

Reflecting on Ontario’s new “Guidelines for supporting adults with a developmental disability when applying to, moving into and residing in a long-term care home”

The revised guidelines include important policy statements that can serve to protect people who have developmental disabilities from being transferred to long-term care facilities.

Introduction

In November 2022, the Ministry of Children, Community and Social Services (MCCSS) and Ministry of Long-Term Care (MLTC) released an updated and revised version of a document that guides the transfer of people with developmental disabilities from the developmental services sector into long-term care facilities. The [document](#) offers valuable insight into the perspective and approach of the Ministry of Children, Community and Social Services on this issue.

Context

Community Living Ontario believes that the long-term care sector is generally unable to effectively meet the needs of people who have an intellectual disability, and this is particularly so for younger adults.

Unfortunately, recent data from MCCSS and MLTC shows that long-term care facilities are serving as 'home' for thousands of people who have a developmental disability in Ontario:

- More than 3,000 adults aged 18-64 are currently living in a long-term care facility in Ontario. Of these, about 800 have a developmental disability.
- There are approximately 2,500 people who have a developmental disability (of all ages) living in long-term care facilities in Ontario. Nearly 2,000 are between the ages of 50 and 79

(This information comes from MCCSS and MLTC documents that have not been made public).

It is, quite literally, no one's first choice to move to a long-term care facility. People who have an intellectual disability generally move – or are moved – to long term care when there are no other options. This fact is the result of shortcomings in health care, home care, housing, developmental services, and income support.

On a positive note, we understand that MCCSS has taken recent steps to transfer Alternate Level of Care hospital patients who have developmental disabilities into community settings (not including long-term care). More generally, we also understand that the ministry has been supportive of renovations to developmental service residential settings to accommodate the changing needs of ageing people who have developmental disabilities. These are steps in the right direction.

Positive elements of the revised guidelines – In brief

The revised “Guidelines for supporting adults with a developmental disability when applying to, moving into and residing in a long-term care home” show a striking ambivalence about the need to resort to long-term care. For example, the document states:

“Placement in long-term care would often be inappropriate for people with developmental disabilities.”

The document also contains a welcome focus on the issues of consent and choice, which is very relevant in light of the coercive elements of the recently-passed Fixing Long Term Care Act. The guidelines include statements that may serve to protect people from being transferred to long-term care, and that will bolster their well-being while in LTC.

Concerning elements of the guidelines – In brief

While there are positive elements in the revised guidelines, they nevertheless reflect the widespread belief within government that people are likely to receive good care in long-term care facilities – and further, that long-term care facilities might be able to provide better care than what is available in the community (a belief that, in some cases, might unfortunately be true given shortcomings in home and community care). They also mostly ignore the role of financial costs in transfer decisions for people with relatively high support needs, i.e., the fact that in many situations it will cost less to support someone in long-term care because people have a right to less (often much less) funding while in the LTC system. The document does not, for example, offer direction to Program Supervisors as to how large a role cost considerations should play in transfer decisions.

Detailed reflections on the new Guidelines

1. The document is clearly a post-Bill 7 creation, and pays a lot of attention to issues of consent

The recently-passed *More Beds, Better Care Act* allows for home and community care workers to take steps, without consent, to prepare to move Alternate Level of Care (ALC) patients from hospital to long-term care facilities not of their choosing. It also increases hospitals' ability to charge patients up to \$400 per day if they do not move.

Bill 7 is clearly lurking in the background of the new guidelines. For example, the word "consent" is used 41 times, and "choice" is used 28 times. The authors are careful to distinguish these guidelines from the Bill 7 strategy for moving Alternate Level of Care hospital patients into long-term care facilities:

"A person's informed consent (or that of the person's substitute decision-maker, if applicable) is required at multiple junctures in the long-term care home placement process."

"People are not required to be placed on a waiting list for a long-term care home or accept a bed in a long-term care home to which they have not applied."

