

Resident and Family Engagement in Long-Term Care

Report for Louis Brier
Home and Hospital



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Contents

- 01 Introduction**
- 02 Methods**
- 03 Study Findings**
- 04 Conclusions**
- 05 References**

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01

INTRODUCTION

In British Columbia, everyone living in a long-term care home has the right to participate in a resident or family council¹. And so do their family members and representatives. These councils provide a platform for residents and family members to meet with each other, discuss concerns and ideas, share input with management, and advocate for change.

In 2022, the B.C. Ministry of Health updated regulations governing long-term care, strengthening the role of resident and family councils, and increasing requirements for long-term care homes to support them¹. The change happened after COVID-19 spotlighted some major systemic problems in long-term care as well as the harmful effects of government restrictions that excluded families from entering buildings and isolated residents out of precaution.

Since the COVID-19 pandemic, interest in resident and family councils has increased, reflecting a growing recognition that residents and families should have a greater say within their home environments.

Now, family councils can access guidance and support through the Independent Long-Term Care Councils Association of B.C.², as well as their respective regional associations of family councils, who provide networking, information, and advocacy. The provincial and regional health authorities have also established forums to connect council members.

Although resident and family councils have been part of the fabric of long-term care homes for decades, we still know very little about how they work and whether they lead to meaningful change. This research study sheds light on the ways resident and family councils operate, how they influence change, and the policies and practices that support their efforts.

02 METHODS

As part of a larger study looking at resident and family councils in long-term care in BC and Manitoba, we undertook ethnographic research with the councils at Louis Brier Home & Hospital between May 2023 and February 2024. To better understand how these councils work in practice, we attended six resident and six family council meetings and took notes about what we saw and heard. We also interviewed eight residents, four family members, and four staff members who interact regularly with these councils. To establish the broader policy context, we interviewed five experts from across BC, each with unique experience in resident and family councils.

After collecting the data, we analyzed our notes and interview transcripts from council meetings, specifically looking at: council structures and processes; topics discussed at each of these meetings; how topics were addressed by the council and management; and the perspectives of residents, family members, and staff on participating in councils. Below we outline some of our key findings, observations, and topics for further discussion.

03 STUDY FINDINGS

What kinds of issues did councils address?

Resident Council

The resident council tended to focus on issues affecting their community's everyday experiences. Food, social and recreational activities, and the home environment were central discussion points alongside considerations about the council itself (e.g. meeting frequency and structure, and elections processes). They worked towards making concrete changes like modifying the menu and improving accessibility.

In the next pages, we highlight two areas where council influenced change, along with insights and ideas for further consideration from our research:

Food Matters

Food was a top priority for resident council, and an important area of influence. The group routinely discussed food-related issues and brought forward feedback to management. In addition, management met with them regularly to discuss food-related concerns and seek input on menu planning.

Food is a priority issue for long-term care residents³. Involving residents in decision-making about food can result in tangible improvements in food satisfaction⁴. In fact, the new national guidelines for long-term care identify engaging residents in menu planning as a best practice⁵.

To better understand how resident council influenced food services, we looked more specifically at four aspects of this domain within long-term care: food and menu planning, mealtime experience, nutrition care, and eating assistance. We learned that the resident council prioritized food and menu planning along with mealtime experience, focusing less on nutrition care or eating assistance. For example, they met regularly with management to make changes to the current menu and provide input on upcoming menu cycles. They also influenced mealtime experiences like ensuring seasonings were available on dining tables and updating the way the menu is displayed.

While the council was able to influence several changes, some suggestions did not progress very far due to conflicting opinions among council members, or because they were deemed unfeasible by management (e.g., reducing food waste). Other issues (like meal timing and temperature) were regularly discussed but did not result in a clear action plan.

Some ideas for further consideration:

Compared to menu planning, issues related to nutrition care and eating assistance were discussed less often, and when broached, were often viewed as “individual-level” problems. Given the high proportion of residents requiring modified diets and feeding assistance, however, additional planning and attention may be required to ensure all perspectives are considered.

The Home Environment

The resident council also influenced issues related to the home’s built environment. They pushed to make outdoor spaces accessible through renovations, and served as consultants during those renovations to ensure the perspectives of people with disabilities were represented. Residents also voiced concerns about building maintenance (e.g. mice) and creating soothing outdoor green spaces.

Changes to the home environment that the resident council helped to initiate:

- 1** Renovating the courtyard to create an accessible and soothing outdoor space.
- 2** Renovating the upstairs patio to create an accessible and enjoyable outdoor space.
- 3** Repositioning the doorbell within reach of residents who use wheelchairs.
- 4** Ensuring elevator renovations were accessible to residents in wheelchairs.

