



**Submissions of
ARCH Disability Law Centre
to the Ministry of Health on Proposed
Regulations under the
*Connecting Care Act***

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A. Introduction

ARCH is pleased to have this opportunity to comment on the proposed Regulations under the *Connecting Care Act* (the Act). Our submissions reflect a general legal analysis of the proposed Regulations in their current draft form. These submissions are informed by ARCH's work with our communities, however the short timeframe of this consultation precluded a fulsome consultation with the communities of persons who will be affected by the Regulations.

On July 30, 2020 the Ministry of Health advised us that these draft Regulations will likely be reposted for further comment in the fall of 2020. We were also advised that the Bill of Rights in the new Regulations will be the subject of parallel consultations.

When further consultation dates and materials are announced, ARCH will engage and consult with our communities to provide more fulsome submissions on issues raised in the revised Regulations and on the Bill of Rights. In the meantime, we hope that the following submissions will assist in any revision of the current draft Regulations.

B. About ARCH

ARCH is an Ontario-based specialty legal clinic that is dedicated to defending and advancing the equality rights of persons with disabilities. ARCH is governed by a volunteer board of directors, a majority of whom are persons with disabilities. ARCH provides a telephone summary advice and referral service and represents individuals as well as provincial and national disability organizations in test case litigation at all levels of tribunals and courts. We provide education to persons with disabilities on disability rights and to the legal profession about disability law. We make submissions on matters of policy and law reform. ARCH maintains a website at: www.archdisabilitylaw.ca

ARCH receives concerning calls from persons with disabilities on a variety of issues related to home and community services including the following:

- no access to home and community services due to waiting lists;
- insufficient hours to meet their service needs;
- reduced hours due to shortages of personal support workers (PSWs) in their area;
- poor quality of home and community services;
- missed shifts due to workers not showing up for scheduled shifts;
- no continuity of care and having to frequently train new staff on the delivery of services

- service cuts imposed as reprisal for being perceived as a “difficult” client, or for making complaints

The comments and recommendations in the following submissions are informed by ARCH’s legal work with persons with disabilities, and working with community organizations and disability groups, on issues related to the delivery of home and community services.

C. Clear and Accessible Language Required

ARCH is concerned that the proposed Regulations and the commentary accompanying them have not been presented in a clear and accessible manner.

ARCH submits the reposted Regulations and accompanying documents be provided in clear and accessible language to avoid misunderstandings or need for additional clarification. The Regulations must be clearly drafted so persons with disabilities understand what their obligations and/or rights are; what has been changed from HCCSA and its Regulations; and where there are no changes, what the application of the Regulations will mean for persons with disabilities. The reposted Regulations must be in their penultimate form. The reposted Regulations must be in an accessible format that will encourage active participation by persons with disabilities in consultations.

Finally, any change of language used in revised Regulations could affect ARCH’s analysis and the issues we choose to consult on with our communities.

Recommendations:

1. The Regulations and any accompanying documentation must be in clear and accessible language.
2. The revised and reposted Regulations under the Act must be in use the actual text and language of the penultimate Regulation in order to conduct meaningful consultation.

D. Use of the word “Patient” is incorrect

The language used throughout the proposed Regulations is inconsistent with the language used by persons with disabilities to describe themselves, and that has been adopted by the home and community services sector. Persons with disabilities who receive home and community services **are not “patients”**.

Persons with disabilities cannot be conflated with patients in hospital, rehabilitation or acute care - their service needs are very different. Persons with disabilities often rely on long-term services, while patient needs are often more short-term.

Moreover, these proposed Regulations are solely directed at issues that only affect persons with disabilities. Patients are not the group of people at the centre of these proposed Regulations.

ARCH has reviewed the submissions of Citizens with Disabilities Ontario (CWDO) on the proposed Regulations. CWDO argues for the use of “people with disabilities”, “service recipients” or “consumers”. Given that these terms reflect how persons with disabilities describe themselves, we urge the Government to adopt disability positive language.

Recommendations:

3. Replace all references to ‘patient’ in the proposed Regulations with ‘people with disabilities’, ‘service recipients’ or ‘consumers’.

E. Location of Services must be Consistent with CRPD

The proposed Regulations create a new setting for service delivery called “residential congregate care” for persons who “do not require the intensity of resources provided in a hospital or long-term care home, but whose needs are too high to be cared for at home.” “Residential congregate care” is left to be defined in the regulations.

At present, the proposed Regulations do not provide a definition for this type of care setting. More importantly, the proposed Regulations fail to specify who will make the decision about an individual’s service needs and whether they are too high to be cared for at home.

In their submissions on the proposed Regulations, the CWDO says that “professionals with little knowledge of independent living and community-based supports will be swift to recommend residential ‘care’.” We share that concern. Consumers have fought for years to ensure that services will be provided in their home so they can live independently and fully participate in their communities. In addition, the proposed Regulations are silent on funding and licensing mechanisms for this new ‘care’ setting, which is a critical concern.

