Standing Committee on the Legislative Committee

Bill 37 Public Hearings

November 25, 2021

Submitted by:
Ontario Association of Residents' Councils (OARC)

Dee Tripp

Executive Director, OARC

OARC is a not-for-profit association, funded by the Ministry of LTC. Our Vision is that "every LTC resident in Ontario shapes the place they call home. Our Mission: We empower Ontario LTC residents to understand their rights, share their lived experience, and inspire a better tomorrow. We do this by working together with our partners to educate stakeholders, build a collective voice and create positive culture change. OARC provides support, education, encouragement to residents in LTC homes to enable and equip Residents' Councils to be as effective as possible.

A report from the Ontario Association of Residents' Councils

Contained herewith, are the speakers' notes OARC team used in the delivery of remarks pertaining to legislative amendments and setting tone/approach of the preamble. (Long-term Care residents' comments are captured in italicized font)

_____

My name is Dee Tripp, Executive Director for the Ontario Association of Residents' Councils. We are the direct conduit between the voice of LTC residents and government.

Devora, who are you?

- *I am 89 years old*
- *I have been a resident in a long-term care home for 11 years*
- *I have severe osteoporosis. In the last 10 years I have had 2 back surgeries, 1 neck surgery, 1 hip surgeries and 2 shoulder replacements – my kids call me the bionic woman.*
- *I am an adult and I don't like to be patronized or talked down to – I definitely see red when someone does this!*
- *I am a Resident Leader of my home's Residents' Council and Treasurer of OARC and through them find more purpose in my life each day*
- *I am part of creating solutions to the challenges in my home*
- *I advocate for residents that can't speak for themselves – it's important that they have a voice.*
- *I have known heart ache and I have known joy*
- *I am a widow, a mother, a grandmother and a great grandmother*
- *I am a teacher and I taught into my 70's*
- *I am a lifelong learner, an avid reader and have a sense of humour*
- *I love ginger, Naan, ice cream, chocolate, opera and live theatre*
- *A decade ago, I was so close to death that my son was told to get my affairs in order and my brother and sister-in law were told to cancel their cruise to prepare for the worst*

I am not done yet...

I am still here, and I am whole!

I am Devora Greenspon

Dee Tripp:

- Residents are not passive recipients of care
- As full citizens, residents are not plucked out of community
- Residents want to be part of the solution

That is culture change. That is person-centred care.

Words Matter!
Our first comment speaks to one of the new Residents' Rights.
#25 reads that "Every resident has the right to be **provided with** care and **services** based on a palliative care philosophy.

Residents have a reaction to this based on the language used.

Devora:

I may be 89 years old, but I still want to live! Listen I didn't' move into LTC to die, I moved into LTC because I couldn't walk and needed a hoist to move me. But guess what?!! I got better, and I'm now walking. People have the wrong image of residents in LTC. We are just like everyone else. We have emotions and feelings too. We want to laugh, dance, have fun, go places, and do all kinds of activities that will provide us with a better quality of life.

Dee Tripp:

- when we're talking about LTC – and residents' lives – the culture, the law, the policies need to be **life affirming**.
- We cannot frame a Residents' Right in the context of palliative care as a service/act done **to** residents
- Palliative care as a philosophy translates to care and attitude every single day

A palliative approach focuses on meeting the residents' full range of needs **every step** of the way and it embraces self-determination and choice. Palliative care does not equate to end-of-life care, however as well as that is understood for medical professionals, for the general public, when the words 'palliative care' are used, thoughts of imminent death are formed. When a loved one is 'deemed palliative' people interpret that condition as close to death.

When I read the new Residents' Right to residents, not one resident responded positively. Phrases included:

- "Now that's gloom and doom."
- "I didn't move into LTC to die!"
- "I don't want to talk about dying when I move into LTC."
- "When I told my son, he had two words…. insulting and insensitive!"

The Residents' Rights are for RESIDENTS. They are not for team members, family member or skilled medical professionals. If the rights are written in a way that residents do not identify with and feel insulted by, then something needs to change.

If the wording must contain the word palliative, then a definition of "palliative philosophy" needs to be in Part 1, Interpretation of the new legislation. Our preference is that the word be removed.

We have a solution, for how to re-word RR #25:

Premise: The Residents' Rights need to be about a 'living philosophy' not 'dying philosophy'.

"Every resident has the right to live each day supported through a palliative care philosophy that affirms and maximizes their self-determination and quality of life."

OR

"Every resident has the right to live in comfort, dignity and self-determination in their home at all times, at every stage of life.

The second point we wish to emphasis is the interconnectivity of QUALITY, Residents' Councils, and Communication.

