The Implications of Self-Directed Home Care in Ontario
A Case Study on Gotcare Services

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Key Points

The Ontario home care system is fragmented. Its services are divided among the public sector, for-profit, and nonprofit home care companies. Publicly funded care is often insufficient and leaves many older adults having to seek out additional privately funded care.

The Reach Alliance conducted a case study on an Ontario home care company called Gotcare to understand how its innovative provision of self-directed home care fits within the province’s home care ecosystem.

We found that self-directed home care offers many benefits to the home care sector, reducing administrative costs and providing care recipients more choice and control. However, more research is necessary to understand and manage the unique risks associated with self-directed home care.

Background

Canada faces a shortage of home care options that will intensify as the proportion of older adults in the country continues to increase—especially in rural and remote regions.¹ In Ontario, the number of older adults (>65) is expected to grow from 2.4 million (or 16.9% of the population) in 2018 to 4.6 million (or 23.4% of the population) by 2046.² Researchers from the Reach Alliance, based at the University of Toronto’s Munk School of Global Affairs and Public Policy, conducted a qualitative case study on an innovative home care company in Ontario called Gotcare. It provides home care services using a self-directed model of care that uses technology. We explore how self-directed home care is delivered, the experiences of Gotcare employees facilitating this type of care, and perspectives from home care experts on the

concept of self-directed home care. Researchers interviewed Gotcare management and care workers, as well as experts in the home care sector (from other home care companies and academia).

Programs and services to support older adults in their homes and communities are cost effective and lead to positive health outcomes. Home care in Ontario is estimated to cost approximately $45 per day, compared to care costs of $135 per day in a long-term care facility and $450 per day in a hospital. The Canadian Medical Association (CMA) notes that older adults need improved support services to avoid unnecessary hospital admissions and allow patients to be discharged back into the community as early as possible.

Despite its cost-effective positive outcomes, home care is not included under the Canada Health Act and remains difficult to access for many Ontarians. Publicly funded home care services are managed by the provinces and territories as well as several federal departments and agencies (e.g., Veterans Affairs Canada and Indigenous Services Canada). Ontario established Community Care Access Centers (CCACs) in the 1990s to deliver publicly funded home care, but these were dismantled in 2017 following a report from the province’s auditor general. The report raised several concerns, including rising and inconsistent costs despite “too little spent on direct care,” and discrepancies in patient experience depending on their location. Currently, Local Health Integration Networks (LHINs) assess care recipients’ needs and fund home care through various nonprofit and for-profit care providers. The number of LHINs has decreased from forty-three to only fourteen despite an increasing scope of responsibility. Insufficient and inconsistent funding has led to long wait lists for Ontarians needing home care.

Home care can also be purchased through private insurance, employee benefit plans, or out of pocket. In 2016, over 730,000 Ontarians received more than 39 million hours of publicly funded home care, while an estimated 150,000 Ontarians are forced to purchase an additional 20 million hours of care annually. Furthermore, Ontario cut acute-care hospital beds by 44 percent between 1990 and 2014, and has fewer hospital beds per capita than any other Canadian province or territory. With fewer beds, hospitals in Ontario face pressure to transition patients into home care, despite many issues with home care services: the number of patients discharged to home care services after a hospital stay increased by 42 percent from 2008–2009 to 2012–13.

Stakeholders do not agree on solutions to address the home care sector’s shortcomings, despite the continuing increase in demand from the province’s population.

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4 Ibid.
5 Heather Gilmour, “Unmet Home Care Needs in Canada.”
Implications of Self-Directed Home Care in Ontario

In 2017 the Ontario government formed the Self-Directed Personal Support Services Ontario (SDPSSO) agency to directly employ a pool of Personal Support Workers (PSWs) and manage their pay and training while enabling care recipients to choose their care provider and schedule their own services. The SDPSSO’s implementation was halted by a coalition of home care service providers (a group of eleven nonprofit and for-profit organizations who in total provide 95 percent of home care services in Ontario) through a judicial injunction. The coalition argued that the new agency would act as unfair competition and threaten service provision because of increased bureaucratization. After a change in provincial government in 2018, the SDPSSO was dissolved and a new Family-Managed Home Care program was introduced, which excludes older adults from its eligibility criteria.

