Seniors for Social Action (Ontang)

SENIORS FOR SOCIAL ACTION (ONTARIO)

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WELCOME TO THE GULAG: ONTARIO'S REGRESSIVE LONG-TERM CARE POLICIES

The Gulag is the place where people disappear. It may have "care and protection" spelled out in friendly script on the sign outside its gates, but inside those gates, the rules of order and efficiency prevail. As Harriet McBride Johnson declared, people don't vanish into the Gulag because that's what they want or need. They vanish because that is what their government offers: "You make your choice from an array of one."

(Catherine Frazee, former Chief Commissioner of the Ontario Human Rights Commission)

All across the world, developed countries are shunning institutions as a way to care for anyone, much less older adults and people with disabilities. Mass institutionalization and exclusion of elders from their home communities and segregation in institutions is now recognized as a human rights issue (United Nations, 2023).

"Canada ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2010. Parties to the CPRD are required to promote and ensure the full enjoyment of human rights of persons with disabilities including full equality under the law." (Government of Canada, 2022). Article 14 of that Convention requires that people with disabilities, presumably those of all ages, not be deprived of that liberty unlawfully or arbitrarily, yet a large number of people with dementia are deprived of liberty in locked wards because, in the case of Ontario, there are no safe, staffed, neighborhood based, residential alternatives available to them. At the \$200 per day paid to long-term care facilities, safe, small, non-profit or municipally-operated community residences could be created, but have not been.

Bill 7 took away elder Alternative Level of Care patients in hospital's rights to even choose where they will live, and eliminated their right to privacy with respect to their health information, which can now be shared with for-profit corporate providers without their consent.

This amounts to forced institutionalization without due process. How does this meet the standard set out in the U.N. Convention to which Canada is a signatory? Or is the federal government just interested in symbolically being a signatory to this Convention without actually introducing policies and procedures to make it a reality?

Many countries are adopting economic policies that support aging at home and in community - but not Canada, and especially not Ontario where the emphasis is on building even more institutions thereby raising the level of institutionalization of elders even more (Government of Ontario, 2022).

Canada Has Among the Highest Rates of Institutionalization in the Developed World

Canada institutionalizes 5.7% of its elders 65 and over, but the OECD average is 4.7% and many countries' rates of institutionalization are much lower (Hebert, 2020).

Canada's federal government should have learned that institutions are dangerous when it comes to infection spread and mortality of residents, since it had the highest mortality rate of institutionalized elders in the developed world (Ireton, 2021). But after that high death rate the federal Minister of Health did not call together the provincial premiers to discuss how the federal government might be helpful in funding alternatives to these dangerous facilities. Instead the federal government embarked on another symbolic exercise in developing voluntary standards that are likely to sit on the shelf and cannot be enforced (Roman, 2023).

There has been an obvious absence of federal leadership after the deaths of thousands of Canada's elder citizens in these institutions, and a studied ignoring of the pleas of elders to be able to age in place in their own homes and communities.

Many countries recognize that institutions are too dehumanizing and financially as well as morally unsustainable, and the case against mass institutionalization has now been made by leading international academics (Knapp et al, 2021).

Institutions are also almost impossible to staff appropriately and care is unlikely to be any better if they are, if we look at the historic example of mistreatment of people with developmental disabilities in Ontario's government-operated institutions that resulted in their closure after years of advocacy, in some cases, by Seniors for Social Action Ontario (SSAO) co-founders (Government of Ontario, 2009).

Younger People with Disabilities Also Being Institutionalized

Ontario continues to fail to properly fund alternatives for younger people with disabilities as well as elders, resulting in the institutionalization of young and old and a rising tide of repugnance at Ontario's policies by elders and younger people with disabilities and their families (Remember Every Name, 2023). Younger people are being driven into institutions with their elder parents because of an absence of aging in place community alternatives for both young and old. In some cases, like the one that recently came to SSAO's attention, people who survived the institutions end up being "placed" miles from their home communities in corporate-operated long-term care facilities with some of the worst track records in Ontario. Some non-profit community agencies are abandoning them in the absence of funding for appropriate levels of care and support to maintain them in place.