Family Council

There were important areas of overlap between the resident and family councils. For instance, both residents and family members expressed interest in improving food, building maintenance (especially dealing with mice), and social and recreational programming. However, compared to the resident council, the family council focused more on issues related to care practices, staffing, and policies and programs (like the companion program).

In the next page, we highlight two areas in which family council influenced change, along with insights and ideas for further consideration from our research:

Admissions Process:

The family council advocated for improvements to the admissions process. They administered a survey to family members, took part in a review and update of the admission process, and helped to revise the information residents and families receive upon admission:

“And so, what [the family council] worked on, and changed, actually—it’s been added to the protocol– when you’re bringing someone into a care home, that there is way, way, more information given to the family members. So that was one thing that I was really pleased to see.” *(Family member)*

End-of-Life Protocol

The family council also brought forward issues related to end-of-life care. They advocated for improving the facility’s end-of-life protocol and augmenting the information residents and families receive.

“An end-of-life protocol was something that was extremely absent, there was no thought put into it, no organization of it. And it happened on an individual basis every time... So, we now have a protocol, we now have a pamphlet.” *(Family member)*

Some ideas for further consideration:

While family and resident councils had differing areas of focus, there was a considerable amount of overlap around improving food services, building maintenance issues, and recreational programming. Going forward, councils may wish to collaborate on these topics of shared interest.

Seeing Meaningful Changes

Residents, family members, and staff emphasized the impact of seeing meaningful changes. Though the pace of change was sometimes characterized as “slow”, participants described contributing to real changes within the home as meaningful and motivating. For residents, seeing their ideas and efforts result in tangible improvements contributed to a sense of purpose and feeling valued. They were proud to be contributing members of the community. For instance, one resident commented:

“It’s nice to see things move, you know, from the ramp upstairs... and the one outside will be completed too. And to see people enjoying the garden more and being safely out there. You know, there’s no holes in the cement... It feels invigorating.”

(Resident)

On the other hand, some council members felt discouraged if they didn't feel their concerns were adequately addressed by the council or by the administration. As one resident expressed:

“Sometimes I get frustrated because some of the other people talk a long time and never get to put your input in. Or the person you ask a question, they go around the question, don't really answer it, but give you some other information.”

HOW WERE COUNCILS RUN?

Meetings

Both councils were administered by an elected executive team (e.g., chairs, co-chairs etc.) and had terms of reference and regularly scheduled meetings structured around an agenda. Whereas family council met once a month over Zoom, resident council met in person on a weekly basis, with assistance from a recreation staff member. Once per month, the resident council hosted a larger meeting in an open area, encouraging more residents to attend.

Residents had differing opinions regarding meeting frequency. Some believed meetings should be held once per week, others found this too much.

Within the family council, some preferred to meet online because it made joining more accessible and convenient, while others missed the social and informal aspects of gathering in person.

“I think meetings, it’s great to have people in-person,” said one resident council member. “You never know where it’s going to go from there, whereas Zoom is a little bit more formal somehow. And disjointed, a little bit.”

One of the family members, who also preferred in-person meetings, though, pointed out the advantage to doing things online:

“I would come in if the meetings were in person... but it’s a bit harder to get others engaged in and in fact, we now have people who join the meetings from somewhere else. And that gives them opportunity that previously they didn’t have.”

Communicating with residents and family members

For both councils, communicating with the broader community of residents and families posed challenges. The family council communicated primarily by email and through a page on the facility website. But due to privacy concerns, their email list relied on family members who contacted them, which limited the reach of their communication.

“Family council doesn’t have access to family email addresses. So, everything we do has to be through [the care home] and their emails,” *said one family council member.*

“Being able to have our own distribution list, and that anytime a new resident joins, we get sent their information, and we.. we can either reach out to them directly and just say, you know, “Hi, welcome. And here’s our deal”. Like, I would happily write that email,” *said another family council member.*

For the resident council, communicating with council members and the broader resident community was really challenging. The council relied on in-person meetings and printed documents for sharing information. But given that most residents did not have access to the internet, computers, or phones, the council could not develop an adequate distribution list. There was no simple solution to this problem. This lack of internet access limited the resident council’s ability to recruit new members, hear from residents about their concerns or ideas, and communicate as a council in general.

“We have a suggestion box, and most people do not fill out those suggestion boxes. So, communication is poor. But that’s a project that residents need to address in 23/24. We have to come up with a way to reach out to them and express their desires,” *one resident council member explained.*

“That’s the thing, is how do we give the information to the general population?”

asked another.

Some ideas for further consideration:

Both councils encountered communication challenges. Resident council in particular faced huge barriers to communication which will require creative solutions to address. Both councils discussed the importance of providing new residents and families with information about councils upon admission and considered the possibility of a welcome card or gift from the council.

