



THE **CHANGE**
FOUNDATION
ENGAGE, EXPLORE, EVOLVE

ENHANCING CARE, ENHANCING LIFE

Family Member Views of Family Councils
in Ontario Long-Term Care Homes

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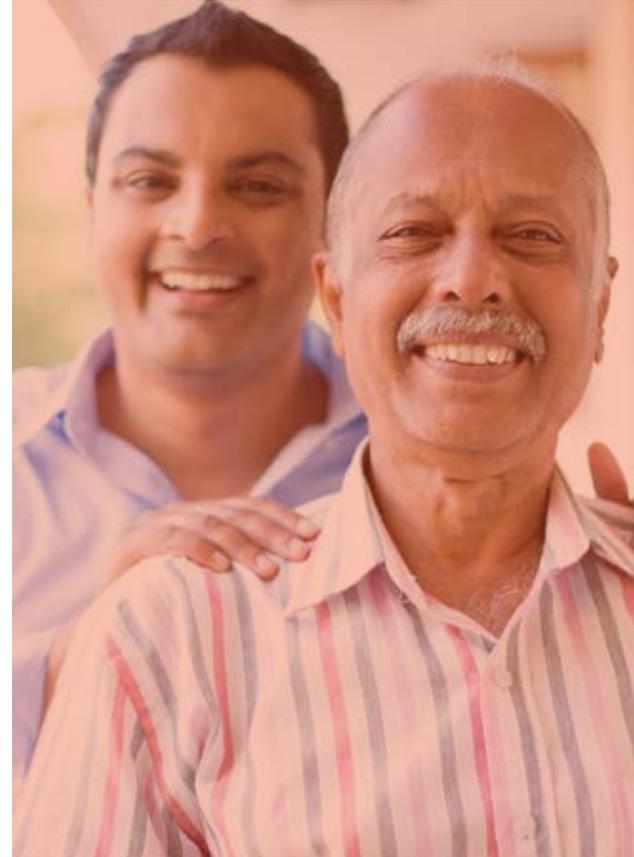
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Project Overview

The Change Foundation has partnered with four organizations for a two-phase project—surveys and case studies—on Residents’ Councils and Family Councils in Ontario long-term care homes. The purpose of the project is to better understand the role, functioning, impact and leading practices of these councils, which are mandated for all homes in the province. This report presents detailed findings from our 2015 survey of family members about the Family Councils. For an overview of the phase one findings and more information about the survey methods, please see our report, *Enhancing Care, Enhancing Life*.

Two groups of family members with a loved one living in the long-term care home were surveyed: family members who participate on a Family Council, and family members who do not participate on a Family Council. In total, 396 family members agreed to take part in the survey, of which 290 (66%) participate on a Family Council and 106 (24%) do not.

For this report, family is defined as anybody of importance to the resident, including but not limited to family, friends, neighbours or distant relatives. Family Council members are defined as those who meet the eligibility criteria under Ontario’s Long-Term Care Homes Act, 2007.



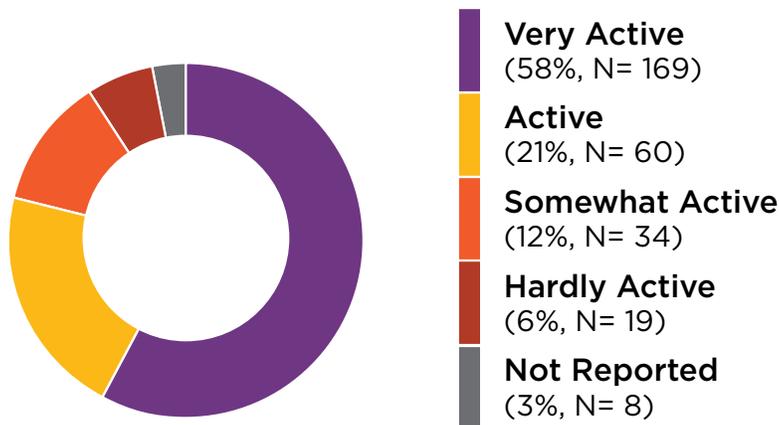
Participating Family Members

This section is a summary of the responses of the 290 family members surveyed who participate on a Family Council.

