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EDITORIAL – OCTOBER 31, 2022

BUT DON'T WE NEED SOME INSTITUTIONS? SSAO RESPONDS

Because Ontario has focused so heavily on institutions for older adults, there are many who believe that we cannot do without them, or that it will take forever to move away from an institutional model to a community-based one. If you are older, you may believe that nothing different can happen in your lifetime. But you may be surprised.

WHY IS SSAO ADVOCATING LESS RELIANCE ON INSTITUTIONS?

Some members of SSAO have been involved in advocating for changes to the long-term care system for over 40 years. Their experience tells them that successive governments have tried and failed to fix the institutional model. Most facilities continue to be out of compliance with basic requirements of the Act (Mancini, 2021) and inspection reports detail continued serious care-related problems.

The institutional model is fundamentally flawed. We need only look at residential schools for Indigenous children, large government-operated facilities for people with developmental disabilities, training schools, orphanages, poor houses, and many others to recognize this. In every case, abuses were discovered that led to the closure of these facilities and a recognition that this was not how care-related and social support requirements should be met.

Historical examples of institutional failures and the horrors that occurred there are well known. Use of chemical restraints and drugs prescribed without a diagnosis (Pierce, 2022); labeling and devaluation of residents with resulting dehumanization and objectification of them (Friedman, 2019); use of physical restraints, seclusion, and locked wards to contain them (Gibson, 2020); crowding devalued people into wards with little to no privacy, safety, or respectful treatment; feeding them poorly (Harris, 2021); subjecting them to abuse and punishment (Pedersen et al, 2018); neglecting them – leaving them sitting around in hallways or "TV rooms"; appropriate medical care being withheld due to ageism (Mistry et al, 2020); employing a eugenics philosophy where devalued people are seen as not worth saving (Grenon & Merrick, 2014), or their lives are not worth living, with mass institutionalization being the only answer (Herron et al, 2021).

Some efforts have been made to make institutions more palatable by creating "cottages" - the modern version of this concept being Green Houses built on real estate owned by long-term care corporations (Dinki, 2021).

Staff in many long-term care institutions, just as in the institutions for the "feeble minded" of the past, know what is happening, but there is a culture of secrecy, silence, fear and intimidation in many of these institutions, so few take the risk of speaking up. In Ontario the COVID-19 Commission felt it had to grant workers anonymity to overcome this problem so that they could testify (Canadian Press, 2020).

For all of these reasons institutions have been eliminated for literally every group in Canada except older adults and prisoners. Like prisoners, institutionalized residents also park their human rights at the door, beginning with their forced admission. Seniors for Social Action Ontario has, three times, asked for the Ontario Human Rights Commission to hold a public inquiry to address the issue of mass institutionalization of elders in the absence of community alternatives, and has either been refused, or ignored.

A public that is socially conditioned to accept institutionalization of the old and infirm has allowed this to continue. There has been no advocacy to end Ontario's reliance on mass institutionalization of elders until now.

Seniors for Social Action Ontario is advocating an end to Ontario's institutionalization of age and infirmity to be replaced with a 21st Century approach - rights-based, consumer-directed care and treatment of elders and people with disabilities in their own homes and communities.

With the Ontario government grossly over-spending on building even more institutions (Ontario Government, 2022) in which to warehouse elders, the future seems bleak for those who are older. It is also bleak for those who are younger, since the government is locking in 30 year licenses for many of the large companies that have been awarded beds – some of whom had high death and infection rates during the pandemic.

People now in their 40's are also likely to end up in these 19th Century human warehouses.

But There Are Some Good Institutions Aren't There?

There are families who believe that their loved ones are receiving good care in some facilities. They may be unfamiliar with some basic facts about this system. Without 24/7 video surveillance families will not know what is really happening in a facility. These are the realities of this system.

