



SENIORS FOR SOCIAL ACTION (ONTARIO)

Editorial

WHEN SEGREGATION, EXCLUSION, AND STIGMATIZATION SEEM LIKE A GREAT IDEA.

WHY DEMENTIA VILLAGES DO NOT CREATE “INNOVATION” IN LONG-TERM CARE

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Preamble

Imagine for a moment “Intellectual Disability Villages” or “Cerebral Palsy Villages” or “Schizophrenia Villages”. Not your idea of an innovative concept? So why are they being touted as the solution for people living with dementia?

Segregating people, excluding them from their homes and communities and slotting them according to their disabilities is stigmatizing. This is exactly what “dementia villages” do. They are pretend villages for people with dementia where it is suggested we put people so they can be with others “just like them” out of sight out of mind of the rest of the community.

What we no longer accept for younger people with disabilities is still considered just fine for older people with disabilities by government, the long-term care industry, and the general public. But this is far from fine.

We knew it was not fine in 2007 when this article appeared in *The Gerontologist*:

“Disability is common across the age spectrum, but society's response differs substantially by age. Older people are disadvantaged in terms of both the options offered them, and the funds spent on them. Expenditures per recipient are substantially higher for younger individuals with disabilities, largely as a result of more effective advocacy. This disparity reflects a long history of viewing disability among older adults as an expected concomitant of the aging process. Older adults are seen as frail and vulnerable people who need to be protected, whereas younger individuals with disabilities accept risk as the price of full social participation. Care options rejected by younger people with disability (including both institutional and home care) are considered mainstream for older adults. We suggest that these disparities in spending and options represent a form of ageism.” (Kane et al, 2007).

The segregation of elders by age and disability leads to a host of other social problems as well – some of which we are currently seeing in Ontario as the generations turn on each other, increasing numbers of older people are reporting that they are lonely, and ageism is rampant.

“This separation by age has left us ill-equipped for today’s world, where people are living longer and society is increasingly multigenerational. It has contributed to widespread social issues like ageism, generational enmity, and loneliness. Just as troubling, we’re missing out on the many opportunities for individuals to support one another, and bring the talents of young and old to the task of improving life for all.” (Freedman & Stamp, 2021).

Social Conditioning in Ageism?

Why is removal of elders, especially those with cognitive disabilities, from their communities and “placement” in retirement homes, dementia villages, green houses etc. considered appropriate, when we would never subject younger people with disabilities to these options? Perhaps for the same reason that many still think that “there are always going to be people who “need” institutions?”

The Ontario and Canadian publics have been conditioned, for over 40 years, to believe that institutions are good places to “put” old people, so current attitudes should come as no surprise.

How elders might feel having to leave their familiar homes and communities to go and live somewhere else, segregated according to their infirmities, does not seem to merit consideration.

A Marketing Ploy by For-Profit Corporations

Dementia villages are the latest marketing ploy by big retirement home corporations to convince the public that they have come up with a new innovative “concept”.

Canada’s first “dementia village” in Langley, British Columbia (The Village Langley, 2023) is actually operated by a private corporation - Verve Senior Living - based in North York, Ontario. Verve is owned by Diversicare (Verve, 2015). This “village” is essentially a glorified retirement home and retirement homes are lucrative businesses.

MPP France Gelinis put it well in the Ontario Legislature two years ago:

“Make no mistake, 94% of retirement homes in Ontario are for-profit. Chartwell and Revera are the biggest ones. They make a ton of money. Ask them how much of the \$4.7 million they pay their CEOs comes from the profit of the retirement homes—a lot of it.”

She also pointed out that retirement home oversight works for the owners, not the residents (Hansard, 2021).

But At Least They Are Better Than Nursing Homes

An ill-informed public has bought the idea of dementia villages because they seem better than nursing homes, especially since almost anything would be better than those. But why would they be better - because they look nicer?

Retirement homes, even dementia village concepts, draw from the same staff pool. They segregate a lot of stigmatized people together in one place exposing them to infection. There were major COVID outbreaks in retirement homes, including “village concept” ones, across the country (StatsCan, 2021). Regulatory functions are substandard according to Ontario legislators (Hansard, 20221). They are essentially fancier ways to warehouse older adults and charge them and their families a lot of money for the privilege. Dementia villages and other types of retirement homes are not cheap.

Is this really what we are aiming for in reforming long-term care - a segregated, exclusionary model that removes people from their communities because it is not as bad as a long-term care institution? It, at least, allows people to walk around and visit shops or hairdressers?

Some have the fantasy that paid staff will appear out of nowhere to care for residents in kind and compassionate ways in these “villages”. Where are these “kind and compassionate” staff to come from?

Schlegel Villages: A Case Study in the “Village Model”

Schlegel Villages tout a “village” concept of care for their residents as well (Schlegel Villages, 2023). Their promo says: *“The Village concept was always meant to create living space that feels like small town Ontario.... Within the Village model, Main Street connects to the Town Square, which is the social centre and gathering place of the Village.”*

What a perfect place to segregate a lot of old people with disabilities. But how did these “villages” fare during the pandemic? What could possibly have gone wrong with such a lovely concept?

“In a statement of claim put forward by lawyer Gary Will, lead council on the suit for Will Davidson LLP, the proposed class action lawsuit alleges the company “failed to protect” residents of Schlegel Village-owned Long Term Care and Retirement homes from a mass spread of COVID-19.” (Barker, 2021).

