BRIEF TO THE ONTARIO CABINET

MASS INSTITUTIONALIZATION OF PERSONS WITH DISABILITIES OF ALL AGES

"They aren't nursing 'homes', they are institutions.
They aren't long-term 'care' facilities, they are institutions.
End the euphemisms.
These are institutions."

(Gabrielle Peters, 2020)

Gabrielle Peters is a dis-abled Canadian writer and policy analyst and co-founded Dignity Denied.

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

(Catherine Frazee, 2022)

Catherine Frazee is a dis-abled Canadian, is a professor emerita from the Metropolitan University School of Disability Studies, and a former Chair of the Ontario Human Rights Commission.

A JOINT SUBMISSION OF

Citizens With Disabilities Ontario
Seniors for Social Action (Ontario)
Ontario Disability Coalition
People for Personalized Funding
Ontario Federation for Cerebral Palsy
Disability Justice Network of Ontario
Childhood Disability Network Canada

OAC
Ontario Advocacy Consortium

BRIEF TO THE ONTARIO CABINET ON

MASS INSTITUTIONALIZATION OF PERSONS WITH DISABILITIES OF ALL AGES

For the first time in decades organizations representing older adults and younger persons with disabilities and their families have come together with a serious message to the Ontario Cabinet. It is time to change direction in long-term care policy.

It is time to redirect a significant portion of funds currently designated for the expansion of long-term care institutions into supporting persons with disabilities – old and young - in their own homes and communities.

The Ontario Cabinet will not have heard the plaintive cries of "I want to go home" by residents of all ages in long-term care institutions across this province. But we have all heard them, and are responding with this brief to you. We ourselves and our loved ones could all find ourselves in this position.

Ontario's Long-Term Care Policy Needs a Change in Direction

Ontario has the highest rate of institutionalization of people with disabilities of all ages in Canada (CIHI, 2024). With over 620 long-term care institutions, the majority operated for-profit, much of Ontario's funding is currently directed at institutionalizing its population with disabilities. That is neither humane nor progressive public policy.

Ontario also had consistently high death rates in these facilities (CIHI, 2020/21) during the pandemic which should have demonstrated, beyond doubt, that institutions are dangerous and dehumanizing for people requiring support and assistance (Knapp et al, 2021).

The Cabinet is aware of the horrific scene that unfolded in these institutions during the pandemic - the horrendous conditions documented by the military report; the ongoing detailing of failure to meet legislated care requirements in inspection reports; and the need for medical officers of health to ask public hospitals to take over care of residents in predominantly private facilities in

order to save lives. Similar conditions had been documented in long-term care for at least forty years previously.

The tragedy that unfolded in Ontario's long-term care institutions from 2020 to this day should have caused this government to change direction. Instead, it has doubled down, warehousing even more people who want nothing more than to remain in their own homes and communities with the necessary support. Warehousing human beings in this way, affording them no other viable community-based options, is a violation of their human rights (United Nations, 2006).

A landmark legal victory in Nova Scotia's Court of Appeal (Nova Scotia Court of Appeal, 2021) by the Disability Rights Coalition supporting the rights of individuals with disabilities to live in the community with necessary supports and not be confined to institutions made this point emphatically, underscoring the right not to be confined to institutions.

That province has learned its lesson. The Government of Nova Scotia has initiated a five year plan to guarantee the rights of people with disabilities. They will be able to move out of institutions and be provided housing to support them in the community. An expert monitor is being named to ensure that the province provides progress reports and creates a website with statistics on whether or not goals are being met (Tutton, 2023).

Institutionalization of People with Developmental Disabilities

Today, in Ontario, people with developmental disabilities are being institutionalized younger, and in greater numbers.

Data from the Ministry shows that there are now 2566 individuals with developmental disabilities in long term care facilities, with 1375 under the age of 70, and 88 aged 19 - 39. (Health Analytics and Insights Branch, Extracted April 2024). This is in direct contradiction to the Ministry of Community & Social Services Journey to Belonging initiative where the Minister states: "The journey has been a long one; from a place and time when people with developmental disabilities were living in institutions separated from the community, to one where we are in reach of community inclusion and true

belonging". (Government of Ontario, n.d.). Sadly continuing to belong in their homes and communities is an outcome still denied to too many people with disabilities – old and young.