- Comprehensive, proactive annual inspections were suspended by the Ontario government in 2019 (Pedersen et al, 2020), and most inspections now occur retroactively once harm has been done based on complaints by families and critical incident reports submitted by the facilities. At least 2000 such complaints come in per month to the Inspection Branch thereby indicating significant problems in the long-term care system (Chou, 2020:35). Many more do not complain. Complaint and critical incident inspections are very narrow in scope, only examining the immediate circumstances of the complaint or critical incident, so it is likely that inspectors entering a facility for the purpose of this type of inspection will not address other care-related problems there (Chou, 2020: 42,46, 49).

Nevertheless these are considered an inspection therefore an annual proactive inspection is unlikely to be done if a complaint or critical incident inspection has been done. Critical incident inspections are half of those done and Complaint inspections comprise 37% (Chou, 2020: 54).

- Penalties for facilities repeatedly out of compliance with the Act are generally inadequate with Written Orders most often issued that facilities voluntarily address. Even the fines introduced by the Ontario government are considered "toothless" (Howlett, 2021).
- Even where Compliance Orders are issued, facilities may have repeats of the same problems again and again with these orders being issued and re-issued repeatedly and no sanctions levied. This may be why 85% of facilities remain out of compliance with the Act and regulation (Pedersen et al, 2020).
- The Ministry of Long-Term Care has advised SSAO that it does not monitor when staffing has fallen below 80% of full complement which could result in residents not obtaining the needed assistance. It also does not monitor when physicians are not seeing residents in person, or even whether or not facilities are admitting residents during infection outbreaks.
- Where facilities are falling below 80% of their staffing requirements, Cease Admissions orders should be issued until staffing issues are addressed, but this rarely occurs according to most inspection reports.
- Families report feeling frustrated in attempting to obtain assistance from the Inspection Branch. The usual checks and balances that should be available such as the Patient Ombudsman, Ontario Ombudsman, and Ontario Human Rights Commission have been ineffective according to reports by SSAO members.
- Families whose loved ones died during the pandemic face a higher bar - gross negligence - to be able to sue companies, even in facilities where death rates were very high, and they had to be taken over by hospitals and/or the military and were the subject of a damning military report (Arthur, 2020).
- The Ontario government has failed to ask police forces to investigate reports by families of alleged criminal acts in these facilities (Nasser, 2021).

Hidden Cameras Reveal Abuses

Many families were under the impression that their loved ones were receiving good care until they placed hidden cameras in their rooms and were shocked to see a variety of abuses occurring. Please see: https://www.cbc.ca/player/play/1810662979896

Families are not there overnight or often at other times of the day, and many residents are unable to communicate their distress effectively or be believed if they do. In some cases, families have learned that residents are being given mood altering drugs without their knowledge, and so they appear content. Increased drugging occurred during the pandemic, apparently without the knowledge of residents' essential caregivers who were barred from facilities during this time (Alkenbrack, 2020).

Residents are living in facilities with poor oversight, inadequate penalties for even repeat offences, and where even criminal acts are often not investigated by police in spite of two Commissions having issued recommendations to governments concerning these and other inadequacies in this system.

Many families are not even aware that Inspection Reports are available online for each institution by typing the name of the facility and inspection report.

With little to no change having occurred to correct problems in this system over a period of decades, it has become clear to SSAO that the only way to ensure that harm does not come to older, vulnerable people is to keep them out of these facilities in the first place.

If These Places Had Full-Time Staff and Enough of Them the Problems Would Be Solved

Several SSAO co-founders were involved in advocating for, and achieving the deinstitutionalization of the large facilities for people with developmental disabilities. These were government-operated Schedule 1 facilities that employed well paid, full-time government staff. Nevertheless the conditions in them were horrendous with abuse and neglect rampant. Survivors have described horrific conditions and abuse by staff as well as a host of other abuses common to institutions (Remember Every Name, 2022).

Co-founders of SSAO witnessed first-hand, the unspeakable conditions and some wrote reports documenting them. One SSAO co-founder put it succinctly – “there were horrors there that you can’t unsee”.

