PRESENTATION TO COVID-19 LONG TERM CARE COMMISSION

SENIORS FOR SOCIAL ACTION ONTARIO (SSAO)

Monday, December 14, 2020

BACKGROUNDER TO POWERPOINT

Presenters:

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Doug Cartan: Disability advocate and Consultant for the past 20 years to developmental service organizations in British Columbia and Ontario, co-founder of the Special Services at Home (SSAH) Coalition in Ontario (self-directed funding program) 1990's, member of the Minister's Advisory Group (MCCSS Ontario) 1991-95, Executive Director of a local Community Living Association for 10 years, personal friend and advocate for a person living in their community who otherwise would be in a nursing home

Dr. Patricia Spindel – Co-Founder SSAO; former President Concerned Friends of Ontario Citizens in Care Facilities (1980's); Co-Founder Advocacy Centre For The Elderly; Retired Associate Dean of Health Sciences, Humber College (responsible for Gerontology, Palliative Care) and former Coordinator of the Social Services Worker Program and full-time Professor at the University of Guelph-Humber, and adjunct Professor for the Advocacy in Aging course, Ryerson University. Doctoral thesis at University of Toronto on the role of stakeholder organizations in long term care reform in Ontario (1996).

Seniors for Social Action Ontario (SSAO) Overview

We are a province-wide group of individuals with decades of experience in policy development and analysis, legislation, program development and implementation, disability and elder rights advocacy, and systemic change initiatives. We have advocated for disability and elder rights and for change in the long term sector dating back 40 years to the 1980's. We have all come together again after seeing the devastating impact the pandemic was having on older adults and people with disabilities in long term care institutions, realizing we had to speak up and try to make a difference.

ROOT CAUSE ISSUES IN LONG TERM CARE

Our many decades of experience with this sector have led us to the conclusion that there are three root cause issues of the symptomatic problems in this system that if addressed, would bring about positive systemic change.

We are convinced that the underlying philosophy and principles upon which the long term care system in Ontario was built are the wrong ones.

Many of the presentations to the Commission that we have read address only the symptoms of the problem (substandard care, lack of accountability, problems with staffing and wages) not the

underlying systemic issues that have caused them. Without addressing the root causes, no fundamental reform of this system will occur. This is the reason we have asked to address the Commission.

The Principles Are Wrong

The long term care system in Ontario is founded on the wrong principles:

- Medicalization of age and disability leading to high rates of institutionalization;
- A deficit approach that leads to labeling and dehumanization.

These need to be replaced by:

- A social not medical model of care and support;
- A strengths and resources based approach that builds on each person's and community's capacity;
- A home and community-based, not institution-based approach to long term care.

Literally every country in the world that has changed its long term care system for the better has adopted these more progressive principles.

Why Do Principles Matter? A Few Personal Stories

Tom was originally seen by his disability label and highly aggressive behavior (broke lamps, furniture, tore pictures off the wall), not as a person, and so he was institutionalized at age 9. Professionals said he was too "high needs" to be successful in the community, so he was placed on a "back ward" of the START Centre – an institution in London. When that Centre closed, there was no agency set up for people considered to be on the "back wards", heavily medicated because of their "behaviors". Tom was to be transferred to his new home in the community on a papoose board, but staff refused to transfer him that way. Now known by his name instead of his "behaviors", Tom ended up on reduced medication for real medical issues, and once out of the institution, he moved into an apartment with 24/7 staffing, with realistic expectations from staff, and respect for his wishes. He became a different person and flourished in the community – volunteering delivering papers, attending community activities, cheering at sporting events, eating at restaurants, and visiting friends. It was a far cry from the "back ward" that some professionals felt he could never leave.

Another person, considered medically fragile due to his disability (kidney disease), was determined by professionals not to be able to survive for two years if not institutionalized. He lived over 30 years successfully in the community and died last year at age 42.

Becky, a little girl with cerebral palsy was rescued from Jann Lynn nursing home in the 1980's weighing only 22 pounds at the age of 9. Because of the severe malnutrition she had experienced in that nursing home she suffered major organ damage to the point where literally all of her organs failed. A current member of SSAO took her home and eventually adopted her. While living at home she had to rely on significant medical interventions, such as continuous intravenous nutrition and hydration through a central venous line implanted into her chest, intravenous medications infused round the clock, a tracheostomy which resolved her breathing challenges, but robbed her of her voice and the speech she had developed against all expectations, multiple (7) tubes in her body were used to manage her failed organs. Her adoptive mother was warned that Becky would die if taken out of the nursing home. Becky also lived four more decades enjoying everything from Brownies, to camp, to

waterskiing, to excelling at downhill skiing, to going to her high school prom, to becoming an artist and a dancer. Along the way, she influenced people worldwide, enabling them to see past her challenges and to recognize her as a valued and competent human being. She became a cover girl three times, her story published in three books, and story after story of her vibrant spirit graced the pages of many newspapers and was featured in many television broadcasts. A CBC documentary, Becky Belongs by Rae Hull, documented her tragic history and amazing transformation. It can be viewed here on YouTube - https://www.youtube.com/watch?v=E_ZTY-GqdfY

What Are The Three Underlying Systemic Issues?

