



**Citizens With Disabilities – Ontario**

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**“Together We Are Stronger”**

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**Written Comments on the Draft Regulations  
under Bill 175 - Connecting People to Home and  
Community Care Services Act**

**from**

**Citizens With Disabilities – Ontario (CWDO)**

**July 24, 2020**



## **About Citizens With Disabilities – Ontario**

Citizens With Disabilities - Ontario (CWDO) is committed to the rights of all persons to participate fully in the civil, cultural, economic, political and social life of their communities.

We actively promote the rights, freedoms and responsibilities of persons with disabilities through community development, social action, and member support and referral. Our primary activity is public education and awareness about the social and physical barriers that prevent the full inclusion of persons with disabilities in Ontario.

CWDO acts in the interests of the 1.85 million Ontarians who live with one or more disabilities. Our registered members reside in almost every electoral district in the province.

### **Limited Consultation Time**

Through the ARCH Disability Law Centre we recently learned that the government is open to additional written feedback on the proposed Regulations of Bill 175 until July 24, 2020. This gave ARCH eight days to respond and it gave us even less.

This short time frame is indicative to us at CWDO that the government is not concerned with the lived, academic, and professional experience that those of us living with disabilities bring to the table.

This is frustrating and insulting to community groups who put in a lot of time to provide constructive and thoughtful feedback. In the case of organizations like ours, we do not have year-round paid staff. We do the best that we can on a volunteer basis.

CWDO requests that the government provide a more detailed version of the draft regulations for consultation and input and that the minimum consultation time is three full months. The draft regulation should be shared broadly with community organizations, including CWDO. Notice should be sent directly to organizations, which can be easily achieved by using an email list including any organization you have heard from on this topic as well as others that you would expect to hear from.



The above comments notwithstanding, our recommendations are outlined below.

We hope you will take the time to read our recommendations, include them in your analysis and reflect our input in the next draft of the regulations.

## **Learning From the Past**

In 1991, major changes were contemplated to the health regulation. Until the government heard from community organizations, these changes would have made it impossible for people to receive services at home that are of critical import to our regular routines. These services included “controlled acts” like catheterizations, injections, and medications.

Although community-based attendant services have been widely utilized by the disability community, policy makers and healthcare professionals are largely unaware of their existence, although the Ministry of Health was providing funding for them (Connolly, Grimshaw, Dodd, Cawthorne, Hulme, Everitt, Tierney, and Deaton, 2009).

Fortunately, the government of the day listened to the community and built in an exception, so that these controlled acts could be performed not only under the direction of a nurse, but under the direction of people who were directing their own services under community-based programs like Direct Funding, Support Service Living Units and Outreach attendant services. This exemption was built into the Regulated Health Professions Act, 1991.

Community-based attendant services operate with the philosophy of “Independent Living”. The Independent Living Movement was born on California university campuses in the 1970s, spread to Canada in the 1980s, and has since reached around the globe and changed the way people view and respond to disability.

Central to Independent Living is the right of people with disabilities to:

- Live with dignity in their chosen community;
- Participate in all aspects of their life; and
- Control and make decisions about their own lives.



Community-based attendant services grounded in the Independent living movement are **thriving** today. The Direct Funding (DF) program received a series of increases, which helped reduce the program's waiting list significantly. DF now serves approximately 1000 people across Ontario (Katzman, 2018). The benefits of DF have been documented in several research reports showing the positive outcomes for people receiving DF as well as its cost-effectiveness, since the recipients of the funding bear the costs of recruiting and training their own attendants, managing their own scheduling and a substantial portion of their payroll administration (CILT, 2008).

If the community had not spoken up in the early 1990's and more importantly, if government had not listened, most if not all of the people managing DF and those of us receiving community-based services through Outreach and Support Service Living Units would be living in long-term care facilities today with little ability to have autonomy and control over our own lives. It is important to note that even with the existence of DF and outreach attendant services, 18% of Canadians with a physical disability under age 65 reside in long-term care, rather than in the community, due to the combined issues of long wait lists for community-based support and funding, and a lack of knowledge on the part of healthcare professionals regarding independent living and community options for support (CIHI, 2004; Mohler, 2020).

