

# Manor Transition Initiative: Outcomes and Evaluation Year One

Shirmin Bintay Kader, Alexis Cook, and Isobel M. Findlay



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# **EXECUTIVE SUMMARY**

Since the Second World War, there has been a notable shift toward embracing the principles of normalization, respecting the rights of people living with disabilities, and ensuring they enjoy the conditions, choice, and opportunities that the rest of society expects. This paradigm shift in thinking brought about a substantial transformation in the housing, caregiving, and support of individuals with intellectual disabilities, moving them from institutional or congregate settings to community-based homes. Broadly, this movement subscribes to a social or community inclusion model of disability affirmed in the first article of the United Nations (2006) Convention on the Rights of Persons with Disabilities and ratified by Canada in 2010.

A growing body of research has shed light on the benefits of community-based living arrangements resulting in a significant improvement in individuals' quality of life (QoL) and functioning. Studies have found that various factors, including age, medical diagnoses, family connections, and behavioural issues, influenced the timing of individuals' moves. Carefully considering individuals' characteristics and needs at the beginning of deinstitutionalization planning and the flexible timing of community transitions are essential. As part of its commitment to community-based service delivery, Elmwood Residences Inc. in partnership with the Ministry of Social Services, Community Living Service Delivery (CLSD) is closing Kinsmen Manor and moving over three to four years to a community-based home model in which residents live together in groups of four. The move is motivated by (a) best practice literature for residential service delivery showing improved health and well-being outcomes for residents and (b) aging infrastructure that no longer meets individual resident physical needs.

The move from the congregate setting to a community-based living model offers an important research, policy, and practice opportunity to fill gaps in knowledge:

- To examine the impact of living arrangements on people living with intellectual disabilities
- To examine the change in quality of life experienced by residents as a result of the move
- To understand the process by which the change in quality of life occurred
- To provide data to help policy and program further improve quality of life outcomes
- To establish baseline data and quality of life indicators in year one in support of a longitudinal pre-and post-transition study

The study methodology co-designed with the Research Advisory Group and input from self-advocates involved in-depth interviews with both residents and non-residents (family, support persons, staff, board members, and other key stakeholders) before and after transition to ensure that the voices of those most affected by the transition are heard and that their experiences, hopes, and concerns are at the forefront of the study.

## Quality of Life (QoL) for People with Intellectual Disabilities

The World Health Organization (WHO) defines QoL as an individual's perception of their life within their value systems and cultural context. QoL is an **essential indicator of social care outcomes** for adults with intellectual disabilities (ID). However, assessing QoL can be challenging for those with disabilities as they often depend on others for their care. A comprehensive framework identifies key factors and domains for evaluating QoL, encompassing **personal development**, **self-determination**, **interpersonal relationships**, **social inclusion**, **rights**, **emotional well-being**, **physical well-being**, and **material well-being**. Individuals with intellectual disabilities often experience lower QoL due to factors such as **discrimination**, **limited access to education**, and **social exclusion**. Recognizing QoL as a fundamental aspect of human rights is advocated to safeguard their rights.

Studies began showing that transitioning to community-based homes could substantially improve QoL for persons with ID, **including increased freedom, improved living environments, better staff support, frequent family visits, and enhanced community integration**. Furthermore, behavioural indicators improved, self-harming behaviours reduced, and staff turnover decreased, positively affecting individual's lives. However, some challenges remain, including availability of day programs, nighttime staff, outings, and access to essential therapists and to family visits. **Selecting compatible housemates** and **ensuring ongoing support** is crucial.

## **Year One Findings from Non-resident Interview Respondents**

Sixteen non-resident interviews reported on the living arrangements at Kinsmen Manor and their impact on the QoL of residents under the eight domains. Four major themes emerged: non-resident perception of QoL indicators, ongoing challenges to QoL, QoL in a congregate setting, and the impact of a community-based home on QoL. Respondents emphasized that measures of QoL can vary from person to person, but the most important factors generally included **social inclusion**, **recreational activities**, **choice**, **autonomy**, **and independence**, and **health & safety**.

Respondents emphasized the importance of **social inclusion**, highlighting the significance of friendships, positive relationships with staff and caregivers, independence, participation in outings

and activities, and consistent staff support. Building **rapport and respect** between staff and residents is critical.

Respondents also highlighted the importance of **recreational activities** as a key indicator of QoL, connected to social inclusion. They emphasized the need for personalized programming and involving residents in group and community activities. Both family members and staff stressed the significance of **community involvement** for socialization, promoting interactions with others rather than passive engagement. Additionally, promoting **independence** and **social engagement** through community outings, games, and concerts was considered essential for resident well-being and sense of belonging.

Choice, autonomy, and independence were also considered important QoL factors. Respondents stressed resident ability with support to choose and decide for themselves, including the ability to leave the facility and choose their own activities and meals, which the congregate setting may challenge. Routine and predictability, such as work schedules, were seen as essential for promoting a sense of control and well-being.

**Health & safety** emerged as a critical indicator of QoL according to many respondents. They emphasized the importance of ensuring residents receive **adequate health and medical support**: proper medication and treatment plans, timely responses to changes in medical needs, and nursing support. Safety was a vital aspect of residents' care.

#### **Challenges of Change**

Kinsmen Manor has experienced a range of changes impacting its residents' QoL. The **aging and physical changes** of residents have been a primary concern, particularly as they face increasing mobility issues. Significant **institutional changes**, including shifts in leadership and staff, and the **COVID-19 pandemic** brought challenges, notably restricting social interactions and outdoor activities. A major change is the **transition to community-based homes** which, coupled with a **freeze on new admissions since 2017**, has led to a tighter-knit Manor community where **private spaces** for each resident, replacing shared rooms, enhances living conditions.

#### Adapting to Change

Residents at the Manor have demonstrated significant resilience in adapting to changes. Despite challenges such as extended isolation and a loss of a resident during the pandemic, a staff member noted their strength: "They are strong, you know, stronger than we thought." The transition to community homes has elicited mixed emotions among residents, ranging from excitement to fear

and uncertainty. Aware of these varied reactions, the staff is working to ease the transition for the residents.

## **QoL** in a Congregate Setting

Feedback on **service quality** at the Manor was gathered using a **five-point Likert scale**. Most respondents rated the **quality of support** for day-to-day care as **high to very high**, with only one considering it average. The residents' **diet quality** received a more moderate assessment, with about half rating it as **average**. **Recreational activities** stood out **positively**, with all respondents rating them as high or very high quality, indicating the success of the Manor's recreational program. **Medical treatment facilities** were also **well-regarded**, with the majority rating them as high or very high quality. **Personal Space and Privacy:** Participants gave **mixed reviews** on privacy at the Manor, acknowledging that while staff strive to respect this **fundamental right**, the assistance required for some residents impacts privacy.

Regarding resident **decision-making capacity**, most participants indicated that residents 'sometimes' have the autonomy to decide on their daily activities. They have opportunities to choose their interests during monthly program planning and can voice their goals annually. However, the ability to make decisions is often hindered by **limited resources** such as staffing and transportation. Support at the Manor is acknowledged as extensive and flexible, but the **staff-to-resident ratio** poses a significant challenge.

The **interpersonal relationships** at the Manor are predominantly viewed as **good**. Caregivers note the long-term bond between residents. Staff play a key role in fostering **inclusion**, carefully managing group activities to avoid conflicts and encouraging connections based on shared interests. Regarding the **house environment**, most participants expressed happiness with the residents' ability to personalize their rooms. However, concerns were raised about some suites appearing too hospital-like, which could impact the comfort of the residents.

#### Perception of the Impact of a Community-based Home on QoL

Residents of the Manor are expected to experience **enhanced personal attention and services** in smaller community-based homes, which could lead to improved living conditions and increased autonomy in daily activities. Caregivers and family members emphasize the **need for clear communication and reassurances** to ease this transition. As for privacy, opinions are divided. Some anticipate more personal space, while others fear a reduction in privacy. Finally, there's apprehension about the potential **loss of services**, particularly in medical support and recreational activities in the absence of a dedicated rec team and transportation challenges.

## **Year One Findings from Resident Interviews**

Interviews were conducted with twenty residents of Kinsmen Manor, whose time living at the Manor ranged from **five to 53 years**. **Social inclusion** and **cohesion** stand out as vital components of their well-being, with **family involvement** and **friendships** within the Manor being particularly important. The residents also **cherish their participation in social and recreational activities**.

Many residents valued working at **Cosmo**. Respondents mentioned interactions with peers and co-workers, implying a social connection within their work environment. Their employment contributes to their **social fulfillment** and **autonomy**, and offers a sense of purpose, community and belonging. One supporting member confirmed:

And when she got this job, we had no problem after that day. She called me and said, "I got a job. I am just like you."

#### **Challenges of Change**

Changes in living conditions, such as alterations to personal spaces and the turnover of familiar staff, evoke strong emotional responses. Age-related challenges affect activities, while staff changes are felt deeply, underscoring the importance of **continuity in care**.

Residents also appreciate the opportunities for decision-making, although they experience some frustration due to the limited availability and long wait times for certain activities. The **support from staff is well-regarded**, with many residents feeling listened to and cared for.