Readers can surely see where this is going. Segregation by age and disability is disastrous for those who have to endure it – whatever pleasant title it is given.

Older Adults Live in Fear of Being Institutionalized

Many elders live in fear of being institutionalized by their families, hospitals, doctors, the government. How horrible is it that many worry that the people and institutions they should be able to count on the most have actually been brainwashed and weaponized against them?

Why do we, as a society, accept the mass institutionalization of elders? Why do we think concepts like dementia villages are a good idea when so many other more inclusive and respectful alternatives exist?

What are the Alternatives?

Seniors for Social Action Ontario (SSAO) has listed these alternatives like a broken record over the past three years:

- For those needing residential care - small, actual homes in elders' own neighborhoods staffed 24/7 and operated by municipalities or non-profit organizations. These should be available in neighborhoods, towns, and cities across the province;
- Hub and spoke models that bring services to people in naturally occurring seniors' communities and community housing, and also serve elders for miles around the "hub" building;
- PACE (Program of All Inclusive Services for the Elderly) models recently brought to Ontario by an enterprising Councillor in Burlington, that are keeping people out of long-term care institutions;
- Greatly increased in-home care options that cut through the red tape and inadequacy of Home Care and deliver services based on need, not on bureaucratic requirements;
- Direct funding up to the amount paid to nursing homes, where money is tied to the person instead of to a facility so that individuals can arrange their own service and support options;
- Significantly increased in-home respite care that could allow family caregivers to go on vacations and take breaks;
- Paying family caregivers to be able to take leaves of absence from employment and arrange additional supports for themselves and their loved ones;
- Funding community-based hospices for those who have dementia and other serious illnesses and need end of life care.

Segregation and Exclusion are Never Good Policy

Ontario moved away from institutions for other groups with disabilities decades ago because it was recognized that segregating large groups of people by disability resulted in abuse, neglect, and despair for residents (Remember Every Name Survivors of Huronia Group, 2023).

Disability Justice put it succinctly for people with developmental disabilities:

Whenever a group of people is deemed less valuable or less important, they become vulnerable to abuse, neglect, discrimination and exploitation. Stereotypes, misinformation and a general lack of interest all contribute to a culture of ignorance where people with developmental disabilities are viewed as a single, homogenous group, rather than as individuals with unique abilities, skills, interests and needs. (Disability Justice, 2023).

The same is true for elders.

In the U.S. Inclusion and Community Integration Are the Law

It has long been recognized for younger people with disabilities that services and supports should be delivered to them using the least restrictive alternative – in-home and community-based support - not the most restrictive alternative – institutions.

In the U.S. it is actually the law. A case called *Olmstead v L.C.* established in the Supreme Court that the Americans with Disabilities Act “prohibits the unnecessary segregation of people with disabilities who have a right to live and receive services in the most integrated setting appropriate” (U.S. Department of Justice, 2022). The most recent *Olmstead* case addressed the inappropriateness of even segregated work settings for people with disabilities.

Because of *Olmstead*, older people with disabilities have also been assisted to leave long-term care facilities in the tens of thousands through the Money Follows the Person Program – a program that promotes the empowerment of people with disabilities of all ages by providing funding directly to them to arrange their own supports and services. This has allowed them to live more independently according to their own wishes, not those of the state (Medicaid, n.d.).

Why is Ontario so behind in its thinking and policies?

Ageism is Embedded in Public Policy at All Levels of Government

The Government of Canada clearly understands the problem of ageism, and recognizes that social inclusion is critical for older adults.

“Social inclusion describes how a society values all of its citizens, respects their differences, ensures everyone’s basic needs are met, and welcomes and enables full participation in that society.... Inclusive societies support the economic and social inclusion of older people, including those who are vulnerable or at increased risk of exclusion.” (Government of Canada, 2023).

But so far the Federal government has done nothing about mass institutionalization, segregation, and exclusion of elders.

The Game Changer: Direct Funding

It has been suggested that one way to reduce segregation and exclusion of elders in society is through the use of direct funding, so that elders and their loved ones are in the driver's seat when it comes to care provision in a client-directed as opposed to a client-centered approach.

“One way to reduce ageism in long-term-care policy and programs would be to promote individual resource management for disability program enrollees, usually referred to as consumer-directed care. If everyone could agree that people can have different values, needs, and goals at various stages of their lives, giving money directly to the disabled individuals would allow them to spend it how they want. Presumably, preferences would not be used to set payment rates. Rather, consumers would determine how funds allocated on the basis of consistently assessed needs could be spent.” (Kane et al, 2007).

This would allow those needing assistance to decide how and where that assistance could be provided and by whom.

Time for Self-Examination?

The Ontario public does not understand that dementia villages are examples of segregation and exclusion of people from their own homes and communities.

Mass institutionalization and segregation anywhere represent a major failure in public policy and elders have not received better because the public has not demanded better of its governments. Instead it has bought into “simple” marketing concepts like dementia villages, without thinking through the implications of this new kind of segregation.

It is important that we, as members of the public and as elders re-examine our own attitudes. Why have we so easily embraced concepts that segregate people according to their infirmities, excluding them from all that is familiar – their homes and communities? Why do we so easily accept the stigmatization, infantilization, and caricaturing of elders with dementia in pretend villages made to mimic “normal” villages?

Why can we not even imagine building understanding in the broader society so that people of all ages with all types of disabilities are assisted to continue to embrace their full humanity, remain engaged to the best of their ability in their communities, and be respected as human beings.

Why is this so much to ask?

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