"A person, or their substitute decision-maker, must also consent to any bed offer before the person may move into a long-term care home."

"Separate consents are also required whenever information is to be shared between sector agencies and in situations where information is to be shared with persons other than a substitute decision-maker, such as a primary caregiver, family members or friends."

"Limited exceptions apply to ALC patients."

The document also includes elements that protect ALC patients with developmental disabilities from the coercive provisions of Bill 7. For example, it repeats the following statement three times:

"ALC patients with developmental disabilities who may already be on a waitlist or should be on a waitlist for community-based developmental services would likely not be eligible for long-term care placement."

At times, the document reads like a conversation between MCCSS staff (whose guiding strategy, *Journey to Belonging*, prioritizes choice and control) and MLTC staff (who spearheaded Bill 7, which undermines choice and control). For example, the following statement comes shortly after a section about ALC patients with developmental disabilities not being eligible for long-term care placement:

“Where an ALC patient **requiring** long-term care declines to participate in the admission process, the *Fixing Long-Term Care Act* and Regulation 246/22 allow for the process and conversation to continue. Legislative and regulatory changes have been made to enable the collection, use and disclosure of personal health information by and to placement co-ordinators for the purposes of determining long-term care eligibility of ALC patients and determining admission of an ALC patient to a long-term care home in circumstances where consent may not be provided.” [emphasis added]

This section serves as a reminder that Bill 7 exists, and the government is not afraid to use it – after all, more than 2,400 ALC patients were recently transferred to long-term care in a matter of months.

We address the idea that a person may “require” long-term care in the next few sections.

2. The document expresses a belief that some people can only have their needs met in a long-term care facility

“... part of the eligibility criteria for long-term care home admission includes determining that the publicly-funded community-based services available to the person and the other caregiving support or companionship arrangements available to the person are not sufficient, in any combination, to meet the person’s requirements.”

3. Ironically, the document also states that some people’s needs cannot be met in a long-term care home

“Eligibility is also based on whether publicly funded community based services and other caregiving, support or companionship arrangements are sufficient to meet the person’s requirements and *whether that person’s care needs can be met in a long-term care home.*” [emphasis added]

“When a MCCSS-funded developmental services agency is involved in supporting a person, the local designated long-term care home placement co-ordinator will co-ordinate and work with the developmental services agency to arrange discussions with potential long-term care homes to identify how the home can meet the person’s needs and what additional supports, if any, may be required... *When a person has very high care needs, this discussion may occur prior to a determination of eligibility in order for the placement co-ordinator to determine whether a person’s care needs can generally be met in a long-term care home.*” [emphasis added]

This raises an important question: are there people for whom neither home and community care nor long-term care are appropriate to their needs? And if so, what is the solution for those people?

4. The presence of ‘responsive behaviours’ is a key factor in making a person ineligible for placement in long-term term care

Long-term care homes simply do not have enough qualified staff to manage situations where a resident might engage in behaviour that could harm co-residents or staff. Many Ontarians have experience with a loved one being discharged from a long-term care facility because of physical aggression or unpredictability. The following statements from the guidelines are instructive:

“When an individual or their substitute decision-maker decides to complete an application for determination of eligibility for long-term care home admission, the placement co-ordinator will work with the person, or substitute decision-maker if any, to gather all of the necessary health and functional assessments, and any other information required to complete the eligibility determination... *It is very important that this information be comprehensive and accurate, particularly in respect of any behavioural issues.*” [emphasis added]

“Under the *Fixing Long-Term Care Act*, the functional assessment must include an assessment of the applicant’s functional capacity, requirements for personal care, current behaviour and behaviour during the year preceding the assessment... If an applicant has previously demonstrated responsive behaviours, another separate assessment related solely to behaviors is triggered.”

