# EXPLORING THE EXPERIENCES OF CHSLD (LONG-TERM CARE HOMES) RESIDENTS AND THEIR INFORMAL CAREGIVERS DURING THE COVID 19 PANDEMIC AND THEIR SOLUTIONS FOR IMPROVING QUALITY OF LIFE AND WELL-BEING

## STUDY SUMMARY

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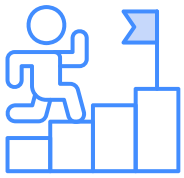
# STUDY SUMMARY

The problems with the quality of care in long-term care homes (CHSLDs) in Quebec have existed for a long time. The COVID-19 pandemic made these problems much worse. During the first wave of the pandemic, Quebec had the highest percentage of deaths in long-term care in the world. Residents in CHSLDs faced not only poor care services but also extreme social isolation. Strict restrictions caused many negative effects including serious emotional distress. For over 100 days, most residents were confined to their rooms, and their unpaid caregivers (family and friends) were refused entry to CHSLDs to visit or continue to provide personal care for them. On March 14, 2020, the Quebec government declared a state of emergency prohibiting visits to all CHSLDs throughout Quebec. The lack of access to family and friends harmed the health, quality of life, and well-being of residents. It also caused emotional distress for caregivers, who had to face the impossibility of supporting them.

As we planned this study, we realized there was very little research about what CHSLD residents and their caregivers went through during the first two waves of the pandemic. To address this gap, we sought to better understand the challenges faced by residents and caregivers and gather the solutions they propose to enhance quality of life and well-being of residents and caregivers whether it be currently or in the future.

# OUR RESEARCH QUESTIONS



1. What type of challenges did CHSLD residents and caregivers face during the pandemic?

2. How did the CHSLD environment affect these challenges?

3. What solutions do CHSLD residents, and their caregivers have for improvement?

# HOW WE DID THE STUDY?

We used a qualitative approach, which means we focused on understanding people's experiences and perspectives. We organized focus group discussions and interviews to give residents and caregivers a chance to share these experiences and perspectives. During the interviews, we used photos to help them better describe their experiences and the solutions they proposed. We carefully analyzed the information to find common themes. Additionally, we reviewed reports and government documents to confirm or question our findings.

# STUDY PARTICIPATION SUMMARY

**17**

**Participants**
joined one of four focus groups, organized by role (residents or caregivers) and language preference (French or English).

Residents' ages ranged from 48 to 94 years, with their length of stay in a CHSLD ranging from 5 months to 29 years. Caregivers' ages ranged from 55 to 83 years, with their caregiving experience in CHSLDs ranging from 3 months to 21 years.

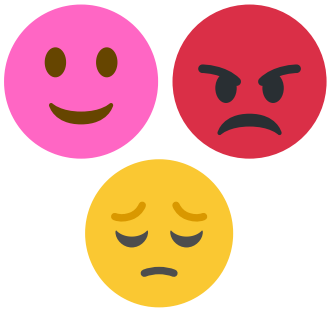
3 residents identified as men, and 3 as women while 2 caregivers identified as men, and 9 as women.

**13**

**Participants**
later participated in individual interviews in their chosen language (French or English).

# FOCUS GROUP AND INTERVIEW OBSERVATIONS

Most participants were pleased to take part in the study, even though sharing their experiences often brought up negative emotions like anger, sadness, or distress.



Some residents and caregivers raised questions about their participation, such as:

Did any of the focus group facilitators, note-takers, or interviewers work at the CHSLD where residents lived?

Was the study led by CHSLD administrators, and could they have hidden intentions, like controlling the results or retaliating against residents and caregivers?

## FOCUS GROUP AND INTERVIEW OBSERVATIONS

We repeatedly reassured these residents and caregivers that none of the researchers in this study worked at a CHSLD and that all that they shared would be kept confidential. Most participants talked about events that occurred during the first two waves of the pandemic, but also included those before and after that time. We noticed that the focus groups and interviews provided participants with a long-awaited opportunity to share frustrations they had been holding back about CHSLDs as well as the healthcare system.

## HOW WE ANALYZED THE DATA?

We conducted an initial analysis that led to common themes within each group for resident experiences, caregiver experiences, resident solutions and caregiver solutions. Afterwards we conducted a second analysis that led to themes common to both groups: common resident and caregiver experiences and common resident and caregiver solutions (Figure 1).

# SUMMARY OF COMMON THEMES: EXPERIENCES

The experiences residents and caregivers shared were overwhelmingly negative and profoundly poignant. These residents and caregivers suffered from or witnessed serious neglect and insufficient care of many types. The care provided was often described as cold and lacking kindness and compassion.

Many were afraid to speak up about problems because they feared punishment, and a few had even been subject to reprisals in the past. Both residents and caregivers were upset by the imposition of strict measures during the pandemic that led to inhumane and extreme isolation for residents and fear and distress for caregivers.

# SUMMARY OF COMMON THEMES: EXPERIENCES

They felt treated unfairly and subjected to a double standard compared to other members of society. Additionally, they were completely excluded from decisions that directly affected their lives in negative ways.

Most felt ignored and excluded by CHSLD staff, administrators, as well as society, although several recognized that a few CHSLD staff members provided important support during an extremely difficult time.

# SUMMARY OF COMMON THEMES: PROPOSED SOLUTIONS

While residents and caregivers spent more time sharing their experiences, they were deeply engaged in suggesting solutions.

