



SENIORS FOR SOCIAL ACTION (ONTARIO)

A PERSONAL MESSAGE TO SSAO MEMBERS FROM THE CHAIR

February 5, 2024

In 1982 my grandmother, who came to Canada in 1938 having fled Hitler, entered a nursing home in Durham Region where she was attacked and burned. I was 34 at the time and could not believe that such a thing could happen in Canada. I could also not believe the lack of concern on the part of the government of the day, and the lack of response from the Inspection Branch. That was the beginning of my journey trying to change long-term care in Ontario.

Fast forward a year. Working for what was then the Ontario Association for the Mentally Retarded (now Community Living Ontario), I was part of a team that found over 500 children being starved to death in nursing homes. One such child became the adopted daughter of another co-founder of SSAO. Her name was Becky Till and this is a video of her story - <https://www.youtube.com/watch?v=cAvjidwzIb4>

For years, I and a stalwart group of nursing home advocates in Concerned Friends of Ontario Citizens in Care Facilities fought for changes to what was then the Nursing Home Act. We achieved public reporting of inspection reports; a Residents Bill of Rights in the Act; mandatory reporting of abuse and neglect; financial accountability; resident and family councils, and much more. Yet the problems in nursing homes continued. See "Hansard Inspection of Nursing Homes" June 20, 1983 <https://www.ola.org/en/legislative-business/house-documents/parliament-32/session-3/1983-06-20/hansard>

That Act was as unenforceable then as it is today. Big long-term care corporations have deep pockets and good lawyers and lobbyists that are used to thwart government efforts to protect residents and influence public policy.

In spite of efforts by then Health Minister Larry Grossman and a very good Director of the Inspection Branch who laid charges and lifted licences, the nursing home companies beat the government in court – every single time.

Even at Ark Eden Nursing Home in Stroud where children were dying of starvation and there had been a Coroner's Inquest into the death of one of those children, Yves Soumelidis, the nursing home operator's license was restored by a court, and he was back in business "serving seniors". See Hansard Transcript about history of Ark Eden, February 18, 1983 <https://www.ola.org/en/legislative-business/house-documents/parliament-32/session-2/1983-02-18/hansard>

Institutions - Not Pay, Funding, or Full-time Staffing - Are the Problem

All of the co-founders of SSAO played a role in achieving the closure of the large institutions for people with developmental disabilities. Institutions that were so bad that former Premier Wynne was forced to apologize to those who had survived them after former residents won a class action lawsuit against the Ontario government. Wynne apology here: <https://www.cbc.ca/news/canada/toronto/kathleen-wynne-apologizes-for-huron-1.2456565>

Those institutions were operated by government directly or by non-profit community boards. They had well paid, full-time staff, and they had enough of them. Yet residents were horribly mistreated in them. Staffing, licensing status, and pay made no difference. It was the nature of the total institution – too many vulnerable people, devalued by society, housed in one place with no power over their lives. That is what laid the groundwork for the conditions of dehumanization, neglect, and abuse. And what convinced SSAO's co-founders that it is institutions themselves that are the problem, not the array of other symptoms people believe to be the problem. You cannot fix them. You cannot humanize them with Eden Projects or emotion-focused care. You cannot fight them, especially if they are operated by big corporations, because the odds are stacked against governments and citizens who try it. And that is why nothing has really changed in long-term care for decades.

I documented all of this in my 1996 doctoral thesis *Private Interests or the Public Interest* – abstract found here: <http://www.socialeconomyhub.ca/content/private-interests-or-public-interest-critical-examination-role-stakeholder-groups-developme-1> It will soon be digitized, re-released and publicly available.

Everything old is new again – because literally nothing has changed in 28 years. Not the public policies, not the conditions in the institutions, and not the deck being stacked against stakeholders other than the long term care industry and government bureaucracy. It is all about unequal power relations in this society that cause the most vulnerable to suffer, as the rich and powerful further enrich themselves at their expense and at the expense of those who try to provide care to them.

The only way to avoid the horrors of institutionalization and privatization is to support the creation of in-home and community-based non-profit alternatives to them.