Aside from this being a tragic outcome for all those in this situation, it is a warning to the provincial government that its long-term care policies are failing individuals with disabilities of all ages. They are costly, regressive, unsustainable, dehumanizing, and out of step with the policies of other developed countries.

A Significant Absence of Non-Profit In-Home and Community-Based Services and Support

The absence of provincial government support for a continuum of non-profit in-home and community-based supports and services for people with disabilities of all ages has caused families and exhausted caregivers to have to face the heart breaking and gut wrenching decision to place their loved ones in these facilities.

Rather than embracing the more progressive policy directions of most OECD countries, Canada and Ontario have continued to expand an 18th century houses of industry model of warehousing disabled people of all ages.

Not only a failure of public policy, this has also contributed to personal tragedies for thousands of individuals and their families – individuals who have been uprooted, excluded from their own communities, and segregated in long-term care institutions where they are subjected to institutional routine, and suffer a complete lack of control over their lives.

A recent letter from a resident of a brand-new long-term care facility in Owen Sound poignantly illustrates this point. She says "Decorations were beautiful in the lobby but lacked on higher floors. I've been here for almost a year without vitamins or fresh fruit. The ministry is not helpful. Lunch is forgotten while supper is poor. My spirit is broken. I am on every crisis list to get out, even willing to move away from family for proper care" (Broekestein, 2024). Ms Broekestein writes of hunger and despair, and of the complete inadequacy of the Long-Term Care Inspection Branch to improve conditions – a story that has

been going on for decades. The Inspection Branch is no match for the power, influence, and wealth of the corporate long-term care industry in this province.

Class action lawsuits in government-operated institutions for people with developmental disabilities, and now in long-term care facilities, make the case that institutions are an unworkable system that needs to be dismantled in favor of intensive in-home supports and non-profit community residential living options (Leslie, 2016; Lang, 2024) .

Staffing and Legislated Standards are Not the Issue

The issues are not staffing levels, or full-time work, or even legislated standards. All have failed over the decades when you consider that provincial institutions for people with developmental disabilities were government-operated, hence non-profit, well-staffed, with staff members that were well paid. In spite of this, completely unacceptable conditions prevailed there, and abuse and neglect were rampant (Remember Every Name, 2024).

The issue is also not legislated standards. The long-term care inspection branch and one Minister after another have, for decades, been unable to ensure that long-term care facilities meet legislated standards. What has been demonstrated over decades of Ontario history is that when you congregate hundreds of vulnerable people in institutions, significant abuses and human tragedy will result.

Institutions have closed in this province for every other group of people deemed in need of care or supervision except for old people, some younger people with disabilities, and prisoners. Convicted prisoners are institutionalized for set terms. For people with disabilities – young and old – institutionalization is often a life sentence – a cruel irony when you consider that aging and having a disability are not crimes.

History has shown that institutions cannot be fixed. Ontario cannot build its way out of the long-term care crisis with a costly, regressive bricks and mortar institutional approach.

The Ontario Cabinet has a responsibility to change direction, dismantle this 18th century prison-like system containing locked wards for people with dementia, and some people with developmental disabilities, and introduce more progressive and humane policies outlined in this brief.

The Facts

At the present time, because of its policy and funding framework, Ontario is offering people with disabilities of all ages only three options – a dysfunctional, ineffective, and unreliable Home Care system, an institution, or medical assistance in dying. These are the stark choices facing older individuals and younger people with disabilities because of this failure of public policy.

Most Residents of Long-Term Care Facilities Have "No Significant Disability"

- Continuing Care Reporting System Data 2020/21 from the Ministry of Health shows that 69% of residents in long-term care facilities have "no significant disability" (Data extracted February, 2021).