SSAO was also recently informed about a young Indigenous woman in her 20's who was institutionalized in a Toronto long-term care facility with a terrible track record after having been in an accident. She has waited a very long time to get out because of an absence of available supported community accommodation.

All of this should give people of all ages pause. We are all just a serious illness, car accident, or fall away from being institutionalized.

Countries Can and Have Made the Shift

Many countries have made the shift to home and community care because it is more respectful and supportive of elders and people with disabilities as well as being more cost effective.

"Denmark now provides 80% of its aged care services in the home after the Danish Government passed legislation in 1988 to put a brake on the construction of new aged care homes. The legislation also forced existing homes to convert to single-occupancy rooms, leading to a 30% fall in the number of aged care beds available between 1985 and 1995. In total the number of aged care places in nursing homes fell from around 49,000 in 1987 to 27,600 in 2001 and 15,400 in 2006" (The Weekly Source, 2020).

No Level of Government Is Listening to its Elders

Elders have said repeatedly that they do not want to be institutionalized (National Institute on Aging, 2020). But are the Canadian or Ontario governments even listening? It appears not. In a blatant act of ageism both levels of government are simply ignoring what elders are saying and are proceeding with their own costly institutionalization agendas or ineffective symbolic policies.

There is no national effort to negotiate a Canada-wide standardized Home Care program with federal funding attached. And Ontario just keeps throwing money at the institutional sector while largely ignoring the need to invest in supports where elders live, or pay family caregivers, or double expenditures on Home Care.

Institutions Are Financially Unsustainable and Cannot Be Staffed

Ontario wants to institutionalize 30,000 more elders but is running into financial headwinds and staffing shortages. The Ontario government, in another financial windfall for large nursing home corporations, has more than doubled construction funding for nursing homes where no one wants to live and few want to work (Howlett, 2023). As the Omicron variant drove up infections again in 2022, long-term care institutions were trying to recruit restaurant workers and family caregivers to help keep their daily operations running (Canadian Press, 2022). Who is supposed to staff those 30,000 additional institutional beds Ontario is trying to build – cooks and bartenders?

How many times does all of this have to happen, and how much money does the Ontario government think it can keep wasting on institutions prone to outbreaks of infection, staff shortages, and cost overruns before it finally recognizes that this is not the way to provide care to older adults and people with disabilities?

Ontario Has a History of Failure in Enforcement of Legislated Standards

In spite of repeated assurances by one Ontario government after another, over a period of decades, nursing homes remain out of compliance with legislated standards (Pedersen et al, 2020; Mancini, 2021). Historically this has been the case in Ontario. No Ontario government has ever been able to enforce even minimal legislated standards. Yet governments and the general public have continued to embrace standards as the way to clean up long-term care facilities irrespective of their history of not having done so (SSAO, 2023).

There Are Other Ways of Providing Care

Those who are interested in world affairs will have watched the recent U.S. State of the Union address, where President Biden stressed the need to help elders to age in place with community

care supports. This is an area where the U.S. has led Canada in creating innovative programs to keep elders and people with disabilities out of institutions.

Funds Tied to the Person Not the Service Provider

The concept that money should follow the person rather than being tied to the service provider is one Canada and Ontario have yet to grasp - this, in spite of the U.S. Money Follows the Person program having gotten hundreds of thousands of people out of nursing homes and helped many return to the community. On March 31, 2022, the U.S. government increased the reimbursement rate for Money Follows the Person for supplemental services to 100%. These services support individuals transitioning from institutions to the community and include short-term housing and food assistance. The changes are intended to increase community transition rates (Medicaid.gov).

It's working.

The U.S. is an example where nursing homes are closing in the thousands because of progressive policies like Money Follows the Person, staff shortages, and heavy investment in home care. By holding the line on increases to nursing homes and richer investment in community-based care, the U.S. is moving away from mass institutionalization of elders and people with disabilities. Staff are leaving the institutional sector, elders are receiving care at home, and thousands of U.S. nursing homes are closing (Leys, 2023; Huber, 2023).