We draw the Government’s attention to the *Convention on the Rights of Persons with Disabilities* (CRPD). The CRPD is an international treaty that promotes and protects the human rights of persons with disabilities. Canada ratified the CRPD in March 2010. This means that Canada and its provinces and territories must strive to respect and incorporate the rights contained in the CRPD to the best degree possible.

Article 19 of the CRPD states that persons with disabilities have the equal right to: independence and live in their community; make their own decisions about where they live and with whom; are not obligated to live in a particular living arrangement; and be offered equal opportunities to participate and be included in society. This Article also includes that persons with disabilities must be able to access a range of services in one’s own home. The proposed Regulations must be drafted to ensure compliance with the CRPD, and to include that persons with disabilities who want to receive services at their home cannot be forced to leave and be placed in a “residential congregate care” setting.

The proposed Regulations state that the Ministry will be consulting with the public, clients, and caregivers when developing these new models. ARCH underscores the need to ensure that consumers of home and community services, and persons and organizations representing them, are among those consulted. ARCH also asks that the Ministry provide dates and materials well in advance of any consultations to provide adequate preparation time.

Recommendations:

4. Provide a definition for “residential congregate care” settings.
5. Ensure compliance with all Articles of the CRPD, but most importantly, with Article 19.
6. Be clear on whether someone can be moved to a residential congregate care setting without their consent.
7. Provide details on funding and licensing mechanism for residential congregate care settings.

8. Ensure broad and fulsome consultation with persons with disabilities on any proposed new settings.

F. Modes of Delivery must be accessible and available

The proposed Regulations state that the Ministry will continue to provide services virtually. The Ministry must ensure that low-income Ontarians, who may not be able to afford technologies, have access to the same services as other Ontarians. In addition, devices may require additional security software and modifications to accommodate persons with disabilities. The proposed Regulations must be clear about who will be responsible for purchasing, setting up, maintaining, and replacing technology required for virtual service delivery. The technologies must also be accessible. ARCH encourages the Government to provide, or at minimum subsidize, accessible technologies for individuals who cannot afford them, as well as funding for regular updates, maintenance, and security software.

Recommendations:

9. Low-income persons with disabilities must be able to access necessary accessible technologies for virtual health services.
10. The Government should fund or subsidize technology to ensure equal access to services. The government must also provide funding for updates, maintenance, and software must also be provided to low-income persons with disabilities.

G. Fee for Services

Currently, the Government allows service providers to charge user fees for certain services. Co-payments are also allowed. This will continue under the proposed Regulations. In reality, this means that people who are eligible for publicly funded home and community services will receive what is available as opposed to what they actually need, because additional services may be subject to user fees.

In the proposed Regulations, the government must be specific about the circumstances when user fees and co-payments are allowed. If permitted at all, user fees and co-payments should be narrowly limited to ensure that persons with disabilities, many of who are low income, receive public services and supports that will allow them to live independently and in the community. In addition, there should not be a two tier service structure providing basic services for one group of Ontarians and enhanced services for those who can pay for them.

The home and community services sector is woefully under-funded. While outside the scope of the proposed Regulations, the Government must commit to adequate and improved funding in order to appropriately meet the service needs of persons with disabilities. The Government must consult with persons with disabilities and organizations that support them about adequate funding for services, and the gaps in services experienced by persons with disabilities.

Recommendations:

11. The government must clearly state what services are subject to user fees and co-payments.
12. The Government must conduct meaningful and broad consultation about adequate funding for necessary services.

H. Care Coordination Functions

Care co-ordination functions were a critical component of the HCCSA. These functions have a direct impact on the delivery of services to persons with disabilities. However, care coordination was removed from the *Connecting People with Home and Community Care Act 2020*. Care coordination is now found in the proposed Regulations. ARCH provided submissions on Bill 175 that addressed our concerns about moving key provisions from legislation to regulations. Our submissions can be found at: <https://archdisabilitylaw.ca/resource/submissions-on-bill-175/>.

Care coordination functions include:

- determination of eligibility;
- assessing a consumer's service needs;
- reassessment of service need;
- developing a service plan;
- updating service plans; and
- managing issues with service delivery.

The proposed Regulations now state that “Health Service Providers” will be responsible for care coordination functions. Under this proposed Regulation, detailed expectations of care coordination functions are left to be outlined in **policy**, and what this policy “could” include is listed in general and vague terms. There cannot be a patchwork system of policies across the Province. At the very least, the Government should provide minimum requirements that these policies must address to ensure consistent care coordination.

Health Services Providers may be for-profit or non-profit agencies and can vary in capacity, size, and resources. Health Service Providers will have the discretion to assign care coordination functions to contracted providers or partner organizations that can also be for-profit or non-profit.