We need government to learn from this history and once again to listen to the community as new regulations are formed.

## **Proposed "Residential Congregate Care Settings"**

Our members are concerned with the proposal for a new type of healthcare setting: "Residential congregate care settings".

We surmise that this is the halfway point between being in an expensive hospital room and being at home. The regulation suggests that a person would be placed in a residential congregate care setting when their needs were too high to be cared for at home.

Without details, our members are concerned about how this setting would be structured and supports implemented.

**First, our members have concerns surrounding who makes the decision for a person to no longer live at home. Is this decision to be made in consultation with the person themselves? Family? Others that know the person?**

We are concerned that professionals with little knowledge of independent living and community-based supports will be swift to recommend residential “care.”

Consistent with the Independent Living philosophy, CWDO recommends that the person themselves should be the ones to decide whether they could cope at home. Furthermore, there should be a full array of services to support a person deciding to live at home. Currently, there are many gaps such as a lack of equipment and funding to pay for repairs or equipment, sufficient hours available for someone at home and flexibility for allocated hours to increase or decrease according to a person’s changing needs. If the person is not able to make that decision themselves, would funding and commensurate services be made available to a family member or a trusted friend? We note several examples of where supported decision-making has been effective in ensuring an individual’s wishes and dignity are respected (Microboards Ontario, 2019).

CWDO believes, consistent with the Independent Living philosophy, that if a person wishes to be at home, resources should be available to make that possible. Only as a last resort should a person be moved to any type of congregate setting – large or small, temporary or permanent.

**What is the evidence that people with high needs receive better care in a congregated setting, rehabilitation setting, or nursing home?**

In our experience, people receive far *less* direct service in congregated settings of any size. In nursing homes, people are left in bed, as there are often insufficient staff to assist individuals in and out of bed. People remain up when there are not enough staff to put them to bed. Staff do not have time to feed people who cannot feed themselves and so the residents become malnourished. People become dehydrated because staff don’t have the time to assist a person to drink and, because drinking leads to the need to go to the washroom, staff are not motivated to create more work for themselves that drinking sufficient fluids will cause. In sum, the schedule of when one



wakes, eats, engages in recreational activities and ultimately the routinized way of life assigned to individuals in long-term care is dictated by the allocation of funding for staff and resources (Durocher, Gibson, & Rappolt, 2017).

In our experience, people have great difficulty going to school, work or pursuing activities outside of the residence when they live in congregate settings. Staff are not available to help people get up and out on time to connect with paratransit services. If an individual misses their transportation too frequently, residents are disincentivized from using transit to pursue community-based activities, due to the penalties associated with missing transportation.

The Canadian Armed Forces' May 26, 2020 report exposed the disgraceful conditions at five Ontario long-term care homes. These conditions have been known to our community for decades, and it is these conditions that make us concerned with prematurely being placed in long-term care or other congregated living settings.

In a nursing home, we know we will receive less support than we would at home, and that we would lose autonomy and the ability to direct our own services. In a nursing home, we know that our quality of life and life expectancy is much less than it would be living in the community under Direct Funding.

## **Bill of Rights**

A second concern raised was around the Bill of Rights under the existing Home Care and Community Services Act, and the repeal of this Bill under Bill 175, leaving it to be decided in regulation.

We, at CWDO, feel the former Bill entrenched in legislation provided a strong platform for individuals to know their rights and to express complaints with quality, type, and amount of service, and to have those complaints dealt with in a fair and equitable way.

The Home Care and Community Services Act, 1994 contained the Home Care Bill of Rights (Bill of Rights): a set of rules about how people who receive services should be treated – both by the people providing the services and also by the people managing the services.

The Bill of Rights listed nine (9) rights. These are:

1. Be treated with respect and to be free from abuse
2. Have your privacy and dignity honoured
3. Have your needs and preferences respected
4. Receive information about the services you get
5. Take part in decisions about your services
6. Consent to or refuse services
7. Raise concerns without anyone taking action against you
8. Receive information about home care laws and policies and how to make a complaint
9. Have your home care records kept confidential.

