HQCA
Health Quality Council of Alberta

November 2021

The Lived Experiences of Residents in Designated Supportive Living

(January to March 2020)

The Health Quality Council of Alberta is a provincial agency that has a legislated mandate to promote and improve patient safety, person-centred care, and health service quality for Albertans. We engage with Albertans to gather information about their experiences and collaborate with Alberta Health, Alberta Health Services, and other stakeholders to identify and drive actionable improvements. Our responsibilities are set forth in the *Health Quality Council of Alberta Act.*

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About the Health Quality Council of Alberta (HQCA)

The Health Quality Council of Alberta is a provincial agency that brings together patients, families, and our partners from across healthcare and academia to inspire improvement in patient safety, person-centred care, and health service quality.

Acknowledgements

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Listening to the voices of residents who live in designated supportive living is critical to learning about how to improve their lives and experiences.

Stakeholders' support and residents' willingness to share their experiences made this study possible. We sincerely thank you for your invaluable contributions.

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STELLA'S STORY

Stella had been living in her rural Alberta home for many years with her beloved dog Buddy. She was diagnosed with Parkinson's, which her family doctor advised would compromise her movement over time, and urged her to consider moving to continuing care. After thinking it over, Stella decided to stay at home for as long as she could. Over time, her condition made it very hard to cook, clean, and walk up and down the steep stairs of her home. One day, she felt so unwell, she ended up in the hospital. While there, Stella came to the conclusion she could no longer live on her own, and she began the process of finding a continuing care living option. Stella wanted to stay in her home town close to family, and luckily a suite at one of the homes in her town was available within days of making the decision to move.

However, Stella was frightened about moving into continuing care, which she learned would happen within several days, giving her no time to mentally prepare or process the reality of the move. She had no previous experience with continuing care and did not know what to expect. At the same time, Stella found herself having to think about selling her home and about rehoming her dog because her new home would not accept him. This was a lot to take in, and she found herself grieving these losses.

When Stella moved into her new home, her first impression was that it was a terrible place to live. She did not know anyone, the sights and routines were unfamiliar, and she often got lost trying to get around. She missed being by herself with Buddy. Her family did their best to make the transition easier by helping her feel at home in her new surroundings by setting up her suite with her personal belongings and by visiting her. Her sister, who took ownership of Buddy, brought him often and they visited outside where there was a bench to sit on near a garden. The nurses also frequently talked with Stella about everyday things and asked her how she was doing, which made her feel cared for.

Stella eventually became comfortable living in her new home, but she experienced some difficulties, and some that continued. She found it hard to live with large numbers of people and the routines of her new home felt odd and uncomfortable. For example, she was not allowed to shower herself and was bothered when she realized a male staff member would assist her. She made it very clear that she would not accept help from a man with showering, and staff were quick to accommodate this. Despite these challenges, Stella appreciated that she got the help she needed through the care and services she received, and did not have to cook or clean. She enjoyed going to happy hour where live entertainment was a regular occurrence, and she gradually became friends with some of the residents she could relate to and joke with. Being looked after and creating friendships helped Stella to feel more content.

Over the years, Stella has become more comfortable in her home. She values the personal relationships she has developed with staff and her friends, and feels that staff take good care of her and help her when she needs it. What Stella continues to miss most is her dog, Buddy. Stella would love nothing more, especially as her health declines, than to have her beloved dog live in her suite and she has petitioned for it as a member of the Resident and Family Council. She hopes that it will be a possibility, even if it takes some time to happen.

BACKGROUND

In 2020, the Health Quality Council of Alberta (HQCA) conducted a study to better understand residents' experiences in designated supportive living in Alberta. The purpose was to understand what factors contributed to a more or less positive experience, and to explore if residents' experiences differed based on whether they lived in a high- or low-ranking site according to the Overall Care Rating the site received from the 2019 HQCA *Designated Supportive Living Resident Experience Survey*. This 2020 province-wide study was in follow-up to the 2017 HQCA *I'm Still Me: The Lived Experiences of Residents in Designated Supportive Living* pilot study that was conducted in the Calgary Zone, and confirmed the feasibility and value of conducting similar work across Alberta.

To explore residents' experiences, the HQCA conducted 27 in-depth interviews with residents from 18 designated supportive living sites across Alberta from January to March 2020. During the interviews, residents were asked to reflect on:

- Their experiences before, during, and after their move into designated supportive living;
- their lives at the present moment; and,
- whether their lived experience in designated supportive living aligned with their expectations.

The voices of these 27 residents provide valuable insights about how to improve the lives and experiences of residents in designated supportive living.

Interview participants were sampled to include men and women, younger (i.e., under 65 years of age) and older residents (i.e., 65 years of age and older), and residents who had lived in their designated supportive living home for varying lengths of time (i.e., 1 to 6 months, 7 to 18 months, and over 18 months). Designated supportive living sites were also sampled to reflect diversity in Alberta Health Services Zones, high and low site rank, and geography. More information about methods is in the Appendix.

WHAT WE LEARNED

Key findings were identified that provide a detailed understanding of residents' experiences and the factors that contributed to a more or less positive experience in designated supportive living, including:

1. Residents' experiences are generally similar.
2. Residents' expectations are linked to their lived experiences.
3. Moving to a new home is challenging.
4. Residents adjust at their own pace.
5. Common factors influence residents' experiences.

These key findings are detailed below. Residents' experiences are illustrated through direct quotes and examples that use pseudonyms. Opportunities for learning and improvement from residents' perspectives are also outlined as *paths to best experiences* throughout this report.

KEY FINDINGS

Finding 1: Residents’ experiences are generally similar

In general, residents shared similar experiences with respect to transitioning into and living in designated supportive living, regardless of age, sex, geographic location, site rank, and how long they lived in their home. In some specific instances, differences were present and are reported below where relevant.