#### **QoL** in a Congregate Setting

Residents rate their relationships with other residents at the Manor highly; most responded **good** or **very good**. While most residents reconfirmed repeatedly that their privacy was protected and people usually knocked on their room before entering, some reported cases of people entering without permission, with other residents failing to respect their space.

## Impact of a Community-Based Home on QoL

A **sense of freedom** to decide how residents want to use their space emerged as essential for QoL. From participating in household tasks to enjoying outdoor spaces and pursuing personal interests, moving to a new home appears to empower these individuals with greater control over their living environments and activities.

In terms of service provision, there's a spectrum of emotions. A few residents are anxious about potential changes, with worries that the new environment may be too controlling or may not

accommodate their needs. By contrast, there are many residents looking forward to the move without concerns, feeling excited about what lies ahead. A supportive and thoughtful transition process is key.

## **Concluding Reflections**

Residents of Kinsmen Manor have voiced their contentment with their life at the Manor, and the relationships and routines they have established, along with their concerns and hopes for the future. The mixed emotions regarding the move—a blend of both excitement and anxiety—emphasizes the need for a supportive and thoughtful transition process. The anticipation of enhanced personal space and autonomy in the new homes is a source of optimism, but the fear of losing familiar support systems must be addressed to ensure a smooth transition.

# INTRODUCTION

Since the Second World War and especially since the 1960s and 1970s, there has been a notable shift toward embracing the principles of normalization, a commitment to respect the rights of people living with disabilities and to ensure they enjoy the conditions, choice, and opportunities that the rest of society expects, to focus on integrating individuals with disabilities into communities to align their lifestyles and daily circumstances "as closely as possible to the regular circumstances and ways of life of society" (Nirje, 1975, p. 231; cited in Perrin & Nirje, 1985, p. 69). This paradigm shift in thinking brought about a substantial transformation in the housing, caregiving, and support of individuals with intellectual disabilities. As a result of this philosophy, a worldwide movement of deinstitutionalization involves individuals with disabilities, including those with intellectual and/or developmental disabilities (IDD), moving from institutional or congregate settings to communitybased homes. Broadly, this movement subscribes to a social or community inclusion model of disability (rather than the medical, deficit/protective model) consistent with people's fundamental right to dignity, quality of life, and full citizenship (Brown & Radford, 2015; Galer, 2015; Lemay, 2009; Lynch & Findlay, 2007; Perrin & Nirje, 1985), affirmed in the first article of the United Nations (2006) Convention on the Rights of Persons with Disabilities and ratified by Canada in 2010 (Findlay & Damji, 2013; Galer, 2015). Neoliberalism in the 1990s slowed progress although new critical disability studies began to reverse that trend and advance both political and legal rights (Galer, 2015).

Numerous countries, particularly the United States (US) and the United Kingdom (UK), began providing community living options for people with IDD in the early 1970s (I. Brown & Radford, 2015). In Canada, the federal government has advocated for the deinstitutionalization of individuals with developmental disabilities since the early 1980s, following the release of the 1981 report (Smith, 1981) and the 1982 progress report *Obstacles* by the House of Commons Special Committee on the Disabled and the Handicapped. Lemay (2009) comments on the understandable range of emotions among families and other stakeholders in response to deinstitutionalization and the relatively few studies in Canada.

A wide body of research indicates that moving to the community after deinstitutionalization results in a significant improvement in quality of life (QoL) and functioning among British and American people (Kim et al., 2001; Lemay, 2009). Martin & Ashworth (2010) conducted a study to understand the process of changing QoL during the transition period on individuals with ID moving from institution to community settings in Ontario. They found various factors influenced the timing of individuals' moves during deinstitutionalization. Younger age, bladder incontinence, and a higher number of medical diagnoses were associated with moves earlier than anticipated, while strong family connections, supportive family relationships, psychiatric diagnoses, destructive behaviour, and aggression were linked to later moves (Martin & Ashworth, 2010). In spite of this and some literature on QoL (R.I. Brown et al., 2009), limited research has been conducted on the effects on QoL of deinstitutionalization and its processes on individuals. As Martin & Ashworth (2010) argue, carefully considering individuals' characteristics and needs at the beginning of deinstitutionalization planning and the flexible timing of community transitions are essential. They suggested assessing the experiences of both individuals and their families during the transition process (Martin & Ashworth, 2010).

## **Study Purpose**

Elmwood Residences Inc, a Saskatoon community-based organization, provides a residential home for individuals living with intellectual disabilities. As part of its commitment to community-based service delivery, Elmwood in partnership with the Ministry of Social Services, Community Living Service Delivery (CLSD) is closing Kinsmen Manor and moving to a community-based home model in which residents live together in groups of four. The transition to a community-based group living model, over three to four years beginning in the fall/winter of 2023/2024, is motivated by (a) best practice literature for residential service delivery showing improved health and well-being outcomes for residents and (b) aging infrastructure that no longer meets individual resident physical needs.

The move from the congregate setting to a community-based living model offers an important research, policy, and practice opportunity:

- To examine the impact of living arrangements on people living with intellectual disabilities in Saskatchewan
- To examine the change in quality of life experienced by residents as a result of the move
- To understand the process by which the change in quality of life occurred
- To provide data that will help policy and program further improve the quality of life of people living with intellectual disabilities

- To establish year one baseline data and quality of life indicators in support of a longitudinal study pre- and post-transition to community-based homes
- To fill an important gap in Canadian disability research

This evaluation is of interest not only to residents, their families, and caregivers but also to policymakers, the larger disability sector in Canada, and disability research more generally.

# LITERATURE REVIEW

The World Health Organization (WHO) defines quality of life (QoL) as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHO, 2012, p. 11). QoL has been promoted over the last three and more decades as an essential "indicator of social care outcomes for adults with intellectual disabilities" (ID), including "self-rated health" and "suitability of home design" engaging the voices of those impacted in shaping policy and practice (Rand & Malley, 2017, p. 1607). In the interests of policy and program development, Rand & Malley (2017) use the eight domains of the Adult Social Care Outcomes Toolkit (ASCOT) to explore "the relationship between QoL and non-care-related factors" drawing on data from the annual Adult Social Care Survey in England. Such measurement is promoted as part of "the wider movement towards outcomes-based performance management across the public sector" while recognizing much research remains to be done to identify causal relationships (Rand & Malley, 2017, p. 1607). Because people with intellectual, physical, and multiple disabilities depend on others for their care and may neither understand verbal nor symbolic communication techniques, it is challenging to apply the principles of QoL, though important to do so in the context of objectives of social inclusion (Nakken & Vlaskamp, 2007). Also, it is a useful tool for developing a feasible framework for service providers in the field of disabilities (R. I. Brown et al., 2009).

## Conceptual Framework for QoL for Persons with Intellectual Disabilities (ID)

In the 1970s and 1980s, the QoL of people with developmental disabilities was considered a means for gaining adaptive behaviour (Campo et al., 1997). Later, in the 1980s and 1990s, the term QoL was used as a "sensitizing notion", providing guidance on the individual's perspective and focusing on the person and their environment as well as family behaviours and needs (R. I. Brown et al., 2009, p. 2). Hence, QoL is a principle at the heart of efforts to enhance an individual's well-being and to foster collaboration for programmatic, community, and societal changes; however, we do not yet know how best to evaluate services and outcomes or how best to shape public opinion and achieve meaningful reforms (Schalock, 2004).

Schalock et al. (2008), drawing on the existing literature, identified key factors, domains, and indicators of QoL for persons with ID. They developed a conceptual framework emphasizing the importance of considering multiple factors, including independence, social participation, and wellbeing, based on twenty-four core indicators and eight domains. This framework was developed for a service delivery system founded on values of person-centredness, holistic empowerment, cultural & contextual, evidence-based, and practical application (Verdugo et al., 2005). The framework has embedded multiple core ideas, including the need for rigorous and reliable tools to measure QoL (R. I. Brown et al., 2009; Higgins, 2004). According to Brown et al. (2009), QoL should be improved through "evidence-based" resources that are "methodologically sound" and sensitive to lifespan and cultural contexts (p. 4). Schalock et al. (2002) also insisted that tools should be used equally for people with or without disabilities.

Over time it has become widely recognized that the QoL concept significantly influences various domains, including research, policymaking, and practice-based events for people with disabilities. Moreover, QoL has been applied in diverse settings, such as residential care, education, and employment, with the aim of enhancing the well-being of individuals with intellectual and developmental disabilities (Verdugo et al., 2012). Emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights are all essential to consider while doing studies with persons with disabilities (Jenaro et al., 2005; Schalock et al., 2008).

Schalock et al. (2005) conducted a cross-cultural survey in five geographical groups that found that the QoL domains and indicators identified in the international quality of life literature were largely consistent across cultures, although there were some cultural differences in the importance attached to specific indicators and certain domains. In the US, for instance, personal well-being was more important than social well-being, whereas social well-being was identified as more important in China. Similarly, in the US, personal well-being was measured by a self-esteem indicator whereas in China, it was measured by self-acceptance. The person-centred approach used in the study is a useful tool for evaluating the QoL of individuals with intellectual disabilities across cultures. It is also essential to consider cultural differences when developing QoL frameworks (R. I. Brown et al., 2009).

## **Rights of Persons with ID**

Verdugo et al. (2012) propose that individuals with intellectual disabilities often experience lower QoL compared to the general population because of factors such as discrimination, limited access to education and employment opportunities, and social exclusion. They advocate for recognizing

QoL as a fundamental aspect of human rights and emphasize the significance of enhancing QoL for people with intellectual disabilities to safeguard and promote their rights (Verdugo et al., 2012).