This is why SSAO understands that institutionalization itself – and the resulting dehumanization and objectification of those forced to live in these facilities is the issue. Not staffing, not wages, not full-time work. All of these were addressed in government-operated facilities for people with developmental disabilities, and the conditions were horrific enough that a provincial Premier apologized publicly to survivors and they won a major class action lawsuit against the government for having been subjected to the conditions in them (Remember Every Name, 2022).

THE NEED FOR ALTERNATIVE OPTIONS

SSAO is not recommending that the only alternative to these facilities be Home Care. The Home Care system is, itself, in significant need of repair and remains grossly underfunded and overly bureaucratic with well documented accessibility and reliability problems. To be an effective alternative to institutions accessibility, reliability, and funding issues need to be addressed in the Home Care system.

In Denmark individuals needing assistance can receive up to 10 hours of home care a day – a major reason that country has not built any institutions in decades (Johnson et al, 2022). If Ontario was to make the decision Denmark did, there would be no need to spend $6 billion on expanding institutions – where no one wants to live or work.

There are also residential alternatives that are far better for older adults – more home-like, that could be located in their own communities – small, non-profit, staffed community residences, apartments, condos, naturally occurring older adults' communities as well as elder care co-ops. But government at all levels has failed to fund these.

That needs to change.

Just because someone needs 24 hour support and supervision does not mean that this needs to be provided only in an institution. It can be provided in a fully staffed, real home, located in a person's own neighborhood and community, allowing them to continue to receive the support of neighbors and friends and to visit local parks and coffee shops as they always have.

SSAO has sent out information about programs like Memory Lane in Richmond Hill – a small co-operative living program in a regular house in a neighborhood, for women with dementia (See: https://www.memorylanehomeliving.ca/).

It has discussed health hubs that could be providing in-home support to elders in active living communities.

It has talked about programs of all-inclusive care like PACE and Hub and Spoke models that could be located in apartment buildings where older adults live, also serving surrounding communities.

BUT ALL THIS WILL TAKE A LONG TIME

The former Deputy Minister of Long Term Care testified to the COVID 19 Commission that 22,000 residents (one quarter of the resident population) die in long-term care facilities every year (Steele, 2020:22).

Shocking? Yes.

The challenge is to cut off admissions to these facilities from hospitals and the community by creating a range of alternative options – individualized, direct funding, in-home, paid family caregivers, and residential alternatives - so that people are not forced from hospitals or family homes to be unjustifiably institutionalized because nothing else exists.

Would anyone really choose one of these institutions if they had a range of other options?

This is where all of us come in.

What Can We Do?

All of us need to press our elected officials at the provincial and local levels whether or not they wish to listen to:

- Create direct funding programs for individuals and their caregivers;

- Pay family caregivers as part of the Home Care Program. See: https://www.gov.nl.ca/hcs/long-term-care/family-caregiving/
- Remove the current bureaucracy, and institute an empowerment oriented system of in-home care, that is fully funded, accessible, and reliable with stiff penalties when contracts go unfulfilled;
- Create and fund - at the same level as long-term care facilities are currently funded - residential care in the community in small neighborhood homes, not institutions. Every community in Ontario should have a memory care home delivered by a municipality or non-profit agency that is much more appropriate for people with dementia. Large municipalities should have several.
- Fund elder care cooperatives across the province.
- Create and fund health hubs in every community, and especially naturally occurring seniors' communities, that provide medical, nursing, rehabilitation, and in-home support services to older adults.
- Create and fund an empowerment-oriented case management system where community-based professionals visit people in the hospital to help them prepare for discharge – back to their own homes, or to small, staffed home-like settings of their choosing, in their own communities.
- Institute a Money Follows the Person program tying funds to the individual not to the institution, thereby allowing current residents to obtain the support necessary to leave the institutions (Medicaid, 2022).

All of us need to speak up and lobby for these things and refuse to accept that institutions are the only answer. By working together we can, community by community, address the current maltreatment and removal of the rights of older adults and people with disabilities. They deserve decent care where they live.

The time is now. It is up to each of us.

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