Finding 2: Residents’ expectations are linked to their lived experiences

Residents’ expectations or beliefs about what life would be like in their new home in designated supportive living were formed in the following ways:

> **Values and aspirations.** Throughout their lives residents accumulated values and aspirations that informed how they wanted to live in their new home. For example, some residents wanted to pursue health and wellness goals or take part in activities consistent with their lifelong interests and values.
>
> **Past experiences.** Residents had former experiences with congregate care through either their work history, by visiting a family member or a friend in congregate care, or by previously living in a congregate care setting. Through these experiences, residents formed perceptions about designated supportive living that informed what they thought life would be like in their new home. For example, some residents thought the meals or the level of care they would receive, or the size of their suite would be similar to what they experienced in their previous congregate care home.
>
> **Information conveyed or endorsed by others.** Residents received information and service descriptions about their new home from family, sites, and healthcare professionals such as a social worker. This information was also presented in a positive manner. Residents accepted this information at face value, especially when they trusted the source, which created unrealistic expectations about what life would be like in their new home. These concerns related to descriptions about the size and layout of their suite and the quality of the meals and the dining service.

When residents moved into designated supportive living, they compared their expectations to their lived experiences, and then evaluated their current experiences using these expectations. In doing so, they determined if their expectations were either exceeded, met, or unmet. Notably, some residents did not have any expectations. How residents evaluated if their expectations were exceeded, met, unmet, or not present, is important because their evaluation impacted how they experienced their move into designated supportive living, adjusted to life in their new home, or their experience of the care and services provided. The interconnections between expectations and experience are illustrated below:

> **Exceeded expectations.** Residents’ expectations were exceeded when their lived experiences were better than expected. Most often, residents described their experiences positively because they moved into designated supportive living with low expectations. For

example, Norma expected the cleanliness of her new home and personal hygiene to be poor due to her past experiences visiting congregate care homes, but she was pleased this was not her experience.

> *"I expected it to be a hell of a lot worse, okay? I expected it to be like the old ones used to be, and I saw enough of them . . . the ones I knew, the place stunk. It smelled of urine . . . but it's not like that. I'm not like that, either . . . Even the shut-ins, you never smell them . . . It doesn't come out of there, because it isn't like that. They keep them scrupulously clean . . . You're clean and your clothes are clean." – Norma*

Met expectations. Residents' expectations were met when their lived experiences aligned with their expectations. For example, Ronald understood what his life would be like in designated supportive living because he had previously worked in congregate care. In circumstances such as these, residents described their experiences in generally neutral terms.

> *"I would say so, because it's assisted living. It's what I would think, yes . . . Because I was familiar with the atmosphere out there, of working at the hospital and the long-term care. I more or less knew what it would be here, you know?" – Ronald*

Unmet expectations. Residents' expectations were unmet when their lived experiences were worse than expected, and in this situation, residents were more likely to describe their experiences negatively. For instance, Cynthia expected the quality of care and services would be similar to what was provided in her previous congregate care home. Her expectations were also based on how the manager of her former home described the features and services of her new home. However, Cynthia's expectations were unmet because the meal quality and level of walking support was not the same. This made it difficult for her to adjust to her new home.

> *"I was told this was so wonderful. Oh, this was so great—not true . . . I expected to be able to walk around a little bit, like I did at [my previous home] . . . I'm just really discouraged here . . . Everybody had me convinced this was just such a beautiful place. I don't know where the beauty is or was . . . [the manager of my previous home] sugar-coated it way more than it was . . . I'm not happy here." – Cynthia*

No expectations. Some residents, particularly those who were older, did not have previously formed expectations about what their life would be like in designated supportive living. This happened if a resident had no previous personal experience with or limited knowledge about congregate care, and if their move was sudden or unexpected due to changes in their health. Under these circumstances, residents experienced anxiety because of the unknowns.

> *"I was scared. Excuse my French, but shitless, and I was coming from the hospital to here. 'What am I going into? What am I going to do? Are people going to be nice? Are they going to make fun of me?' So I had all that to think about." – Phyllis*

Overall, residents' experiences suggest that it is important to understand, set, and manage expectations before they move into designated supportive living to improve their understanding of what life in their new home will be like. This can be facilitated by healthcare professionals, such as transition or home care nurses, who support residents in arranging a place to live while in hospital or at home, and especially by site operators and staff who support residents during their transition by providing tours and meetings with residents and their family. In doing so, residents may experience less uncertainty or "surprises" from not knowing what life is going to be like and may improve the likelihood that their expectations will be met. Consequently, residents may have more positive experiences.

> *"I was told what was going on before I moved in. I had no surprises. I was told the way things are, like the time meals are, the room, the rules and regulations, and the building, it's like any place." – Matthew*

Paths to best experiences

- Understand, help set, and manage residents' expectations before they move into their new home.

Finding 3: Moving to a new home is challenging

Most residents felt it was challenging to move into designated supportive living for the reasons described below.

A sudden and major life event. Moving to a new home was often experienced as a sudden and major life event that residents were not always ready for. Some residents spent time considering changes in their health and the need for support, where they gradually accepted that they would need to move into designated supportive living, while others had not. Although some residents considered their circumstances and health changes, they were not always prepared for a sudden health decline that resulted in hospitalization and a necessary transition into a congregate care home.

> *"I couldn't live at home anymore. Because I couldn't handle it. But I stayed home as long as I could. My doctor kept telling me that I better think about it. And I did . . . But then I ended up . . . in the hospital." – Eleanor*

Lack of choice in a new home. When a decision had been made to move into designated supportive living, residents reported that there were limited housing options to choose from, and in some circumstances, only one option was available. This was especially true for residents in rural locations who reported limited and less desirable options, such as having to live in a hospital unit.