ROLE / FUNCTION

The 290 family members who participate on a council were asked how active they were on the council. Level of activeness was determined by their participation in the meetings, which generally took place for an hour or more, once a month. Just over 50% were very active on the council, and 79% described themselves as being either active or very active in council meetings (Figure 1).

Figure 1: Family Activeness on Council



Many participating family members believed that information sharing, enhancing the quality of life for residents and enhancing the quality of care for residents were the main roles of the Family Council. Advocacy was another role that was frequently cited (74%). This suggests that many who participate consider themselves the advocate for their loved one in the long-term care home.

- 82% (N= 239) Information sharing
- 84% (N= 244) Enhancing quality of life for residents
- 80% (N= 231) Enhancing quality of care for residents
- 74% (N= 214) Advocacy
- 70% (N= 202) Education
- 64% (N= 185) Peer support
- 45% (N= 131) Networking
- 34% (N= 99) Program planning

Some family members thought that all of these roles were appropriate roles of the Family Council, while some mentioned additional roles such as providing a voice for residents, advising the home and the staff, and creating a collaborative environment.

The majority of family members, 76% (N= 221) believed that the Family Council is fulfilling its role and function, while 18% (N= 52) did not.

Family members articulated a number of reasons why they believed the council is fulfilling its role: the council is being responsive to the needs brought forward, the council meets regularly, the council has

“We have a very strong council with many members. We have regular meetings as well as those deemed necessary in between our regular meetings. We are introducing new programs. We do a lot! We are a very strong presence.”

— PARTICIPATING FAMILY MEMBER

management support, and the council is proactive in creating new initiatives and improving programs.

Those who did not believe the council is fulfilling its role and function noted that they were not seeing many changes and they saw a drop-off in family participation.

“We do not have the family attendance and input we need to have an effective role in supporting our residents. It seems to me that there is no interest by family members to attend except for a few. I would like to see more family involvement.”

— PARTICIPATING FAMILY MEMBER

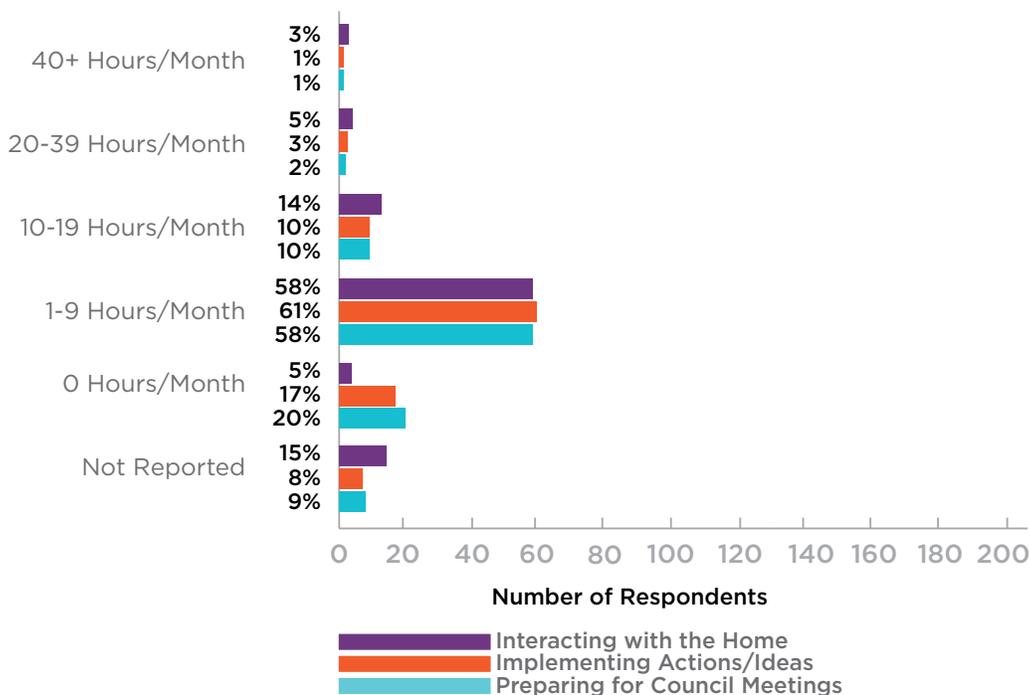


INTERACTIONS AND RELATIONSHIPS

Three-quarters of family members (77%, N= 222) said the council meets monthly. Others said they meet on a quarterly basis (9%, N= 26) or on a bi-monthly basis (6%, N= 18).