These issues illustrate how fragmented home care is in Ontario. The lack of consensus on how the province’s home care should be organized has led to a patchwork situation where PSWs are at the mercy of different home care companies—with no consistency and no guaranteed quality of employment.

A problematic outcome arising from a lack of consistency in the coordination and delivery of home care in Ontario (including the creation and dissolution of provincial agencies and the vast decrease in the number of LHINs) is the chronic shortage of PSWs. According to the Ontario Ministry of Health and Long-Term Care, the turnover rate among PSWs reached 60 percent in 2014, but there is yet to be a long-term strategy in place to improve the viability of the profession that is widely agreed to be overworked and underpaid. The ministry has announced a forthcoming 2020 study that will focus on staffing of PSWs and other key roles, but it will focus on long-term care homes.

PSWs have no official governing body and are not considered a “registered” health profession, and therefore lack both job security and recognition—their employment conditions vary with each contract. The shortage of PSWs requires people working in the sector to manage higher caseloads (many of which are complex) in a shorter amount of time, which contributes to burnout. Transportation is also a significant issue—PSWs often must travel to various homes which adds a high level of stress as unexpected delays arise, and transportation costs are not always reimbursed. According to Home Care Ontario, uncompetitive wages, inadequate human resource strategies, and unrealistic scheduling and time allocations to provide quality care must be addressed in the home care sector.

13 Ibid.
17 Katerina Kalenteridis and Ito Peng, "Caring About Home Care: A Framework for Improvement in Ontario."
18 Ibid.
20 “More Home Care for Me and You.”
From the premier of Ontario’s Council on Improving Healthcare and Ending Hallway Medicine’s latest report, one of the ten recommendations to improve health care is to “modernize the home care sector and provide better alternatives in the community for patients who require a flexible mix of health care and other supports.” It calls for the government to “modernize home care legislation so that innovative care delivery models focused on quality can spread throughout the province.” Some sector analysts are considering whether a new self-directed model of home care might address both PSWs’ as well as care recipients’ needs. Terms such as “self-directed” or “self-managed” care refer to a growing trend across health care that provides care recipients with more autonomy in procuring and receiving services. In the context of publicly funded home care, self-managed care refers to a direct funding structure that has long served adults with physical disabilities: the government provides funding to care recipients who then purchase home care services directly from a provider of their choice. However, self-directed care can also be understood more broadly: according to the Alzheimer’s Association, “self-directed care services, often referred to as consumer-directed services, is a philosophy and practice that assumes that caregivers have the right and ability to assess their own needs, determine how and by whom those needs are met, and evaluate the quality of the services they receive.” Gotcare, the subject of our case study, is one company that provides self-directed home care for recipients, most of whom are covered by private insurance.

Gotcare

Gotcare, established in 2018, is the largest privately operated, self-directed home care provider in Ontario, with the mission to make home care a “viable career for front-line workers and find operational efficiencies.” Using short message service technology (text messages), Gotcare matches those seeking care with those willing to provide it based on their geographical proximity, and enables care recipients and care workers to manage their care relationship independently from the company. While traditional home care companies employ PSWs and nurses, Gotcare also employs people such as neighbours to aid with day-to-day tasks such as buying groceries. Currently, the company estimates their network of care workers in Ontario to be over 9,000. Care recipients using Gotcare services are provided with a short list of potential home care workers located nearby, and then recipients vet and choose their own care workers. The vetting process includes interviewing candidates, checking references, requesting criminal record and vulnerable sector checks (an expanded police information check to include record suspensions for sexual offences), and verifying CPR/first aid certifications. Once the match is made, care recipients schedule appointments with care workers directly, determine which tasks they require to meet their needs, and manage the provision of these tasks.

Gotcare suggests they are improving career opportunities for home care workers because they can minimize commute times (made possible by location-based matching with care recipients) and offer working hours throughout the day, rather than the traditional home care model of “split shifts.”

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24 “The Need for an Alternative Home Care Delivery Mechanism,” Gotcare, 8 November 2018, Gotcare.ca.

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In their study sampling “500 care appointments,” Gotcare found that 22.7 percent of care recipients preferred receiving care in the afternoon. And as a result of their emphasis on proximity between care recipients and home care workers, the company reported that among the 500 care appointments they sampled, only 0.2 percent of appointments were missed.