In the United States, serious efforts to address the rights of individuals with disabilities began as early as 1974 with the establishment of the Supplemental Security Income (SSI) program, which provided financial assistance to those with disabilities, visual impairment, and financial need (Kearney, 2006). The Individuals with Disabilities Education Act (IDEA) of 1975 ensured the right of children with disabilities to a free and appropriate public education (Lakin et al., 1998). Later, the Americans with Disabilities Act (ADA) of 1990 guaranteed disability rights in housing and education, amending previous acts such as The Fair Housing Amendments Act of 1988 and Rehabilitation Act of 1973 (ADA, 1990). All these acts were approved to normalize the life and preserve the rights of persons with disabilities.

Similarly, during the 1970s and 1980s, Australia and Canada began taking significant steps to protect the rights of individuals with disabilities, including those with intellectual disabilities. In 1986, Australia approved The Disability Services Act 1986, which emphasized equal fundamental rights for the disability community as for the general population. After decades of segregating people with disabilities in institutional settings, Canada, sensitized by injured and impaired returning war veterans, began addressing disability rights. The formation of provincial disability clubs in the 1970s combined to establish the Coalition of Provincial Organizations of the Handicapped which would be renamed in people-centred terms as the Council of Canadians with Disabilities (Galer, 2015). The 1981 United Nations International Year for Disabled Persons added impetus to efforts in Canada, including protection under the Charter of Rights and Freedoms and inclusion in the Employment Equity Act. Although neoliberalism would threaten gains in the 1980s and 1990s, the rise of critical disability studies maintained momentum until March 11, 2010, when Canada ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) (Galer, 2015).

Actions by the United Nations (UN) continued to influence internationally from the 1971 Declaration on the Rights of Mentally Retarded Persons, including access to medical care, education, and economic security and the right where possible to live with family in the community. This declaration was adopted by the UN General Assembly in 1975 and would be followed that year with the Declaration of the Rights of Disabled Persons (United Nations, 2021). However, global discrimination against the disability community persisted. To address this injustice, the UN proposed the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which was later replaced by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006—ratified in 2010 by Canada, ensuring rights to education, health, employment, transportation, and housing for persons with disabilities (Galer, 2015). By May 2022, the UNCRPD

had been ratified by 185 countries and signed by 164 countries (United Nations, 2008). This convention encompasses 34 articles covering various aspects of QoL, such as independent living, education, privacy, health, and rehabilitation. See Table 1 for detailed timelines.

Table 1. Timeline of Disability Rights and QoL Enhancement for Persons with Intellectual Disabilities

Year	Event Description
1971	The United Nations (UN) adopted the Declaration on the Rights of Mentally
	Retarded Persons.
	Establishment of the Supplemental Security Income (SSI) program in
1974	the United States, providing financial assistance to "disabled, blind, and
	financially needy individuals."
1975	The UN's Declaration on the Rights of Persons with Disabilities is adopted by
	the UN General Assembly.
1976	Approval of the Individuals with Disabilities Education Act (IDEA) in the
	United States, ensuring children's right to a free and appropriate public
	education.
1986	Approval of The Disability Services Act 1986 in Australia, emphasizing
	equal fundamental rights for individuals with disabilities as for the general
	population.
	In Canada, disability clubs are formed in different provinces, leading to the
1980s	establishment of the Coalition of Provincial Organizations of the Handicapped
	(renamed Council of Canadians with Disabilities).
	Signing of the Americans with Disabilities Act (ADA) in the United States,
1990	guaranteeing disability rights in housing and education and amending previous
	acts.
	Replacement of the Standard Rules on the Equalization of Opportunities for
2006	Persons with Disabilities with the United Nations Convention on the Rights
	of Persons with Disabilities (UNCRPD) as an international effort to address
	discrimination.
2010	Canada ratifies the UN Convention on the Rights of Persons with Disabilities
	(CRPD), ensuring rights to education, health, employment, transportation, and
	housing for persons with disabilities.
May 2022	As of May 2022, the UNCRPD had been ratified by 185 countries and signed
	by 164 countries, encompassing 34 articles covering various aspects of QoL
	for persons with disabilities, including those with intellectual disabilities.

#### A Concise Account of Deinstitutionalization

Adequate housing is a fundamental need—and human right recognized by the International Covenant on Economic, Social, and Cultural Rights and in Canada by the 2019 National Housing Strategy Act (Olauson et al., 2022) —for all individuals, and its role in influencing health outcomes is widely recognized (Benfer et al., 2021; Chenier, 1999; Doll et al., 2022; Hwang, 2001; Kunzekweguta et al., 2022; National Health Care for the Homeless Council, 2019). Housing or residential environments are a significant indicator of QoL (Kyle & Dunn, 2008; Oliver et al., 2020). Evidence suggests that dampness, cold environment, and overcrowding/ inadequate personal space at home negatively impact mental health among healthy adults (Braubach et al., 2011). The scenario is no different for persons with ID. One scoping review shows a strong linkage between housing, health outcomes, and QoL for people with disabilities (Oliver et al., 2020).

Historically, group homes or institutional settings separated from the community were normally allocated for people with disabilities (Wiesel, 2015). Unfortunately, Kilroy et al. (2015) argue, these arrangements may lack privacy and fail to meet individual needs due to insufficient awareness of mental health status. Nursing homes were one of the alternative but increasingly controversial solutions for residency for the last three decades (Lakin et al., 1991).

The deinstitutionalization process has gained momentum over the last three decades, with a notable shift from group homes or congregate settings to community-based living in various countries, including the USA, the UK, Sweden, and Norway (Beadle-Brown et al., 2007; Emerson & Hatton, 1996; Lakin et al., 1998). In Canada, the federal government has also actively advocated for the closure of facilities catering to individuals with intellectual and developmental disabilities (IDD) since the early 1980s, following the release of reporting by the House of Commons Special Committee on the Disabled and the Handicapped (McColl et al., 2017).

#### Impact of Transitioning to Community Homes on the QoL of Person with ID

Young et al. (1998) observed that overall QoL would improve if a person with IDD moved from a congregate setting to a community-based home. In a systematic review, McCarron et al. (2019) discovered that most studies found that transitioning from an institution to a community home has a substantial positive impact on the QoL for individuals, and this improvement is sustained over time. Furthermore, there was evidence of ongoing QoL improvement when individuals moved from one institutional setting to another with better conditions (such as refurbished units and accommodating fewer than 25 people). These scattered settings provided better physical well-being, access to the community, consistent routines, increased self-determination, improved residential conditions, and overall enhancements to QoL. However, there were no notable improvements identified in terms of

material well-being and social/emotional well-being (McCarron et al., 2019).

McCarron et al. (2019) have identified five positive impacts of transitioning to a community home: freedom, an enhanced living environment with compatible roommates, improved staff support in smaller settings, frequent family visits, and community integration. Kilroy et al. (2015) conducted interviews with eight key worker representatives for ten individuals with intellectual disability. They explored the key workers' perspectives on the effect of transitioning to a community home on the QoL of these individuals. The key workers reported improvements in behavioural indicators, particularly in adaptive activities such as learning new things. They also observed a noticeable reduction in self-harming behaviours. Furthermore, the key workers mentioned that the staff turnover was reduced, which positively impacted the individuals' lives (Kilroy et al., 2015).

One longitudinal prospective study conducted in Australia by Young (2006) revealed that the QoL of 60 persons with moderate to severe disabilities (intellectual and developmental) had significantly improved outcomes after moving to a community-based home. Similarly, Douglas et al. (2023) found despite having a small study sample (15 participants), more positive effects were reported in post-move than pre-move QoL. Most importantly, individuals with disabilities, after moving to the community-based home, showed increased adaptive behaviour, evidently enjoying spending quality time with family members and caregivers (see too Young et al., 1998).

Claes et al. (2012), however, found that social-care support and non-care factors are responsible for a good QoL. Claes et al. enrolled 186 persons with disabilities from the Dutch population. They found that social care directly accounted for only 10% of the variance in QoL of adults with intellectual disabilities in the Netherlands and that 44% of the variance was accounted for by personal characteristics and 8% by environmental factors (Claes et al., 2012). Rand & Malley (2017) conducted a quantitative study based on the UK's Adult Social Care Survey (ASCS) data. In ASCS, besides ASCOT, they also considered non-care factors like socio-demographic status, housing design, health status, and level of difficulty based on daily activities (Rand & Malley, 2017). Rand & Malley compared the relationships between QoL and non-care-related factors, finding several factors associated with QoL among adults with intellectual disabilities. These include adequate support, good communication, positive relationships, and appropriate living arrangements. The study also found that the quality of care provided by staff and the level of social inclusion experienced by the individual are also important factors (Rand & Malley, 2017). Rand & Malley conducted ordered logistic regression to compare the impact of non-care factors (home design and difficulty in daily activity) with the ASCOT-QoL score. Like the Dutch, British people also reported that non-care factors have an impact on QoL. Rand & Malley (2017) also found those with poorer self-perceived health, worse ratings of home design, or higher levels of anxiety/depression

were more likely to report lower QoL, which suggests that a policy strategy should be developed that recognizes the interrelationships between health, social care, and housing needs. However, Wehmeyer & Mithaug (2006) noted that self-determination was a causal agent for QoL besides being one of the core domains.