Home Care is Grossly Underfunded and Inadequate

- If you divide the amount of funding received by each HCCSS area office by the number of people it serves, it shows that individuals receiving Home Care services, on average, obtain less than $5500.00 a year in funding – which amounts to less than $458.00 per month (Freedom of Information, Ministry of Health, 2024). Compare that to the generous funding received by long-term care institutions and it becomes clear what is driving individuals into them and increasing wait lists.
- More generous estimates, like those from the National Institute on Aging, suggest that $103 per day is spent on Home Care versus $200 per person, per day on long-term care institutions (Casey, 2021), and this does not include the resident co-payment. Even these higher Home Care funding estimates show that Ontario still spends at least twice as much on institutionalizing people than it does on keeping them at home.

- The hospital at home and intensive home care programs are often time limited when people with highly complex needs require them over the longer term.
- Home Care has been demonstrated to be unreliable, with many Home Care companies having failed to meet the requirements of their contracts (Seniors for Social Action Ontario, 2024; Johnson et al, 2022). A Provincial Auditor's report in 2021 pointed out that Ontario apparently does not track missed Home Care visits. The Ministry has also not used available data to inform its investments in Home Care or assessed its effectiveness, and assessments of individuals were found to be open to agency bias. The public has little information about how to access what little Home Care there is (Office of the Auditor General of Ontario, 2021).

Lack of Funding to Assist People to Remain in Their Own Homes

The Government of Ontario has not, historically, funded programs that bring services to where elders and people with disabilities live – in community housing, shelters, rent-geared-to-income units, and seniors' buildings.

It did recently fund one seniors' building in Kenora with care built in, but has not expanded this model across Ontario even though it is badly needed. In the former Long-Term Care Minister's own words, this program offers an alternative to institutionalization. "Our government's investment in the new Kenora mixed-market seniors' housing complex is an innovative way to help seniors who want to continue living at home and avoid admission into long-term care or hospital, but need support to do that," said Paul Calandra, Minister of Long-Term Care. "We're taking action so people can live and receive care where they can have the best possible quality of life, close to their family and friends." (Government of Ontario, 2022),

With some retirement homes closing in Ontario, it would make sense to renovate these buildings for accessibility, make condos or apartments in them available for older adults, and contract with non-profits to provide PACE (Program of All Inclusive Care of the Elderly) or other programs like those offered by University Health Network in naturally occurring retirement

communities (NORCs) with funding from the provincial government (Bradbury, 2024).

Exclusionary Criteria, Red Tape, and Bureaucracy in Direct Funding

- The Government of Ontario has not adopted a workable needs-based direct funding program to empower individuals and families to organize their own care where, when, how, and delivered by whom they wish. The Family Managed Home Care program discriminates against elders in its access criteria, making it almost impossible to apply, and involves considerable bureaucracy and red tape for those attempting to use this program. This makes it difficult for families to manage care of their loved ones along with the program's bureaucratic requirements. Capped hours of care, even for people with very complex needs, in violation of a 2016 settlement between the Ontario Human Rights Commission and the Ontario government (Ontario Human Rights Commission, 2016), and lack of back office administrative support to individuals and families using Family Managed Home Care add to the problem. This creates an unnecessarily bureaucratic, difficult to access direct funding program that does not address the actual needs of the people it is intended to serve.

No Paid Family Caregiver Program as an Option in Home Care

- Ontario lacks a Paid Family Caregiver program that would be especially helpful to rural, Indigenous, and cultural communities. This province is behind Newfoundland and Labrador, which has successfully adopted this program, and the Northwest Territories that tested it as a pilot program (Government of Newfoundland and Labrador, 2015; Government of Northwest Territories, 2024). The program in Newfoundland and Labrador has expanded because of its success and popularity, and the pilot project in the Northwest Territories has concluded, but planning is now underway for continuing care support programs like those delivered under this pilot to support aging in place.