Policy Considerations for Self-directed Home Care in Ontario

Self-directed home care is on the rise in Ontario. Providers such as Gotcare offer care recipients increased control over their care through the use of digital applications. Although private, these providers can be publicly funded (Gotcare receives a small minority of referrals from LHINs). This model of home care presents many opportunities to a sector in need of innovation, but also risks that should be carefully considered and mitigated by policy-makers. (See Annexes 1 and 2 for considerations for both self-directed home care recipients and care workers.) What follows are some of the issues we identified in our case study.

Universality:

- Home care is not included under the Canada Health Act. Publicly funded home care services vary across jurisdictions when it comes to eligibility, types and amounts of services provided, and whether recipients need to pay for a portion of their care. A 2015–16 Canadian Community Health Survey found that over one-third of adults over eighteen years of age with home care needs did not have these needs met, with lack of availability of services as the most frequently reported barrier to obtaining home care. As Ontarians are purchasing the equivalent of an additional 50 percent of total publicly funded home care hours, policy-makers should ensure that older adults who are most in need of care are able to access the support they require, whether through self-directed home care or traditional models of care. This is especially important for older adults without access to employee benefits, private insurance, or the financial means to pay out of pocket.

Gaps in research and health policy:

- There are currently no accreditation standards or regulations governing self-directed home care despite the fact that home care recipients are generally a vulnerable population. Research is needed on health and well-being outcomes for care recipients who have received self-directed home care. Guidelines must be developed to ensure high-quality care.

- Standards or regulations governing self-directed home care should account for various types of cases. For example, Gotcare serves care recipients with severe injuries who are receiving care from PSWs or nurses, as well as those seeking companionship or home-making services who are receiving care from neighbours or family members registered as Gotcare employees. Different use cases are associated with different levels of risk—a key factor for consideration when establishing standards or regulations.

- Any new standards or regulations should include corresponding plans for oversight by an independent party to ensure they are being

26 “The Need for an Alternative Home Care Delivery Mechanism.”
27 Ibid.
28 Heather Gilmour, “Unmet Home Care Needs in Canada.”
29 Ibid.
implemented by home care companies. This oversight should be routinely conducted and transparent to home care recipients.

- Policy-makers should clearly delineate and communicate the responsibilities of home care companies, care recipients, and care workers. Each party should be provided with the tools they require to meet their responsibilities. For example, if care recipients and their families are expected to vet care workers’ qualifications, references, and police checks, they must be given appropriate training and support to do so. An absence of rigorous vetting has been an issue in the past. In 2011 the province of Ontario contracted the establishment of a provincial registry of PSWs. This registry was discontinued in 2013 in part because it lacked sufficient vetting of PSWs—numerous PSWs listed in the registry had criminal records or poor employment histories that they did not disclose.\(^{30}\)

- Policy-makers must produce neutral and reliable information that is readily available to potential home care recipients in Ontario. There is currently a lack of neutral and reliable information, which is particularly important to assist care recipients in making an informed decision between self-directed care or more traditional home care (assuming both are available).

**Quality of employment:**

- Gotcare’s self-directed care model provides flexible part-time work for care workers. While this may be ideal for some, it does not provide the full-time hours or job security that is currently missing from the home care sector. However, the company claims its use of technology creates a “lean” operational structure that enables them to pay their care workers above the market average. As the home care sector faces a shortage of care workers, policy-makers should ensure that care workers are paid a competitive wage, have job security, and have the option of full-time work, should they require it.

- Allowing home care recipients to select their care workers may be especially beneficial in a diverse province such as Ontario, where visible-minority seniors are becoming the fastest growing segment of the aging population.\(^ {31}\) As over 50 percent of immigrants to Canada settle in Ontario, choosing a care worker who speaks the same language or who understands the recipient’s ethnocultural context can make a difference to the care recipient’s quality of life. However, care workers also need to be treated fairly and protected against discrimination on prohibited grounds (such as ancestry, colour, and race) that would prevent them from being employed and would violate their human rights.\(^ {32}\)

**Technological considerations:**

- Gotcare’s location-based matching service reduces the geographical distance between care recipients and care workers, leading to more community-based care. Its digital “app” allows care workers and recipients to schedule shifts without going through management. Other

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\(^{30}\) Katerina Kalenteridis and Ito Peng, “Caring About Home Care: A Framework for Improvement in Ontario.”


technological offerings include a budgeting tool that ensures care recipients are not scheduling hours beyond those paid for by their insurance plans. Policy-makers should ensure that digital infrastructure such as network connection is available to all Ontarians who might require access to such applications, including in remote and rural areas, and that digital literacy is promoted among populations such as seniors.