A post-transitional study (Doody, 2012) was conducted with family members to understand their perspectives on the shift from institutional to community settings. According to the family members, the transition was beneficial, improving their loved ones' QoL and positively influencing their cognitive processes. The improved environment in the community setting seemed to significantly impact both the individual with the intellectual disability and their family members, leading to a more favourable experience overall (Doody, 2012).

One longitudinal pre-/post-transition quasi-experimental study in Manitoba, Canada (Camaranesi et al., 2022) aimed to measure changes in quality of life across eight domains of 33 persons with profound intellectual and multiple disabilities at two time points: pre-transition and at least six months after using the standardized San Martin Scale. They found "significant improvements" across all eight domains. In a November 2022 update, Shooshtari et al. (2022) report that since 2014, over 60 people with intellectual and developmental disabilities have moved from St. Amant's institutional setting in Winnipeg, Manitoba, to homes in the community. Their ongoing study (now in its sixth year) measures changes in health, access to healthcare, and quality of life. For the health changes, they use the Comprehensive Health Assessment Program (CHAP) tool. To assess changes in quality of life, they use both the INICO-FEAPS (for those who can speak for themselves) and San Martin Scale (for those who need proxies). In health profiles for 52 persons, they found lower rates of chronic conditions than for other persons with IDD in Manitoba. Among the 26 who had transitioned to community homes, they found decreased problem behaviour, diet concerns, and decreased epileptic seizures, back pain, and chronic constipation as well as improved mental health, although they also noted increased chronic constipation and sleep issues (Shooshtari et al., 2022). The quality if life of 33 persons after the transition improved substantially in all domains.

However, it is essential to acknowledge that negative impacts on the QoL for persons with intellectual disability resulting from this transition have been reported. McCarron et al. (2019) compiled findings from five studies and highlighted the challenges faced by individuals after moving to community homes. They noted that community homes had lower availability of day programs compared to institutional settings, and not all homes had access to speech and language therapists. Additionally, while some community homes experienced increased visits from family members, a few faced fewer visits due to their location (McCarron et al., 2019).

Kilroy et al. (2015) emphasized the significance of selecting compatible housemates to achieve maximum positive impact on QoL and maintain harmony within the community home. They also highlighted a shortage of funding, leading to a decrease in nighttime staff and outings, which had a notable impact on the QoL for individuals (Kilroy et al., 2015). Despite the potential for transitioning to community homes to enhance community integration, Kirloy et al. (2015) reported a decline in this integration over time. These negative aspects must be addressed to ensure that the benefits of community-based living options are sustained and that the overall QoL of individuals with intellectual disabilities is improved effectively.

# **METHODS**

The research was conducted adhering to the stringent policies of the University of Saskatchewan Behavioural Research Ethics Board (REB). The study was reviewed and approved by Behavioural Ethics of the University of Saskatchewan Research Ethics Board (BEH#3555) in two phases: 1) by delegated review on July 29, 2022, for the minimum risk associated with interviews with non-residents; 2) by full board review on January 18, 2023, an amendment to cover the interviews with residents considered above minimum risk.

#### Literature Review

A literature review was conducted first to gather important information from peer-reviewed articles and gray literature including the organizational documents (annual reports, surveys, volunteer or other evaluations). We reviewed articles and documents relevant to studies conducted in Canada and involving individuals with intellectual disabilities to identify important variables and gaps in Canadian disability research.

Regular progress reports were shared with the Research Advisory Group (including representatives of the funders, the Ministry of Social Services, Inclusion Saskatchewan, and the Manor Transition Initiative Outcomes and Evaluation Framework Sub-Committee) for feedback. Findings from the literature review sharpened the focus on quality-of-life indicators and determined the details of the methodology used in subsequent stages. It was helpful for preparing key stakeholder interview guides, related to pre- and post-studies. This longitudinal pre-post study (subject to continuing funding) will allow us to compare the experiences of transition processes and their quality-of-life outcomes among the residents of Kinsmen Manor. Findings will help shape the planning, implementation, timing, and supports related to the transition to community-based living. The interview guides were approved by the Research Advisory Group and by self-advocates before submission to the REB

## **Qualitative Research Approach**

A qualitative research approach was taken to study objectives. Important findings were probed deeply through in-depth face-to-face (or virtual) interviews with key informants: most importantly, with 20 residents and 16 interviews with families, caregivers, support workers, Manor Board, staff, and other key stakeholders. Invitation letters (Appendix A) sent to potential phase one participants explained the research project and objectives, explaining that their participation was voluntary and confidential. Whether or not they chose to participate would have no impact on access to services, employment, or how they would be treated. No mass emails were used for invitations to maintain participant privacy. If they agreed to participate in the study, we sent them a consent form (Appendix B) explaining the benefits and risks of involvement in the research project. Before the interview began, COVID protocols were followed before reviewing the consent form and process. The consent form highlighted the individual's right to withdraw from the interview process at any time without penalty up to one month after the interview by which time data may be aggregated. The consent form assured participants that the researchers would protect their confidentiality and noted any limitations on their confidentiality. If virtual, interviews were conducted via Zoom for which the University license ensured that all data were stored on servers in Canada.

A similar approach followed in phase two with the residents of Kinsmen Manor. We included proxy participants (support persons) for individuals with severe intellectual disabilities. We also respected any participant's need to have the interview over two sessions. The support person reviewed the consent form where needed and signed to signal that, to their knowledge, the participant willingly gave consent. We informed participants during the consent process that the interview would be recorded if they agreed. No names would be used during the recording as well to maintain confidentiality. If participants agreed to recording, the audio recordings were saved on the researcher's local password-protected computer (backed up on One Drive- U of Saskatchewan). Only the researchers who have signed confidentiality agreements had access to the recordings and were responsible for transcribing.

Researchers and participants agreed not to make any unauthorized recordings of the interviews. Before the individual interviews, participants were reminded again of their right to discontinue the interview at any time. They had the right not to answer any questions if they did not want to. Participants could ask for the recording to be turned off at any point without giving any reason. After the consent process, face-to-face interviews were conducted at Elmwood Residences in a private room (or virtual, as allowed) following the interview guide (Appendix C). Guided by the interview conversation guide, researchers kept the interview as conversational and as attuned to participant needs as possible. We kept focus on tone of voice, eye contact, body language, level of language, use of visuals, for example, for those with intellectual disabilities. The guide focused on the impact of the current living arrangement and the transition process on their quality of life. When the researcher conducted online interviews from their own home with participants, the researcher was in a location where they could not be overheard to maintain participant privacy and confidentiality. The privacy

policy of Zoom Video Communications, which hosts the Zoom platform, is available at https://us02web.zoom.us/privacy-and-security. Still, participants were reminded that no currently available virtual platform could guarantee privacy.

Transcriptions were completed by the CUISR research assistant who had signed a confidentiality agreement and reviewed and revised by the Principal Investigator. Pseudonyms were used during transcription to maintain privacy. All transcriptions were also stored securely and separately from consents (and the master list) on the PI's password-protected computer and backed up on One Drive-U of Saskatchewan. Data will be securely stored for a minimum of five years after publication after which they will be destroyed permanently and beyond recovery. The coded master list was also held on a password-protected computer at the PI's office (and backed up on One Drive-U of Saskatchewan) and will be destroyed beyond recovery after data are aggregated in the report. We invited all participants to review, add, delete and change the final transcript before signing the release form.

## **Data Entry and Analysis**

The CUISR research assistant was responsible for data entry and analysis (using NVIVO) under the supervision of the Principal Investigator. She drafted the final report (with PI guidance and input) after both qualitative and quantitative data analysis. All identifying information was removed before generating the report. Responses were reported generally, as in "one of the respondents said…" or "several participants stated that…"

#### **Knowledge Translation**

We will concentrate on delivering the results of our study to the Elmwood community, broader disability community, policymakers, public and the wider research community. Participants were informed that a summary of research findings would be available to them. We will focus on publication of findings that may include presentations in conferences, in conference proceedings, policy briefs, infographics, book chapter, academic or technical papers. In all such dissemination circumstances, we will acknowledge the funder.

# FINDINGS AND DISCUSSION

Both non-resident and resident participants of Kinsmen Manor were interviewed to better understand the impact of living arrangements on people's QoL.

## Year One Findings from Non-resident Interview Respondents

Sixteen non-resident respondents were interviewed about the resident living arrangements at Kinsmen Manor and their impact on QoL and their needed support, dreams, and fears about the move to community-based group homes of four people. In-person or virtual interviews were conducted with five staff members from Kinsmen Manor, seven family members, two Board members, and two other key stakeholders from relevant organizations. See Table 2.

Table 2. Number, Type, and Gender of Non-resident Interviewees

Relationship with residents at Manor	Number of respondents (16)
Family Member	7
Elmwood staff	5
Key stakeholders from other organizations	2
Board member	2

Gender of the interviewed non-resident participants			
Male	4		
Female	12		

We collected information under eight domains (Table 3) indicated in the literature (R.I. Brown et al., 2009; Rand & Malley, 2017; Schalock, 2008; Verdugo et al., 2005, for instance).