During the pandemic, communication was terrible. Residents reported feeling 'in the dark' and punished. They didn't have the information nor the communication channels they needed as Residents' Councils were not top of mind, and fell silent.

Residents' Councils provide:

a) peer to peer support for residents
b) management with consensus decisions and suggestions that inform quality improvement from lived experience.

RCs are the main driver of communication b/w residents and the management of their home.

OARC is asking for the following in Bill 37:

- RCs are declared essential, linked directly to legislation on Quality
- **RCs are continuously** supported - licensees must allocate dedicated human resources to support RCs well

Issues pertaining to the Resident and Family/Caregiver Experience Survey:

The current Act reads that the licensee shall seek the advice of the RC in **DEVELOPING** and carrying out and acting on survey results. In Bill 37 the word 'developing' has been removed, meaning that Residents' Councils do **NOT** need to be involved in developing the very survey that measures their quality of living. This change is not acceptable. Residents, living in their homes, need to have some ability to formally contribute to the evaluation, collection, analysis of quality of living in their home [while consistency across the sector is important in measuring key, common, human and care related variable, residents living in various homes, from various socio-economic areas, various ages and conditions, etc., need to be able to 'tap' into what is meaningful to them. This work is done best through respective Residents' Councils, so removing the 'developing' component from the ability of Residents' Councils is problematic.]

The last item we wish to address today relates to the staffing crisis.

Carolynn Snow:

I am Carolynn Snow, a resident in LTC in Keswick. We residents feel the role of RSA/Ambassador RSA should be embedded in this legislation. Their duties include assisting with visiting programs and screening, portering residents to and from activities and dining rooms, assisting with meals, answering call bells, providing non-medical care, reading to and playing cards etc., with residents, assisting recreation staff with programs. These activities free up the nurses and PSWs to provide physical care to residents without having to rush through it. Many of the behaviours exhibited by the residents with dementia occur because their care is rushed and the PSW does not have time to explain what they are going to do with the resident step by step. The RSAs minimize responsive behaviour because the residents are kept busy and occupied.

RSAs are essential to the staffing strategy for LTC. They do not take away from the role of PSWs or RPNs, or Activation; they support, add valuable time and attention to meet the needs of the ongoing, often unspoken and unmet 'simple pleasures' in a resident's day.

Thank you for your attention and consideration of our comments.

Additional comments/queries not spoken (d/t lack of time):

1) Part IV, Councils, Residents' Council:

"Duties"

(2) The Residents' Council shall comply with any duties provided for in the regulations.

This is troublesome and confusing. The Residents' Council is a separate and distinct entity from the LTC home. It is supported by and through resources provided by the LTC home, but the leadership and membership of the Council is resident based (volunteer), and the Council is not funded by Ministry or home.
How can the Council (a voluntary, independent entity) be held accountable to regulations?
Councils are groups of volunteer residents, have no Board of Directors or legal governing body.
Can a Residents' Council be found non-compliant?
Why is a Residents' Council being held accountable by law to performance measures?
Residents' Councils have the right to action any 'powers' independent of the LTC home.
Does this infer that there is legal obligation on the Residents' Council Assistant (who is usually a paid team member of the LTC home) to ensure that the Council performs certain acts, or fulfils certain legislative requirements?
Does this give firm grounds for the provision of a full-time team/staff member in each home to ensure that the Residents' Council is fully supported in carrying out duties? Currently, the support for Residents' Council is 'off the corner of someone's desk' i.e. not a dedicated role that functions exclusively in that capacity.
What are the consequences of non-compliance?
Who is responsible for the legal functioning of the Residents' Council when the form and function is resident led?

OARC assists Residents' Councils in understanding their rights, their powers but ultimately, Councils can decide what they wish to concentrate on, which powers they wish to use, and how they wish to communicate/relate to the management team and each other.

2) "Minister to Consult"

(4) The Minister shall consult, in a manner the Minister considers appropriate, with organizations that represent the interest of Residents' Councils on an annual basis.

OARC recommends that this consultation occur in person as it allows, is verbal in nature and at a minimum, bi-annually. Are we correct in our assumption that the 'organizations that represent the interest of Residents' Councils' includes OARC?? Is this exclusive to OARC? Why is 'organization' pluralized? This is puzzling as OARC is the only organization that represents LTC residents in Ontario.

3) Addition to Residents' Rights:

Every resident has the right to free, reliable internet service where such service exists across the province.

OARC recognizes that there are some areas of Ontario where internet service is patchy, and unreliable, however the vast number of homes are in areas where robust, strong signal is available, and residents should have access to that service to maintain connection with their community and friends/family members.

Yours sincerely,

Carolynn Snow	Devora Greenspon	Dee Tripp
Director, OARC	OARC Resident Expert Advisor & Leader (REAL)	Executive Director, OARC