5. The document includes statements that can work to protect people with environmental sensitivities from being transferred to long-term care

In general, long-term care homes have trouble supporting people who are mobile, restless, and/or sensitive to environmental stimuli. While this is not openly addressed in the guidelines, it is notable that placement coordinators are encouraged to identify “obsessive needs and routines,” the use of behavioural therapists, potentially negative reactions to living in close quarters with others, and “unusual sensitivity to sensory stimuli.”

6. There is no acknowledgement of the fact that many developmental service organizations have taken steps to support people to age in place, and will not transfer to people to LTC unless a substitute decision-maker forces the issue

Community Living Ontario has called on MCCSS to develop guidelines to support people who have intellectual and developmental disabilities to age in place. Many organizations in Ontario have knowledge and information to contribute to such a resource. To our knowledge, no such resource exists at the current time.

On a positive note, the guidelines acknowledge the primacy of aging in place:

“... it is the hope to have everyone live in their home for their entire life...”

7. The guidelines include ideas about long-term care that are not reflective of the reality of that sector

In long-term care facilities, people currently receive, at most, about 2.5 hours of direct care per day. Staff-to-resident ratios are often vastly inferior to those in developmental services. For years, LTC associations have been calling attention to the “human resources emergency” in the sector. Nevertheless, the provincial government continues with the fiction that people will receive more and better care in nursing homes:

“Some people, including those with more complex, age-related health needs, may feel that they require the 24-hour a day nursing care and personal support available in a long-term care home.”

“Long-term care homes are *required* to meet the individualized care needs of their residents.” [emphasis added]

“... a long-term care home is primarily the home of its residents and is to be operated so that it is a place where its residents may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met.”

8. While the guidelines highlight the importance of choice and consent, true choice is difficult in the current environment

The guidelines state that, “Ultimately, it is the individual choice of the long-term care home applicant, or their substitute decision-maker, to select the long-term care homes to which they wish to apply and to accept a bed offer.” And this is technically true. However, we would argue that, given the substantial waitlist for supportive housing, developmental services and supports, and direct funding through Family Managed Home Care (to name just a few variables), many people with disabilities have few options apart from long-term care if they wish to have their needs even partially met.

9. The guidelines offer clarity re: the ability of developmental service agencies to support people living in long-term care facilities

“There needs to be careful consideration by the individual, primary caregiver, the placement co-ordinator, long-term care home and developmental services agency as to the supports a long-term care home applicant or resident with a developmental disability may require to improve their quality of life while residing in a long-term care home.”

“Long-term care home supports that could be required include enhanced staff training and education as well as additional supports to maintain health and quality of life such as behavioural therapists, therapeutic recreationalists, social workers, rehabilitative assistants, developmental services workers and modified equipment.”

“People who were receiving MCCSS-funded services and supports as part of the 2006 Long-Term Care Home Access Protocol for Adults with a Developmental Disability and/or a related initiative, should continue to receive these services and supports if they continue to be eligible and the supports are appropriate and necessary to support their quality of life, health and well-being.”

“MCCSS-funded services and supports for adults with a developmental disability in long-term care homes should be reviewed regularly or as required by the long-term care home with the developmental services sector for need and appropriateness. Developmental services and support would not continue if they duplicate or replace supports typically provided by the specific long-term care home in which the person resides.”

“Individual support plans are mandatory... These plans should be aligned with the support plan developed in consultation with the long-term care home.”

10. Concluding Thoughts

The revised *Guidelines for supporting adults with a developmental disability when applying to, moving into and residing in a long-term care home* are required reading for developmental service and long-term care agencies. It will be important for agencies to incorporate this very careful guidance into their processes and protocols.

Importantly, the guidelines include information that can serve to protect people who have developmental disabilities from being transferred into a long-term care facility. It is crucial that developmental service stakeholders understand this information and put it into practice in ways that support people to age in place. It is also vital that regional MCCSS staff fully understand these guidelines, and are open to working collaboratively with agencies for whom aging in place is a guiding objective.

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