Table 3. QoL Domains and Indicators

Domain	Indicators	
Personal Development	Residents' adaptation capacity towards change and support to engage in various new, meaningful activities. (e.g., outdoor activities, in-house activities or training, employment).	
	Staff use appropriate communication and <b>support</b> residents' choices.	
Self-Determination	Residents are invited to <b>express their preferences</b> to participate in recreational activities.	
	Residents are part of person-centred planning and lead individualized lives.	
Internessed Deletionshins	Residents experience positive and respectful interaction.	
Interpersonal Relationships	Residents are positively regarded by staff.	
Social Inclusion	Staff are proactive and <b>support positive contact</b> with family members.	
Rights	Residents are treated with dignity and respect.	
Emotional Well-being	Residents are comfortable in their environment.	
	Residents are supported to stay in a safe environment.	
Physical Well-being	Residents have access to personalized support immediately.	
Material Well-being	Residents are comfortable with the residential arrangement.	

After completing transcriptions and securing their release where requested, the initial coding was completed using NVivo. We identified four major themes (Non-Resident Perception of QoL Indicators, Ongoing Challenges to QoL, QoL in a Congregate Setting, and the Impact of a Community-based Home on QoL) and arranged sub-themes under each theme. The themes and subthemes are listed below.

## Non-Resident Perceptions of QoL Indicators

- · Social Inclusion
- · Recreational Activities
- · Choice, Autonomy, and Independence
- · Health & Safety

## Challenges of Change

- Changes as Challenges
- Adapting to Change

## QoL in a Congregate Setting

- Recreational Activities
- Personal Space and Privacy
- Decision-making Capacity
- Available Supports
- Interpersonal Relationships
- · House Environment

#### The Impact of a Community-based Home on QoL

- Improved Living Conditions
- Increased Flexibility
- Impact on Relationships
- Impact on Privacy
- Fear of Losing Service

Besides basic human needs, most participants pointed out that measures or indicators of QoL vary from person to person. The most frequent words in response to the question, "What do you think are important factors in or measures of their QoL?" are plotted in the following word cloud (Figure 1).

Figure 1. Interviewee Most Important Measures of QoL



Based on the responses, we identified four major sub-themes under the Indicators of QoL: Social Inclusion, Recreational Activities, Choice, Autonomy, and Independence, and Health & Safety.

#### Social Inclusion

Most respondents discussed aspects of social interaction and activities for residents in congregate living facilities. The respondents highlighted the importance of having friends and good relationships with staff and caregivers, promoting independence and participation in outings and activities, and ensuring consistent staff support for residents. According to one staff member of Kinsmen Manor, "rapport and respect" are critical:

I think being able to have friends, be with them; I believe this is important. And clearly, being able to have a great rapport and respect for the staff is really critical. And for the residents to feel that the staff really values them.

Some explained that promoting independence and prioritizing social engagement through community outings, games, and concerts are key to enhancing resident well-being and sense of belonging. One family member expressed it this way:

I think just giving them as much independence as possible. For them, like the staff, their social life is very important to them. So, like all the outings they get, they go out to the community and participate in games and concerts.

Participants also highlighted the importance of both group and individual interactions. They mentioned it is important for promoting recreational activities and a sense of belonging for residents of Kinsmen Manor. According to one staff member, "engaging activity" is important:

We have independent recreation activities. And then we also have large group recreation activities. And I think the large group of activities like wheelchair bowling, we do yoga,

we do dancing, we do a pet therapy group—all of those offer not only recreation but also has a role in social aspects. So, they get to see people from the community homes. They get to participate in a larger activity with their peers and friends.

Overall, the responses emphasized the significance of socialization and engagement in enhancing the QoL for residents in assisted living facilities.

#### Recreational Activities

Respondents identified involvement in recreational activities as important an indicator of QoL as social inclusion and indeed the two are intimately connected. In addition to personalized programming, respondents stressed that involving residents in different group and community activities is vital. Both family members and staff stressed that community involvement is important in socialization. One family member emphasized the value of activities that get residents interacting with others and not simply passively taking in the outside world:

And then supporting them to ensure they have the activities they'd like to do. No one likes to sit around and watch TV all day or look outside. But engage in activities outside, maybe interacting with other residents and making crafts.

Similarly, one of the staff stressed the values of activities outside the Manor:

We have to ensure that people are getting opportunities if they can get out and do additional activities besides the ones within the household. Like the concerts, the trips to the games or sporting things; just making sure that those things are being offered.

#### Choice, Autonomy, and Independence

Another important factor identified by respondents was resident ability to choose and decide for themselves. They recognized the importance of promoting independence, autonomy, and choice for individuals with disabilities, including making decisions with support and providing opportunities for socialization, work, and recognition. The routine and predictability of activities, such as work schedules, are also highlighted as essential factors in promoting a sense of control and well-being for individuals with disabilities. One family member commented on critical work routines for their family member:

I think always knowing that you know certain things will occur at certain times is very important, and an ongoing factor for my brother is being able to go to work. To know that he has a work schedule and can go to work, and he's getting recognized for that work by a pay slip. And so, he knows he goes to work and has a pay slip, and he got some funds that he can use to buy clothes or go to a movie or something like that. That's an important thing for my brother.

Respondents also identified that independence includes the ability to leave the facility and choose their own activities and meals, which the congregate setting may challenge. One stakeholder expressed the concern in this way:

You know, in a large congregate setting, that's quite difficult to do because, as I said, there is a limitation to how much independence you can have, but I think, giving them the feeling that they are in control of as much of their life as possible is important.

Overall, the emphasis is on empowering individuals with disabilities to lead fulfilling and selfdirected lives, despite the challenges posed by living in a congregate setting.

## Health and Safety

Many respondents also identified health and safety as another crucial indicator of QoL. Among them, the importance of providing adequate health and medical support to the residents is mentioned in multiple interviews. This includes ensuring that the residents receive the proper medication and treatment plan, responding to changes in their medical needs quickly and positively, and providing nursing support. Safety is another vital aspect of the residents' care, with one family member explicitly mentioning that the resident's care improved after moving from a group home to the Manor:

Well, I think, in terms of his QoL, it actually improved a lot when he transferred to the Manor..... the safety and his care improved. I am not sure about the safety, but his care definitely improved when he moved from the group home to the Manor.

## Challenges of Change

Most of the residents spent a large part of their life at the Manor. Being part of this congregate setting, residents have seen significant changes over the years, and even decades, and faced several challenges. Caregivers, family members, and administrative facilitators have identified that during their stay at the Manor, residents have faced diverse changes such as these:

- Aging and physical changes
- Institutional, management and personnel changes
- COVID-related changes
- Changes related to the anticipated transition to community-based homes

They described the changes as both positive and negative for the QoL among the residents of Kinsmen Manor.

Aging and physical changes: Several respondents highlighted residents' advancing age and diminishing physical capabilities, which may impact their experiences at the facility. This was

identified as one of the negative changes by the caregivers and family members. Getting older on top of previous limited mobility is more challenging than usual, which may impact their experiences at the facility. One staff member pointed out the challenges regarding physical mobility:

I must say, one of our residents recently lost their ability to move. Some might need a wheelchair; in some cases, the door is not wide enough right now.

Multiple respondents touched on changes in the leadership and personnel at the facility, which may affect processes, procedures, and the experiences of residents and staff. Almost everyone agreed that the changes in administrative personnel brought a more positive atmosphere to the Manor, including a significant change in activity programs. One of the board members said:

One of the changes we recently made is bringing a community home coordinator who has more experience at support work, on the medical side of support work. So, I think this change is good and provides overall support to each resident.

Changes due to COVID: Two respondents discussed the effects of the pandemic, including restrictions on outings and visits. One staff member pointed out that during COVID, they restricted resident movement and shut down socializing programs, and improvised activities had to be implemented, which she identified as a negative change:

The funded socializing program was shut down, and COVID-19 made it impossible to go outside. The staff improvised and built a tent to continue the gym activities.

One of the family members appreciated the staff efforts in this regard:

And, during COVID, we had him here for three months. I thought that it was the safest thing to do. But when I think of it and look back on it now, my husband and I have discussed that he could have easily stayed at Elmwood for those three months. Not because he missed out on all the social things that they did even with all the restrictions. So as far as the socialization, the friendships he made, the care he had, it's been great. Like it's been a positive thing.

Challenges related to Transition: Five out of the sixteen respondents identified that the significant change or challenge they are going to face is the upcoming transition. One of the family & board members identified this announcement as the biggest change in the life of the residents of Kinsmen Manor. Another family & board member commented:

I think the biggest one is the transition that's going on right now, from the institutional setting to the group homes. Until this point, or until this transition goes ahead, there haven't been too many changes in many ways.

As a part of the transition, the Manor had a freeze on new admissions from 2017. Still, services

provided by the Manor have remained constant in meeting residents' physical, mental health, medical, and emotional needs. The freeze on new admissions has resulted in a tighter community, making any change in setting or staff significantly impact residents, which the respondents noted as a positive change. The greatest benefit has been that residents had their own space, as one staff member put it:

In the past, even though we only had 40 rooms within the building, we had ten shared rooms here when there were 50 residents living at the Manor. And then, the other 40 individuals have their own private space, but for a good number of years now, all residents have had their own private space (bedroom).