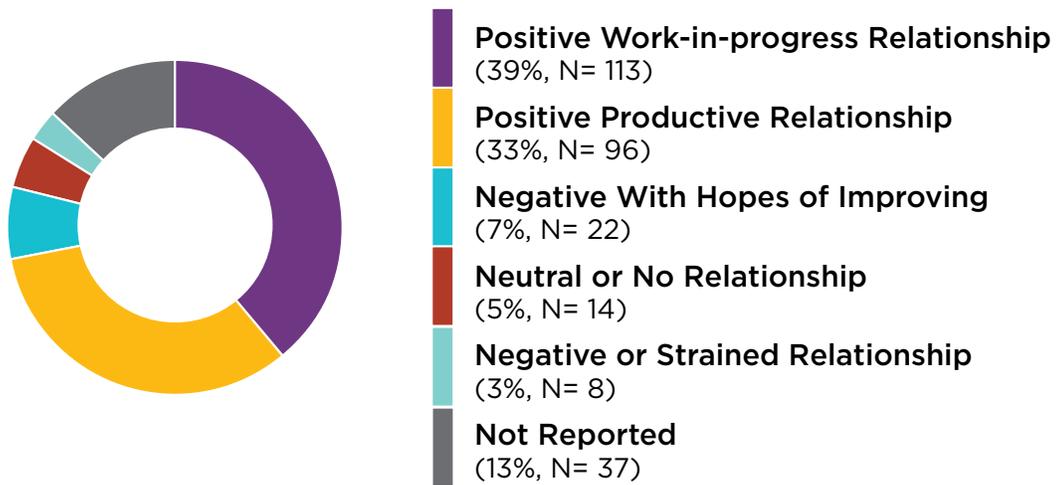
Family members who participate on a Family Council spend a range of hours preparing for council meetings, implementing the actions and ideas from the council meetings, and interacting with the home staff and administration regarding council activities. One to nine hours per month is the most common amount of time that family members spend on these activities (Figure 2).

Figure 2: Time Spent on Council Functions



A majority of family members 72% believe that the council's relationship with the home is a positive one (Figure 3).

Figure 3: Perceptions of Family Council's Relationship with the Home



Just under half of families, 48% (N= 138), said the Family Council has a relationship with the Residents' Council at the home, while 42% (N=122) said there is no relationship between the two councils.

Of the 138 participating family members who said there is a relationship between the Family Council and the Residents' Council, most (76%, N= 105) thought the relationship is a positive one; 21% (N= 29) said the relationship is a negative one (3%, N= 4, did not respond).