> *"It was either here or [city], and there's no way I want to move to [city]. I'm a [region] person. Moving to [city]...I don't know what that would do to me." – Kimberly*

Lack of knowledge about their new home. Primarily older residents felt they lacked information about their new home and an orientation to their new living environment. For example, they did not know how long it would take to receive their meals, what the meals looked like and how much would be served, and that the quality of the meals would differ from their own cooking. Further, residents were unaware of what amenities and transportation were available, or how to get around the building without getting lost. Lack of information made residents experience moments of fear, stress, uncertainty, disappointment, and confusion. In general, residents who felt they lacked information about their new home lived in low-ranking sites.

> *"Nobody told me anything. I don't know how [living at this place] works . . . I just watched to see how people...because a lot of them . . . have been in here for [a number of] years already." – Eleanor*

Loss and change. When residents reflected on moving into their new home, they discussed what they missed about life in their past homes, such as being near trees or walking trails. Older residents who had more recently moved into designated supportive living were most likely to grieve the loss of their previous home and the space and privacy it afforded them.

> *"It was pretty bad. I lived [in a place] for many years, and lots of trees and just different, different lifestyle than here . . . I had my own place and I loved it, you know? By myself, just me and my dog . . . It was the life. I miss my place. I had it all." – Shirley*

Regardless of these challenges, residents reported their move was easier when they were supported by:

Staff. Residents appreciated it when staff made them feel cared for by being welcoming and social, and helping them to get around their new home. Men especially valued staffs' helpfulness, while women appreciated the way staff treated and interacted with them.

> *"They take care of me . . . they're very patient . . . not overbearing and sarcastic. I was scared. "What am I getting into?" Then I was afraid I'd die. I wanted to die, because I'm just a burden to somebody. But . . . the nurses care." – Phyllis*

Family. Residents, particularly those who were older and living in urban locations, reported that their family helped them set up their suite to make it feel more like home. They also helped them cope by visiting regularly and providing emotional support.

> *"[My family] brought me here . . . and kept coming back and looking after me . . . They knew I couldn't cope, when I first came in here . . . it made the transition much easier for me." – Norma*

Paths to best experiences

- Provide residents with information about, and an orientation to, their new home such as:
    - what the quality, presentation, and portions of the meals are like
    - where to go for meals and when mealtimes are
    - what the policies or rules are (e.g., mattresses, pets)
    - what amenities are available (e.g., kitchen, exercise room)
    - whether or not their suite is furnished
    - what local businesses are available (e.g., grocery store)
    - what transportation is available
    - how to get around their new home

- Acknowledge the loss and hardship residents may experience when moving into their new home.
- Be kind, welcoming, and helpful to residents when they move into their new home.

Finding 4: Residents adjust at their own pace

Residents described experiences with adjusting to, or becoming comfortable with, life in designated supportive living. From these descriptions, it was recognized that residents adjusted at their own pace, as some settled in more easily than others. Residents described the following factors that influenced their ability to adjust:

Accepting and managing change. Residents adjusted more easily when they coped well with change, perceived personal benefits to moving into designated supportive living such as having meals cooked for them, or recognized they needed more support and accepted that they would benefit from the transition as a whole.

> *"I was ready. Well, you figure stairs at the old place. I was just tired . . . I had no problems coming into the place and adjusting." – Nancy*

Living life in familiar ways. Residents were able to adjust well when they could continue, as much as possible, to live their life in their new home in familiar ways. This involved being engaged in meaningful activities that reflected their personality and passions, and lifelong habits like smoking, cooking, or daily bathing. Being able to maintain freedom, choice, and a desired degree of independence was also important, especially for older residents. For these reasons, residents appreciated access to home-like amenities like a kitchenette, and women valued being able to personalize their suite. Residents were also pleased when staff treated their suite as their home and treated them "like an individual", respecting their preferences and routines. However, residents adjusted less well when they were unable to live their lives in familiar ways. For instance, older residents struggled when they lost independence and became more reliant on staffs' help especially for bathing. Some residents in low-ranking sites desired more privacy as they wanted staff to ask for permission before entering their suite. Lastly, women in particular wanted to live with their pets.

> *"They treat you like an individual . . . I go outside when I want, smoke with my group there . . . just things like that that are important to you . . . they let you be yourself. You don't have to fit into any mold or this kind of thing." – Carol*

> *"I'm not allowed to have a shower on my own . . . It took me a long time to adjust to that . . . I had no objection to my [spouse] seeing what I was in or not in . . . but I don't feel that way about somebody else coming into my room, especially of the opposite gender. I find that very difficult to have." – Raymond*

Having a sense of community. Residents adjusted better if they felt part of their home's community and developed meaningful connections and friendships with residents and staff. This was particularly important for women as they valued being able to relate to, and laugh and joke with, others. However, residents struggled to adjust if they were unable to connect to or develop friendships with other residents and staff.

> *"They [staff] like my warped sense of humour . . . We just goof around lots . . . It helps me keep a positive attitude towards myself and everyone else." – Kimberly*

Living in congregate care. Most residents felt it was difficult to adjust to life in congregate care as they had to learn new routines and adapt to the scheduling of care tasks, mealtimes, staff shifts, and figure out how to navigate differences in staff personalities. They also had to learn to live with other people and become accustomed to less privacy, as many residents were used to living alone. For example, older residents who had recently moved into their new home were more likely to feel discomfort and fear when staff, and other residents with varying mental capabilities, came into their suites uninvited. Their entry invaded their privacy and made them feel unsafe. Residents adapted by closing and locking their doors, which was not always comfortable for them. Some residents felt safer over time because they became more familiar with and trusting of staff and other residents who came into their suites.