SSAO considers there to be three root cause issues that, if effectively addressed, would bring about the necessary systemic change in this sector.

- **Creation and funding of non-profit community-based in-home and residential alternatives to medicalization and institutionalization.** Without alternative options for placing residents in safe, secure environments, there can be no effective sanctions to ensure appropriate enforcement of the Act and Regulations. There would be nowhere to move the people if a license was to be revoked, and no way of addressing a lengthy waiting list if a Cease Admissions was ordered.

  Furthermore, elderly people and people with disabilities all say they do not want to be institutionalized. They want to remain in their own homes, or if that is not possible, to live in home-like environments in their communities where they can maintain control over their lives.

  Small, non-profit home-like environments have also proven to be much safer during the pandemic than nursing homes.

  SSAO is making the case for greatly expanded, less bureaucratic, non-profit, community-based health and in-home care options as well as small, home-like environments, staffed 24/7 including condo and apartment programs (Supported Independent Living as funded by the Ministry of Children, Community & Social Services {MCCS}) for people with disabilities, many with complex needs. We are also recommending the creation of non-profit community residences - group homes currently funded and delivered by the same Ministry. Residential options are required for individuals who, for various reasons, are unable to be cared for in their own home or a loved one's home.

  We are also suggesting that in-home assistance delivered by non-profit community care agencies, needs to be greatly increased through Home Care (SSAO, n.d.), and that direct, individualized funding (N.Y State, 2019; MCCS, 2020) can play a role in achieving this, as can a publicly mandated long term care insurance program (Grignon & Pollex, 2020) and a Money Follows The Person initiative (Medicaid.gov, n.d.).

- **Need for more rigorous inspection and enforcement once alternatives are in place, reinforced by effective sanctions -** fines (to be legislated), cease admissions notices, non-renewal of licenses, license revocations, imposed interim management.

  Once there is alternative system capacity, it is much easier to enforce effective sanctions for facilities and companies that repeatedly flaunt the law.

Better cooperation between the Inspection Branch and police, the cross appointment of a Crown Attorney to the Branch from the Ministry of the Attorney General, assistance from the Auditor General's office to conduct forensic financial audits of problematic facilities that regularly short staff and are short supplies are also needed as adjuncts to current enforcement activities.

- **Downsize and eliminate the role of privatization, corporatization, and for-profit provision of long term care.** The Commission has already heard about how for-profit companies fail to hire full-time staff, and how not enough funding goes into staffing and supplies at the same time as shareholders are being paid millions (SSAO, December 9, 2020) therefore SSAO will not expand further on this. But there are other reasons why for-profit involvement should be eliminated.

  For decades long term care companies, their lobbying bodies and their lobbyists have exerted undue influence on public policy. This has resulted in unbalanced policies favoring institutionalization (economy of scale) and continued expansion of the for-profit sector. The result is that Ontario has a regressive, archaic, outdated service model that long ago outlived its usefulness. It is directly opposed to the stated wishes of older adults and people with disabilities who have said repeatedly that they do not want to be institutionalized. Sadly their voices have been drowned out by the incessant lobbying of the corporate long term care sector and its lobbyists demanding expansion opportunities and more funding. Older adults and their families do not have the funds to pay lobbyists to advance their interests, therefore government pays little heed to the people who have historically been disempowered in Ontario but are directly affected by policy and programming decisions. Consequently the system does not change.

  In addition to undue influence, examples from other jurisdictions also raise concerns about possible criminal activities. In the U.S. and in Quebec, investigations have revealed fraud, criminal negligence in providing substandard care, money laundering, kickbacks, and other illicit activities (Berklan, 2020; CBC News, 2020; Kauffman, 2018; AP News, 2018). Even the Trump Administration has, during this pandemic launched, through the Department of Justice, an investigation of facilities with high infection and death rates (Hamel et al, 2020). Ontario has taken no similar action in spite of calls from families like those of victims of Orchard Villa who have asked for a police investigation.