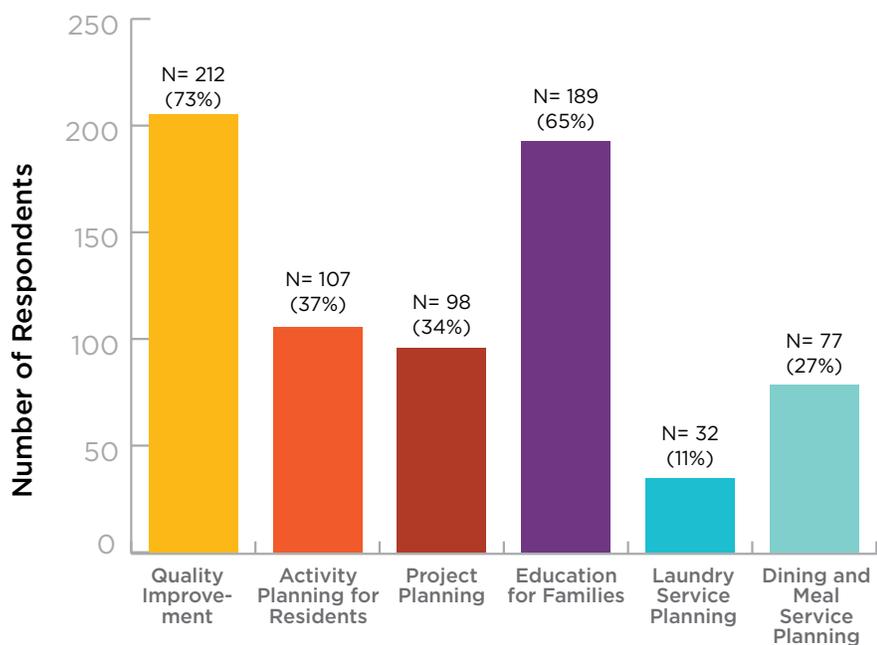
COMMUNICATION PRACTICES AND ENGAGEMENT

Most family members said they communicate in-person with the administrator or staff assistant (75%). Although in-person communication can be more personable and direct and it can facilitate the interpretation of body language and tone, it can also be more time-consuming. Fewer family members said they communicated via email and bulletin boards or flyers.

- 75% (N= 104) In person
- 22% (N= 30) Email
- 21% (N= 29) Bulletin board / flyer
- 11% (N= 15) Telephone
- 10% (N= 14) Newsletter
- 9% (N= 12) Written letter

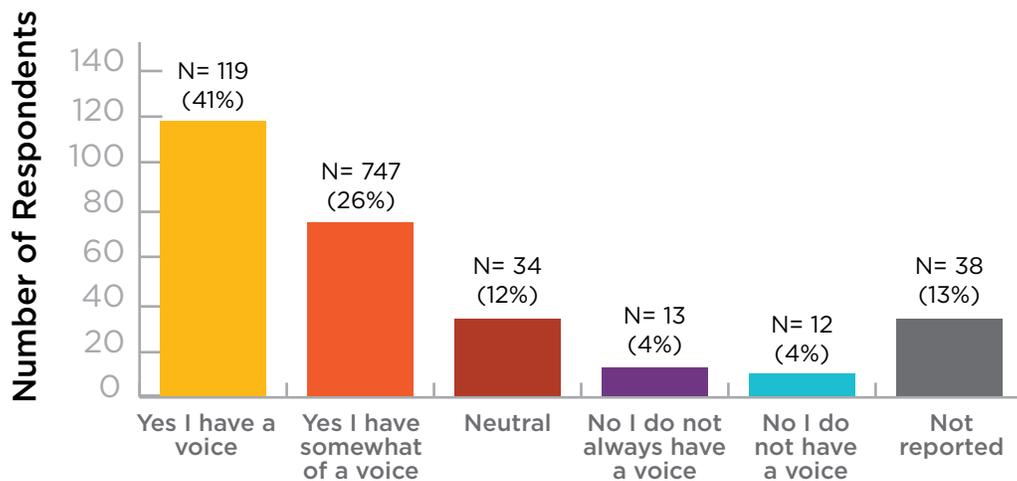
Family members reported that the top two areas of life at the home that their Family Council was involved in are quality improvement and education for families (Figure 4).

Figure 4: Family Council's Involvement in Life at the Home



A majority of family members, 67% (N= 193), said they do have a voice through the Family Council while 8% (N= 25) felt they do not (Figure 5).

Figure 5: Family Members' Perceptions of Their Voice Through the Family Council



Families who felt they do have a voice said it is because they have open communication with the home, and the family members and staff communicate well and keep in touch. Also, families said they hear many of the same issues when they get together, and when they bring up an issue as a group, it is dealt with in a timely manner.

Those who felt they do not have a voice said the Family Council was not rotating its membership or its executive. In larger homes in particular, family members noted that certain units had specific problems and they felt the council was not addressing the differences in these units.

