

Feedback from the Alzheimer Society of Ontario on Proposed Regulatory Changes Under the *Connecting Care Act, 2019*

Sent by email: HCCB.Modernization@ontario.ca

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Thank you for the opportunity to provide feedback on proposed regulatory changes under the *Connecting Care Act*, brought about by passage of the *Connecting People to Home and Community Care Act*.

The Alzheimer Society has embraced the Ontario Health Team model, and we are in favour of any measures that advance connected and client-centred provision of care. As mentioned in our testimony on Bill 175 at committee, we are broadly supportive of this legislation and the proposed supporting regulations. Our feedback will focus on five areas: maximum service hours, the Bill of Rights, location of services, client co-payment, and care coordination. A summary of our recommendations is included at the end of this document.

Maximum Service Hours

We are in favour of removing maximum service hours, a constraint not placed on other, equally vital facets of the health-care system. While this move means care can be tied directly to client need, we caution that it creates the risk of limited resources skewing towards higher-needs clients. The “policy to promote equity of access across the province” mentioned in the summary of proposed regulations must consider situations where de facto service maximums arise, due to limited resources.

Bill of Rights

We are also supportive of client protections enshrined in the proposed regulations, including the Bill of Rights and grounds for complaint. The current Bill of Rights, while a strong commitment to inclusion and equity, can be improved in transference to regulation.

In 2018, the Alzheimer Society of Canada supported those living with dementia and their care partners in drafting the *Charter of Rights for People Living with Dementia*¹. This document was written by and for those with lived experience. One right highlighted by those who have lived Canada’s health-care system is: “To get the information and support I need to participate as fully as possible in decisions that affect me”. We suggest similar language be added to section four of the current Bill of Rights, explicitly recognising the right of clients to be involved and active partners in their own care in addition to being informed.

¹ <https://alzheimer.ca/en/Home/Get-involved/The-Charter>

Location of Services

Expanding service locations to include public hospitals has the potential to improve continuity of care during periods of high stress for clients. We are supportive of this change, subject to well-defined restrictions.

The current version of the summary document states that hospitals would only be considered eligible locations in cases where community care services “are not expected to be needed post-hospitalization”. As the main beneficiaries of expanding service locations to include hospital settings will be those clients who receive community supports both before and after hospitalisation, this should be changed to remove the word ‘not’. We understand this is an error that has already been flagged for correction, and mention it here only because the change is a crucial one to fully realise the benefits of adding public hospitals as an eligible care setting.

When drafting language governing home and community care involvement in public hospitals, it should be made clear that community staff may only be used to complement, not replace, hospital staff. If the hospital services a client receives while in hospital are scaled back in proportion to the community supports they receive, then no actual improvement to care has been achieved; rather, community staff would be filling hospital roles, often at a lower rate of compensation. This cannot be permitted.

To further promote patient-centred collaboration between hospital and community staff and providers, we suggest that in addition to classifying public hospitals as an eligible care setting, home and community care staff be included in discharge planning for their clients. This is not current practise, even with written consent from the client and requests from their family and/or care partner.

Hospitalisation should not mark an abrupt pause in the supports clients receive from home and community care staff. Subject to well-defined limitations, we support adding public hospitals as a care setting, and recommend this be taken further by including HCC staff in discharge planning with consent from the client.

The same case made in favour of adding hospitals as an eligible setting—promoting continuity of care, reducing stress, and improving client outcomes—also apply to long-term care. We suggest adding long-term care homes, as defined in the *Long-Term Care Homes Act*, as an eligible setting subject to clearly defined restrictions.

Transitioning to a long-term care home is often an upsetting experience, and for individuals living with dementia, a change in environment or routine can lead to responsive behaviours. Allowing home and community care workers to continue seeing and supporting clients in the two weeks immediately following a move to long-term care would be a source of reassurance to the client and family alike. Such a move would be one constant amongst an

overwhelming pace of change, and may help alleviate avoidable hospital visits following a move to long-term care.

Home and community care involvement in long-term care homes must be well defined to avoid a permanent diversion of community resources into long-term care. Home and community care staff should be limited to supporting only clients with whom they have an existing relationship, and only for a transition period immediately following the client's move to long-term care. This transition period should be limited to two weeks, inclusive of a cap on service hours.

Done right, adding long-term care homes as an eligible care setting would provide much-needed continuity during a period of extreme stress for clients and their care partners and families.

Client Co-Payment

The proposed regulations would maintain charges for some services, which the summary document says recognises “that community services are provided through a combination of government funding, volunteer services, charitable donations and client co-payments”. In practise, client co-payments represent both a barrier to care and a financial burden on providers.

The Alzheimer Society makes every effort to accommodate clients regardless of their financial situation. In cases where clients cannot afford their co-payment, we try to absorb it—however, many decline this out of a sense of pride, either reducing or eliminating care to which they are entitled and on which they depend. Even when a client accepts their co-payment being covered by us, or by any other provider, that represents a downloaded cost. Fundraised dollars used to cover client co-payments are diverted from front-line programs and staff, reducing the number of clients served.

Unlike the relative stability that comes from base, public funding, co-payments are covered by fundraised dollars which vary from year to year. The services available to lower-income clients are limited to what their provider can afford to cover—a service maximum by another name.

We suggest regulations reflect the reality that client co-payments are a barrier to care, and are often borne by the provider. The regulations should make clear that co-payments are not to be prohibitive to a client receiving a program, or to a provider offering it.

Care Coordination

The Alzheimer Society supports moving care coordination closer to clients. This is a model we have pursued through our First Link[®] program, which provides a single point of contact for both an individual living with dementia and their care partner. This contact, a First Link[®] Care

Navigator, offers system navigation in addition to dementia-specific education, ongoing follow-up, personalised care plans, and other resources.

As care coordination is decentralised, it should not be provided as a standalone service. Similar to the success achieved through the First Link[®] program, care coordinators should provide expertly informed care plans, advice, and education to clients, families, and care partners. Specialised knowledge is crucial in providing clients with a source of trusted information and tailored support.

Policies governing care coordination should prioritise this specialised knowledge. We envision a system where care coordinators are a trusted source of information, providing proactive follow-up and disease- or condition-specific education to clients and families, helping them better understand and manage their unique situation.

Providers with existing experience offering care coordination and system navigation should be consulted when policies and expectations are being drafted.

Summary of Recommendations

1. Include guidance for providers on how to equitably allocate limited resources when maximum service hours are removed.
2. Modernise the Bill of Rights to explicitly recognise a client's right to be an active participant in their own care.
3. Clarify that public hospitals would be an eligible care setting for complex clients whose connection to HCC services pre-dated their hospitalisation *and* is expected to continue post-hospitalisation.
4. Enshrine the principle that hospital resources cannot be withdrawn from clients who are receiving HCC support during their hospital stay.
5. Enable the inclusion of HCC staff in hospital discharge planning for clients they support, with the consent of the client.
6. Add long-term care homes as defined under the *Long-Term Care Homes Act* as an eligible care setting, within a two-week transition period following a client's move to long-term care.
7. Make clear that client co-payments are not to be a barrier to clients accepting care, or to providers offering it.
8. Adopt a care coordination model where coordinators are trusted sources of information and tailored care plans, learning from providers with existing experience providing navigation and coordination services.

We thank you for the opportunity to share our thoughts on the proposed regulations, and would be happy to discuss further.