  An announcement by the U.S. Department of Justice (2014) stated "Extendicare Health Services Inc. (Extendicare) and its subsidiary Progressive Step Corporation (ProStep) have agreed to pay $38 million to the United States and eight states to resolve allegations that Extendicare billed Medicare and Medicaid for materially substandard nursing services that were so deficient that they were effectively worthless, and billed Medicare for medically unreasonable and unnecessary rehabilitation therapy services…"(U.S. Department of Justice, October 10, 2014). It is not unreasonable that the Ontario public wonders why a large corporation with this kind of track record is allowed to continue to obtain licenses in Ontario, especially since Ontario has had to have hospitals take over management of some of its facilities, and residents and families in Ottawa have launched a class action against the company alleging negligence and breach of residents' human rights (Ferguson, 2020; Pfeffer, 2020).

ALTERNATIVES: TURN OFF THE SPIGOT

Many professionals and the general public have been conditioned to believe that aging and fragility equal either having to rely on inadequate home care or admission to an institution and that these are the only choices available to them. Hospitals have become a funnel for institutional placement in the absence of any alternative options. Ontario needs to turn off the spigot.

We often hear "there are some people who will always need an institution" or residents are so "high acuity" or "medically fragile" that they cannot live in the community. The facts prove otherwise. People with highly complex physical, behavioral, medical, and cognitive challenges already live in the community. Individuals with very complex needs are being cared for at home, in staffed condo and apartment programs, and in community residences (small group homes) sponsored by over 300 non-profit agencies. These models are all an example of what could be done for older adults. They are funded primarily by the Ministry of Children, Community & Social Services, but high support group homes for individuals with serious mental illness are funded as a niche sector by the Ministry of Health as well.

This is why many people with medical, nursing, and health backgrounds do not know about these options, and continue to believe that an outdated medical model of institutionalization is the only option for people who are labelled "high acuity". Their only suggestions relate to "fixing" an inhumane, unworkable, and unsustainable long term care model, not how to replace it. This is why the Commission is hearing about these alternative options for the first time.

The History: An End to Institutions

This same situation occurred fifty years ago with the early hospital schools for people with developmental disabilities. Large institutions like Huronia were being funded by the Ministry of Health, and the treatment of "residents" was so horrendous that some ran away or killed themselves. That led to first the Williston and then the Welch reports – a commission and a report that recommended transfer of responsibility for people with developmental disabilities from the Ministry of Health to the Ministry of Community and Social Services to get people with developmental disabilities out of a medical/institutional model and into a social, community-based model of care and services.

In June, 1971 Walter Williston was commissioned by the Health Minister A.B.R. Lawrence to investigate the death and injury of 2 residents of Rideau Regional Centre in Smiths Fall early that year and make recommendations for change. His report, tabled in three months, issued a 16 point scathing indictment of the large institutions in which he called for the downsizing of them to 40% of their capacity, while also calling for the development of a range of community-based residential and other support services located as close as possible to people's homes. Williston wrote "I suggest that we must all soon spell the death knell to our poor law legacy (from England's Poor Laws of 1601) as applied to handicapped persons and to the social attitudes and practices that stem from them". His report entitled "Present Arrangements for the Care and Supervision of Mentally Retarded People in Ontario, A Report for the Minister of Health" said that "the Ontario Hospital School system (i.e. the Ontario-operated institutions for people with a developmental disability) was isolated from mainstream health, education, social and family services and could not adequately establish and administer services that responded to community needs." His recommendations were that institutions be phased out and residential supports provided in the community..."

His report aligned with the emerging concept of normalization developed by Wolf Wolfensberger who advocated that people with developmental disabilities should "live in environments typical of the

general population; have opportunities for growth and development, be included in ordinary activities with the general population and develop relationships with others in their communities" (Ministry of Children, Community and Social Services, n.d.).

Williston's report was widely acclaimed.

In 1974 the Hon. Robert Welch, Provincial Secretary for Social Development brought in a new policy focus for people with developmental disabilities based largely on the Williston Report, entitled "Community Living for the Mentally Retarded in Ontario: A New Policy Focus". Noting that some government policies appear to be "unintentionally encouraging the perpetuation of institutional care" his Green Paper established the basis to reallocate resources from institutions to the community and recommended coordinating mechanisms at the local and provincial levels to build a new community based services system (Ministry of Children, Community and Social Services, n.d.).

The Williston Commission and the Welch report changed everything for people with developmental disabilities. A whole system of in-home, direct funding to families, and community residential care was developed, and the old hospital schools were all closed over time.

The people who came out of those institutions did not have the use of their limbs, they were emaciated, and had complex health conditions as a result. Some had dual diagnoses – developmental disability and psychiatric labels, others had dementia in addition to numerous other comorbid conditions, some brought about by having been forced to live in institutions where they were neglected and abused. Today these individuals would have been labelled extremely "high acuity", except that they were re-patriated to the community where they were not labelled. Instead they flourished.

