

ABOUT ACTION NOT WORDS

Who We Are:

We are concerned Ontarians who recognize the urgent need for change to ensure what has happened in long term care (LTC) residences during the COVID-19 pandemic never happens again.

In addition to our seniors, thousands of person with disabilities, living in LTC, have been equally affected.

Congregate care homes are the better setting for persons with disabilities. They too have struggled to cope with the pandemic.

We are group of retired professionals with experience at the federal, provincial and municipal levels of government and with not-for-profit organizations and private sector companies in health care, housing development/administration and education.

We are speaking out. We are demanding action.

Our Mandate:

Advocate for immediate action resulting in fundamental and lasting change in the provision of residential care for seniors and persons with disabilities in Ontario.

Insist that the Province of Ontario provide leadership and work effectively with those delivering these vital services to Ontarians.

Valuable insights already exist. This work can inform and guide efforts to address the issues facing us today. Experts in this field must be listened to. We are listening and, as advocates, we are adding our voices.

REFERRAL TO _____
RECOMMENDED _____
DIRECTION REQUIRED _____
RECEIPT RECOMMENDED _____

Position Paper on Congregate Care for Persons with Disabilities A Call for Reform in Ontario

March 2021

Provincial Responsibility

The Province of Ontario is responsible for the provision of Congregate Care for a variety of groups of persons who require support to live successfully in the community. These groups include:

- persons with physical disabilities
- persons with developmental disabilities, including autism
- persons with serious mental disorders.

Legislation and associated regulations provide the Province of Ontario with the authority and tools to deliver Congregate Care residential services using agency agreements/licenses with municipalities, entrepreneurs and non-profit organizations. Through a complex system involving a number of Ministries with varying policies, programs and practices, the Province provides oversight.

The Challenges and Opportunities

The 2020/21 coronavirus pandemic has revealed serious challenges in the existing congregate care system. The shocking situation at the Participation House in Markham that became public early in the pandemic (40 of 42 frail residents with a variety of physical and developmental disabilities became ill and 6 of them died) serves as a wakeup call about the need for urgent measures to keep residents safe. Unfortunately, the number of outbreaks in the province's Long Term Care LTC residences overshadowed concern for others in Congregate Care and their plight fell off the radar.

Most Public Health Units do not report outbreaks in small Congregate Care homes so data on numbers of residents, staff and essential caregivers who may have become ill is not published for the Province as it is for Long Term Care residences.

The COVID-19 pandemic however has had a disproportionately negative impact on people who live in congregate settings and the organizations that support them. For example:

- People in congregate settings have been in lockdown for many months. The ability to see family and friends (including essential caregivers) and access to services is unpredictable, varies substantially among organizations, and is a heavy influence on mental health.
- People have lost work and continue to face a decline in employment income.
- Service providers scrambled to obtain PPE for staff even where residents were medically fragile and at high risk.

- Congregate Care continues to be disadvantaged by the higher wages and benefits available in health care and long-term care (LTC) settings. It is a major barrier to hiring and retaining qualified support staff.
- Pandemic-related incentives, for new workers to enter into LTC residences, have drawn qualified staff away from congregate homes.
- The physical and mental health of people living in congregate settings depends on renewed access to family and other essential visitors. However, increasing rates of burnout, turnover and staff shortages are making it very difficult to safely open up congregate settings to family and essential caregivers and visitors.
- Congregate day services for people with physical and developmental disabilities remain closed across the Province due to pandemic-related safety concerns. The consequent lack of recreational and educational opportunities is further exacerbating the mental health deterioration of those in residential programs.

The Need for Systemic Reform

Each of the individual challenges we have described points in the direction of needed reform. The aggregation of challenges demonstrates the need for systemic rather than band-aid reform.

We believe there is a need for fundamental and lasting change in the provision of Congregate Care for Ontarians that recognizes the complex needs of those who are cared for, those results in a system that is both sustainable and resilient, and provides a safe home for those in care.

Our Guiding Principles for a Reformed System of Congregate Residential Care

We believe that the following Principles must guide the creation of a reformed system in Ontario:

- A reformed system must be based on the needs of those cared for, first and foremost.
- Our residential care system must provide a welcoming, supportive, and safe home for those in care.
- Our residential care system must be sustainable in terms of resources and resilient in terms of its ability to meet unforeseen emergencies.
- Our residential care system must have the capacity to address, in an integrated fashion, the needs of Ontarians with a range of special needs.
- Our residential care homes must build in the best available infrastructure and technology.