Inclusion and Participation

Resident and family councils are responsible for making decisions and determining which issues they want to bring forward to management. When someone shares an idea, suggestion, or concern, their comments are heard by the council and any present staff members. This deliberation process can be challenging because people living in long-term care are diverse, and have unique experiences, needs, and preferences. So, some people may feel uncertain whether they should share their concerns with the group.

“Sometimes I don’t know if we should bring [things] up with family council or not, over... you know, are other family members having this, or am I the only one?” *said one family member.*

Making this even more challenging, some of the topics raised can be very personal in nature (e.g. intimate care) or may stem from distressing experiences. For residents, many of whom have disabilities, as well as experiences with ageism, ableism, sexism, and/or racism, this process of sharing can be intimidating. Some residents described feeling excluded, unheard, or even disrespected at some council meetings.

“The [council member] would bring us the information of the steps they had taken, that this area had been picked. So, everything was brought to us as a completed task. Nothing that anybody that I know of participated in. And to me, that’s not the way it should be,” *said one resident.*

Some ideas for further consideration:

It is important to create a safe space, in which council members feel included and respected. As one resident pointed out, accomplishing this requires training and experience in group facilitation and participation:

“People have to be taught then how to participate if they’ve never been taught or if they’ve never known how. It may be many of these people haven’t been in meetings.”
(Resident)

Some of the resources available through the Ontario Association of Resident Councils⁶ may be useful in this regard, but we could not find provincial training opportunities or resources specifically designed for BC residents on the subject of group facilitation, or equity, diversity and inclusion. This is an important policy gap affecting how councils run in BC's long-term care sector. Going forward, we would like to see tailored and accessible training opportunities developed for resident councils.

ORGANIZATIONAL CONTEXT

In this section, we discuss the organizational practices and contexts that influenced how councils operated.

Establishing clear communication channels

A key function of resident and family councils is to provide input to management. Often, concerns or suggestions were raised by council to management. At other times, management sought feedback from councils on specific topics (e.g., menu planning; new ID badges). Residents, family members, and staff emphasized the importance of having a clearly defined mechanism of communication and feedback.

For instance, the family council executive team and the senior leadership team met once every two months. Council members valued this system of communication:

“We changed the format so that we didn’t have this poor staff liaison having to come into our meetings at 7pm after their very long day, and trying to.. manage the myriad of questions that are really geared to all the disciplines... And so we organized ourselves to have [regular] meetings with senior leadership.” *(Family member)*

Staff members also felt this system helped to clarify communication and accountability:

“I think just like really clear action items, who’s responsible for what, keeping, like really good documentation, making sure that the follow-up’s there, sort of having logs, who’s accountable for what, I think that’s kind of key.” *(Staff)*

For the resident council, the mechanism of communication and feedback was somewhat less clear. Managers and members of the senior leadership team frequently attended council meetings and met with council executives, but it was not clear to all residents how ideas and concerns were communicated or followed up on. This could lead some residents to question what happened with their concerns:

“[The manager] nods her head and she says “yes, I’ll look into it.” And if she does, I don’t know, and if she doesn’t, I don’t know that either. So, I don’t know what happens once we bring that up.” *(Resident)*

Some ideas for further consideration:

Resident and family council have different needs, so they may require different methods of communication with management.

But one thing is clear: the regular attendance of managers and senior leadership at resident council meetings really helped to build relationships between the council and staff. At the same time, the system of communication and accountability between the resident council and management was not always clear to everyone involved, and some residents found this discouraging. Management or senior leadership could produce a follow-up document after meetings to outline which action items had been taken care of, and which were still in progress, for example.

Organizational Support

Both council members and staff valued having strong support from senior leadership. This “support from above” helped staff prioritize the council’s concerns even with other competing workplace demands at play.

“There needs to be real buy-in from the facility operator, and the staff, and even the board... They need to know who we are as resident and family councils, our benefits to the community, to the residents, to the family, and ... you know, really how to work together for the common good,” *said one family council member*

“Now, family council nudges the CEO if they’re waiting for a response, they’ll say, you know, ‘we haven’t gotten a response on this,’ And the CEO will then follow up with a member of whoever... It changes things considerably when the CEO is doing that, right? It obviously gets more traction, and then people kind of follow up a lot faster,”
one staff member explained

Some ideas for further consideration:

Supporting councils can be complicated for staff. In some cases, they may not agree with a council’s decision, or they may have concerns about council processes and dynamics. Staff are often grappling with competing demands on their time as well, and may encounter difficulty getting their peers to follow up on issues. For these reasons, staff felt it was important to have support from senior leadership to prioritize the council’s concerns and to help staff navigate any issues that arise.

Resource Requirements

Resources are always required to support and respond to councils. This includes a considerable time commitment from staff and management, as well as space, equipment, and resources like a website, email, and access to printing etc. Council chairs and executive members also devote significant unpaid labour to each council.