In 1970 there were 232 people with developmental disabilities living in small, staffed community residences in Ontario. Today there are over 15,000 living in a wide range of residential alternatives in neighborhoods, towns, villages, and cities across Ontario.

This is the legacy of Walter Williston and Robert Welch. The historic parallels are obvious for older adults.

Fifty years after Williston wrote his historic report, this Commission has the opportunity to bring about systemic change, this time for thousands of frail older adults who have also been labelled and subjected to medicalization and unjustifiable institutionalization.

High Acuity – Medical Condition, Misleading Label, or Response to a Noxious Environment?

Misleading Label

The misleading "high acuity" argument masks what is really occurring in nursing homes in Ontario. It implies that those admitted receive high levels of nursing and medical care, but nothing could be further from the truth. As Till (2020) points out, inspection reports show, and the pandemic revealed, most of the interventions people might expect to happen in nursing homes – everything from palliative care including pain control and symptom management, skin and wound care, catheterization, oxygen, suctioning, falls prevention, tube feeding and many other interventions, actually do not occur, or do not occur optimally in these institutions.

Furthermore in spite of combinations of physical and cognitive abilities being considered to contribute to "high acuity" (Ontario Long Term Care Association, 2016) very little is available in the way of

individualized care for these specific conditions in these institutions. Residents are more likely to get good physical and cognitive care in smaller settings with staff who are familiar with the latest innovative treatment approaches for their conditions.

Environmental Response

One of the reasons for the "high acuity" argument in long term care is that people exhibit "responsive behaviors", placing staff and other residents in harm's way. The term "responsive" itself indicates that residents exhibiting aggressive behaviors are responding to something, and indeed they are – often environmental and situational triggers.

SSAO has, in its membership, professionals with a high degree of familiarity with so-called responsive behaviors who know that they are generally the result of antecedent events – how individuals are being treated or not treated for various maladies, the environment itself – boring, routinized, and dangerous, or internal triggers because of earlier traumatic events in their lives. We have seen from earlier examples that this kind of behavior can change significantly once people are living in more understanding and humane environments.

Institutionalization and routinization themselves often exacerbate behavioral issues in long term care. They certainly make depression in older adults worse, including irritable forms of depression.

Institutions are also probably the worst places to house older adults with dementia. There they are often subject to neglect, abuse by insufficiently trained staff and by other residents. They may be locked up in wards where they almost never have access to the outdoors. The government's own inspection reports tell the story of life in these institutions for these residents. Most of us would become angry and irritable and possibly act out in similar circumstances.

Trauma-informed care, which has been found to be particularly useful in the management of dementia (Janssen, 2020) is not easily delivered in institutional settings. Small, home-like environments with safe areas to wander, sit, and take part in activities are much more conducive to people with dementia flourishing.

Long term care facilities have become human warehouses in which to store individuals with a range of disabilities who should not be there. These kinds of "case mixes" that do not go together cause myriad problems for people forced to live together in these facilities and for poorly trained staff who work with them.

Approximately 40% of residents are considered to have a psychiatric diagnosis (Ontario Long Term Care Association, 2016), some of whom are said to have schizophrenia or bipolar disorder. These are individuals who should not be living in long term care facilities. They should be housed in high support group homes delivered by community mental health agencies where they can be cared for by professionals with mental health knowledge and experience.

Over 2400 residents currently in long term care have developmental disabilities (LHIN reports). They are only in these facilities because government has not funded enough residential spaces for them through the Ministry of Children, Community and Social Services. LTCF's are the fallback position when there is a shortage of community-based services, and that is not appropriate. People could live for life in community group homes if some nursing support could be built in, and agencies delivering these services had access to nurse practitioners with developmental disabilities expertise. Even without these some group homes house people aged over 100 with numerous comorbid conditions.

No one, except those requiring critical care in hospital, needs to live in an institution to be properly cared for. Long term care facilities are not equipped to provide many of the services people believe they do to those with the highest needs (Till, 2020). How is it possible that most care is delivered to people with supposedly "high acuity" by workers with barely a year of training or less if these residents' needs are so complex?

The Problem With the "Some Will Always Need Institutions" Argument

There was a time when medical and nursing professionals argued that people with psychiatric labels had to be institutionalized, people with developmental disabilities had to be institutionalized, people with physical disabilities had to be institutionalized. When children with developmental disabilities and significant physical disabilities were found in Homes For Special Care in the 1980's medical and nursing professionals warned that if they were taken out of nursing homes they would die. They did not die. They flourished in the community in non-profit, home-like settings.

It turns out that none of those groups **had** to be institutionalized.