> *"You got to get used to the system . . . You gotta adjust to a time schedule, [and] to the shifts, [and] the way you feel about different people." – Eleanor*

Feeling trapped and isolated. Some residents living in rural locations experienced difficulties adjusting when they felt trapped and isolated within their new home. In particular, their new home's location was far from family, in an isolated location, or lacked transportation options to recreational activities, community outings, or to appointments.

> *"It's like if you've been in jail, if you can't get out." – Phillip*

Paths to best experiences

- Consider offering a variety of activities that best reflect residents' personalities and passions.
- Support residents to maintain their lifelong habits, and consider their desired level of freedom and independence.
- Support residents to feel at home through personalization of their suite and ask permission to enter their suite.
- Facilitate opportunities for residents to meet and socialize with each other and staff.
- Help residents become familiar with their new home and how to access transportation.

Finding 5: Common factors influence residents' experiences

Many of the residents interviewed had lived in their home for some time, from at least three months to over ten years, and thus were able to reflect on what life was like for them in the present. In these reflections, residents discussed what factors contributed to a more or less positive experience as they settled into life in their home. Residents' experiences were more positive when they had:

Personal relationships with staff. Residents appreciated friendly, patient, and cheerful staff who socialized, listened, and respected their choices. Women especially liked it when staff took a personal interest in their lives, while men valued when staff were easy to get along with.

> *"They're all really super nice, and they listen to you, and they care about what you're saying." – Denise*

Timely and proficient care. Residents felt it was important that they receive gentle, unrushed, and timely care that skillfully met their needs and accommodated their preferences.

> *"When I need them [staff], they're here for me." – Carol*

A home environment. Residents valued a home-like environment that was spacious, clean, scent free, and provided access to areas they enjoy such as an exercise room, a library, and a garden. Cleanliness of their suite and home was most important to older residents.

> *"Well, we have a sunroom . . . There is the library . . . Of course we have an activity room . . . It's really nice. They have nice chairs to sit in and so on." – Lois*

Engaging activities and opportunities for socialization. Residents appreciated access to a variety of activities and social opportunities that were consistent with their personal preferences, provided enjoyment, and ways to connect and sustain their relationships with other residents.

> *"[The Director of Activities] arrange bus trips, and there will be games downstairs a lot of days . . . There will be barbecues in summer . . . There's always something new." – William*

In contrast, residents identified common opportunities for improvement that included:

The meals and the dining experience. Residents felt the meals and dining service did not always align with their preferences. Specifically, they did not always like what food was served and how often. Residents, particularly from low-ranking sites, wanted the meals to: incorporate more fresh and nutritious foods; be tastier, appropriately seasoned, and served at a hotter temperature; and, be larger portioned. Older residents expressed the desire for meals to be plain, well cooked, and appropriate for diabetics. Older residents, mainly from low-ranking sites, felt the dining experience was not home-like because meals were scheduled at set times, seating was assigned, and meals were pre-plated. A few residents wanted to be able to serve themselves from a buffet, which would enable them to pick their portion size and pick from an array of food options.

> *"Old people, as a rule, don't like modern food, so why do they force them to eat it?" – Phillip*

Maintenance of autonomy. Residents were not always able to maintain autonomy in their life in the ways they wanted. Some residents were frustrated when they were unable to choose their own mattress or were required to purchase a hospital bed out-of-pocket. Being able to replace their mattress was important because the mattress provided by their home was uncomfortable and impacted the quality of their sleep. Older residents from low-ranking sites felt it was most important to have their own mattress. Further, some residents were unable to self-administer medications or were required to use their home's pharmaceutical provider instead of a more affordable and trusted local pharmacy, which made them feel that they lacked autonomy. Using a local pharmacy was most important for rural residents.

> *"At this place, you either have to go through their drugstore, the one that they believe in, or nothing. You don't get a choice. For me to take my pack and say, 'Could you put these in at certain times?' the times are the same as theirs for meals— nope. As long as you have a drugstore that is not their drugstore . . . they won't help you . . . [I wish they would let] us use our pharmacies here in the [rural town]. There's nothing wrong with them . . . if it was involving my pharmacist, I would be a lot more trusting of the prescriptions and so on, definitely." – Katherine*

Addressing concerns and feedback. Residents, especially from low-ranking sites, did not always feel safe and comfortable voicing their concerns, and felt that when they did express their concerns they were not addressed, or addressed in a timely manner. Older women were especially hesitant to express their concerns as they feared reprisal against themselves and staff. For example, Shirley questioned the purpose and effectiveness of the Resident and Family Council because the concerns raised at the meetings went unaddressed, and she reported that residents do not express their concerns to management because they "take it out on the staff."

> *"We have a meeting . . . I went for the first [number of] months. I never went back, because nothing happens. Nothing ever happens, on anything that the residents bring up, ever . . . If you do say something to them, they can make it pretty ugly for some of the staff. They take it out on the staff. That's the way it is, so we don't say anything."*
> *– Shirley*

Paths to best experiences

- Be patient, caring, respectful, and sociable towards residents.
- Provide timely, gentle, and unrushed care that addresses residents' health needs.
- Provide a warm, clean, and scent-free living environment.
- Consider ways to align meals with resident preferences and improve variety.
- Consider alternative serving styles and allow residents to choose their tablemates.
- Consider ways to maintain residents' autonomy in the ways they feel are important.
- Support a safe and comfortable space where concerns and feedback are welcomed and responded to.