“I was quite grateful that [the council co-chairs] took up their time to chair this organization, and I felt in good hands, you know, like they had experience.”

(Family member)

It's important to make note of the additional resources resident councils require to enable their full participation. This includes having support staff facilitate meetings. For example, recreation staff typed and printed the weekly agenda, set up the tables and microphone, brought residents to and from meetings, passed around the microphone, and typed and distributed meeting minutes. Because the council communicated primarily through face-to-face meetings, this required management, allied health staff, and senior leadership to regularly attend meetings.

“If the leadership of the organization is really serious about being person-centered, I think they have to recognize that the resident council and the family council are two important mechanisms... So these are important groups that I think the organization, if given the resources, need to support. But I think if the government also writes it as a regulation, I think they also need to give support. But most of the time, they will mandate but won't give the necessary support.” *(Staff)*

Council Visibility

Given the time and energy that residents, families, and staff put into councils, and the resulting achievements, some participants pointed out the importance of recognizing and celebrating this work.

“I think we should have a party or something and recognize what we’ve achieved so far.” *(Resident)*

“In today’s world, if every care home has a website, then there should be a web page, or part of a page attributed to your resident and/or family council. Because it is for the sake of the community. There needs to be resources.” *(Family member)*

Some ideas for further consideration:

Unlike the family council, the resident council did not have a page on the home’s website. While a website may be inaccessible to many residents, it has the potential to make the council visible and accessible to other resident councils, the organizations that support councils, and the broader community. This kind of visibility could lead to partnerships with other long-term care homes and community groups, and could be of interest to potential residents and families looking for a long-term care home. Additionally, the councils might consider holding an annual ‘Council Appreciation Lunch’ event (like the “teacher appreciation lunch” model used in BC’s public schools) where residents, staff, and family members gather to share a meal, and recognize the councils’ achievements that year. Another possibility is to provide council executives with a small stipend or honorarium for their work.

THE BROADER LEGAL CONTEXT

Access to Information and Outside Support

The family council had established ties to organizations that support family councils including the Vancouver Coastal Association of Family Councils and the Independent Long-term Care Councils Association of BC. The council executives were well informed of the current regulations and rights of family councils. By contrast, resident council members were not aware of the changes to regulations that impact resident councils. Residents wanted more information about their rights, the purpose of councils, how other councils work, and opportunities to connect with other resident councils. During one council meeting, a resident commented:

“Rights? Do we even have any rights?”

(Resident)

Another resident wanted more information about the status of the resident council:

“I’d like to see us established as a bonafide council. And we would operate under the rules... as such. Is there an actual... formal... is there a formal list someplace that councils have to register with?” *(Resident)*

Some ideas for further consideration:

Without provincial resources tailored to residents, resident councils face barriers to accessing pertinent information. In light of these barriers, councils may want to consider other avenues to gain information about the rights of resident councils such as meeting with the family council executive, requesting a staff member provide in-person information about councils, rights and legislation, or reaching out to organizations such as the Independent Long-term Care Councils Association of BC.

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CONCLUSIONS

- The resident and family councils addressed issues that may otherwise be overlooked. They contributed to a range of meaningful changes.
- The councils focused on distinct but overlapping issues. Going forward, they may wish to consider collaborating on topics of shared interest.
- Residents and family members have diverse experiences, preferences, and concerns. Finding common ground can be challenging.
- It is important to create a safe space, in which all council members feel included and respected. Accomplishing this may require training in group facilitation.
- Participants emphasized the importance of having support from senior leadership and a defined mechanism for communicating with management.
- Residents, family members, and staff dedicated significant time to council activities. Councils and leadership may wish to consider ways to recognize their contributions and increase the visibility of both councils and their achievements.

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REFERENCES

1. B.C. Reg. 96/2009. Available here: https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96_2009
2. Independent Long-Term Care Councils Association of BC. Available here: <https://iltccabc.ca/>
3. Boelsma, F. et al. (2014) “Small” things matter: Residents’ involvement in practice improvements in long-term care facilities. *Journal of Aging Studies*, 31:45–53.
4. Baur, V., & Abma, T. (2012). ‘The Taste Buddies’: participation and empowerment in a residential home for older people. *Ageing & Society*, 32(6), 1055-1078.
5. National Standards of Canada. HSO Long-Term Care Services (2023) Available here: [https://healthstandards.org/standard/long-term-care-services-can-hso21001-2023-e/#:~:text=The%20standard%20focuses%20on%20promoting,term%20care%20\(LTC\)%20homes](https://healthstandards.org/standard/long-term-care-services-can-hso21001-2023-e/#:~:text=The%20standard%20focuses%20on%20promoting,term%20care%20(LTC)%20homes)
6. Ontario Association of Resident Councils. Available here: <https://www.ontarc.com/>