## Adapting to Change

According to family members and caregivers, the residents of the Manor have adapted to the changes brought about by the institutional and personnel changes and the COVID-19 pandemic relatively well. According to one staff member, the residents showed remarkable resilience.

I can say far more resilient. Considering the COVID period, you know we had to maintain safety. When COVID outbreaks happened at Kinsmen Manor, we had to make sure about their safety. We had to isolate them for 7-8 weeks. It was challenging for us because it was difficult to explain to them. We were so scared about their health. One of our residents died. . . . But the rest of them did quite well. They are strong, you know, stronger than we thought. But definitely, it was challenging.

However, the residents adapted to the changes related to the transition in diverse ways. The staff highlighted that the residents had expressed mixed feelings about the transition; some were excited, and some expressed fear of moving, especially fear of uncertainty. One of the family members reported the diversity of resident reactions:

During the first time that they were informed about the transition from the Manor to the group home, we didn't expect them to understand right away. Some were a little bit excited, some were scared, and some were lonely. Others are looking forward joyfully to how they are going to live with others in a small group home.

Overall, the non-resident responses suggest that while some residents are excited about the move, some are also experiencing anxiety and uncertainty. Residents' attachment to their current living space and belongings significantly contributes to their emotions and attitudes. Staff members are aware of these emotions and are trying to address residents' concerns and questions about the move process.

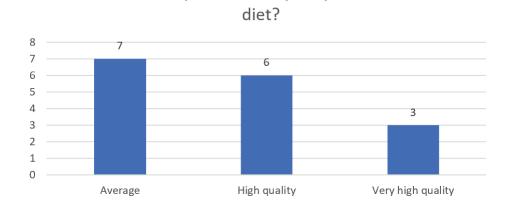
## QoL in a Congregate Setting

To understand the current state of resident QoL at Kinsmen Manor, we asked respondents to rate the available services at the Manor: the day-to-day support, diet, recreation activity, and available medical treatment facilities at the Manor. We used a five-point Likert scale to determine the ongoing quality of service at the Manor. We asked respondents to rate the quality of support provided on the day-to-day care, and most reported that they were satisfied with the service. Out of sixteen participants, six expressed the quality of support was very high, and nine of them said it was high. Only one said it was average in terms of day-to-day care. See Figure 2.

Figure 2. Non-resident Satisfaction with Day-to-Day Care Quality at Kinsmen Manor



Asked about their perception of the Quality of residents' diets, nearly 50% of the respondents (n=16) said it was average. Only three rated the Quality very high, and the rest said it was high (Figure 3.).



How would you rate the quality of residents'

However, the scenario was different for recreational activities. All of the respondents rated the recreational activities at the Manor very positively. Out of sixteen, nine rated it very high, and the rest rated it high (Figure 4.).

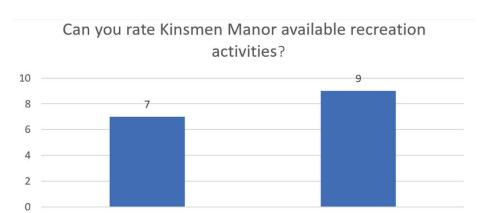


Figure 4. Non-resident Ratings of Recreational Activities

Although respondents were happy about the 24-hour nursing facilities at the Manor, which actually are no longer available, two out of the sixteen rated the medical treatment facilities at the Manor as average. And others rated it either high (n=6) or very high (n=8). See Figure 5.

Very high quality

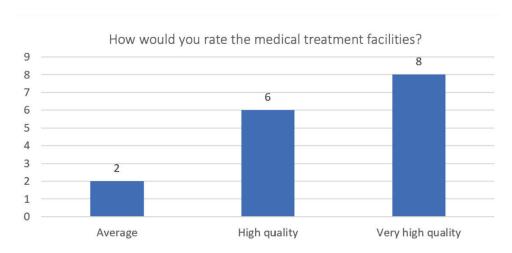


Figure 5. Non-resident Satisfaction with Treatment Facilities

High quality

Several open-ended questions aimed to evaluate the current QoL of the residents at Kinsmen Manor. Most of the study participants had identified both positive and negative impacts of living in congregate settings based on the service provided at Manor. They compared the available activities at Manor with their expectation. Based on their responses, we have identified seven sub-themes under the "QoL at congregate setting" theme.

#### Recreational Activities

The general sentiment regarding the quality of recreational opportunities for individuals living in the Manor is positive. Most participants reported that the activities offered are of high quality and that the recreation staff does an excellent job providing support. They also mention various in-house and out-of-house activities, including arts and crafts, gym activities, social clubs, and outings to sports events, dances, and concerts. One staff member commented:

There are a lot of residents who look forward to going to concerts because they love the music and they're able to attend concerts. They're able to attend football games as well as play games, and do community work in-house, where they get to see their friends come in and cheer at yoga together.

Most of the family members also gave positive feedback on available recreational activities. One of the family members said:

They do a lot there. They not only bring in kids to provide stimuli, and they have people playing the piano. They have a movie night, and they do a lot of crafts in the crafting room. Yeah, they have a lot of activities, and I think enough variation for people to participate. For some, they may not like crafting, but they'll like, maybe, like to watch a movie night, a football game, or go to the gym.

Based on the responses, the recreational programs at the Manor focus on inclusivity, community engagement, and variety for residents. The community inclusion program also provides socialization support to individuals, and many residents participate in activities organized by Special Olympics. One of the rec team members explained the available recreational service at the Manor:

We have chair yoga; we have art club, a drama club, they do paint. Special Olympics rents the building to host sporting activities, and many of our residents participate in Special Olympics activities like soccer or hockey, basketball; it's very broad.

There is also a sense that the recreation staff is knowledgeable about resident preferences and needs, such as scheduling activities for individuals who may not get along with each other. Additionally, some respondents highlight the advantage of having dedicated recreation staff who can be flexible in organizing outings and in-house activities. One family member reported:

From what I've witnessed, the recreational staff takes great planning consideration. And they (rec staff) look at meeting different goals with the activities. So, for example, let's see the slip and slide that happened this summer. We could expect that. Oh, my gosh! How could that not be fun for everybody? So, the recreational staff created this slip-and-slide opportunity. They have enough skill, expertise, and understanding of the residents to know that that might not be everybody's preference.

Overall, the sentiment suggests that recreational opportunities in group homes are valuable and provide meaningful engagement and stimulation for residents. However, participants also pointed out that due to the large number of residents at the Manor, they have to minimize and prioritize the activities, especially the outside activities. One board member said:

But again, the flip side is that you have so many people. You have to pick one activity that might not be liked by everybody. Not everybody wants to go to the Zoo, but you were going there (Zoo) because that's what we're doing today.

#### Personal Space and Privacy

As a human being, it is essential to reserve personal space and privacy. It is one of the fundamental human rights. Asked about their perception of the privacy maintained at the Manor, participants gave a mixed response. Many participants said that residents deserve basic human rights and the right to privacy, regardless of their disabilities or living situation. The participants acknowledge that staff members do their best to preserve the privacy and rights of the residents, but there are limits to what can be done. Some residents require assistance with daily tasks such as bathing, which can impact their privacy. According to one family member:

I think they (staff of Manor) are as best as you can. An example is bathing for people that require lifts if you need a bath. Suppose the bath that you're using is far from your bedroom. You have to use the lift; they transport you through the building on the lift to get to the top. Now you provide coverage, and you provide as best privacy as you can. But in a small house, you're only going to be a hallway away from the bathroom.

#### Decision Making Capacity

The participants agreed that "decision-making capacity" is one of the critical indicators of QoL when responding to both open-ended and close-ended questions about resident ability to make decisions or choices at the Manor. Most respondents answered "sometimes" in response to the question, "Do the residents decide their daily activities?"

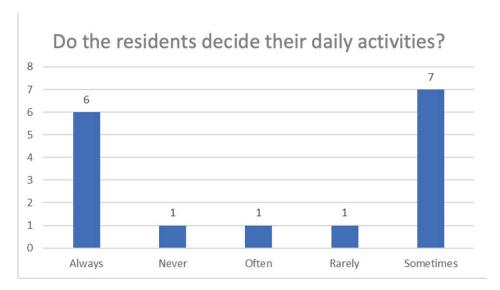


Figure 6. Non-resident Perceptions of Resident Decision-Making Capacity

When making the open-ended response, they pointed out positive and negative sentiments for the "capability of making decisions." The positive aspect is that the residents have the option to decide and participate in activities based on their needs, wants, and interests. The participants said that the residents have the freedom to choose what they want to do, and their preferences are considered in monthly programs, smaller group outings, and planning meetings. The participants are allowed to choose who they want to go with for activities, and they have a say in their goals for the following year. One of the family members said:

I think he does. I don't think he's (the participant's brother) forced to do anything. He's usually asked, and it's ahead of time. And usually, like, he has a meeting once a year, and I participate in that too, as far as his goals for the following year.

However, the choices provided to the residents are limited due to the lack of resources, such as staff, budget and transportation. The participants mentioned that sometimes residents could not participate in individual activities, like going to KFC or other places, due to the lack of staff and resources. Moreover, the lack of transportation limits the residents' options, and they can only sometimes go to their preferred locations. In responding to the question, "Do the residents decide their daily activities?" one support worker said,

I think sometimes they're involved like it's somewhat limited. Of course, they've to work within budgets and everything like that. So, the rec staff develop some activities; they do try and keep things in mind what people might be interested in.