Alternatives Advocated by Seniors for Social Action Ontario

Over the past almost four years, SSAO has outlined the alternatives:

- **Direct funding** – expanding the Family Managed Home Care Program to empower elders and their families to access funding to arrange their own care. That would help provide more personal and individualized care to people, especially in rural areas, address cultural and LGBTQ+ issues more effectively, and help ease the staffing shortage. It puts elders and their families in the driver's

seat. *But watch the vested interests in the service system – for-profit and non-profit - lobby against that to protect their own interests, and watch government cater to them. Not what most would consider a person-centered approach, but then that is just a buzz word used to try to gloss over what is really happening.*

- **Paid Family Caregivers** – ease the financial burden on family caregivers wishing to take unpaid leaves to care for loved ones so they do not face financial distress for their efforts. With long-term care institutions receiving \$200+ per person per day, in many cases providing substandard care, there is no question that paying families would be a better option. This would be especially helpful for young people taking care of grandparents and great grandparents – which many do. *But watch government ignore this recommendation making the argument that family caregivers can't be trusted, even though long-term care institutions have been far less trustworthy than families for decades, but have received billions in funding from government to this day.*
- **A Comprehensive, Intensive System of Home Care** – up to 10 hours of home care a day as is available in Denmark, to support people with the most complex needs to be able to stay at home. That is what the Ontario government should have invested in. *Instead the Ontario government has invested only \$1 billion in additional dollars to support Home Care – and they can't seem to get that right – while investing six times that much - \$6.4 billion to build and refurbish the institutions where no one wants to go and fewer and fewer people want to work. Watch this government continue to send our tax dollars to the predominantly for-profit institutional sector.*

Residential Alternatives in the Community

Some, irrespective of the level of in-home and community support, will need residential services. But that need not automatically spell institutionalization. There are many residential alternatives that do not involve institutionalization.

- **Hub and Spoke Programs** like those delivered by Peel Senior Link where a case manager is attached to naturally occurring retirement communities (NORCs) and seniors' buildings, organizing care and support according to residents' instructions in a person-directed approach. Please see: https://peelseniorlink.com/_content/uploads/2018/08/Board-Orientation-version.pdf
- **PACE (Programs of All Inclusive Care of the Elderly)** where services come to where elders live in seniors' buildings, rather than elders having to be uprooted and institutionalized. The Burlington model brings services to community housing programs in that city and it is preventing hospitalizations and institutionalization. Please see: <https://alzda.ca/pace-wellness-hub/>

In Kenora, the government actually funded a PACE-like program and acknowledged that it keeps people out of nursing homes. Please see:

<https://news.ontario.ca/en/release/1002387/ontario-building-new-seniors-housing-complex-in-kenora> **But watch government fail to fund expanded versions of these**

programs across the province. They might actually keep people out of the institutions in which the Ontario government has invested so heavily at the behest of their friends in the long-term care industry, and the expensive lobbyists representing them – many of whom were previously employed by the government. Please see: <https://democracywatch.ca/dozens-of-ford-and-pc-party-connected-lobbyists-corrupting-ontario-policy-making-integrity-commissioner-letting-them-violate-law/>

What chance does a volunteer-driven advocacy organization that accepts no funds from these big companies or the government have in actually changing policy for the better for individuals who do not want to be institutionalized? That deck is stacked.

- Staffed condos and apartments, termed **Supported Independent Living (SIL)** programs have kept younger disabled people out of institutions for decades. But none are available to older adults, because they actually work to prevent institutionalization. *So watch the Ontario government fail to expand the SIL program to elders.*
- **Small, non-profit, fully staffed community residences.** These kinds of homes already house people with very complex needs far greater than those found in nursing home residents, yet none are available for older adults with cognitive, neurological, and physical disabilities in spite of them being more home-like and promoting people continuing to be part of their communities. *Watch the government completely ignore this recommendation, as they have for almost four years, when it would make a huge difference in every community for people with dementia and their families. Far better to force them into locked 30 bed wards in institutions – a recipe for responsive behaviors? And fail as well to create enough of these small residences for people with other disabilities and build in nursing care to prevent them from entering institutions as well?*
- **Locate an Adult Protective Services Worker (APSW) program in the Ministry of the Attorney General.** Finally provide advocates for elders, located in community legal clinics across the province to uphold the rights of elders, especially those being pressured to enter long-term care facilities. *Watch the Ontario government also ignore this recommendation by SSAO. Too threatening to the status quo.*