Moving important aspects of home and community services in this way expands the scope of private companies that may sacrifice quality of services for fiscal efficiency. We have witnessed the tragic impacts of how private companies may sacrifice quality of services for fiscal efficiency during the COVID-19 pandemic.

Leaving details of care coordination to policy contributes to a serious lack of public governance, accountability, and transparency. The proposed regulations, as drafted, provide minimal detail on this shift in responsibility. There is a need for uniformity in issues described above, to ensure equity across the Province. The draft regulations provide no detail about how this will be carried out.

Recommendations:

13. Given the essential nature of Care Coordination functions, ARCH reasserts its position that these functions must be enshrined in the Act.
14. The Government must set minimum standards for policies addressing Care Coordination functions.
15. The Government should reconsider any expansion of home and care services to the for-profit sector.
16. The Government must provide additional details about public governance, accountability and transparency in Care Coordination.

I. Service Maximums

ARCH supports the Ministry's decision to remove service maximums for consumers of home and community services. However, once service caps are eliminated, the Government must turn its mind to adequately and appropriately meeting consumer demand for services. Removal of a hard cap on services hours cannot be replaced with an unspoken cap on those hours because of inadequate staffing to meet service demands. We also refer back to our earlier submissions under Charges for Services.

Recommendations:

17. The Government must review and plan to meet consumer demand once service maximums are eliminated.

J. Complaints and Appeals

The Health Services Appeal and Review Board (HSARB) holds jurisdiction over certain issues that arise in home and community services is continued. However, the issue that affects most consumers are with the **quality** of services they receive. Neither the legislation nor the Regulation adequately addresses this issue.

In ARCH's view, the distinction between quality and quantity of services is an artificial one. In our experience quality and quantity of services go together, or not easily siloed. The quality of services received by a consumer is often a feature of the quantity of services received. For example, if a person needs assistance with getting out of bed, bathing, hair washing, dressing and having breakfast within an hour, both the quantity and quality of services will likely be poor.

Other quality of service issues might also arise because the Bill of Rights in the former has been violated. These included, but are not limited to:

- abuse.
- no respect for the consumer's dignity.
- not taking into account a consumer's preferences.

Important issues like these should not be the subject of an internal investigation and decision by the service provider. There is a real need for an independent tribunal or group of persons who have the authority to review, investigate and make decisions beyond an investigation and decision made by a service provider about the services it provides.

The internal complaint process can be fraught with bias, unfairness, and a lack of transparency and accountability. There must be an independent external process available to the consumer so that abusive behaviour does not go unchecked or unaddressed.

At present, the jurisdiction of the Health Services Appeal and Review Board (HSARB) does not include quality of service complaints. ARCH recommends that quality of service complaints be included as an issue that can be appealed to the Board.

Alternatively, ARCH recommends that a transparent, accessible, accountable and independent body affording due process be available to service users who experience quality of service concerns and violations of the Bill of Rights. An independent adjudicative body, whether newly created or expanding the jurisdiction afforded to existing tribunals such as HSARB, is necessary to ensure accountability and the delivery of appropriate services.

Recommendations:

18. The jurisdiction of the Health Services Appeal and Review Board (HSARB) be expanded and include quality of service complaints and appeals.
19. Alternatively an independent body must be established to hear appeals of quality of service complaints or review internal decisions made by the service provider.

K. Conclusion

ARCH hopes that these submissions will assist the government when considering the proposed and revised Regulations and what ought to be changed or clarified in them before the penultimate Regulation is posted for public comment and consultation.

Please do not hesitate to contact ARCH if you have any questions or if we can be of further assistance.

Appendix A

Recommendations:

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5. Ensure compliance with all Articles of the CRPD, but most importantly, with Article 19.
6. Be clear on whether someone can be moved to a residential congregate care setting without their consent.
7. Provide details on funding and licensing mechanism for residential congregate care settings.
8. Ensure broad and fulsome consultation with persons with disabilities on any proposed new settings.
9. Low-income persons with disabilities must be able to access necessary accessible technologies for virtual health services.
10. The Government should fund or subsidize technology to ensure equal access to services. The government must also provide funding for updates, maintenance, and software must also be provided to low-income persons with disabilities.
11. The government must clearly state what services are subject to user fees and co-payments.
12. The Government must conduct meaningful and broad consultation about adequate funding for necessary services.

13. Given the essential nature of Care Coordination functions, ARCH reasserts its position that these functions must be enshrined in the Act.
14. The Government must set minimum standards for policies addressing Care Coordination functions.
15. The Government should reconsider any expansion of home and care services to the for-profit sector.
16. The Government must provide additional details about public governance, accountability and transparency in Care Coordination.
17. The Government must review and plan to meet consumer demand once service maximums are eliminated.
18. The jurisdiction of the Health Services Appeal and Review Board (HSARB) be expanded and include quality of service complaints and appeals.
19. Alternatively an independent body must be established to hear appeals of quality of service complaints or review internal decisions made by the service provider.