

SUPPORTING FAMILIES IN LONG TERM CARE

RESULTS FROM A RESEARCH PROJECT



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The Supporting Families research project was developed and led by Olivia Saric, FCO Special Projects Coordinator. We sincerely thank her for her work to develop, execute and manage the project, as well as write this report.

WHO WE ARE

Family Councils Ontario (FCO) is a registered charitable, nonprofit provincial organization that works with over 500 Family Councils and 2500 Family Council members and Staff Assistants across Ontario. Our mission is to lead and support families in improving quality of life in long-term care (LTC). We seek to cultivate effective Family Councils, advance public policy and system planning, and mobilize knowledge exchange. We have established strong collaborative relationships with community and government stakeholders and seek collaborative community partnerships to impact positive change.

ACKNOWLEDGMENTS

Family Councils Ontario is grateful to the families, caregivers, and sector professionals from across Ontario who took the time to participate in this project. FCO wishes to thank them for sharing their experiences, insights, and reflections. Without their participation and commitment this project would not have been possible.

PROJECT OVERVIEW

Family Councils Ontario launched the “Supporting Families Project” in November 2017. This research project was brought about in response to growing concerns from both service providers (Social Workers and Social Service Workers) and caregivers about the availability and offerings of social service supports for families in long-term care. FCO was interested in learning more about the nature of Social Work & Social Service Work (SW/SSW) in Ontario long-term care homes (LTCH) and how these services were experienced by families.

In order to capture sector experiences and better understand the role, functioning, and impact Social Work and Social Service Work (SW/SSW) have on families FCO developed a two phase research project.

Phase 1 featured the administration of surveys to service providers (SW/SSW) either currently working in a long-term care home or with previous professional

experience in LTC. Additionally, surveys were distributed to family members and caregivers of residents in LTC. They aimed to capture data on existing SW/SSW supports in LTCH. Surveys aimed to measure the effectiveness and impact of these services and overall family and caregiver satisfaction levels with current SW/SSW services.

Phase 2 featured individual interviews with families and caregivers and service providers in LTCH. We wanted to understand the experiences and perspectives of families/caregivers and service providers. Our goal was to gain an integrated understanding of the services provided, how they impact families, the challenges faced in providing these services, and the changes needed to improve services.

METHODS

Participants for this project were recruited through an open invitation to participate in one of our surveys. FCO promoted the opportunity through information posted on our website and social media channels. FCO also launched an outreach initiative to service providers and families/caregivers registered with the FCO emailing service.

53 individuals responded to our open call for surveys.



21 Participants self identified as service providers (either Social Workers or Social Service Workers).

32 Participants self identified as either family members or caregivers of an individual in LTC.

Surveys were followed by semi-structured interviews. Of the 53 survey respondents, **15** respondents were interested in participating in individual interviews to help us gather more information. Of these **15** participants, **10** were family/caregivers and **5** were service providers (SW/SSW).

In-depth qualitative, semi-structured interviews were conducted with consenting participants. These interviews allowed for the study of complex experiences of both families/caregivers and service providers. This methodology sought to capture an accurate understanding of participants' unique experiences either receiving or providing care in LTC. This methodology allowed us to ask participants open ended questions that remained unanswered from the close-ended survey methodology.

Two separate interview guides were developed. One was designed for families and caregivers; the other for service providers. The interview guides followed a consistent format. The design, however, allowed participants to lead discussion and share their experiences and insights. This helped us develop a more natural discussion with participants.

Interviews with all participants were conducted one-on-one over the phone and took an average of 40 minutes to complete. Because the residing location of participants varied, in-person interviews were not possible.

All participants gave their consent for the interviews. All interviews were audio recorded and transcripts of the interviews were prepared. Qualitative analysis was undertaken as interviews were being conducted to identify thematic consistencies. The themes and patterns that emerged in the interviews were further reviewed. The most prevalent and salient themes are presented in the key findings of this report.

KEY FINDINGS

FAMILIES & CAREGIVERS

I. FAMILIES EXPERIENCED LITTLE TRANSITIONAL SUPPORT

Transitioning into long-term care is a difficult and emotional process for most families. Interviewees described this time as “heartbreaking” and “draining” while some families felt as though they had no other choice but to enter LTC. For families with little to no experience in LTC, transitioning into care was described as a burdensome, emotional, and physically draining experience.

Transitional support for families entering LTC for the first time was described as a crucial and necessary service. It helped families feel confident in the LTCH in which their loved one was placed. The support offered during the transition period varied for families. Some families found a very supportive and accommodating staff, while others felt alone and unsupported.

One family member felt that the transition into care was difficult because she received no formal welcome to the home by way of an admission meeting or tour of the home. In particular, there were no supports in place to help her resident adjust to the changes that were going to take place. Seeing her loved one in distress increased her own stress and anxiety.

Other families had very different experiences. One individual felt the transition was handled very well by the home. They described a smooth transition with a lot of guidance and support from the Social Work staff. The home had a welcome committee, an orientation, and the Social Worker was present throughout the transition. This helped the family feel comfortable and assured in their decision to move into LTC.