These solutions included ensuring that:

- care is adequate, consistent, and humane;
- communication be frequent and clear; food be healthy, tasty, and respectful of cultural preferences;
- residents and caregivers be supported in building and maintaining meaningful relationships with others through improved physical spaces and the use of technology.

Finally, residents and caregivers must have a strong voice in decision-making processes that affect them (Figure 1).

# SUMMARY OF THEMATIC COMMONALITIES OF EXPERIENCES AND SOLUTIONS


*Figure 1*

# DISCUSSION

The experiences and solutions shared by both residents and caregivers showed two main issues at the heart of this study's recommendations: 1) ensuring CHSLDs provide meaningful personalized care and 2) giving residents and caregivers a strong voice and decision-making power in matters that affect them.

## 01. Ensuring CHSLDs provide meaningful personalized care

The care in many CHSLDs is mainly focused on medical treatments, which frequently leads to care that neglects the quality of life and well-being of residents and caregivers.

This creates a strict, task-focused system where rules and checklists appear to be more important than personalized care. Residents and caregivers are calling for a shift to a model that genuinely prioritizes their needs and experiences. They would like to see several improvements including the establishment of a minimum staffing rule to ensure that sufficient numbers of employees are available to provide adequate care. They also want a more personal and home-like environment, often referred to as a "milieu de vie," rather than an institutional one.

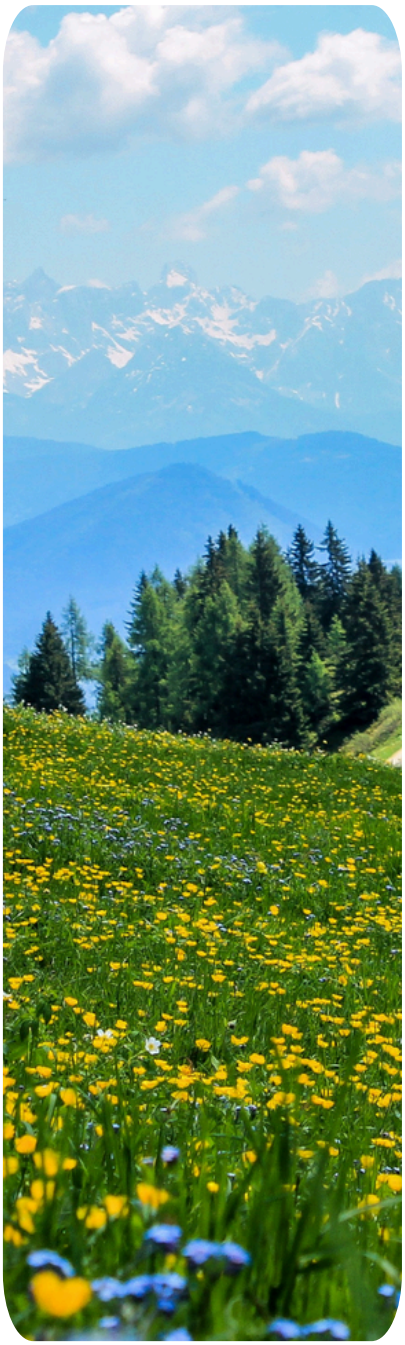
## 01. Ensuring CHSLDs provide meaningful personalized care

We need a social model of care that gives residents and caregivers the freedom to make choices, helping residents live in the best possible health, quality of life, and well-being while also supporting their caregivers. To meet residents' specific social needs, they should be grouped based on the presence or absence of a cognitive disability. Those residents who want to live independently in their own homes should be allowed and supported to do so. The healthcare system should promote inclusion, equity, and diversity while also providing personalized support for caregivers that considers their unique situations and abilities.

## 02. Representation and decision-making power

The intolerable and inacceptable experiences of residents and caregivers during the pandemic was due to the Quebec government's lack of preparation for such an emergency. Residents and caregivers had little to no say in decisions that affected them. Their voices were not heard. They believed that having been excluded from decision-making, before, during, and after the pandemic, led to many very serious problems. Policies that are overly controlling, combined with discrimination like ableism (discriminations against persons with disabilities) and ageism (discriminations against persons who are older), are largely to blame. Residents and caregivers want to obtain real decision-making power so they can make meaningful changes to improve their lives and whereby they no longer feel invisible. CHSLDs need better management to enforce important rules effectively and remove unnecessary or harmful ones. Resident committees need to be given authority to protect the rights and interests of residents and caregivers. In reality, the vast majority of these committees give an illusion of resident and caregiver involvement but instead serve as token gestures where residents and caregivers hold no real decision making power. Residents and caregivers also lack guaranteed representation at higher levels of institutional or government decision-making, leaving them without a voice where it matters most. They want a voice that counts.

# RECOMMENDATIONS



This report serves to address existing biases of ableism and ageism, among others, by promoting residents' and caregivers' voices that are seldom heard. The recommendations stemming from this report focus on solutions from the perspectives of CHSLD residents and caregivers. In particular, they propose taking clear and concrete steps to provide personalized care for residents, providing better support for caregivers, giving residents and caregivers a meaningful say in decisions that directly concern them. These sets of recommendations are based on the two emerging issues of this report, described above. Another set of recommendations outlines bringing about change through a structured approach to advocacy for achieving the first two sets of recommendations. The last set of recommendations addresses the need for more research and establishing research partnerships that includes the meaningful participation of residents and caregivers.

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