CONCLUSION

The key findings from this study revealed opportunities to facilitate more positive experiences throughout residents' transition into designated supportive living and beyond. It is important for healthcare professionals such as transition or home care nurses, and especially site operators and staff who are involved during residents' transition, to better support residents understanding about what life will be like in designated supportive living. This involves understanding, setting, and managing expectations with residents before they move into their new home. Site operators and staff can provide residents with an orientation, and be kind and welcoming towards them when they move in, to help them feel supported in their new home. During this transition, it is important that staff personalize the support that is offered to help residents adjust in the ways that are meaningful to them. This personalization involves helping residents to live their life in familiar ways, meet and socialize with staff and residents, and become familiar with their new home and community. Further, site operators and staff can facilitate more positive experiences by helping residents develop personal relationships with staff, and providing timely and proficient care, a home-like environment, and meaningful social activities. Residents' experiences can also improve by providing meals that align with their preferences, helping them to maintain their autonomy, and listening to and addressing their concerns.

These interviews with residents revealed that understanding and honouring each resident as a person, through the ways of being and living that are important to them, matters most to their experiences. This finding is consistent with the 2017 HQCA *I'm Still Me: The Lived Experiences of Residents in Designated Supportive Living* pilot study, which found that residents' experiences were more positive when they felt their personal interests, lifestyles, and expectations were preserved. Overall, by better understanding residents' experiences, leaders, operators, and staff can learn how best to support residents as individuals throughout their entire designated supportive living journey.

APPENDIX

Method

In 2020, the HQCA conducted a study to gain a deep understanding of residents' experiences in designated supportive living in Alberta. This 2020 province-wide study was in follow-up to the 2017 HQCA *I'm Still Me: The Lived Experiences of Residents in Designated Supportive Living* pilot study that was conducted in the Calgary Zone, and confirmed the feasibility and value of conducting similar work across Alberta. Prior to the start of the study, an ethical review was conducted with the Alberta Innovates' A Project Ethics Community Consensus Initiative (ARECCI) Ethics Guideline Tool and by an independent ARECCI second-opinion reviewer.

Twenty-one designated supportive living sites were purposively sampled to reflect diversity in Alberta Health Services Zones, geography, and high and low site rank according to the Overall Care Rating the site received from the 2019 HQCA *Designated Supportive Living Resident Experience Survey*. This question asked residents '*using any number from 0 to 10, where 0 is the worst and 10 is the best, overall what number would you use to rate your home*?' Using responses to this question, a list of sites by Overall Care Rating rank was prepared, and sites at the top were identified as high-ranking and sites at the bottom were identified as low-ranking. Sites did not participate if competing initiatives were underway.

A contact at the selected sites was asked to confirm a list of all residents eligible to take part in an interview. Residents were eligible to participate if they: lived in designated supportive living levels 3 or 4; had a Cognitive Performance Score less than 4; were able to communicate in English and take part in a 60-to-90-minute interview; and, did not have a personal directive enacted.

From this list, participants were purposively selected to reflect diversity among men and women, younger and older residents (i.e., younger defined as under 65 years of age and older defined as 65 years of age and older)[1], and length of stay in designated supportive living (i.e., 1 to 6 months, 7 to 18 months, and over 18 months)[2] until a minimum of one to a maximum of three residents were recruited.

Using contact information that was provided by sites, selected eligible residents were invited by the HQCA to participate in an interview via a mailed invitation (Figure 1) and information letter (Figure 2) that explained the study. The information letter outlined the purpose of the study, the risks and benefits of their participation, the steps taken to protect their confidentiality and anonymity, how their information would be used, and when their information would be destroyed. In this letter, residents were also invited to include a family member or a trusted person in their interview if they wished, but were informed the focus of the conversation was their experience. If residents wished to participate, they were encouraged to contact the HQCA interviewer directly by phone to schedule

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[1] Younger residents were sampled in addition to older residents to better reflect and understand residents' experiences in designated supportive living, rather than solely reflect the experiences of older residents.

[2] Residents who lived in their home for different lengths of time were sampled to better understand residents' transition experience into designated supportive living. Length of stay groupings were developed using information collected from the 2016 HQCA *Designated Supportive Living Resident Experience Survey* and the 2016 HQCA *Designated Supportive Living Family Experience Survey*.

a date and time for their interview at their convenience. If after 10 days residents did not make contact with the HQCA interviewer, the HQCA interviewer followed-up by phone to determine their interest in participating.

Recruitment and interviewing took place between January and March of 2020. In total, 27 residents took part in an interview, from 18 designated supportive living sites across Alberta. One family member was present at an interview with a resident. Twenty-three interviews were conducted in-person and four by telephone. Table 1 and Table 2 detail the participating site and resident characteristics, respectively. To protect anonymity, participating sites and residents are not named.

Table 1: Participating site characteristics

Zone	Geography		Rank	
North (N=4)	Rural (N=2)	Urban (N=2)	High (N=2)	Low (N=2)
Edmonton (N=3)	Rural (N=0)	Urban (N=3)	High (N=2)	Low (N=1)
Central (N=4)	Rural (N=2)	Urban (N=2)	High (N=2)	Low (N=2)
Calgary (N=3)	Rural (N=1)	Urban (N=2)	High (N=1)	Low (N=2)
South (N=4)	Rural (N=2)	Urban (N=2)	High (N=2)	Low (N=2)