### **What will be the tone and strength of the Bill of Rights when it is in regulation?**

The Bill of Rights being left to regulations is troubling, as it does not offer a legislative framework for the complaints and appeals process.

Such a document must be developed with a strong voice of people with disabilities – “Nothing about us without us!” Will the balance of rights shift more toward service providers, funders and regulators than it does towards persons with disabilities?

In addition to the Bill of Rights formerly included in the Home Care and Community Services Act, 1994, new rights entrenched in regulation should include:

- **The right to choice** about how their attendant support services are provided and recognition that the person with a disability has the right to change their mind about how the services are provided over time.
- **The right to assist in the selection and evaluation of attendants** who will be providing services to the person with a disability.
- **The right to report concerns to the service provider.**
- **The right to have these concerns responded to promptly, and effectively.**
- **The option to participate in training sessions** designed to resolve conflicts between people with disabilities, their service provider and attendants.

- **Assurance** that when service providers are obligated to take corrective measures which may impact a person with a disability, **that there is a fair process that allows for the opportunity to appeal decisions that impact their services.**
- **Every front-line worker to be trained in conflict resolution and de-escalation techniques** before beginning work with any person with a disability.
- **Input into the service provider’s policies and procedures that deal with disputes** between people with disabilities and attendants.
- **Input into the service provider’s policies and** procedures about determining the quantity of services, the type of service and where and how they will be delivered.
- **Due process if the service provider and person with a disability disagree on the level of service required** to meet the person’s needs.
- **Due process involving an impartial third party if the service provider determined that the person with a disability cannot or should not be served by their agency.**

## Language of “Care” is Problematic

Third, our members strongly opposed the language of “care” and “patients” as it is used exclusively in Bill 175. Throughout the Bill and regulations there is reference to people with disabilities as “patients”. Both words, “care” and “patients,” reflect a medical approach to attendant services and those who receive them. The language needs to reflect that services are provided in other setting besides hospitals, clinics and nursing homes. People with disabilities might have services at home, in the community, at work and at school.

Inclusive terminology such as “people with disabilities”, “service recipients” or “consumers” more aptly describe our role rather than being exclusively referred to as patients.” The term “patient” is associated with the medical model: hospitals, clinics and long-term care homes. These medical terms don’t reflect the fact that persons with disabilities live rich, textured lives in community and can do so with appropriate supports. The terminology we recommend is consistent with the Independent Living philosophy and acknowledges that most times, people with disabilities are experts in their own disability and knowledgeable about how to direct the services they receive.



The new regulations must acknowledge that persons with disabilities want to and do live independently, participate in our communities and make our own choices. Instead, the language in the proposed draft regulations perpetuates our unfortunate history of marginalization and of being objects of pity or charity. The language in the proposed regulations does nothing to dismantle negative stereotypes of persons with disabilities and ableism.

Finally, CWDO is concerned with the requirement for a “care plan” since such a requirement will force upon people with disabilities an unwelcome medicalization of attendant services. For many of us, attendant services are provided at home and in the community, relate to activities of daily living and are not viewed as medical services. Furthermore, people with disabilities living in the community are the ones who should decide what services they need and how they are delivered – in effect designing and delivering their own care plan.

A formal care plan should be restricted to formal medical settings, and not foisted upon those of us living independently in the community. If medical needs arise and a care plan is necessary, then, individuals with disabilities should be the stewards of how that plan is to be delivered. and take into account advice from medical professionals involved.

Our members noted the importance of having options for supported decision- making as individuals with disabilities age. This could take the form of a Microboard, a “circle of friends” or simply be a close friend or family member that works with the individual to ensure their wishes and preferences are respected.

## **Conclusion**

It is difficult to give helpful advice when the regulations provided are ambiguous in nature.

We implore you to share another version of the regulations with the public for consultation, and to allow plenty of time for the public to review the proposed changes.

We trust our comments will be incorporated in the next draft. CWDO would like to help to get these regulations right, and to make sure the



regulations do not discount the type of services that people in the community receive such as Direct Funding.

Please do not hesitate to contact me if I can clarify any of our suggestions or provide further information.

Sincerely,

A handwritten signature in blue ink that reads 'Tracy Odell'.

Tracy Odell  
President

Attachment

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