Families who had involved SW/SSW staff when entering LTC, overall described better experiences transitioning into care. They felt that a professional was available to help guide them into care. Families who were either unaware of a

SW/SSW presence or received no transitional support described their transition as distressing, difficult, and unsupported.

Social Workers and Social Service Work staff play an integral role in the transition phase. They are often the first face a family member sees when walking into a home. These individuals have the professional skills needed to help families and their residents integrate into LTC.

II. EDUCATION THROUGHOUT THE JOURNEY

Families identified the need for increased education both when entering LTC and throughout their residents’ stay in LTC. In most cases, while a wealth of information is provided upon admission, little exists for families as they continue on their LTC journey. Many family members felt that they were poorly equipped to handle the realities of LTC. In fact, most families were unaware of the presence of a Social Worker/Social Service Worker in the home and felt they

“I didn’t know what the role of a Social Worker was in Long Term Care, in the 11 years that I was in Long Term Care I had never seen the Social Worker.”

had no one to turn to when they had questions or needed information. As one interviewee said “I didn’t know what the role of a Social Worker was in Long Term Care, in the 11 years that I was in Long Term Care I had never met the Social Worker”.

Interviewees felt that the role of educating families was critical in improving caregiver experiences. Families would have liked to see education on home policies, staff, and procedures as well as on resources and supports available to them. Families identified interest in having homes more involved in providing workshops on for example, Alzheimer’s & Dementia, Palliative Care, LTC Legislative changes, etc. Interviewees felt it was important to stay informed and to have LTC homes involved in providing education and information.

It was identified that staff (Personal Support Workers & Nurses) often do not have the time to provide educational support and resources to families. However, the SW/SSW is ideally suited for this role. Families felt it was crucial to have an individual(s) who was present within the home to act as a guide for families. LTC is a complex and often overwhelming system and, as such, families felt that SW/SSW were key players when it came to educating, informing, and keeping the lines of communication open. As one family member put it, “I want to be in the loop.” Struggling to obtain critical information adds to the stress and frustration of families and caregivers in LTC. SW/SSW are gatekeepers to this information and can act as valuable sources of information, thereby improving the overall experience of families in LTC.

III. INCREASED CONTACT

A difficulty many families who were interviewed faced was having little contact with a Social Worker/Social Service Worker beyond that of a crisis. While the reality of LTC often means that few Social Work services exist for family members beyond emergencies, it also means that families feel unheard. One family member candidly stated “I didn’t feel like anyone was listening to me.” Families identified the need for a bigger SW/SSW presence within LTC. Families who either didn’t have a SW/SSW in home or had little to no contact with the SW/SSW felt unsupported. In reference to the lack of support one family member said “I feel like everything weighs on me.”

The families that received regular care from a SW/SSW found that it had positive impacts on both their residents and themselves. These families accessed counselling services, support groups, workshops and other formal and informal supports. These services in turn helped family members manage caregiver burnout and better support their residents. Families who had access to a SW/SSW not only felt increased confidence in the home but felt that they had someone on their side. Families felt that Social Workers and Social Service Workers had a

positive impact on the quality of life of residents and that they provided an essential support service to families.

IV. RECOGNIZE & LISTEN TO FAMILIES

Families come into care with excellent knowledge about their resident. Many families interviewed acted as caregivers to their resident long before they were placed into care. They understand and have excellent insights into the care needs of their resident. While families recognized that LTC is an institutional setting they felt that homes needed to do a better job at listening and recognizing the expertise of families.

Social Workers and Social Service Workers act as an intermediary between families and other LTC staff. They are able to listen to the needs of families and advocate on their behalf to facilitate positive change.

As one family member put it *“Every home would benefit from a Social Worker; they are looking after our loved ones but they need to be aware that there is a family component to this. When I go home at night I want to feel that my mom is in good care.”* Families are an important piece in the LTC puzzle. It is detrimental to ignore

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their experiences. Interview respondents felt a greater need for collaborative relationships between SW/SSW staff and families. They felt that when collaborative relationships were built between service providers and themselves they were able to contribute to solve care issues, provide meaningful feedback, and improve the quality of care in Long Term Care Homes.

SOCIAL WORKERS & SOCIAL SERVICE WORKERS

I. LACK OF CONSISTENCY

Social Workers and Social Service Workers interviewed felt that their roles within LTCH lacked consistency. Every Social Worker and Social Service Worker described their role differently. While most SW/SSW worked on admissions into LTC, the similarities in roles ended there. SW/SSW felt that their roles lacked definition and as a result their time was taken up with non SW/SSW duties.

“I can’t reach every resident; I don’t really see residents that don’t need it (Social Work). I am only there when a crisis occurs, we’re putting out fires. We are not solving care issues just managing them.”