No Money Follows the Person Program

- Ontario does not have a Money Follows the Person program (Medicaid, n.d.) as exists just over the border in New York State. There, nursing home residents, who do not wish to continue to be institutionalized, can access funding that follows them, and is not tied to the institution. This facilitates their re-entry to the community helping them to live in their own homes with appropriate levels of support. Money Follows the Person and the inability of operators to staff long-term care facilities in the U.S. have resulted in low occupancy rates and closures of institutions there. Ontario is beginning to witness something similar as the Baby Boom generation refuses to enter institutions, and over 90% of elders are saying they do not want to end up there (IPSOS, 2022). It is time Cabinet initiated a humane response to the cry "I want to go home" and gave nursing home residents who want to return to their communities the ability to do so with appropriate levels of support and funding.

An Absence of Community-based Residential Options that Provide Real Homes

- Ontario lacks a range of residential options, particularly those where people with disabilities and their caregivers are able to create and maintain consensual relationships that maintain people in their communities, including in staffed condos, apartments, shared housing, cooperatives, and neighborhood-based community residences. At the present time older adults have few to no staffed community-based residential options, and many of these options that younger people with disabilities might choose are grossly underfunded, rely on strict routines, and do not provide adequate living conditions. Ontario made a mistake in allowing real estate investment companies to operate long-term care facilities. Care should be provided separate from who builds and owns the buildings. This is one reason why non-profit supportive housing models like Richview Residence in Etobicoke are better options – one company built the building, but a non-profit provides the care and upkeep (Richview Residence, 2024).

Questions for the Ontario Cabinet

This raises some questions about why the Ontario government has continued to pursue a policy of warehousing vulnerable human beings rather than supporting public policies designed to help them to remain in their own homes and communities with necessary social and personal support as they have asked.

Why has this government chosen not to empower individuals and families with direct needs-based funding?

Why has the Ontario government not chosen to empower long-term care residents who do not wish to be institutionalized with Money Follows the Person funding so that they are able to return home with the necessary supports?

Why has the Ontario government not adopted a range of assisted living programs across the province to support individuals with disabilities of all ages to remain in their own homes and communities as so many other countries have? Denmark has not built institutions since 1987 because it chose to fund intensive home care and the other community-based options outlined in this brief. "Since the law on dwellings for older people from 1987, no new nursing homes have been constructed, and instead a varied range of dwellings adapted for older persons have been developed" (European Network of Economic Policy Research Institutes, 2010). This would seem to belie the common belief in this government that people with disabilities need institutions.

Why does Ontario continue to waste billions of taxpayer dollars that are invested in predominantly for-profit, financialized real estate investment trusts with failed track records that operate long-term care facilities in this province?

This locks future governments into an archaic approach that lacks the flexibility to review these policy decisions, re-evaluate, and improve long-term care in the future. The options outlined in this brief provide the government with this kind of flexibility and the ability to modify its long-term care policies in the future.

WHAT WE ARE ASKING

Ontario does not, at the present time, have a progressive, humane, or effective 21st century policy of providing support and services to people with disabilities of all ages. Instead it has an expensive, dehumanizing, unsustainable, bricks and mortar strategy of institutionalization. It is a failed public policy and demonstrates a need to change direction.

According to IPSOS, over 90% of older adults have said they do not want to end up in an institution. Younger people with disabilities have long stated their desire to remain in their homes and communities with the necessary support. It is time the Ontario Cabinet listened to the people it is intending to serve.

Instead of investing billions of dollars in institutions, we are asking the Ontario Cabinet to redirect that funding by investing in initiatives designed to maintain people with disabilities of all ages in their own homes and communities using a continuum of support model ranging from the least to the most restrictive alternatives. End the emphasis on "beds" and begin emphasizing "spaces" that actually meet peoples' needs.

LEAST RESTRICTIVE OPTIONS

Intensive in-home support

Currently the Ontario government provides $200+ per person per day to long-term care institutions (Migneault, 2022) to provide about 3 hours of care per day. Redirecting that same funding to Home Care would, at $25 per hour for PSWs, fund more than double the hours of home care per day with no costs attached for construction, redevelopment, or bed expansions.

Direct funding through Family Managed Home Care.

Funds could be redirected from institutions to this program - and redistributed once the discriminatory criteria based on age and type of disability are eliminated to allow people with disabilities of all ages to access it.