Gotcare requires care recipients and workers to use their digital application and provide data such as their location. Given growing concern over data security and privacy, companies must ensure they are being transparent with recipients and care workers regarding what data they are collecting and whether there is an option to opt out; how they are storing this data (e.g., whether it is de-identified and stored on a secure server); whether they are sharing it with any third parties; and what happens if and when either party exits the platform. Home care companies must abide by privacy laws such as the provincial Personal Health Information Protection Act (PHIPA), and these standards must be kept current with technologies employed by the home care sector.33

**Continuity of care:**

Many older adults seeking home care have complex needs arising from comorbidities. They may require that their care be coordinated among various healthcare professionals, across hospitals, clinics, etc. Gotcare’s infrastructure currently does not facilitate communication or the regular sharing of updated information between care recipients’ “circle of care.” This issue is not specific to Gotcare—Home Care Ontario has also reported on this lack of coordination despite the potential of digital technology and electronic health records. Frontline home care workers are unable to access or contribute to patients’ health records because “patient information is currently contained in islands of data that reside mostly within the walls of each health care provider.”34 This results in patients and their families having to be the primary source of healthcare information between providers, which can put them at risk if information is overlooked and cause frustration when information must inevitably be repeated.35

### Conclusion

Canada’s universal healthcare system, and its core value of high-quality health care for all regardless of a person’s ability to pay, is arguably foundational to Canadian identity. The provision of health care in Canada is dominated by the public sector rather than the private sector. Some stakeholders such as Gotcare argue that this centralized approach has resulted in a lack of innovation, especially in sectors such as home care that typically do not prioritize choice or personalization of care. It is apparent that publicly funded home care is currently insufficient to meet the needs of the aging population in Ontario. Those in need of home care will continue having to top up or otherwise privately purchase home care from nonprofit and for-profit providers for the foreseeable future. If companies such as Gotcare can offer innovative services that increase the availability of home care for recipients, this may provide some relief to an overburdened home care sector.

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35 Ibid.
It is important that policy-makers conduct a thorough analysis of how to modernize the home care sector without compromising the safety of Canadians and the quality of their care. Ensuring that home care is a viable career option for care workers must also be prioritized, in terms of providing job training, job security, and fair compensation. The sector will also have to carefully consider reliable processes to screen care workers before they go into vulnerable peoples’ homes. Modernizing the sector will no doubt involve technology as a powerful tool in creating efficiencies, such as reducing care workers’ commute times and allowing care recipients to coordinate directly with their care workers. There should also be safeguards in place to ensure that recipients who choose self-directed care are doing so after considering options that provide more oversight. And of course, potential care recipients must have the cognitive capacity to take on the responsibilities associated with managing self-directed care.

Allowing home care to be provided by employees with a broader range of qualifications, from neighbours to nurses and personal support workers, may indeed be an effective way to address the shortage of PSWs. However, if this broadening of the home care sector is not managed in a way that ensures care workers are able to safely care for recipients’ specific needs, vulnerable Ontarians will be at risk. Care recipients experiencing negative outcomes caused by insufficient oversight from home care company management, or the Ministry of Health and Long-Term Care more broadly, could result in a loss of public trust in the self-directed home care model. It is important that policy-makers, home care companies, and other stakeholders such as patient advocacy groups proactively and transparently work together to ensure that risks to care recipients and care workers are lowered to an acceptable level.

Self-directed care could become a core fixture in the healthcare sector. Through the use of technology, Ontarians can now control when they receive care, from whom, and in what way. We found that different participant groups (namely Gotcare management and home care experts) have different interpretations of how to balance providing greater choice, control, and responsibility to care recipients while ensuring that oversight and safety protocols are in place. Policy-makers will need to conduct their own assessments of self-directed home care. Decisions surrounding standards or regulations should be based on empirical evidence which is currently insufficient. In the meantime, companies like Gotcare will continue to fill a gap in the home care sector and provide much-needed home care to Ontarians, who in some cases have no other options.