Now the same argument is used in relation to frail older adults labelled "high acuity". But they do not need to be institutionalized either. Some, otherwise headed for an institution, are currently being cared for in the community by non-profit organizations like Neighborhood Link, Senior Link, and other seniors' organizations that deliver both in-home and residential services. If these same services were significantly expanded, older adults currently forced to live in institutions, sitting in wheelchairs crying "I want to go home" could be repatriated.

Not everyone can live at home or with family, but everyone can stay out of an institution if 24/7 staffed condos, apartment programs, and community group homes are available for them.

Examples of Alternatives Already in Place in Ontario

Richard Steele, the Deputy Minister for Long Term Care testified to the Commission that he would welcome community partners to provide services to ease the pressure on waiting lists and long term care institutions. Those potential community partners already exist.

Municipalities and regions are more likely to step up if they can operate community-based services that are properly funded and not institutional in nature. Operating institutions is a headache because it is difficult to obtain appropriate levels of staff, resist infection outbreaks, maintain quality, and obtain insurance, among other things. Municipalities currently already operate supportive housing, which is a natural environment to institute escalating levels of in-home support to keep people out of institutions. Making intensive in-home supports available in existing and proposed supportive housing projects can help reduce reliance on institutional services.

Many other non-profit organizations also exist that could be helpful in introducing both in-home and community residential options. These include Associations for Community Living, Intentional communities like L'Arche, Family Service Associations, community hubs like Scarborough's Healthy Communities initiatives, community health centres, community mental health programs, and community centres like Woodgreen, Neighborhood Link, and others. If the Ministry was partnered with these organizations to make funding available for creative proposals to keep older adults in the community the pressure on wait lists and long term care institutions could be greatly eased.

Associations for Community Living and Developmental Services Providers

At the present time 15,000 people with developmental disabilities, many with complex physical, developmental, and cognitive needs, are being supported by over 300 agencies offering in-home and community residential services for those unable to be at home (Community Living Ontario, 2020). Many, if not most, would be in institutions including long term care facilities, if this was not the case. Organizations like Rygiel Supports for Community Living provide community-based residential services to people with very complex needs and have done so for decades. https://rygiel.ca/

The Community Mental Health System

Programs like McKay House, in Whitby, operated by Durham Mental Health Services are high support group homes assisting clients with serious mental health challenges. It is double staffed 24 hours a day. There are also co-op and medium support group homes available throughout the community mental health system for people who would otherwise be at risk for nursing home placement.

Jean Dudley House operated by Neighborhood Link is one of the few smaller group homes for seniors who would otherwise be institutionalized. Residential programs like this could be greatly expanded in Ontario as alternatives to institutions.

Had the Ontario government approached these community providers in May, and asked them to rent or purchase condos, apartments, and homes in the community, and provided funds to staff them, hundreds, if not thousands of residents of troubled nursing homes could have been moved to safe, non-profit, community based homes prior to the second phase of the pandemic.

Approaches to Community Care in Other Jurisdictions

Denmark

Denmark has long been a model of care to elders because of the philosophies and principles that underlie its policies. Unlike in Ontario, the focus in Denmark is on involving and empowering older adults to increase the chances of a dignified old age characterized by independence, control of their own lives, and staying healthy and at home (Healthcare Denmark, 2020). Older adults and professionals use technology to collaborate in sharing information and developing treatment options. By 2001 after Denmark implemented integrated systems for home and community-based services in 272 municipalities, expenditures for the over 80 population leveled off and dropped as a percentage of the gross domestic product (Stuart and Weinrich, 2001).

Denmark, also unlike Ontario, builds senior care around peoples' resources and abilities instead of their limitations and deficits. This approach reinforces older adults' physical strength, independence, and improves their quality of life. Employees are also more satisfied providing strengths rather than deficit-based care (Denmark/Japan seminar, 2018).

United States

There is a change afoot in the United States as the Olmstead decision is applied to older adults, reinforcing their right to not be unjustifiably institutionalized (Olmstead Rights, n.d.).

Organizations like the Center for Policy and Evaluation, Administration for Community Living (2016) is beginning to examine the need to greatly strengthen community support and care (Tilly, 2016).

Since 2015, the United States has increasingly moved towards reinvestment in the community to ensure that community living for older adults is a realistic option (Quinn & Campbell, 2020). The incoming Biden administration has made a commitment for $450 billion to enhance Medicaid home-based care, in order to clear 800,000 people from the program's waiting lists for community care (Gleckman, 2020).

Ireland, Israel, and Australia

Since 1988 Israel has had a law providing older people with a legislated right to continue living in their own communities. The Australian government is calling for submissions on alternatives to institutions for elders, and in Ireland the head of the government suggested that perhaps it was time to make institutions a thing of the past (Quinn & Campbell, 2020).