This program empowers service users to obtain the right care at the right time in the right place, and not be reliant on a dysfunctional, unreliable, and unresponsive Home Care program to provide it.

This would also address staffing shortages in the Home Care sector, as individuals and families recruit and fund their own in-home support services.

Home care provider organizations should not be allowed to dictate to the Ontario government what programs and services it supports and funds as they did in bringing a judicial injunction in 2017 to prevent the creation of a system of direct funding for older adults (Dansereau et al, 2019).

This injustice needs to end now. The human rights of older adults to equitable treatment in the Family Managed Home Care program trump home care providers' business concerns, especially for those providers that have been unable to meet their contractual obligations to provide necessary in-home supports.

Paid Family Caregivers.

Newfoundland and Labrador and the Northwest Territories already have this option under Home Care. It is time Ontario followed suit. This program would be especially helpful to Indigenous and Cultural communities where family-based care remains paramount.

Younger or non-disabled family members often provide care, support, and company to family members with disabilities of all ages. Assisting them to juggle school, part-time jobs, and providing family support by paying them to provide this would go a long way to addressing the stress of younger caregivers and would also help to ease the staffing shortage. Providing training and support to all family caregivers through Ontario's paramedicine programs would also help to build caregiving capacity in families.

Expand the Adult Protective Services Program (Renamed Adult Community Service Worker Program) to People With Disabilities of All Ages.

Adult Protective Service Workers currently provide case management and advocacy support to people with developmental disabilities. In recent years their advocacy mandate has been weakened, and insurance costs to cover transport of clients in their cars are not currently covered. Both issues need to be addressed to re-build this into an effective person-to-person support program for people with disabilities of all ages.

Currently funded by the Ministry of Community and Social Services, this program could easily expand to serve all people with disabilities to provide advocacy and system navigation support and be renamed the Adult Community Service Worker Program.

Consideration should also be given to housing this program under the Ministry of the Attorney General through the legal clinic system in order to strengthen its advocacy mandate.

MODERATELY RESTRICTIVE OPTIONS

Intensive Home Care, In-Home Palliative Care, and Hospital at Home Expansion

The Ontario government introduced Bill 7 forcing vulnerable alternate level of care patients out of hospital beds and into long-term care institutions – often without their consent. It could instead have invested in intensive in-home palliative and hospital at home supports that have been found to be working.

The St. Mary's Hospital at Home program provides care for people in their own homes on an intensive basis as other longer-term community-based services are arranged for them. There the Ontario Health team has brought together a group of 40 service providers to create an integrated model of care for individuals (St. Mary's Hospital, 2024).

Hospital at Home Programs could also deliver palliative care to individuals allowing them to remain at home as they receive pain control and symptom management support.

For those individuals with complex care needs, extended intensive Home Care programs of this nature can prevent both hospitalization and institutionalization, and need to be available over the longer term.

PACE and Hub and Spoke Programs

Programs of All Inclusive Care of the Elderly (PACE) need not just be for older adults. They can also be of critical assistance to younger individuals with disabilities, supplying everything from assistance with activities of daily living to physiotherapy and occupational therapy or the services of a nurse practitioner. PACE brings services to where high concentrations of individuals who need them live – in community housing, rent-geared-to-income units, and seniors' buildings. This program is expanding in Burlington and should be expanded across the province (Alzheimer's Society, 2024).

Hub and Spoke Programs

The hub refers to an apartment or other community-based congregate living building where individuals requiring daily assistance live. The spoke refers to the areas surrounding the building.

Hub and Spoke models provide 12 -16 hours of support daily to residents in the buildings they serve and to the surrounding area, and incorporate a service coordination component whereby service coordinators operate on a person-directed model taking their instructions from the people they serve.

This model has been in place in Peel Region for several years now and has kept nearly 3000 older adults with complex care needs in their own homes, avoiding hospitalization and subsequent institutionalization. This is a model that could be easily expanded to also serve younger people with disabilities, especially in rent-geared-to-income apartments (Peel Senior Link, n.d.).

It is recommended that this program be expanded across the province and also employed in neighborhoods where there is a high percentage of individuals requiring assisted living support.