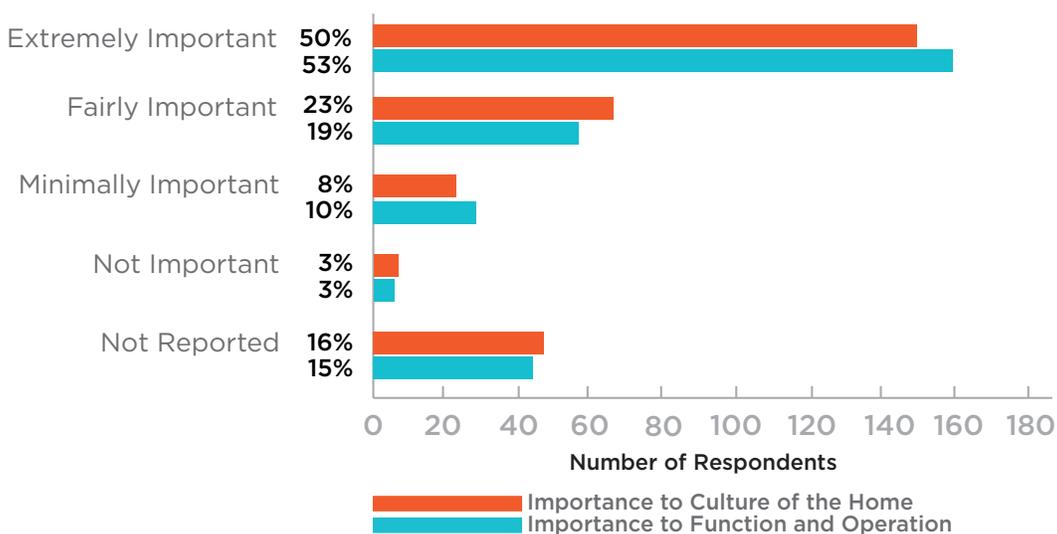
“We encourage and maintain lines of communication with staff and administration. We strive to be a positive group which offers support to the frontline staff as well as residents.”
 – PARTICIPATING FAMILY MEMBER

“I don’t think the council is very effective in demanding management accountability or asking the right questions. It is also always the same people talking and not really caring about the difference in quality of activities/services/ cleanliness in the secure/Alzheimer’s units.”
 – PARTICIPATING FAMILY MEMBER

FAMILY COUNCIL IMPACT

A majority of participating family members, 73%, believe the council is important to the culture of the home, while 72% believe the Family Council is important to the function and operation of the home (Figure 6).

Figure 6: Importance of Family Council



Family members stated that the Family Council is important for function, operation and voice because the council is a place to come if a family member doesn't know how to deal with a troubling situation. Families saw themselves as a bridge between their loved one in the home and the staff. They said the council allows for a productive partnership between families and the staff and administration, and that partnership is important for service provision in the home and for their loved ones.

Those who said the council is not important or minimally important believed that people were not participating and ideas were not being vetted; thus, the council did not represent the voice of the majority.

Family members mentioned various changes in the homes, resulting from the council's work that had benefited residents, staff and families. These changes included:

- Programs
 - Introduction of “Montessori for the Elderly” school/lessons
 - More music programs (family members assist staff in providing music and culture programs)
 - More programming for family and residents to do together
 - Creation of Family Day celebrations
 - More books and reading material for residents

- Operations
 - Meal improvements for residents
 - Higher level of cleanliness
 - Involvement in quality improvement meetings with all management staff
 - Introduction of iPads for residents
 - More volunteer opportunities
 - Improvements in consent to treatment
 - Education sessions for families about aging and dementia
 - Bulletin board updates for residents and families about what's going on in the home
 - Changes in the smoking area and rules about smoking in the home

“Family members encourage, help and support each other. Bridges of communication and teamwork are also built with staff. There is more of a ‘we are all on the same team’ (families and staff) attitude.”