Accountability Structure of Community-Based Non-Profits vs For-Profits

Non-profit community agencies are operated by Boards of Directors to whom the agency executive director is accountable for the quality of services and supports delivered by the agency as well as its fiscal management. Community boards can, and have ordered organizational reviews if they were not satisfied with quality and fiscal outcomes.

For-profit corporations are accountable to shareholders or senior executives and the emphasis is often on the bottom line. We have seen in inspection and press reports that many for-profit companies in long term care were accepting large payouts by government and paying shareholders millions while staffing and supplies, including PPE, were in short supply in their facilities. The emphasis appeared to be on minimizing cost rather than providing care. And it was difficult to determine who, exactly, was responsible for care of residents in these facilities and at the corporate level during the pandemic.

Non-profit agencies are inspected proactively yearly by program staff of the Ministry of Children, Community, and Social Services to ensure that the terms of their service agreements are being met.

In contrast, for-profit long term care facilities are generally inspected reactively only after harm is done and the Inspection Branch receives critical incident reports or complaints.

Non-profits are subject to the conditions outlined in their funding agreements and government can order a forensic audit if there are concerns about fiscal management. Furthermore non-profits can be subject to being asked by government for their Board's resignation and/or imposed interim management orders. These are not challenged in court.

For-profits facing license revocation, management orders, or other sanctions have challenged these in court, drawing government into extended legal proceedings.

Non-profits are not allowed to make campaign contributions and generally do not have adequate funding to hire lobbyists to pressure government to ease accountability restrictions for them or increase their funding.

For-profit companies regularly engage lobbyists to ease accountability restrictions on them and demand more funding (i.e. ending yearly comprehensive inspections, easing minimum staffing requirements, demands for additional funding for renovations and air conditioning etc.).

Accountability structures tend to be stronger, clearer, and more effective in non-profit service providers, and government tends to have a greater ability to act if it has concerns with a provider's care-related or fiscal management.

EFFECTIVE INSPECTIONS

At the present time, the Long Term Care Homes Act is unenforceable. It is a good Act, with a Residents' Bill of Rights, all of whose provisions have been violated without consequences during the pandemic and prior to it.

Compliance orders are issued and re-issued repeatedly and even where facilities have been found again and again to be in violation of the Act, there are no effective sanctions applied. There is no provision in the Act to issue fines, cease admissions orders are rarely used, Director's referrals rarely result in Director's orders, and most facilities, even those with the worst track records have no concerns that their licenses will be revoked or not renewed. Quite to the contrary, Orchard Villa received more beds after 78 people died there in the first wave, it had to be taken over by Lakeridge Health and the military was called in. Its story provides a case study in all that is wrong with for-profit facilities and with an unworkable Inspection Branch (Spindel, 2020).

Government would have nowhere to put the people in the current absence of alternatives to this system if it was to revoke licenses of operators.

Ordinary citizens do not have the funds to ask lawyers with the expertise required to file a Writ of Mandamus to force the government to enforce its own legislation, and so the law is on the books, but it does the residents and their families no good.

Recently the government responding to long term care industry lobbying, also raised the bar on what constitutes negligence to further limit families' abilities to seek redress for the treatment of their loved ones in these facilities.

Facilities are regularly understaffed, but government does not reduce admissions until appropriate staffing levels are in place nor does it order forensic financial audits to determine why facilities are not able to provide appropriate staffing levels or basic supplies such as PPE and bed linens. There are concerns about long waiting lists in the absence of older adults and their families having any other viable options except institutions and so few case admissions are ordered.

The History

Even the Health Facilities Special Orders Act was only used once to take over the Ark Eden Nursing Home after children died in that facility in the 1980's because of complicating factors of malnutrition, dehydration, and hypothermia (UPI, n.d.).

Attempts to revoke licenses in the past have resulted in injunctions or lawsuits by the industry. In the case of Ark Eden it continued to operate for a period of time as a seniors' residence after the owner took legal action.

In the 1980's a Crown Attorney was seconded to the Inspection Branch from the Ministry of the Attorney General, and a prosecution policy was introduced. This policy was effective in raising standards and reducing the more grievous care violations in many facilities, however it was later dismantled after lobbying pressure by the long term care industry when the government changed.

Also in the 1980's, an OPP investigation of nursing, rest, and retirement homes was launched at the request of then Attorney General Ian Scott, and led by OPP Inspector Ted Rowe. Criminal charges were laid against operators, some serious.

No Criminal Referrals

In spite of high infection and death rates in Ontario's nursing home before and during the pandemic, frequent press reports, damaging inspection reports, and a devastating military report, police have shown little interest in investigating these facilities, and no one in government has requested criminal investigations.