Annexes 1 and 2: Checklists for Determining Appropriateness of Self-Directed Care

The following checklists were developed based on findings from our case study. The first checklist is intended to be a guide for healthcare professionals responsible for connecting patients with home care services, as well as care recipients and their families, to determine suitability for self-directed care. The second checklist is intended for home care workers who are considering employment with a self-directed home care company, where the nature of service provision differs from more traditional home care companies. While these checklists can be used to support the development of best practices in initiating self-directed home care, given the emerging nature of this care model they should be updated as future research is conducted.
Checklist to Determine Appropriateness of Self-Directed Home Care for Care Recipients

Care Recipients who plan to initiate Self-Directed Home Care must be informed of the choices they will face in the provision and experience of Self-Directed Home Care, and must make a conscious and deliberate decision to engage with this model of care. Care Recipients should consider this checklist carefully and speak with their family and primary health care provider before seeking Self-Directed Home Care.

**Care Recipient’s Ability to Self-Direct Care**

☐ Care Recipient must be willing and able to conduct ALL aspects of Self-Directed Home Care, including:

- Vetting potential Home Care Worker, including interviewing multiple candidates before selecting the best fit.
- Learning about the risks and benefits of Self-Directed Care, including personal liability, and the liability of the Home Care Worker and the respective agency.
- Managing elements of day-to-day care delivery and coordination, such as delegating tasks to the Home Care Worker and effectively addressing any issues that arise.
- Using technology to communicate with the Home Care Worker and to schedule shifts, while also managing the number of care hours they are entitled to receive (based on public or private health coverage).
- Fostering a positive professional relationship with a dedicated Home Care Worker to ensure long-term continuity of care.

**Care Recipient’s Health Needs**

☐ Care Recipient is NOT in an emergency situation.

1. If urgent care is required, the Care Recipient or their family is advised to call 911 for emergency services.

☐ Care Recipient is NOT cognitively impaired.

1. Care Recipients with severe brain damage and/or cognitive impairment are not considered appropriate candidates for Self-Directed Home Care. [Unless the Care Recipient has an identified Substitute Decision Maker or a Power of Attorney in place who may determine the appropriateness of Self-Directed Home Care and make subsequent care decisions.]
Home Care Workers seeking employment with home care agencies that offer Self-Directed Home Care must be informed of the responsibilities they are undertaking in this model of care. Home Care Workers should consider this checklist carefully, and gather necessary information from potential employers before providing Self-Directed Home Care.

### Home Care Worker’s Ability to Provide Self-Directed Care

- **Home Care Worker must be an independent and highly motivated professional:**
  - Learning about the risks and benefits of Self-Directed Care, including their own liability, and the liability of the Care Recipient and the respective agency.
  - Demonstrating strong professional judgement to know when to proactively seek clarification and assistance from management, such as communicating when they are unable to meet a Care Recipient’s needs.
  - Demonstrating initiative to maintain qualifications and skills without rigorous oversight from employer. [In Self-Directed Models of Care, employer agencies may not provide onboarding or ongoing professional development.]
  - Providing potential Care Recipient with the information they require for vetting purposes and participating in interviews conducted by Care Recipient and their family or substitute decision-makers.

- **Home Care Worker must be willing and able to manage their work directly with the Care Recipient (interacting with management only if and when necessary):**
  - Assessing the fit between Care Worker and Care Recipient, both in terms of personal compatibility and the Care Worker’s ability to complete tasks outlined by the Care Recipient.
  - Receiving direction for the delivery and coordination of care directly from Care Recipient, such as the delegation of tasks. Effectively addressing any issues that arise with Care Recipient.
  - Using technology to communicate with the Care Recipient, and scheduling shifts with them directly.
  - Fostering a positive professional relationship with Care Recipient to ensure long-term continuity of care.
  - Understanding that the hiring decision resides with each Care Recipient individually, and not with the home care agency. Care Recipient can choose to terminate this relationship at any time, resulting in a loss of employment.

### Home Care Worker’s Employment Needs

- **Home Care Worker is willing and able to operate within a flexible work style:**
  - Understanding that Self-Directed Home Care often provides part-time hours rather than full-time employment.
  - Adjusting shifts when necessary, according to the Care Recipient’s schedule.
  - Providing care with less guidance than is typically provided by traditional home care agencies, such as formalized care plans, note-taking, or regulations regarding a limited scope of approved tasks.
  - Serving Care Recipients who live in close proximity to where Care Workers live, due to location-based matching.