Overall, responses showed that while the residents have some individual choices, limited resources restrict their options. There is a need for more staff and resources to provide the residents with more choices.

### Available Supports

Most participants mentioned the extensive service provided by the staff at Kinsmen Manor, although they expressed mixed opinions about the service. The respondents highlighted the various aspects of daily living that support workers attend to, such as medical care, nutrition, recreational activities, cooking, cleaning, and laundry. The challenges of meeting the needs of all residents due to the large number of people in the building were also noted. However, the participants also suggest that support workers try their best to be flexible and meet the needs of residents. One of the staff commented:

Yeah, as best as we're able to facilitate. Because you have 29 people in the building, we have to ensure staffing is in place. But it is more challenging here because of the number of people that reside within the building. So, we try to offer as much opportunity and show as much flexibility as possible with that, but it's challenging just because there are so many people here and we try our best, but we might be lying if I said we were always able to meet needs.

The respondents also mentioned the staff-resident ratio at Manor, highlighting one of the biggest challenges to providing a better service to the residents. Participants expressed concern over the limited number of staff available to attend to the needs of residents. They also mentioned that residents might only sometimes receive the attention they seek due to limited staffing. One of the staff spoke to this issue:

Here, if you look at the staffing to resident ratio, you might have three care staff for direct support, the direct care. There are three care staff only for 29 residents. So, it's more like one staff per eight to 10 residents. So even that ratio will be half in the homes......Now, you can imagine the staff-resident ratio. It is difficult for them to attend all the time.

The families highly value the presence of nursing staff and medical support. Indeed, having 24/7 nursing support was identified as the most beneficial service at the Manor, although 24/7 nursing care was suspended as of December 31st, 2021. At that time the Manor introduced a Night Supervisor through the nighttime hours to address any concerns at these hours, including medical questions/concerns. The Night Supervisor remains in place in 2024. The preferred level of support may prove impossible in community homes without additional funding.

#### Interpersonal Relationships

As a part of social inclusion, we tried to understand the interpersonal relationships among the residents, staff, and other residents. When we asked about their perception of the relationship among the residents of Kinsmen Manor, most respondents said it was good. See Figure 7.

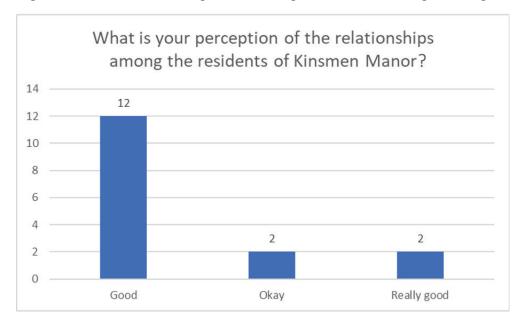


Figure 7. Non-resident Perceptions of Interpersonal Relationships Among Residents

The Manor residents have a mix of relationships, including close friendships and animosities. Some people get along well, while others do not. One of the caregivers said:

I think they're really good. They've all lived together for many years, and of course, you have your best friends, and then sometimes you have people that you don't get along with. But that's life.

Similarly, one family member mentioned:

I think it's highly interactive. I think they (residents) have choices with whom they get to interact. Not everyone gets along, or at least on a particular day. So, they may not like "J" (resident) today, but they'll love "J" (resident) tomorrow.

Many participants pointed out that staff members are essential in fostering social inclusion among residents. They can facilitate interactions between residents with similar interests, avoid conflicts by not involving individuals who do not get along in the same activities, and provide person-centered care to promote independence and maintain residents' rights. According to one staff member, staff are savvy:

You know the staff have a pretty good idea of who gets along with whom. And they (staff) do take some steps to try to ensure that if people aren't getting along, they're not involved in the same activity at the same time. They also try to connect people if they feel that works. Like on an outing or something, take people with similar interests.

Overall, family members expected that good communication between staff members, residents, and managers is crucial to ensure that the needs and preferences of residents are met effectively. One

of the family members pointed to sometimes invisible services:

I think the support that the staff are giving isn't just giving something. Like, I'm thinking of someone who comes in and cleans my brother's room. It isn't just that service. It's when they do that, they interact with my brother in a way that he finds positive. That's also a part of the service. It isn't just, you know, a clean room; it's a clean room with something else combined.

Overall, social inclusion in care settings requires a concerted effort from staff, residents, and managers to ensure that the needs and preferences of residents are met in a way that promotes independence and maintains their rights. Good communication and adequate resources are necessary to support social inclusion.

#### House Environment

Most participants were happy about the residents' room at Kinsmen Manor (Figure 8).

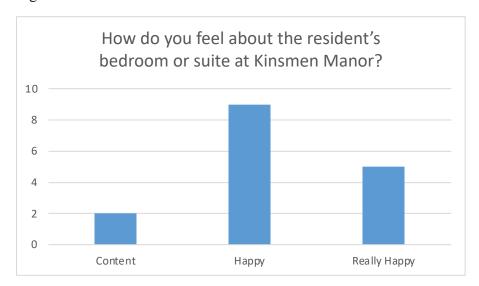


Figure 8. Non-residents' Satisfaction with Residents' Rooms at Kinsmen Manor

Respondents expect that residents can personalize and decorate their rooms to reflect their preferences and tastes. One staff said:

> She (the resident) chose how she wanted her room to be painted and how it looked. We try as best as possible to make sure that they decorate their rooms as they would choose. We're just not putting them into some sterile room that's painted the same colour.

However, a few respondents suggested that some of the suites in Kinsmen Manor feel more institutionalized and hospital-like, which may not be ideal for some residents or their families. One key stakeholder said:

I find the other suites, where that's a little more hospital, a little more long-term care, a little more institutional kind of bedrooms. I don't like those, and I find those a little bit sad in terms of I wouldn't want to live in those spaces.

# Perception of the Impact of a Community-based Home on QoL

We asked participants multiple questions to get their perceptions of this transition. In response to the question, "Do you think moving to community-based homes will increase the opportunities for deciding or selecting the daily activities?" most answered yes. However, six of the sixteen respondents explained that it would depend on several other factors. Based on their response, we identified four major sub-themes under this theme.

#### Improved Living Conditions

Anticipating a shift to community-based homes, respondents expressed a mix of optimism and caution regarding improved living conditions. One participant envisions enhanced services and personalized attention:

And if anything, they said it would be better because they will be in smaller groups. It'll be easier for them to attend different things.

However, concerns linger about staffing and potential challenges, as another family member expressed her concern based on previous experience from a group home:

Well, that's one of my worries. Based on my experience, when my brother was at home. I'd say that they would not improve.

Amidst these expectations, the consensus remains that the transition could yield a more fulfilling lifestyle, offering increased autonomy and engagement. One stakeholder reported:

You'll have two bathrooms with a bathtub and a shower, and you could, 'hey? I want to have a bath today.' I can go have a bath today, whenever I so choose or even choose the channel on the TV.

As the prospect of change looms, uncertainties persist alongside hopes for a positive impact on residents' well-being.

#### *Increased Flexibility*

Participants agreed that residents would have more flexibility in choosing their preferred activities and routines. For example, they can decide when to take a bath or shower. They mentioned moving to a small home will increase their ability to choose meals, and the residents can also participate in basic household chores. They identified the importance of allowing residents to participate in

meal preparation, grocery shopping, laundry, and other household chores. These activities will help residents learn new skills and give them a sense of community belonging. But participants expressed their doubts about continuing and monitoring this activity. One family member said:

Yes, that could be a positive thing. But that has to be a goal that every home should set. When my brother lived in a group home, that didn't happen. It happened on a token basis but not regularly. But I think that could be a huge advantage over the Manor, that you could involve these people and their lives. And they could be doing a lot of this stuff like food prep, laundry.

### Impact on Relationships

All of the participants said that residents in smaller groupings would be able to enjoy each other's company and have more meaningful interpersonal relationships. However, some mentioned the negative impact of the transition on the relationship with the residents and staff. They said residents and staff would miss each other. There is a concern about how the move will affect the social interactions and support they have grown accustomed to. Even residents of the Manor have a fear of losing their dear ones. One caregiver said:

Definitely, they (residents) would. It's the worst part of this transition. They have to make an adjustment, but yes, they will miss them. They will miss the staff and other residents. But if they share their feelings with us, we try to assure them. They asked us with whom they are moving; we are giving them assurance that their friends are coming. We have to comfort them and assure them that everything will be fine, and they will attend the activities together.

However, some residents may benefit from a smaller home, where they can form closer relationships with fewer people. The participants highlighted that relocation could be challenging for residents and staff, but it can also offer new opportunities for growth and interaction with the community. Community homes may provide a sense of community and allow residents to interact with neighbours more frequently. One family member reinforced the point:

The only thing that would be improved is interaction with the community at large. Remember what I mentioned earlier with neighbours? Now, when you're outside, they'll get to know you. They get a new relationship.

Communication and assurance are vital in mitigating and addressing resident anxieties through the transition, which suggests the importance of considering the unique needs and preferences of the individuals involved when planning for such a transition.

#### Impact on Privacy

Although many assumed that moving to the community home would improve resident privacy and give them more personal space, some raised privacy concerns, particularly for those who have to share washrooms. Some showed concern about even losing space. One family member expressed fears:

I don't think the privacy would improve. Because I think having a large space helps with privacy. You know, in a group home, you've got a bedroom, kitchen, and one sitting area, or living place.