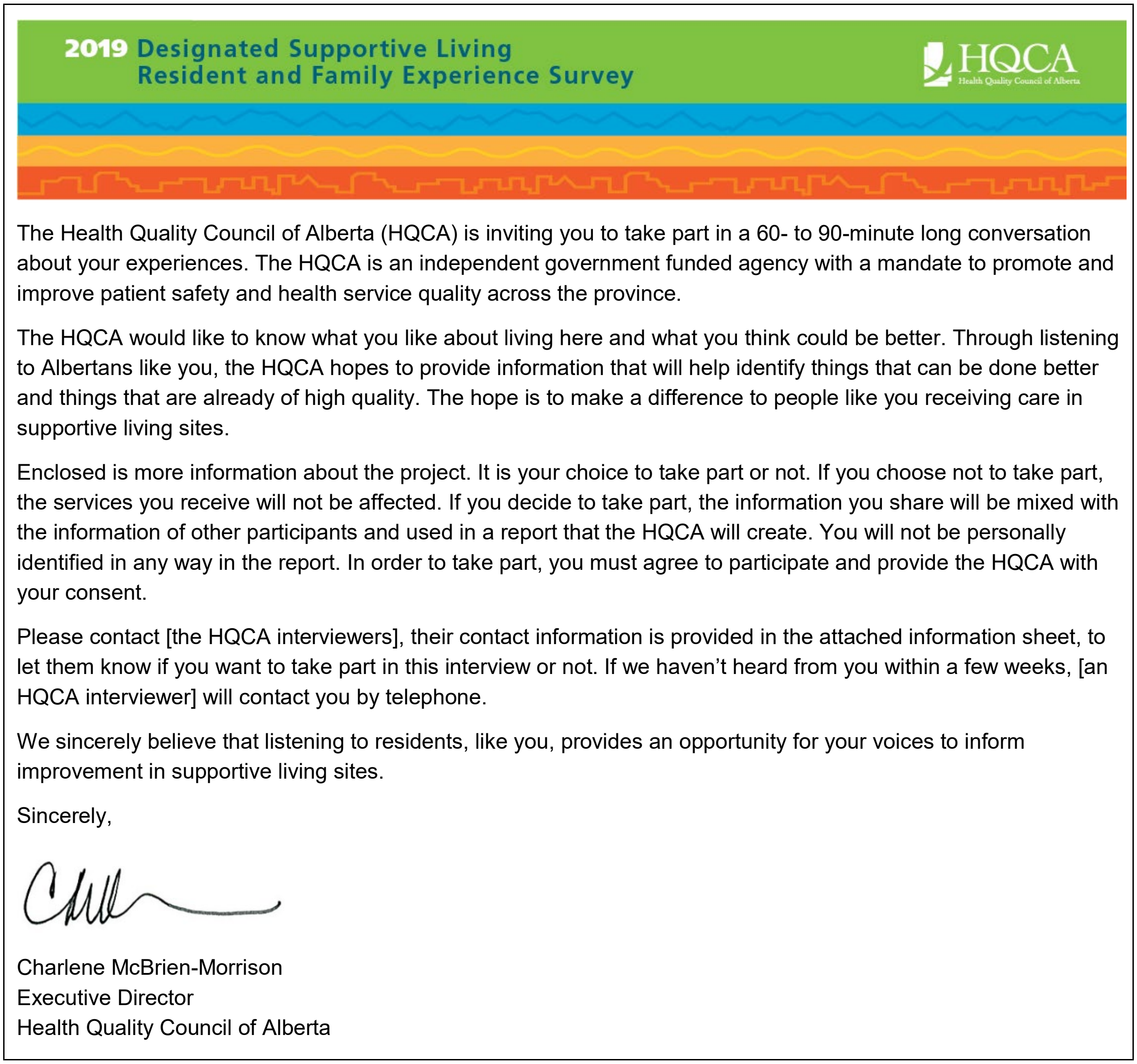
Table 2: Participating resident characteristics

Age		Sex		Length of stay		
Older (N=20)	Younger (N=7)	Women (N=17)	Men (N=10)	1 to 6 mos. (N=7)	7 to 18 mos. (N=8)	>18 mos. (N=12)

At the start of each interview, the information letter was reviewed with participants and informed consent obtained. During the interviews, residents were asked to reflect on their experiences before, during, and after their move into designated supportive living, their lives at the present moment, and whether their lived experience in designated supportive living was consistent with their expectations. The semi-structured interview guide (Figure 3) was informed by the 2017 HQCA *I'm Still Me: The Lived Experiences of Residents in Designated Supportive Living* pilot study's interview guide, stakeholder feedback, literature on resident experience and quality of life in continuing care, and the HQCA's Patient and Family Advisory Committee.

On average, interviews took 62 minutes to complete. Most interviews were audio recorded with permission from the resident. In a few cases, notes were taken when a resident did not consent to be audio recorded. Audio recordings and notes were transcribed and analysed to identify themes that described residents' experiences. Two HQCA Senior Analysts independently coded and analyzed the transcripts and engaged in a process to achieve agreement to ensure validity of the findings. Themes were then reviewed in detail to assess whether there were meaningful differences in experience based on where residents lived with respect to Alberta Health Services Zone, geography, site rank, and resident characteristics including age, sex, and length of stay. Differences were determined to be meaningful when participants from a particular group discussed their experiences in a similar way. Where relevant, the meaningful differences that were found in experiences are reported.

Figure 1: Invitation to participate



2019 Designated Supportive Living
Resident and Family Experience Survey

HQCA
Health Quality Council of Alberta

The Health Quality Council of Alberta (HQCA) is inviting you to take part in a 60- to 90-minute long conversation about your experiences. The HQCA is an independent government funded agency with a mandate to promote and improve patient safety and health service quality across the province.

The HQCA would like to know what you like about living here and what you think could be better. Through listening to Albertans like you, the HQCA hopes to provide information that will help identify things that can be done better and things that are already of high quality. The hope is to make a difference to people like you receiving care in supportive living sites.

Enclosed is more information about the project. It is your choice to take part or not. If you choose not to take part, the services you receive will not be affected. If you decide to take part, the information you share will be mixed with the information of other participants and used in a report that the HQCA will create. You will not be personally identified in any way in the report. In order to take part, you must agree to participate and provide the HQCA with your consent.