Adult Community Support Workers

There is often a significant need for system navigation and advocacy support of younger and older adults with disabilities. To address this need, the Government of Ontario could expand the current Adult Protective Services program housed within the Ministry of Community & Social Services, rename it the Adult Community Support program, and house it under the auspices of the Ministry of the Attorney General within its legal clinics structure, to reinforce its advocacy mandate.

Rather than use a medical model of nurse system navigators, creating a social justice model whereby these workers take their instructions from the people they serve thereby empowering them, and ensuring that the supports individuals receive are needs-based, not determined on a staff-centered model makes more sense.

It is recommended that the current Adult Protective Services Program be renamed the Adult Community Support Program and housed within the legal clinic system under the Ministry of the Attorney General.

MORE HIGHLY RESTRICTIVE – NON-PROFIT RESIDENTIAL SUPPORT IN THE COMMUNITY

Supported Independent Living – Staffed Condos, Apartments, and Shared Housing Arrangements

There are naturally occurring retirement communities across Ontario and rent-geared-to-income community housing buildings where a higher number of younger people with disabilities also live. Termed NORCs for retirees, there are proven programs like the one delivered by the University Health System (UHN) and its partners that are keeping people out of institutions (Bradbury, 2024; Welsh, 2024).

Cluster care communities, where people with disabilities of all ages have their own apartments but also have the option of socializing and receiving support from a larger community are gaining support in Ontario. The Ontario government could assist by providing person-directed service coordination in these communities that would build the communities' capacity for self-care, and coordinate required direct services to building residents.

Intergenerational housing, cooperative housing, and shared housing arrangements could also be supported by person-directed service coordinators who could arrange supports and services at the direction of residents. By funding service coordination, especially in buildings where hospitals are seeing increases in emergency room visits, it would assist people with disabilities and elders to remain in their own homes and communities and avoid hospitalization and subsequent institutionalization.

Small, Non-Profit Community Residences

Many younger people with disabilities prefer to live in their own homes and communities rather than group homes.

But for elders, small, non-profit neighborhood homes, staffed 24/7 may provide the fully staffed, residential support they require, and help them to avoid being institutionalized.

Being able to remain in familiar surroundings, have access to the outdoors, and visits from neighbors, friends, and families in a smaller, more home-like setting would greatly benefit individuals with dementia, who are currently being forced to live in locked wards in institutions in the absence of any other alternatives.

Specialized memory care homes located in their own neighborhoods, with trauma-informed care built in would greatly benefit individuals with cognitive and neurological disabilities.

To date Ontario has failed to fund smaller settings like these for older adults, delivered by municipalities and non-profit organizations, and this has driven high rates of institutionalization. For the same cost as an institution, individuals can be maintained in these smaller homes in a more humane environment.

Once again the U.S. leads Canada and Ontario in this regard. There, smaller community residences for elders are already in place (Abrahms, 2022).

The Ontario government is in a position to redirect funding from long-term care institutions to municipalities and non-profit organizations to rent or acquire ordinary homes in communities to provide 24/7 staffed residences for individuals with dementia and cognitive and neurological disabilities. These would provide a humane alternative to 30 bed locked wards in institutions that are a recipe for responsive behaviors. We strongly urge the Cabinet to consider this option.

CONCLUSION

This brief has detailed how the Ontario Cabinet could support a 21st century long-term care system in Ontario that incorporates the principles of inclusion, not exclusion from peoples' communities; integration, not segregation; and that is more respectful and supportive of individuals with disabilities of all ages.

What is missing in Ontario's long-term care system at present is true choice. By building a modern long-term care system that incorporates a range of supported living options, the Ontario Cabinet could create a system that gives people options other than a dysfunctional Home Care system, an institution, or medically assisted death.

We are urging the Ontario Cabinet to change direction, abandon its current system of mass institutionalization of people with disabilities of all ages, and begin funding the non-profit, community-based alternative options that have been outlined in this brief.

To do so will prevent thousands of hospitalizations and the institutionalization feared by so many.

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