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A TRANSFORMATIVE VISION FOR LONG TERM CARE IN ONTARIO

Christine McMillan is 91 years old, has a wealth of real world experience, and founded OASIS along with Brian Brophy while President of Frontenac Kingston Council on Aging. OASIS is a naturally occurring retirement community located in an apartment building owned by Homestead Landholding Inc. Hers and Brian's intent was to build a community of tenants and introduce a program that would include formal and informal social events, exercise programs, guest speakers, skill sharing and other projects as well as affordably priced congregate dining. An onsite coordinator would help tenants to access community supports as their needs changed.

While this approach would not appeal to everyone, it came about based upon one simple concept that is missing from long term care planning today – Christine began by actually asking older adults what it is they wanted. No assumptions. No “I know what is best for you”. She just asked them. And they responded that they feared loneliness and dying alone. To a person they dreaded ending up in a long term care institution.

Shared dread of ending up in a long term care institution is now widespread among older adults and some of their family members. A recent Editorial cartoon in Post Media described it accurately, showing a couple looking at a sign in front of a “nursing home” noting it is a LTC FACILITY. One turns to the other and says “Lacking True Compassion”, paraphrasing the meaning of LTC.

On a daily radio show recently on Global News Toronto, the interviewer vehemently confirmed that he plans to stay out of “these places” (LTC facilities) for as long as he possibly can.

Policy and LTC Programming Gone Bad

Collectively, we have constructed something for elders that society dreads - the LTC facility. Instead of dealing with the dread and creating alternatives to long term care facilities this government simply announces more institutional beds. We are building more of what older adults clearly say they don't want and, as many

know, don't actually need. Alternative models of elder care abound and SSAO has written many papers on these options – intensive in-home supports; paid family caregivers; money tied to the person, not a facility; small, staffed residential programs located in condos, apartments, supportive housing, and regular homes in the community, with special trauma-informed programming for people with dementia.

The true transformation of eldercare begins with what Christine McMillan said is so important, – to listen to older adults. If we really do listen to them, honestly, we will hear that they want to avoid being institutionalized in a long term care facility. They want to age at home with whatever support is needed. They want alternatives to “nursing homes” if they cannot stay at home, and they want choice and control over their lives, as much as they can, with help from others.

What Reform of Long Term Care Should Look Like

Reform begins with a set of principles that should guide policy development, practices and funding.

Four principles emerge in regard to Elder Care and how older adults are treated:

- 1) **Listen** to what they themselves are saying;
- 2) **Provide choice** so that they are not funneled into unwanted and unneeded elder services;
- 3) Ensure their **control and autonomy** over decisions about their care, and elder care resources (including recognition for supportive decision making for those who need that assistance because of failing cognitive abilities);
- 4) Facilitate their **independence** by enabling their competence and skills of daily life.

If we build elder care reform on these basic principles we will develop alternatives to costly LTC beds, and this dreaded institutional model of care.

These alternatives will include:

- A significant expansion of home care that is community based, flexible, portable, and based on the needs of older adults themselves – not on the current meager hours per week doled out reluctantly.

- Ways and means to provide incentives to family members to care for loved ones such as the paid Family Caregiver Program in Newfoundland & Labrador.
- Options for person-directed care (with as much help as is necessary) to direct one's own funding and services such as the Family Managed Home Care program in Ontario and a "*Money Follows the Person*" option for elders and people with disabilities that allows people to use their funding in a way that best suits them.
- Small, shared, fully staffed homes in every neighbourhood that accommodate only a few people. These homes could be bought or rented, made accessible and adapted for any special needs that elders may have. They may include condos, apartments, or ordinary family homes.

A Dysfunctional, Illogical, Demeaning System

The current system of elder care is illogical and demeaning.

Pamela's story is a case in point. In the later stages of a debilitating disease that seriously compromised Pamela's physical abilities, plans for her care are unfolding. She lives alone with a few hours of assistance provided by daily home care, and support from family, friends and neighbours. It is not enough. Pamela is assessed as eligible for a "nursing home" but then rejected because she requires oxygen. Pamela is then offered a hospital bed. A "nursing home" bed is about \$200.00 a day. A hospital bed is approximately \$700.00 a day. Costing for these two options do not include the construction costs of these facilities. Home Care is about \$100.00 a day (no construction costs). But Pamela is denied the few more hours of care per day she requires. In lieu of another few hours of support per day from Home Care Pamela will be offered an expensive hospital bed. Pamela is not listened to, has no viable choice, and is denied control over the care she requires.

The Future

The demand for elder care will increase significantly over the next decade, but this does not imply that more institutional beds are the answer. The voice of older adults and those most affected by the risk of institutionalization will not be satisfied with simply improving the status quo. The parents of baby boomers, baby boomers themselves, and the children of baby boomers are a sizable voting block. They have seen the LTC tragedy unfold, and now dread the outcomes from the current system of elder care.

Transformational change is required now. And it is possible if we all demand it of our elected officials.