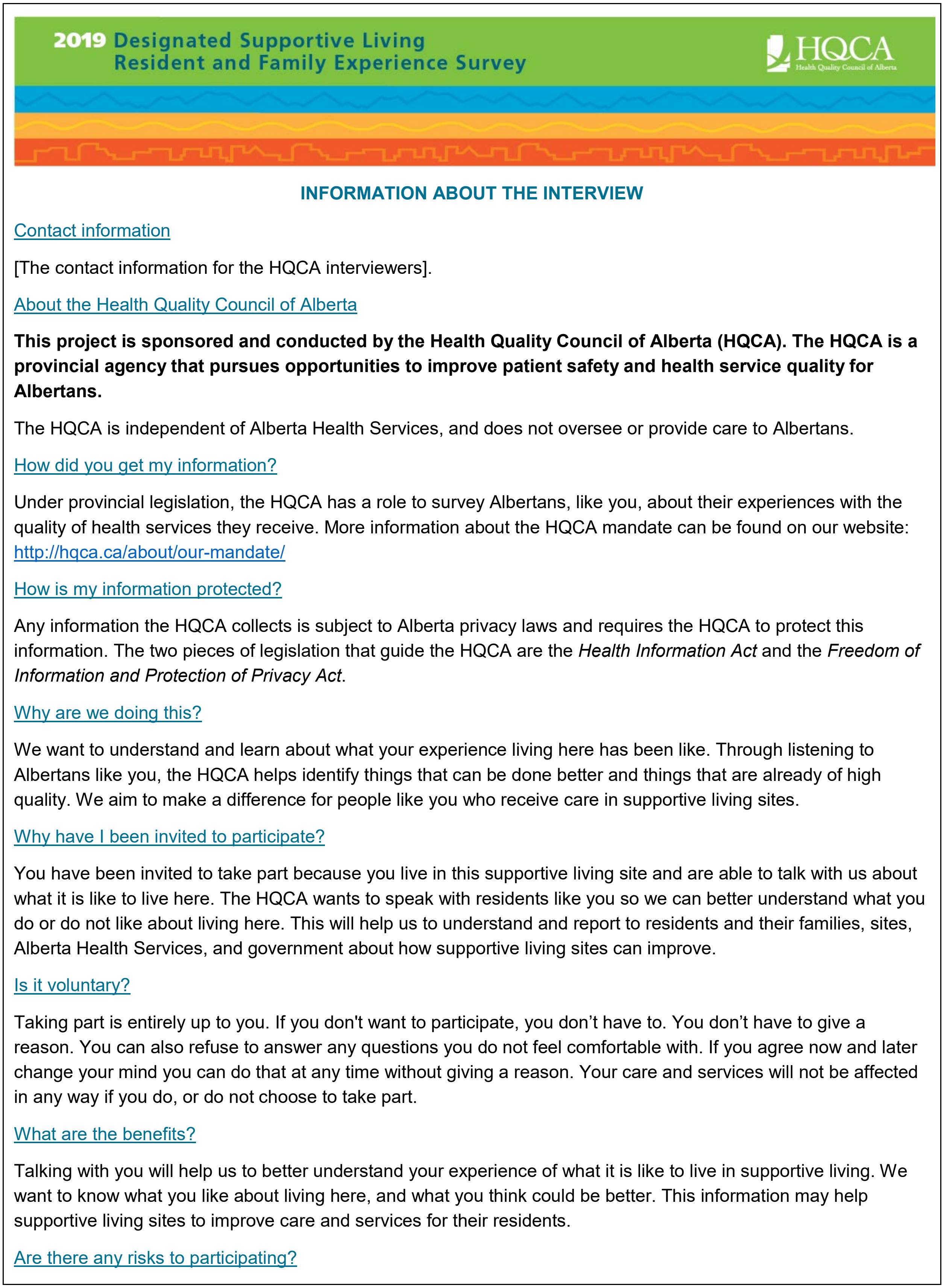
Please contact [the HQCA interviewers], their contact information is provided in the attached information sheet, to let them know if you want to take part in this interview or not. If we haven't heard from you within a few weeks, [an HQCA interviewer] will contact you by telephone.

We sincerely believe that listening to residents, like you, provides an opportunity for your voices to inform improvement in supportive living sites.

Sincerely,

Charlene McBrien-Morrison
Executive Director
Health Quality Council of Alberta

Figure 2: Information sheet



2019 Designated Supportive Living
Resident and Family Experience Survey

HQCA
Health Quality Council of Alberta

INFORMATION ABOUT THE INTERVIEW

Contact information

[The contact information for the HQCA interviewers].

About the Health Quality Council of Alberta

This project is sponsored and conducted by the Health Quality Council of Alberta (HQCA). The HQCA is a provincial agency that pursues opportunities to improve patient safety and health service quality for Albertans.

The HQCA is independent of Alberta Health Services, and does not oversee or provide care to Albertans.

How did you get my information?

Under provincial legislation, the HQCA has a role to survey Albertans, like you, about their experiences with the quality of health services they receive. More information about the HQCA mandate can be found on our website: http://hqca.ca/about/our-mandate/

How is my information protected?

Any information the HQCA collects is subject to Alberta privacy laws and requires the HQCA to protect this information. The two pieces of legislation that guide the HQCA are the *Health Information Act* and the *Freedom of Information and Protection of Privacy Act*.

Why are we doing this?

We want to understand and learn about what your experience living here has been like. Through listening to Albertans like you, the HQCA helps identify things that can be done better and things that are already of high quality. We aim to make a difference for people like you who receive care in supportive living sites.