So why is Ontario moving in the opposite direction and building even more costly institutions that it cannot staff and where no one wants to go? It's a problem of ethics. The wishes of developers and nursing home corporations are, again, taking precedence over the needs and wishes of elders. Big nursing home corporations can afford to hire paid lobbyists to advance their positions with government (Paling, 2020).

In Ontario money talks. Ethics and the public interest apparently do not.

Ontario's Long Term Care Gulag

Catherine Frazee, a former Chief Commissioner of the Ontario Human Rights Commission, describing nursing homes as gulags also had this to say in a foreword to a joint paper from Community Living Ontario and Seniors for Social Action Ontario (2022):

"An institution is neither a home nor a place of care. An institution is a closed system where problems of human deprivation and indignity are quietly managed, where societal failings are hidden, and where people individually, or, as we now know, by tens of thousands, can die without triggering alarm."

Frazee is right. Ontario has become a gulag for older adults needing care, providing choice from an array of only one – an institution - which is neither a home nor a place of care. The only other option available to elders and their families is a grossly underfunded, heavily bureaucratized, unreliable, and inaccessible Home Care system – which is no choice at all for most.

The question now is when will older adults and taxpayers finally speak up and demand an end to this overzealous waste of our tax dollars by the Ontario government that is putting many of us in the crosshairs of institutionalization ourselves?

Many of us are only a fall or serious illness away. Denial is no longer an option.

When will older adults actually send an e-mail to their MPPs and MPs demanding better?

When will they take a few minutes to pen a letter to the editor of their local or daily newspaper?

It takes only a few minutes – but with so few doing it, all of Seniors for Social Action Ontario's (SSAO) advocacy cannot succeed. It takes a ground game and collective voices – raised together – all at once.

IT IS TIME FOR MEMBERS TO ACT

For three years now SSAO has written very informative and well researched articles and editorials to inform its members about the issues. All of these appear on its website under the Advocacy, Editorials, and Policy and Research tabs at the top: https://www.seniorsactionontario.com/

SSAO has drafted letters to elected officials at the provincial and federal levels that some SSAO members have chosen to sign. Please see: https://www.seniorsactionontario.com/storiesfromltc

It has organized online events to further inform members.

It has created letter templates that could be used as a basis for letters by members.

It has written letters and submitted policy briefs to elected officials.

SSAO leadership has done its part. Now it is time for members to do theirs. A letter template for members to write to their MPPs can be found here in one of SSAO's Action Alerts: https://www.seniorsactionontario.com/storiesfromltc

All that is needed is for members to copy the letter and e-mail it to their MPPs and MP's whose e-mail addresses can be found by clicking on their names here - https://www.ola.org/en/members/current and here: https://www.ourcommons.ca/members/en/search

Please be sure to copy SSAO at <u>seniorsactionontario@gmail.com</u> so that we know how many letters have gone out. Your efforts will determine our future efforts.

Ontario citizens deserve a first-class, 21st Century long-term care system that supports elders to age in place as they have been requesting for over a decade now. It is time to end the ageist policy of mass institutionalization, tie money to the person, not the institution, and empower elders to obtain their own care and supports when and where they require them.

But none of this will happen unless we demand it - all of us - all at once.

We are a big generation with a loud voice if we use it. Staying silent and not acting equals collaboration in maintaining the status quo. And then all of us will have to live with what that entails.

REFERENCES

- Canadian Press. (January 6, 2022). Ontario long-term care homes see staff absences of 20 to 30 percent amid outbreaks. https://toronto.ctvnews.ca/ontario-long-term-care-homes-see-staff-absences-of-20-to-30-per-cent-amid-outbreaks-1.5730144
- Community Living Ontario & Seniors for Social Action Ontario. (2022). Essays on aging in place: A guide for developing good policy and practices, especially for people who have and intellectual/developmental disability.

