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Enhanced Home Care: One Important Alternative to Institutionalization

During this pandemic it is apparent that supports for older adults with complex care needs leave a lot to be desired. We have all heard stories about the negative impact of segregating people in crowded long-term care facilities. These institutions have been a disaster during the pandemic, with people crowded into two, three and four person bedrooms because of a failure of this sector to use resident co-payments to upgrade their facilities.

There is an urgent need for home care reform to address the needs and wishes of an aging population and the increased demands that are being placed on nursing homes and community support systems. Seniors for Social Action believes that enhanced home care is one of the important alternatives to the institutionalization of our elders. People should be supported to age in the community with individualized home care supports.

Current Realities of Long-Term Care and Home Care

Here are some realities that can help to frame strategies for building a robust, family-centred, non-profit home care system.

- Research shows that many people in long-term care do not need a nursing home. The Canadian Institute for Health Information found that more than

12% of Canadians in long-term care could *easily* remain in their own home with community support.ⁱ Furthermore Professor Grignon from McMaster University has said that 20% of people in long term care have no cognitive challenges and could be cared for at home.ⁱⁱ Other countries have shown that a much larger percentage of people can be supported in their own homes.ⁱⁱⁱ

- Many overcrowded hospitals have older adults waiting to be placed in long-term care. An effective home care system, including high intensity supports, could enable most of these folks to age at home.
- Research shows that people do not want to end up in long-term care.^{iv} Not surprisingly, these numbers have been increasing during the chaos in long-term care during this pandemic, with over 90% of Canadians saying they want to age at home, not in an institution.
- The likelihood of people becoming ill and getting infected is much greater in long-term care institutions than in the community, especially in for-profit facilities.^v This has been borne out during this pandemic, with very few cases of Covid 19 attributed to home care as opposed to the huge numbers who were infected in long-term care facilities.
- The impact of loneliness and social isolation of residents in nursing homes has been significant, with thousands of elders unable to see their family members for months. We know that loneliness and social isolation negatively affect mental and physical health.^{vi}
- In Canada, only 13% of funding for frail elders is for home care and community-based supports, while 87% of government funds go to nursing homes. Some European countries, such as Denmark, fund mostly home care and community alternatives for frail elders.^{vii}
- Countries such as Germany, Japan, and Denmark have done much better than Canada at lowering the rates of institutionalization of frail elders. As an

example, in Japan 33.6 per 1000 people aged 65+ are institutionalized compared to Canada at 58 per 1000 in the same age range.^{viii}

- Dr. Samir Sinha, a leading Toronto gerontologist, says that enhanced home care will reduce the need for nursing homes at significant savings. He points out that it costs \$183 per day to house a high-needs person in a long-term care home compared to just over \$100 a day to provide home care.^{ix}

Foundational Principles for Enhanced Home Care

SSAO believes that four foundational principles will help create the right mindset for home care reform.

- To create enhanced home care we must shift our thinking. The focus needs to be on how people can *age in place*, rather than believing that institutionalization is inevitable. People also need to experience a dignified *quality of life*, since most older adults want to stay at home. These two guiding principles can help ensure that people will receive the care and supports they require.
- An enhanced home care system will also be guided by the principles of self-determination and community. *Self-determination* means that supports are person-directed or family driven. It also means not being forced, for financial or care-related reasons, to enter institutions. *Community* means that the home care supports are provided by non-profit community-based organizations. Community also means that home care supports recognize the person's community as an important part of their life. This can include family, friends, and neighbours. These principles are the foundation for reforming home care while expanding its capacity.

Key Features of Enhanced Home Care

SSAO believes that the following features will help us build a robust, person/family-driven, non-profit home care system.

- Enhanced home care will have *no service maximums*. This means that people can access any level of support to remain at home. The weekly maximum hours for home care are generally inadequate to support people with complex needs. As the Alliance for Self-Determination states, personal supports should be available for everyone who wants to remain in their own home. This sometimes will require high intensity supports.
- Enhanced home care will have *direct funding* as an option for individuals and families. Direct funding enables funds to go directly to the person and/or family, who can then manage the funds to hire workers of their choice. Research shows that this approach not only enhances self-determination, but also expands the workforce by making more people available to assist older vulnerable adults. The Ontario Ministry of Health has a small Family Managed Home Care Program that provides direct funding.^x This concept of self-directed funding is an important initiative that needs wide-spread expansion.
- Enhanced home care will *provide supportive assistance* that will help people and families to develop a holistic approach to their situation, including planning, links with other needed services, hiring workers, managing funds, and network development. This can happen through expanded care co-ordination, which currently exists in Ontario. In addition, some people will require intensive case management to address home care concerns as well as personal and social issues they may be facing.^{xi} Ontario already has well-trained facilitators working with people with disabilities. Home care policy

could incorporate some of the lessons learned from the Ontario Independent Facilitation Network.^{xii} OIFN has extensive experience in assisting people with life transitions, planning, and network development. It has been shown that when facilitators and case managers are guided by self-determination and community, they build resilience and capacity in individuals and families.^{xiii}