In every case, the Ontario government has failed to listen to older adults, over 95% of whom over 45 have made it clear they want to age in place in the community and never enter a nursing home. IPSOS poll found here: <https://www.ipsos.com/en-ca/news-polls/Nearly-All-Canadians-45-Want-Age-Home-But-Only-1-in-10-Afford-Cost-PSW>

A Potential Break Through?

Recently senior Ministry of Health officials agreed to provide a Zoom session to members of SSAO on Home Care Modernization. Their presentation was very informative and forthright. And they met SSAO members directly – all of whom were articulate and well informed. For this reason, the Ministry of Health, for the first time,

will be inviting SSAO's input on home care transformation. But SSAO cannot achieve the needed changes alone.

A Call to Arms: Local Action

If you go to the Seniors for Social Action Ontario website, you can view our policy and research papers, our editorials, and our advocacy work under those tabs. Website: <https://www.seniorsactionontario.com/>

SSAO also has a YouTube channel if you prefer to view videos: <https://www.youtube.com/channel/UC0tGeL4P54rO8DWIVc9TNDA>

SSAO has provided literally thousands of pages of resource material to its members in the past four years to support local and individual advocacy efforts. But it is a major effort to turn the Titanic that is long-term care policy and programming in Ontario that has been steeped in an ageist belief system for decades and dominated by powerful special interests.

We need every one of you to be more active. SSAO volunteers are in our 70's and 80's ourselves, and for almost four years, we have done everything we can to raise elders' voices to government and to the professional and service sectors.

We have done our part. It is now up to you to help take it to the streets locally. Lobby your MPPs and MPs and demand better support and services so that neither you nor your loved ones ever have to endure the horror of being institutionalized. They will try to ignore you or give you panned responses. Don't let them. On Fridays they are in their Constituency Offices. Phone and make an appointment.

The more of you who take action locally, the more elected officials in all political parties will get the message. Tell them about SSAO's work and what issues you are most concerned about. And ask them for a response – in writing. Please share it with us if you get one at seniorsactionontario@gmail.com

Engage with your local Ontario Health Team. There are 12 accelerator teams in Ontario outlined in our last mailing to you found here: https://www.seniorsactionontario.com/files/ugd/c73539_c5504632b12545f9bdae688ea81bc234.pdf Take part on advisory boards, at consultations, and try to get onto their Boards and make the case for alternatives to institutions. In Burlington the Ontario Health accelerated team is on board on PACE. Every team in Ontario should be expanding PACE programs.

Elders Vote!

SSAO has tried to be non-partisan, but in the face of overwhelming evidence, it is now clear that the Ontario government is not a friend to older adults. It has:

