, and user satisfaction. Benefit from DPs was particularly affected by the role and function of unpaid care and availability of recruitment support. The freedom to combine funded care packages with self-funded care enhanced the positive impact of the former. Large discrepancies between total care input and that supported through DPs negatively affected outcomes.

The results clarified contested aspects of the policy such as the influence of unpaid care, types of care received, funding levels, and the role of wider support arrangements. Tangible benefits may result from direct payments, but those benefits are highly dependent on policy implementation practices. Implementation of DPs should pay special attention to the balance between DP funded care and unpaid care.

Literature Review (continued)

Questioning "choice": A multinational metasynthesis of research on directly funded home-care programs for older people

FitzGerald Murphy, M.; & Kelly, C.	2018, Canada	Link to article

This qualitative metasynthesis considers 47 research articles published between 2009 and 2017 that explore various DF programs for older persons in the United Kingdom, Australia, and the United States to identify core concepts in the literature.

The researchers found that choice emerges as a central concern. They then assessed the literature to explore the questions: How does the existing literature conceptualise choice, and the mechanisms through which choice is enhanced, in DF programs for older persons? How is choice, and the benefit of choice to older service users, understood in relevant studies? The researchers argue that the concept of "choice" manifests as a normative goal with presumed benefits among the studies reviewed. Particularly when discussing DF for older people, however, it is essential to consider which mechanisms improve care outcomes, rather than focusing on which mechanisms increase choice writ large. In the case of DF, increased choice comes with increased legal responsibilities and often administrative tasks that many older people and their supports find burdensome. Furthermore, there is no evidence that choice over all elements of one's services is the mechanism that improves care experiences.

They conclude by presenting alternative models of understanding care emerging from feminist and other critical disciplines to consider if the literature is, perhaps, asking the wrong questions about why DF is so often preferred over conventional home-care delivery.

Program Review

Home Care Allowance - "Häusliche Pflegegeld"

Handbook Germany	Est. 2004	Germany

In Germany relatives or acquaintances can take over the care at home and the recipient of these services will receive a monthly "care allowance" ("Pflegegeld"), which is at their disposal. The amount of the care allowance depends on the level of care ("Pflegegrad") required according to the initial assessment. Currently, the amount of long-term care allowance is between €332 (care level 2) and €946 (care level 5) per month (as of July 2021). One cannot receive a care allowance for care level 1. When cared for by family members or acquaintances, the recipient will be visited twice a year by qualified care professionals who will give the care recipient and their family members tips and advice.

The assessment is conducted by the Medical Service of the Health Insurance Funds (Medizinischer Dienst der Krankenversicherung or MDK) or an equivalent agency.

Adult Social Care - Direct Payments

City of Wolverhampton Council	Est. 2000	UK

Direct Payments help adults who want to be more in control of who supports them, so their needs can be better met. For example, if one needs help getting in and out of bed in the morning and help with getting washed and dressed, traditionally the council would arrange the help — but with Direct Payment, the council gives recipients the money to buy the service for themselves. A recipient of Direct Payments can either employ their own support worker to carry out these tasks or buy the support from a private care agency. Currently, Direct Payments can be used to buy any type of care and support that one is assessed as requiring in the community but it can only be used for up to 4 weeks stay in a care home (respite or short stay) in any 12 month rolling period. Stays of less than 4 weeks are added together where there are less than 29 days separating them. To get this service one must earn an incoming below £23250 per annum.

Individuals are advised to contact their local council for a care needs assessment. This assessment determines the appropriate measures to help maintain independence at home for an extended period. With consent, caregivers, general practitioners (GPs), or district nurses can initiate the assessment process. When individuals are discharged from the hospital, the ward staff can arrange homecare services to ensure safety and proper support at home, as well as aid in rehabilitation if necessary. The planning of future care and support is typically led by a social worker. If the local council determines that an individual is eligible for home-based care and support, a means test is conducted, considering the person's income and savings. Notably, the value of one's property is not considered in the means test unless the individual is moving into a care home.

Program Review (continued)

Self-Managed Support

Department of Social Development	Est. 2021	New Brunswick

Self-Managed Support (SMS) program for seniors is managed by the Department of Social Development for the province of New Brunswick. SMS gives individuals choice, flexibility and greater independence by allowing them to manage their own services. It means that a recipeint will receive a lump sum payment at the beginning of every month to cover the cost of the services they receive. Through the Long Term Care and Disability Support Programs, the individual is assessed, a plan is developed between the would-be recipient, a social worker, and other people who support them. Services are coordinated that are tailored to their needs. With the Self-Managed Support option, the recipient is responsible for overseeing their care needs by coordinating, managing, and directing services identified in the Support Plan.

Consumer-Directed Personal Assistance Program - Self-directed Medicaid Services for Home Care Independence

Medicaid	Est. Early 1990s	United States

Self-directed Medicaid services means that participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process.

Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided. For example, participants are afforded the decision-making authority to recruit, hire, train and supervise the individuals who furnish their services. The Centers for Medicare & Medicaid Services (CMS) calls this “employer authority.” Participants may also have decision-making authority over how the Medicaid funds in a budget are spent. CMS refers to this as “budget authority.”

Program Review (continued)

Home Care Packages Program - Consumer-Directed Care (CDC) approach

Department of Health and Aged Care	Est. 2010	Australia

The Home Care Packages Program is designed to support older individuals with complex care requirements, enabling them to maintain their independence in their own homes and remain connected to their communities. The program adopts a consumer-directed care approach, ensuring that the provided support is tailored to meet each person's specific needs and goals. Support is delivered through a comprehensive Home Care Package, which encompasses a coordinated array of services, including assistance with household tasks, provision of equipment like walking frames, minor home modifications, personal care, and clinical care such as nursing, allied health, and physiotherapy services. The Home Care Packages Program offers four levels of care packages, ranging from level 1, addressing basic care needs, to level 4, catering to involved care needs. Funding for Home Care Packages is provided by the Australian Government under the Aged Care Act 1997 and Aged Care (Transitional Provisions) Act 1997.