SW/SSW expressed their frustration with this lack of consistency. They found that their role was poorly defined resulting in complicated and often large workloads. They felt that their time could be better used directly supporting residents and their families. When interacting with residents and families one Social Worker commented “I can’t reach every resident, I don’t really see residents that don’t need it (Social Work). I am only there when a crisis occurs, we’re putting out fires. We are not solving care issues just managing them.” Another Social Worker noted that because her role lacked consistency, she did not have the time to make necessary connections with family members. Similarly, one Social Worker spoke of her frustration at not being available for families and residents. Her role within the LTCH was used primarily to accomplish administrative duties.

Social Workers and Social Service Workers interviewed recognized that their role both within the home and more broadly within the field of LTC varied greatly. Professional designations, competencies, skill sets, and job descriptions were different with every interviewee. One participant noted that a lack of consistency within the field makes it difficult to provide a standard of care that ensures all families and residents receive Social Work/Social Service Work supports. Interviewees felt that a defined a clear role would allow them to address more

residents and families and provide services that matched the needs of their clients. SW/SSW identified the need for their unique professional skill set be used appropriately within LTC.

II. LEGISLATION & RECOGNITION

Social Workers and Social Service Workers consistently commented on their professions in LTC being poorly defined and lacking clarity within LTC legislation. Social Work/Social Service Work is not a mandated role within LTCH. While many LTCH do have a SW/SSW on staff many do not. Professionals interviewed expressed their strong belief in having at least one Social Worker in every LTC

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home. The role was described as necessary in ensuring a well balanced and high quality of life for residents, and building strong and confident relationships with families. As one Social Service Worker said “families are minimally supported when this role doesn’t exist. They need time, resources and someone to rely on.” Service providers expressed their desire to have a SW/SSW in every long-term care home mandated by legislation.

In reference to the need for increased legislation one Social Service Worker noted “Our profession is misunderstood- I had one administrator tell me that it was a luxury to have me. I saw my role as a necessity.” Many SW/SSW interviewed referenced the need for clear legislation around their role in LTC. It was felt that regulation would not only help legitimize the role but, would also give SW/SSW more capacity to engage with residents and families in defined and recognized ways. A Social Service Worker expressed that increased regulation would provide safer and more standardized levels of care. Another Social Worker felt that it would allow for more individual connection and support. All Social Workers and Social Service Workers interviewed felt that their role provides critical support

services to residents and families. Additionally, that without their support the quality of care in homes declines.

III. INCREASED SUPPORT TO FAMILIES

Service providers were of the opinion that family members received minimal supports in LTC. Many service providers had firm belief that families are ignored in long-term care homes. They acknowledged the need for increased collaboration with families to foster a trusting and safe environment in LTC. Service providers felt that LTCH needed to invest in social services that involved support groups, counselling services, educational workshops, transitional support, and increased capacity to do outreach and advocacy work. Service providers felt that resources were lacking and that often they were unable to meet the needs of clients. One Social Worker described her work as always having to play “catch-up.” Service providers described their desire to make meaningful connections with families and to provide well rounded services to every family involved in LTC. Social Workers and Social Service Workers have the professional knowledge and skills to work with families in LTC. However, as many professionals mentioned, their work is under funded and not acknowledged within the field. Service providers were aware of the gaps in their service yet, felt that with the current restraints and mismanagement of their roles they were unable to provide services to families.

KEY LEARNINGS AND DISCUSSION

Families that came forward for interviews were disenchanted by the LTC system. In sharing their experiences, they highlighted the need for compassionate and dignified approaches to care. Families felt that they were unheard and that their experiences and expertise was negated. Interviewees felt the need for family oriented supports to be taken seriously in LTC. Families wished for open dialogue and increased communication between service providers and themselves.

Families also shared many experiences that showcased the excellent care delivered by dedicated service providers. These individuals shared the many ways in which service providers creatively worked with families to problem solve, direct resident care, and support families.

Social Workers and Social Service Workers identified many areas of improvement within their practice in relation to work with families. They recognized the need for increased education, support work, and communication. Service providers were frustrated by the lack of resources directed towards their profession as well as the inadequate regulation and legislation that hindered service provision.

Families and service providers were very eager to discuss the ways in which care in LTC could be improved. They provided compelling cases, stories, and examples for the need to increase family oriented services. Families are an integral part of LTC. They care for their residents, work with LTC professionals to improve care, and are deeply invested through their involvement in initiatives like quality improvement and Family Councils. As such, they require a listening ear, guidance, and dignified care along with their residents.

LIMITATIONS

Limitations include the following: 53 individuals came forward to complete a survey yet we received limited interest from participants for the interview phase of this project. Additionally, time constraints and limited outreach capacity may have resulted in less variability and representation in interview participants and responses. Secondly, the nature of this project limited the scope of research findings. The project was unable to provide quantifiable data on the provision of Social Work/Social Service Work in Long Term Care Homes. Data such as professional designations, time spent in home, units of service, and service provision were not conclusively collected due to limited participation and resource constraints. This data would have help contextualize the experiences of both families and service providers in LTC.