Even the Department of Justice in the Trump Administration has announced the investigation of nursing homes with high infection and death rates, as have some states (Berklan, 2020; Hamel et al, 2020), but to date, no such announcements have been forthcoming in Ontario. No police response in spite of families' requests for criminal investigations into conditions in facilities like Orchard Villa in Pickering.

Once alternatives are in place, more effective sanctions could be brought against facilities that repeatedly flaunt the law. However, inspector training in investigations also remains a concern, as does the uneven way that inspectors currently conduct inspections in different facilities (SSAO, September 3, 2020; SSAO, August 24, 2020). Also of concern is a recent Global News report showing that inspectors may be in a conflict of interest (Russell & Campbell, 2020).

Medical Malpractice?

Previous testimony by Dr. Nathan Stall showed that drugging of older adults in facilities, often as a means of chemical restraint, and especially during the pandemic, was a serious problem. He also said that 50% of residents are on anti-depressants. Abandonment of patients by physicians who stopped their regular on-site rounds during the pandemic was also a serious problem (SSAO n.d.). Had physicians been on-site many more residents suffering the effects of starvation and dehydration might have been transported to hospital, but were not. Many died as a result. This is a grievous situation that should not be allowed to re-occur.

There is currently no oversight of the physicians who are contracted, often to several long term care facilities, when they collectively fail their patients. This Commission, with its legal and medical expertise is in a position to make recommendations about what oversight should be in place with respect to groups of physicians who abandoned patients or prescribed psychotrophic medications not tied to specific medical conditions or in the best interests of patients, but to assist facilities that had staffing crises. Questions have also arisen about who was in a position to give informed consent to administration of these medications during a period when POA's were routinely denied access to their loved ones and to theses facilities.

There needs to be medical oversight concerning systemic breakdowns in the care and treatment of residents of this nature.

AN END TO FOR-PROFIT LONG TERM CARE

There are numerous problems associated with for-profit provision of care to vulnerable people, the most obvious being that profits are often put before care and resident co-payments are not used to upgrade facilities. This charge has been made numerous times by staff through their unions as well as a major newspaper's editorial board (Toronto Star, 2020).

Another problem with for-profit care is the undue political influence brought to bear on government policy by corporations with deep pockets able to hire sophisticated lobbyists, some of whom are former staffers from the government in power (rankandfile,ca, 2020). Ontario does not have strong conflict of interest laws with respect to government employees or elected officials not being allowed to accept positions in the long term care industry at the end of their employment and this raises serious ethics challenges. Many former employees, campaign officials, and elected official, including former Premiers and Deputy Premiers (Chartwell, 2020; Leslie, 2020) as well as senior officials of the Inspection Branch (Hansard, December 14, 1983) have gone to work for this industry directly after they leave their employment with government. Some industry officials also leave their posts to take government positions. One very senior official was once the President of Extendicare and the head of the Ontario Nursing Home Association, the lobby group for the for-profit long term care sector that pre-dated the Ontario Long Term Care Association (Ontario Health, 2020).

One of the reasons why Ontario continues to have an archaic, outdated, largely for-profit institutional system of caring for vulnerable people is the influence that this sector has been able to exert on various governments. Non-profit community care agencies and older adults and their families do not have the funds to be able to influence government in the same way so their wishes are often ignored while special consideration is given to those in the long term care sector who have promoted particular policies.

Companies have also started the practice of acquiring nursing home beds with no intention of managing these facilities themselves, and instead hiring a management company to do so, thereby having profits taken from the facility by two companies instead of one. This practice should be stopped. If a company is not capable of managing the beds it acquires, those beds should be awarded, preferably to a municipality or non-profit capable of administering and managing the facility itself, and ultimately downsizing and replacing it with community-based residential alternatives.

A lack of public financial accountability is also a feature of for-profit provision of care. Government should be able to send in forensic auditors when facilities are not supplying the staffing and supplies needed to provide adequate care to residents. The results of audits of this nature should be made public. That is not currently the case in Ontario, therefore for-profits escape another avenue of accountability.

Other jurisdictions have pursued charges against some individuals who have used their long term care businesses to launder money or to defraud the health payment systems as mentioned earlier. Extendicare was investigated in the United States and found to have defrauded the Medicaid payment system, but has continued to be granted licenses to operate facilities in Ontario (U.S. Department of Justice, 2014). All of this delegitimizes the long term care sector, the inspection system and the government that licenses, inspects, and funds it in the eyes of the public.

At the present time non-profits and municipalities are also at a disadvantage time-wise when attempting to bid on LHIN initiated requests for proposals because of the short time lines imposed.

This unfairly advantages for-profit companies in the bidding process (Central East LHIN High Intensity Supports At Home Capacity Assessment, November 30, 2020).