- Introduced Bill 7 forcing elders into institutions 70 – 150 km from their homes and social support systems should they be unfortunate enough to end up an alternate level of care (ALC) patient in a hospital;
- Eliminated comprehensive inspections of nursing homes at the beginning of this government's term, after which it was forced to reinstate them because of the horrific carnage during the pandemic. It is now “announcing” more changes that will also be ineffectual for the reasons mentioned earlier, and if history is any indicator. As activists we cannot afford to fall for this kind of window dressing;
- Provided new funding at a rate of 6 -1 for institutions where elders do not want to go instead of Home Care which they do want. Over 6 billion dollars to build and refurbish more institutions. Only \$1 billion for Home Care in a classic example of systemic ageism where elders' wishes are ignored but corporate interests are supported. It is time to ignore them now when they want your vote. Please see these links for Home Care funding announcements versus Institutional funding announcements. Home Care: <https://news.ontario.ca/en/release/1002107/ontario-investing-1-billion-more-to-expand-home-care> Funding for institutions: <https://news.ontario.ca/en/release/1002523/ontario-increasing-construction-funding-for-long-term-care-homes>
- Announced yet another bureaucratic reorganization of Home Care that amounts to rearranging the deck chairs on the Titanic rather than addressing the solutions SSAO provided to them years ago and in a most recent Home Care Report found here: https://www.seniorsactionontario.com/_files/ugd/c73539_194912a643164a5f980b8b17a4650690.pdf
- Failed to even consider expanding direct funding, the Family Managed Home Care Program, or paid family caregivers, even though that program has been expanded in Newfoundland and Labrador because it is so effective. Apparently service provider interests continue to trump service user interests. Please see: <https://www.gov.nl.ca/hcs/long-term-care/family-caregiving/>
- Failed to even consider non-profit, staffed condos, apartments, and community residences for older adults in every community administered by municipalities and non-profit organizations. They exist in the U.S. and elsewhere, but not one in Ontario. See: <https://www.aarp.org/caregiving/basics/info-2020/group-homes.html>
- Failed to vigorously fund and expand PACE and Hub and Spoke programs across the province even though they have demonstrated their effectiveness. Information on PACE - <https://alzda.ca/pace-wellness-hub/> Hub and Spoke in Peel - https://peelseniorlink.com/_content/uploads/2018/08/Board-Orientation-version.pdf

In conclusion this government has done literally nothing to empower older adults and their families - with the worst track record of helping older adults to remain in their own homes and communities of any government in 40 years.

Baby Boomers remain a huge generation. It is time to exercise our voting power and vote them out. And it is time that we demand that the NDP and Liberal parties listen to us and start focusing on the solutions we have been proposing for almost 4 years now, and put our interests at the top of their policy agendas.

Speak to the candidates of each party and be clear in telling them that you are tired of the ageist policies of successive governments. It is time for a revolution in long term care, led once again, by Baby Boomers.

SSAO Is Shifting Gears

There have been some important wins lately in local areas. In Port Hope, for example, citizen activism has an initial win against the Southbridge long-term care corporation that took the town to the Ontario Land Tribunal (OLT). The OLT found in the town's favor and citizen activists there are now working to demand alternatives to a big institution in that town.

As the co-founders and advocacy team continue their important work provincially, SSAO will be shifting gears towards supporting your local efforts at lobbying your local municipal politicians, MPPs, and MPs and getting alternatives going in your towns, cities, and rural areas.

There will be fewer articles sent to our membership, because the website already contains the research you need to help you pressure your elected officials.

There will also be fewer Zoom events as our leadership shifts gears.

I want to offer a special thank you to those co-founders who are continuing with this important work, assisting individuals, and bringing attention to SSAO's proposals across the province.

I also want to salute those citizens in Port Hope, Port Perry, and Pickering who are so valiantly fighting off Southbridge facility builds and refurbishment while advocating for more progressive alternatives to care for elders in their areas. Your efforts form the bedrock of much of the real work that needs to be done. You are models of citizen action for other areas of Ontario.

To those professionals and researchers who have actually listened to your elders and taken up the cause for alternatives to institutions, thank you. We need allies, and appreciate those who have chosen to ally with us.

I also want to offer a special thank you to those on our advocacy team who are working tirelessly gathering information and filing Freedom of Information requests to support our continued advocacy efforts. Summaries of relevant information we receive will be shared with you as it becomes available.

Finally an extra special thank you to SSAO's Board members – all of whom have put their heart and soul into this work spending countless hours of their own time to do so.

To our older members, we know, because we are all older too volunteering our time, that we all see our time on this planet coming to an end. So we especially appreciate that you would invest your energy in trying to make this province and country a better place for elders and for the generations of elders to come.

To our members, we in SSAO leadership hope that you have found our work beneficial, and it is our hope that you will use it to advance the cause for all of us.

You will still receive bulletins and information articles periodically as the need arises, but the effort needs now to shift to individual and local levels, to win support to create the alternatives we all know that we need.

We wish you all the best in your advocacy efforts and will continue to support those local efforts already underway.

Thanks to all of you for your interest and involvement in SSAO. We could not have done it without you.

Dr. Patricia Spindel is Chair of Seniors for Social Action (Ontario)