- Enhanced home care will *address the context in which people are living* in a more systematic way. Home care tends to be dominated by a “placement” model, where workers are placed in someone’s home for a certain number of hours per week. In some jurisdictions, little attention is paid to whether the person is socially isolated or lonely, even though these are increasingly important determinates of healthy aging and well-being. As Montreal psychologist and journalist Susan Pinker found from extensive research, people’s health and well-being are significantly impacted by strong relationships and social networks.^{xiv} This is the principle of ‘community’ in action. Imagine if care co-ordinators and case managers enabled isolated, vulnerable people to build stronger connections and sense of community with neighbours, friends, and family. As Pinker points out, this is the power of the “village effect.”

Funding for a Re-Designed Home Care System

Building an enhanced home care system in Ontario will require significant funding. People developing policy in this area will have to consider some of the ways that funding can maximize cost effectiveness, while ensuring that the principles guiding the change are embraced at all levels of implementation.

SSAO believes that funding for a re-designed home care system will include:

- The *home care system will be fully funded* so that home care can be expanded to address three areas: community waiting lists; people waiting in hospitals for care and support; and people currently living in a nursing home who would prefer to be at home. In addition, the provision of high intensity supports at home will require new funding.
- In general, *money should follow the person*. This ensures that we stay focused on the person and what they require to age in place and to have a good quality of life. As we begin to de-populate large institutional facilities, money can move with the person. As Dr, Sinha points out, long-term care facilities spend up to \$183 per person per day. This money would allow someone leaving a nursing home to have up to 5 or 6 hours of home care a day in their own home. This is only an average, although some people will need less support and others will need more. The United States has a program with Medicaid called *Money Follows the Person Program*, that ensures that people have genuine options.^{xv}
- *Public health insurance* is an important funding approach that can reduce reliance on institutional long-term care beds by shifting support to homes and communities. Several countries have mandatory national health insurance plans. In another SSAO paper, we have outlined the approaches taken in Japan, South Korea, Denmark, and Germany where institutionalization rates have been lowered significantly.^{xvi} In the Netherlands, for example, this kind of insurance has enabled large numbers of people to chose home care, as opposed to institutionalization, which has lowered the overall costs of long-term care by 5 per cent.
- Funding will enable *workers to receive a decent wage*. Too often workers are poorly paid and this explains the high turn-over rates in some home care systems.

- Families can benefit from approaches which *incentivize family involvement*. As an example, the Newfoundland and Labrador Paid Families Caregiver Program, enables family members to be paid for caring for a family member.^{xvii} With direct funding as an option, this kind of approach would give families more flexibility in terms of who they hire.
- *Creative tax incentives* also need to be explored as a way to support an aging population. The federal government currently provides maternity and paternity leave for parents. Some governments also provide compassionate leave for their employees. Another way to incentivize family involvement is to provide *paid leave* for someone who is providing support to a vulnerable elder at home.
- Community services that will deliver home care will be *not-for-profit* organizations. This will save money in the long run. We have seen the negative impacts of a for-profit long-term care sector, and we cannot afford to replicate that in the community. As Ontario expands its home care capacity, the expectation is that new service providers from other sectors like mental health and developmental services will step up to ensure that we have a more robust, and where required, specialized home care system.

It is time for an enhanced home care system that highlights the principles of self-determination and community, thereby enabling vulnerable elders to age at home with a dignified quality of life. With the demands for home care expected to double in the next 20 years, it is time for bold action that includes significant new funding and decent wages for workers. Reformed home care would also stress relationships and the need for effective formal *and* informal supports. As well, direct funding will enable far more people to remain in their own homes and have control over the supports they receive. Intensive supports at home will allow people to move from

hospital settings back to their own homes, and for a significant downsizing of nursing homes.

To make this happen, home care leaders and policy makers can learn from innovative disability supports across Canada, where many of these practices have been experienced over the last two decades.^{xviii} Linda Till, a member of SSAO, has outlined these practices with implications and possibilities for vulnerable elders.^{xix} Policy leaders should also be inspired by the tragic loss of life in long term care facilities and the need for change that has become apparent during this pandemic.

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