Why have I been invited to participate?

You have been invited to take part because you live in this supportive living site and are able to talk with us about what it is like to live here. The HQCA wants to speak with residents like you so we can better understand what you do or do not like about living here. This will help us to understand and report to residents and their families, sites, Alberta Health Services, and government about how supportive living sites can improve.

Is it voluntary?

Taking part is entirely up to you. If you don't want to participate, you don’t have to. You don’t have to give a reason. You can also refuse to answer any questions you do not feel comfortable with. If you agree now and later change your mind you can do that at any time without giving a reason. Your care and services will not be affected in any way if you do, or do not choose to take part.

What are the benefits?

Talking with you will help us to better understand your experience of what it is like to live in supportive living. We want to know what you like about living here, and what you think could be better. This information may help supportive living sites to improve care and services for their residents.

Are there any risks to participating?

There are minimal known risks, interviews are a common way of finding out about people's experiences. If at any time anything we talk about is upsetting to you, we can take as many breaks as you need, change the subject, or stop the conversation.

All information about you will be kept completely confidential.

If you choose to take part, you will receive a small honorarium for your participation in the interview.

What do I need to know about confidentiality and anonymity?

All information about you or anyone else that you speak about will be kept completely confidential. Results from this project may be used in reports, presentations, or publications that the HQCA will create about what it is like to live in supportive living in Alberta. No names or identifying details from the interviews will be included.

No one involved with your care will have access to what you say during the interview.

It is important for you to know that the HQCA cannot guarantee your anonymity when we are at your site speaking with you. For example, a staff member may witness an interviewer enter your room or may enter the room while the interviewer is present. If you agree to participate we would like to schedule our conversation at a time of day that you are not expecting to receive care to protect your anonymity.

Once we have had our interview, only HQCA staff who are working on this project will have access to the information you share. Any information that [the HQCA interviewers] collect from you will be kept secured at the HQCA office and will be destroyed after the project is complete in the following order:

- three months for audio recordings,
- two years for written documentation, and
- five years for anonymized electronic interview data.

In accordance with the Alberta *Protection for Persons in Care Act* we are legally obligated to report any abuse or neglect, which we are informed about, to the appropriate authorities.

What do I need to do?

1. You can ask [names of HQCA interviewers], the HQCA staff members that will be doing the interviews, any questions you may have.
2. If you choose to take part in an interview let [an HQCA interviewer] know (see contact information at the top of the first page). We will arrange a date to interview you at a time that is convenient for you.

If you do not want to be interviewed at your site, [the HQCA interviewer] can meet you at another location that is preferable to you ([the HQCA interviewer] cannot drive you anywhere).

If you agree to participate, you will need to sign a consent form at the time of the interview, which is a form that lets us know you agree to take part.

With your permission, [the HQCA interviewer] will audio record the conversation and type it out later so that they can give you their full attention during the interview without having to take notes. If you would like to participate, but don't want to be recorded, please let [the HQCA interviewer] know and they will take notes during the interview instead.

If you would like to take part please contact [an HQCA interviewer] who are listed on the first page of this document.

If we haven't heard from you within a few weeks, [an HQCA interviewer] will contact you by telephone.

Figure 3: Interview guide

Resident Experiences of Designated Supportive Living – Interview Guide

1. Tell me about how you came to live at this place?
    - Did you choose this facility (and why/why not)?
2. How would you describe your first few days or nights living here?
    - What made it easier for you to move into this place?
    - What made it difficult for you to move into this place?
    - What do you think would be helpful to other residents when moving in?
    - What is/was it like adjusting to live here?
3. [Now that you're living here…] What makes up a good day? What makes up a not so good day?
    - All probe questions related to activities, food, receiving help, relationships and environment.
4. What in your opinion, does this place do well here?
    - What do you like about living here?
    - What would you not want to change?
    - If relevant: all probe questions related to activities, food, receiving help, relationships & environment.
5. What in your opinion, do you think this place could improve?
    - What do you dislike about living here?
    - If there was something you could change about this place, what would that be?
    - If relevant: all probe questions related to activities, food, receiving help, relationships and environment.
6. [We talked about your experiences living here…] Is it what you expected? If not, why not?
    - How did your life change since becoming a resident here?
    - Was there anything different than you expected when you moved in?
    - Was there anything that surprised you about living here?
7. Is there something I've missed that you would like to discuss?
8. Would you like to ask me any questions?

Limitations

A primary limitation with this study is resident recruitment. Originally, this study aimed to interview 40 residents evenly from each Alberta Health Services Zone, site rank, and geographic location. However, due to the COVID-19 pandemic, 13 interviews that were scheduled to be completed were cancelled because of restrictions implemented within continuing care to keep residents safe. Further, it was recognized that the context of residents' lives had shifted considerably because of the COVID-19 pandemic and would impact their experiences in designated supportive living. The 27 completed interviews were analyzed, and it was determined that saturation of themes was achieved, resulting in the close of the study. Another limitation was that few differences were found among resident experiences. There are some possible reasons for this:

- The scope of the study regarding understanding residents' experiences and the interview guide resulted in broad descriptions of experience that made it difficult to identify patterns and differences.
- Multiple eligibility criteria for sites and residents were used to select participants which may have made it difficult to detect meaningful differences among residents.
- The categories of Alberta Health Services Zone and site rank may have not been meaningful to participants, and thus, lacked sensitivity to pick up differences in residents' experiences.
- The small number of younger residents participating in this study may account for this study's inability to identify differences in experience between young and older residents. As such, further study about the experiences of younger residents in designated supportive living is needed.
- Most, if not all, participants were Caucasian, which may help to explain the similarity in experiences.

HQCA
Health Quality Council of Alberta

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