 https://www.seniorsactionontario.com/files/ugd/c73539_9f7d0232f41b4880a4bbed69b9394bdd.pdf
- Government of Canada. (2022). Promoting rights of persons with disabilities. https://www.international.gc.ca/world-monde/issues_development-enjeux_development/human_rights-droits_homme/rights_disabilities-droits_handicapees.aspx?lang=eng
- Government of Ontario. (March 31, 2009). Closing institutions for people with a developmental disability. https://news.ontario.ca/en/backgrounder/5213/closing-institutions-for-people-with-a-developmental-disability
- Government of Ontario. (April 21, 2022). Ontario on track to build 30,000 new long-term care beds. https://news.ontario.ca/en/release/1002083/ontario-on-track-to-build-30000-new-long-term-care-beds
- Hebert, R. (May 13, 2020). Financing for home care must rise and be done differently. https://policyoptions.irpp.org/magazines/may-2020/financing-for-home-care-must-rise-and-be-done-differently/
- Howlett, K. (January 29, 2023). Ontario government more than doubles construction funding for nursing homes. https://www.theglobeandmail.com/canada/article-ontario-government-more-than-doubles-construction-funding-for-nursing/
- Huber, M. (February 4, 2023). Workforce woes, nursing home closures, pressure sustainability of long term care. https://southdakotasearchlight.com/2023/02/04/workforce-woes-nursing-home-closures-pressure-sustainability-of-long-term-care/
- Ireton, J. (March 30, 2021). Canada's nursing homes have worst record for COVID-19 deaths among wealthy nations: report. https://www.cbc.ca/news/canada/ottawa/canada-record-covid-19-deaths-wealthy-countries-cihi-1.5968749

- Knapp, M., Cyhlarova, E., Comas-Herrera, A., Lorenz-Dan, K. (May, 2021). Crystallising the case for deinstitutionalization: COVID-19 and the experiences of persons with disabilities. *Care Policy and Evaluation Centre, London School of Economics and Political Science* https://www.lse.ac.uk/cpec/assets/documents/CPEC-Covid-Desinstitutionalisation.pdf
- Leys, T. (January 25, 2023). Wave of rural nursing home closures grows amid staffing crunch. https://khn.org/news/article/wave-of-rural-nursing-home-closures-grows-amid-staffing-crunch/
- Mancini, M. (June 4, 2021). Nursing homes with repeated violations continue to break the law despite Ontario's promise to crack down. https://www.cbc.ca/news/marketplace/nursing-homes-long-term-care-1.6049857
- Medicaid.gov. (2022). Money follows the Person. https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html
- National Institute on Aging. (October 13, 2020). Almost 100% of older Canadians surveyed plan to live independently in their own homes, but is this even possible? https://www.nia-ryerson.ca/commentary-posts/2020/9/22/almost-100-per-cent-of-older-canadians-surveyed-plan-to-live-independently-in-their-own-homes-but-is-this-even-possible
- Paling, E. (November 30, 2020). Ontario PCs have raked in \$30K from big nursing home lobbyists. https://www.huffpost.com/archive/ca/entry/ontario-nursing-home-lobbyists-pc-party-donations_ca_5fc53f95c5b63d1b770e8a4d
- Pedersen, K., Mancini, M., Common, D., Wolfe-Wylie, W. (October 23, 2020). 85% of Ont. nursing homes break the law repeatedly with almost no consequences, data analysis shows. https://www.cbc.ca/news/marketplace/nursing-homes-abuse-ontario-seniors-laws-1.5770889
- Remember Every Name. (2023). Keeping people out of institutions. https://www.remembereveryname.ca/keeping-people-out-of-institutions
- Roman, K. (January 31, 2023). New voluntary standards released for long-term care homes devastated by the pandemic. https://www.cbc.ca/news/politics/long-term-care-canada-standards-pandemic-1.6730780
- SSAO. (February 6, 2023). Voluntary national standards in long-term care? Is this the Federal government's idea of a sick joke? https://www.seniorsactionontario.com/files/ugd/50033d_9d7797075db54077a4e16bd6b30d_441c.pdf
- The Weekly Source. (February 6, 2020). Denmark limited construction of nursing homes in 1988 leading to 30% drop in aged care beds. https://www.theweeklysource.com.au/denmark-limited-construction-of-nursing-homes-in-1988-leading-to-30-drop-in-aged-care-beds/
- United Nations. (2023). Leaving no one behind in an ageing world. *Department of Economic and Social Affairs*. https://www.un.org/development/desa/dspd/world-social-report/2023-2.html