Our Proposals for Reform

We urge the Province to adopt and implement the following specific measures in a comprehensive program for change:

1. **Infection control protocols** at all homes must be reviewed and updated where necessary. The protocols must include a plan for isolation of infected residents and replacement of ill staff. All staff must be fully trained in these protocols. Responsibility for coordination of the response to outbreaks must be clearly identified within the organization.
2. All homes must have fully developed **emergency plans**. Staff must be fully trained in the execution of these plans. Responsibility for coordination of emergency response must be clearly located within the organization. An emergency communication plan must be in place to link on-site response to outside emergency agencies and to inform residents and families of the status of the emergency situation and response. These plans must be reviewed annually, or more frequently as warranted, with the Provincial oversight agency.
3. Residential care operators must have ongoing **inventory management processes** that provide staff the necessary supplies and equipment to meet appropriate levels of care for both normal operations and infection control. Inspection processes must include review of inventory management plans and adequate measures to enforce implementation.
4. **Oversight** - The Province needs to find a balance between adequate oversight to ensure the health and safety of residents and burdening providers with unnecessary administration that doesn't contribute to resident well-being.

We agree with the recommendation of the LTC Commission concerning the elimination of the siloed oversight approach used by Provincial Ministries. This recommendation should be equally applied to congregate care. This would include: a centralized system of reporting, report sharing and coordinated inspections by relevant Ministry inspectors. (Source: LTC Commission Interim Letter #2, 04-12-2020).

5. **Staffing issues** must be addressed in consultation with all stakeholders including unions and professional associations. The objectives must include:
 - Appropriate compensation based on relevant levels of education, skill and responsibility.
 - A staff complement designed to ensure safe, reliable, and predictable levels of service within each home.
 - Extend the recently-announced Personal Support Worker Return of Service Program to other sectors.
 - Increase the maximum number of supported graduates to allow for numbers needed.

The Governments of Canada and Ontario can partner to achieve change in Congregate Care staffing including:

- To increase: i) the percentage of regular and full-time staff positions; ii) wages on a sustained/go forward basis; iii) paid sick days for all staff; and, iv) other employment benefits.
- To create recruitment, training and accreditation practices and standards.
- To assist with international recruitment and immigration through the Skilled Worker Immigration Program, especially seeking workers with experience in supporting persons with disabilities
- To provide financial support for the above based on a jointly adopted implementation program with immediate effect.

6. A **sustainable funding model** must be developed for all forms of congregate residential care for persons with disabilities.

The Governments of Canada and Ontario can partner to achieve change in housing for persons with disabilities including:

- Through the Canada-Ontario Affordable Housing Program, provide adequate and consistent capital funding for development of new homes to meet existing and projected need.
- Capital funding should support the development and implementation of technology-based supports.
- These homes would be operated with a fully-funded budget from the Government of Ontario.
- Ensure operating funding to meet or exceed acceptable standards of care.
- The proportion of funding provided by municipalities and charities must be reviewed to ensure affordability given the limited revenue-raising powers of the municipal sector and fundraising capacity of charities.
- Create a Home Care fund so persons with disabilities can stay at home and access services.

7. **Long Term Care** is not appropriate for non-seniors or others needing specialized care such as persons with developmental disabilities or serious mental health disorders.

In 2013, Ontario’s Premier apologized “for our Province’s long history of institutionalizing persons with disabilities. The Premier formally acknowledged these facilities as dangerous, segregating, congregating, and isolating places that lacked oversight and accountability.” Nonetheless, Ontarians with disabilities are still being placed in large Long Term Care residences where services and care are designed for the needs of others - frail seniors. This must stop. (Source: Stop Normalizing Long-Term Care for People Who Have Developmental Disabilities, Community Living Ontario, January 22, 2021)

- Stop institutionalizing persons with disabilities and take a ‘community-first’ approach. Change assessment practices to ensure a proper match between the care needs and living aspirations of the resident and the residential options available.

- Working with families, community agencies and care providers, identify a range of community-based choices. Recommend new choices and means of developing these choices. Make financial commitments for their development and operation.
- Significant coordination between Ministries is required to successfully repatriate those wishing to return to their communities. Policies, protocols and resources between the Ministry of Children, Community and Social Services, and the Ministries of Health and Long Term Care must occur. It will also require coordination and cooperation between Ministries and the agencies providing community-based homes.

Our Call to Action

We urge the Provincial Government to execute the measures proposed in this Call for Reform.

Reform must be approached comprehensively and must position Ontario for complex and challenging service demands now and in the future. It must be premised, first and foremost, on the needs of the persons in care.

Cooperation across jurisdictions must be engaged, with resolve, so as to benefit all Ontarians.

Submitted by: Action Not Words

Contact Information: action@actionnotwords.ca

Website: www.actionnotwords.ca

Twitter: [@words_action](https://twitter.com/words_action)