Written Submission for the Legislative Assembly of Ontario's Standing Committee on the Legislative Assembly

Bill 175, Connecting People to Home and Community Care Act, 2020

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Submitted By:

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Summary of Recommendations:

This submission is in response to *Bill 175, An Act to amend and repeal various Acts respecting home care and community services.* We are pleased to see the provincial government update the home and community care framework in Ontario and we acknowledge that some areas of the new regulations have the potential to help people and families affected by ALS. We recommend that the Ministry of Health clarify the following areas of the regulations and legislation in order to determine the full impact on Ontario families affected by ALS:

- **Service Maximums:** We urge the Ministry to clarify and outline its guidance on how home and community care service providers should allocate care planning and services so that care needs are better met under the new system.
- **Scope of Services:** We seek more clarity on why personal support services are included in both the definition of "home care" and "community care", so that so we can better understand any implications or unintended consequences for members of the ALS community receiving home and community care under the new framework.
- **Complaints:** We would like to know if the "quality of care" topic area allows people to submit formal complaints if providers are not knowledgeable about the type of care they must provide, when a personal support worker does not come as scheduled or if upon arrival does not have or is not appropriately using Personal Protective Equipment (PPE).
- **Care Coordination Functions:** Virtual care cannot become a substitute for or entirely replace the physical in-person care that is needed for people and families affected by ALS.

Improved Home and Community Care for People Living with ALS

Amyotrophic lateral sclerosis (ALS) is a terminal disease that gradually paralyzes people because the brain is no longer able to communicate with the muscles of the body that we are typically able to move at will. Over time, as the muscles of the body break down, someone living with ALS will lose the ability to walk, talk, eat, swallow, and eventually breathe.

Due to the complex and progressive nature of ALS, people living with the disease have substantial home and community care needs. At a minimum, this care can include personal support, occupational therapy, respiratory services and nursing services. As the disease progresses in each person, their care needs also evolve and increase. Under the current home care system, government-funded services provide a small portion of this support; however, the majority of the care falls on the shoulders of family and other caregivers.

Our community is all too aware of instances where Ontarians living with ALS fail to receive enough Personal Support Worker (PSW) hours per day, experience unfilled or cancelled PSW shifts, or have care workers who are unfamiliar with ALS and unable to manage their complex care needs. These difficulties often result in people living with ALS being on their own for long periods without supports that help them to do activities of daily living like moving, eating and going to the toilet. On top of this, family members are often the ones left to provide substantial levels of care, which can be strenuous and dangerous, putting their health at risk.

In reviewing *Bill 175, Connecting People to Home and Community Care Act, 2020*, we want to make sure that the level and quality of home and community care Ontarians living with ALS receive is improved and better meets their unique needs. We have outlined below some considerations and areas for clarification:

- **Service Maximums:** We applaud the Ministry for removing home and community care service maximums in the legislation, which will allow for more flexible adjustments through changes in regulation. We understand that this amendment could allow for more personalized levels of care for people living with complex care needs, such as people living with ALS who might require more care service than is currently allowed under the previous provisions due to the progressive nature of the disease. At the same time, the Ministry also states that it could provide guidance around upcoming care planning and allocation with policy. We urge the Ministry to clarify and outline its guidance on how home and community care service providers should allocate care planning and services so that care needs are better met under the new system.
- **Scope of Services:** In defining the scope of services, personal support services (PSSs) are included as services in the new proposed definitions of "home care" and "community care." Although it is mentioned that the inclusion of PSSs in both definitions is deliberate, the rationale for this decision is unknown. We seek more clarity on why PSSs are included in both definitions, so that so we can better understand any implications or unintended consequences for members of the ALS community receiving home and community care under the new framework.
- **Complaints:** The regulations outline a new list of proposed complaint topics that people have the ability to raise with Health Service Providers with respect to home and community care services. "Quality of service" is one of those topics. Home care service quality is a particular issue in the Ontario ALS community, as their care needs are often not being fulfilled by our home care system. Ontarians living with ALS often face limited, inconsistent or unfilled Personal Support Worker (PSW) shifts or have care workers who are unable to manage their complex care needs. Additionally, in the face of the COVID-19 pandemic, the Ontario ALS community has also had to navigate PSWs who fail to wear, or don't have access to, proper personal protective equipment (PPE), putting both the home and community care providers and the people they

serve at increased risk. This negatively affects the quality and level of care every day. As such, we would like the Ministry to define this complaint topic. Specifically, we would like to know if "quality of service" would include issues with continuity and/or consistency of care. In other words, we would like to know if the "quality of care" topic area allows people to submit formal complaints if providers are not knowledgeable about the type of care they must provide when a personal support worker does not come as scheduled or upon arrival does not have or if is not appropriately using Personal Protective Equipment (PPE).

- **Care Coordination Functions:** While the previous framework reinforced a per hour/visit based approach to delivery of care, the Ministry has said that the new framework will provide for "more flexibility for innovative models of care by supporting care to be provided virtually and removing the emphasis on visit-based care." While adding virtual care has the potential to make receiving care more effective and efficient for those who are able to access it, it does not replace the essential care needed for people living with ALS. During the COVID-19 pandemic we have seen an increase of virtual care. While this has enabled people living with ALS to remain connected to many of their health care practitioners, there are certain assessments that can't be completed in this manner. For example, an occupational therapist must be able to conduct an in-person visit to properly assess safety and access issues in a person's home. We want to underscore that virtual care cannot become a substitute for or entirely replace the physical in-person care that is needed for people and families affected by ALS.

A Flexible and Effective Personal Support Worker (PSW) Framework in Ontario

In addition to these proposed changes, we recommend that the Ministry develop a comprehensive and integrated health human resources strategy that includes a strong focus on recruitment and retention of Personal Support Workers (PSWs). Given the recent experiences with COVID-19 and the recognition

that PSWs often work in multiple settings and homes, new and safer models of care will need to be considered moving forward.

Ensuring a robust and reliable supply of PSWs for home and community care that're knowledgeable and follow guidelines for safe interactions with vulnerable Ontarians will help people and families living with ALS receive the care they need when and where they need it, as well as live more safely and independently at home and out of hospital.

About the ALS Society of Canada

The ALS Society of Canada works with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS. Within Ontario, we provide services and support to help meet the needs of approximately 1,000 Ontarians living with ALS.