— PARTICIPATING FAMILY MEMBER

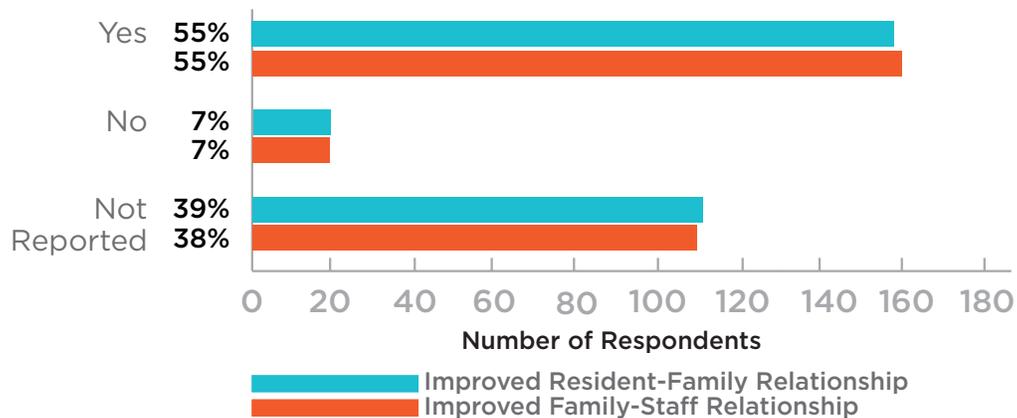
“We need to hear the voices of all participants in the life of the home. That includes residents, staff and family members. The council would be more important if we could attract more members.”

— PARTICIPATING FAMILY MEMBER

- Infrastructure / Renovations
 - More parking for families
 - Installation of cameras in common areas
 - Improvements in walkway into the home
 - New palliative care room, paid for by donations from the Family Council

The majority of family members, 55%, felt that the Family Council did improve relationships within the home. However, there was a high non-response rate to this question (Figure 7).

Figure 7: Perceptions of Family Council's Impact on Relationships



Non-Participating Family Members

Of the 396 families who consented to taking the survey, 106 (24%) said that they do not participate on the Family Council. This section is a summary of their responses.

Non-participating family members were asked why they did not participate on council: 24% (N= 26) said they do not have time, 4% (N= 4) never considered the opportunity, 4% (N= 4) do not feel welcome on council, and many participants 67% (N=71) did not respond. Some family members stated other reasons they did not participate: the council is run at an inconvenient time, they live too far away, or they are new to the home.

Family members who do not participate on council thought the council role is mainly for enhancing quality of care (57%), enhancing quality of life (56%) for the residents, and information sharing (56%). Advocacy was another important function, with 42% of respondents believing it is part of the council's role.

- 57% (N= 60) Enhancing the quality of care for residents
- 56% (N= 59) Enhancing the quality of life for residents
- 56% (N= 59) Information sharing
- 42% (N= 45) Advocacy
- 40% (N= 42) Education
- 38% (N= 40) Peer support
- 30% (N= 32) Program planning

While 42% of family members (N= 44) who do not participate on the Family Council think it is fulfilling its role, 8% (N= 9) do not think the council is fulfilling its role, and 50% (N= 53) did not respond to the question. The high non-response could be the result of people not wanting to comment on, or assume something, they were not sure about.

Some non-participating family members said they do think the council is fulfilling its role because they have seen a difference in the home and there is good

communication back to the rest of the families who have loved ones in the home.

One reason non-participating family members did not believe the council is fulfilling its role was that they didn't hear much from the council in terms of updates and improvements. However, some said that they weren't sure if this was because the council was not promoting itself or they just were not looking for the information.

Only 29% (N= 31) of family members said they get regular updates from the Family Council, while 14% (N= 15) do not, and 57% (N=60) did not report on whether or not they receive updates from the Family Council.

Of those who said they do not receive updates, 94% (N= 14) said they would be interested in knowing what the council is working on and what improvements they are making.

Overall 29% (N= 31) of non-participating family members thought the council represents the views of all families in the home, 14% (N= 15) did not think it does, and 57% (N= 60) did not respond.

“Very good communications and they are advocates for the residents and family. Example: wanted to introduce pay parking – but Family Council advocated and implementation was watered down to still allow a number of free parking spaces.”

– NON-PARTICIPATING FAMILY MEMBER

“Not sure as I have not seen much of their communication. Part of it could be me as I am not looking for it.”

– NON-PARTICIPATING FAMILY MEMBER



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