RECOMMENDATIONS

Alternatives to Long Term Care Institutions

1. **That the Commission recommend that long term care services for older adults either be transferred to the jurisdiction of an Assistant Deputy Minister for Seniors in the Ministry of Children & Community And Social Services (renamed the Ministry of Children, Seniors, & Community And Social Services) or that the Ontario government fund the Ministry of Long Term Care to work with non-profit community providers to downsize long term care institutions in Ontario and begin to build an equally large community-based in-home support and community residential service sector.**

2. **That the Commission recommend that the Government of Ontario reduce funding to the institutional long term care sector and redirect it to the non-profit community care sector in order to expand it until funding parity is reached and exceeded. This would redirect funds towards an emphasis on aging in place and community residential options as opposed to institutionalization.**

3. **That the Commission recommend that government double funding to its Home Care Program and remove caps on levels of care to be provided in-home as well as remove current bureaucratic restrictions on staffing and direct care in order to prevent people from entering institutions.**

4. **That the Commission recommend that government make permanent the High Intensity Support Program funding from LHINs instead of it being a temporary measure until March 31, 2021.**

5. **That the Commission recommend that LHINs be required to allow sufficient time for non-profit organizations and municipalities to respond to expressions of interest, capacity assessment requests, and funding proposal requests to allow potential community partners to meet their accountability requirements before submission.**

6. **That the Commission recommend that government begin funding a Money Follows The Person Initiative, institute Individualized Direct Funding for older adults and their POA's, fund a paid family caregiver program to ease waiting lists, and consider recommending that the province negotiate a Federal government mandated public long term care insurance program.**

Inspections

1. **That in concert with the development of community-based alternatives to the institutional sector, the Commission recommend that government introduce a more rigorous inspection system that incorporates forensic audits, a prosecution policy for repeat offenders, including Cease Admission orders, non-renewal of licenses, the issuing of fines (which would require legislation), and license revocations.**

2. **That the Commission recommend that the Inspection Branch end its policy of hiring inspectors from the long term care sector and replace them with inspectors who have investigative and public health experience and who come from other health sectors.**

3. **That the Commission recommend that the Inspection Branch develop closer ties with the OPP and other police forces and make referrals to the police where criminal acts, including criminal negligence causing bodily harm or death are suspected, as well as assaults on residents.**

4. **That the Commission recommend that a Crown Attorney be cross appointed from the Ministry of the Attorney General to assist the Inspection Branch in determining when facilities' performance reach a level where a prosecution should be initiated because their failure to provide care is in danger of causing harm to residents.**

5. **That the Commission recommend that the Attorney General of Ontario be asked to refer for police investigation incidences where families have requested criminal investigations and/or when conditions in a facility as reported by inspectors warrant police investigation, or when a facility has a high infection and death rate and the military and inspection reports have detailed harm to residents.**

6. **That the Commission recommend an investigation into the actions of doctors who prescribed chemical restraints, possibly without the informed consent of residents or their POA's who were barred from facilities during the pandemic, doctors who abandoned their patients, and who failed to insist on transfer to hospital of critically ill residents with treatable, but life threatening conditions during the pandemic.**

For-Profit Involvement in Long Term Care

1. **That the Commission recommend the reduction of for-profit involvement in long term care and the redirection of funding to the non-profit community-based care sector to promote the development of non-profit in-home and residential alternatives to long term care institutions.**

2. **That the Commission recommend that the government order forensic audits of any facilities that have a history of short staffing, being short of supplies for resident care and necessary PPE for staff, and who received Federal and Provincial government funding during the pandemic, the goal being to ensure that the funding was used for its intended purpose.**

3. **That the Commission recommend that forensic audits be conducted to determine whether or not the long term care industry's repeated calls for more funding are justified, and to what extent profits are being taken out of facilities operated by for-profit companies, especially where one corporation owns a facility and another is hired to manage it.**

4. **That the Commission recommend that the process of corporations hiring management companies be stopped, and that companies be required to manage facilities for which they have received licenses themselves or surrender those licenses so that they can be re-awarded to create community-based residential options.**

SSAO appreciates the willingness of the Commission to hear from us and to review our submissions.

We see the Commission as having a rare opportunity to do what Williston did in 1971 and recommend systemic changes that would greatly improve care and services to older adults, promote aging in place, and smaller, non-profit, home-like residential options in the community.

Nothing less than a full overhaul of the current long term care system will bring about needed change. Simply tampering with symptoms will not achieve it.
Older adults deserve to finally have the same living and care options available to them that are currently available to younger age groups.

The current ageist policy of medicalization and institutionalization of elders needs to end. It is a violation of their human rights to continue to be unjustifiably institutionalized when other, more individualized and humane options are available.

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