However, the basic human rights of the residents appear to be met. The move to a group home is expected to make the residents' days more organic and less programmed. Overall, there is hope and optimism that the move to the group home will benefit the residents, particularly those with specific needs such as yearning for a quieter atmosphere.

#### Fear of Losing Service

The analysis suggested that transitioning to a group home may result in reduced medical support and limited recreational and social interaction (with the staff) opportunities. One family member expressed her concern about the nursing service available at Manor:

I'm a little concerned, in a way, about the medical part. At Elmwood, there's always a nurse on staff in residence. They're not going to have that. Or the doctor comes in at Kinsmen Manor on a regular basis. I don't know if he does come to group homes. So, it's more of the medical thing.

Similarly, some in-house group activities will be limited. The rec team will not be in the community home 24/7. The participants suggested that the administration must ensure that the house is well equipped with the activities of the residents' choice. Besides the limited available recreational activity, one family member raised the issue of transport as well:

So, if you wanted to have a special craft date, now you have to make sure you have the transportation; we don't have to pick up residents from this house and this house and then get them to the home. And sometimes you're picking them up at an hour that is early for them because not everyone's a morning person. And you're picking them up at seven o'clock to get into the Manor for an event that starts at nine. And so those are some of the challenges.

#### **Year One Findings from Resident Interviews**

Under the eight domains described in Table 3, we interviewed twenty residents in in-person settings with the presence of at least one supporting member. The interview aimed to collect information

about resident feelings about their living arrangement at Kinsmen Manor, their feelings about moving to a new home with three friends, and the impact on their QoL. Most of the residents (n=13) were supported by their family members, and we interviewed seven residents with no family members in the presence of a support person from Inclusion Saskatchewan (Table 4).

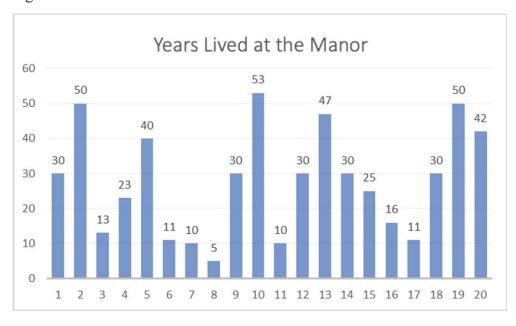
Table 4. Number, Gender, and Relationship of Supporting Members.

Relationship with residents at Manor	Number of respondents (20)
Siblings	10
Mother	2
Niece	1
Support person	7

Gender of the interviewed residents	
Male	11
Female	9

Most of the residents had been living at the Manor for a long time, varying from a minimum of five years to a maximum of over fifty years (see Figure 9).

Figure 9. Years lived at the Manor



After completing transcriptions and securing their release where requested, we analyzed the data using NVivo with the same themes used for the non-resident participants:

### Residents' Perceptions of QoL Indicators

- Social Inclusion
- Recreational Activities
- Choice, Autonomy, and Independence

#### Challenges of Change

- Changes as Challenges
- Adapting to Change

# QoL in a Congregate Setting

- Recreational Activities
- Personal Space and Privacy
- Decision-making Capacity
- Available Supports
- Interpersonal Relationships
- House Environment

#### The Impact of a Community-based Home on QoL

- Improved Living Conditions
- Increased Flexibility
- Impact on Relationships
- Impact on Privacy
- Fear of Losing Service

# **QoL Indicators for Residents at Kinsmen Manor**

Within the scope of the personal development and social inclusion domain, to assess the residents' sense of independence as a component of their QoL, we posed a series of probing questions. Through the residents' responses, we were able to identify critical indicators that contribute to their well-being. We then compared these sub-themes with those reported by non-resident participants. The sub-themes included under this theme are social inclusion, recreational activities, and choice, autonomy, and independence.

#### Social Inclusion

When compared with the feedback from non-residents, who emphasized connections with friends, staff, and community engagement, residents additionally stressed the significance of family involvement. Respondents frequently cited instances of family gatherings as enjoyable moments that hold special meaning for them. When we asked about special days, most identified spending time with family members on different occasions. The frequent words from their responses are plotted in the following word cloud (Figure 10).

Figure 10. Respondents' Perspectives on Special Occasions



During interviews, some conversations touched on the social aspect of working at Cosmo. Respondents mentioned interactions with peers and co-workers, implying a social connection within their work environment. One respondent identified her co-worker as a good friend. And another resident said, "At Cosmo, they listen.". While interviewing the residents, supporting members also acknowledged the importance of interactions with staff members, feeling valued for their contributions, and maintaining social connections. According to one supporting family member, friendship with other residents with whom they worked was important.

Like "M." She was a good friend, right? Your friend that used to be here at the Manor. And now "J," she's just gone to one of the group homes. She was very close.

#### Recreational Activities

Both residents and non-resident respondents highlighted the multiple options for recreational activities. Residents explained they engage in leisurely pursuits, interact with their environment, and find enjoyment in their daily lives. The most commonly expressed words for recreational activities are shown in the word cloud in Figure 11.



Figure 11. Most Important Measures of Recreational Activities Identified by Residents

Many respondents engage in indoor activities such as writing cards, an important form of communication. Music plays a significant role, with individuals enjoying listening to the radio and singing. Television watching is a common pastime, particularly for news and entertainment shows. Card games and board games, including bingo, are popular indoor games enjoyed by multiple respondents. Some respondents also express interest in crafts and colouring, although this is less prevalent. A few residents were involved in choir and sang songs previously. One resident joyfully sang a song during the interview,

There's a church in the valley by the Wildwood,

Oh god, there is a church in the vale.

Oh god, there is a church in the Wildwood,

Oh, come to the church in the vale;

Come, come, come

Oh, come to the church in the vale;

Come to the church in the Wildwood.

Respondents have diverse interests in outdoor activities, such as fishing, which is a popular activity. Other interests include attending hockey and football games, camping and out-of-province trips, going to concerts, watching movies, and exploring different pavilions at events like Folkfest. When we asked about the activities outside of Kinsmen Manor, the options most mentioned are presented in Figure 12.

Figure 12. Most Important Outdoor Activities to Residents



Even though some residents have restricted mobility, they enjoy outdoor activities like observing people, watching vehicles, and relishing the weather. Several residents showed enthusiasm for outings, particularly road trips to enjoy hockey or football games. One resident even shared their joy by recalling a Roughriders game they had recently attended.

#### Choice, Autonomy, and Independence

As identified by the non-resident respondents, decision-making power is critical to developing independence among residents of Kinsmen Manor, something also reflected in resident interviews. The work at Cosmo provides a sense of structure and routine in resident lives. They describe their daily schedules, including the timing of breaks and work sessions, indicating a regular pattern in their engagement. One resident put it this way:

> Well, I wake up in the morning and work at Cosmo. And there they say, and I do the job. It's always like that.

The residents generally expressed satisfaction and a sense of purpose related to their work at Cosmo. One supporting member said:

> And when she got this job, we had no problem after that day. She called me and said, "I got a job. I am just like you." We never had a problem after that.

Indeed, the majority of the respondents embraced their job at Cosmo. During the conversation, residents revealed how actively involved they are in tasks such as paper recycling, tearing pages, and cleaning at Cosmo, which contribute to their sense of belonging and participation within their community. Residents take pride in their work, emphasizing its positive impact on their well-being:

When I am at work, I have a big box of my own. And I take all the paper I have—then take them apart. Then you fold it and put it in the box. When the box is full, you have to give it to the Cosmo staff. They go downstairs, and then they keep it. Then again, repeat, one after the other.

# Challenges of Change

Changes as Challenges: Most of the residents lived at the Kinsmen Manor for five to over fifty years, facing many changes and challenges over time. We asked multiple probing questions to capture how they responded to those changes.

Changes in living settings: When asked about changes they faced in their years of living at the Manor, most failed to identify any. However, when the researcher asked probing questions about living in the same room at the Manor, most identified that their room had changed many times. One of the supporting members reported room changes:

Well, then, she is still here, on this side. But they moved her to a different room. And then she was in the wing she's in now, but at the very far end, the very last one by the room. And that was a good room. It had windows that looked out towards the alley and the park. Yeah. And then the other windows looked to the road.

Few residents changed their bedroom furniture. Families and residents acknowledged this as a challenge for a few of them.

Infrastructure changes: Although few residents identified changes at the Manor, one resident described several changes, including the aging of the place, introducing new bathtubs, a personal move down the hall, and modifying the walls:

The place is getting old. They bring a new thing, new bathtubs. I moved down the hall. And the stuff here like the shower. They shifted the walls, not the whole wall. That was a few years ago. So, washrooms for everyone. And the shower is just for me. And it's shorter; the previous one was higher.

Challenges faced due to aging: Mobility issues impact certain activities, such as bowling or outdoor trips. Moreover, limited staff availability affects participation in certain activities. According to one family member:

She likes to watch people and TV. She used to bowl. But she can't bowl anymore. Well, she can. Mobility right now is an issue. Because she broke her leg.... She fell. But she's been getting better. She's up walking now.

Staff changes: Both residents and their supporting family members acknowledged changes regarding staff. One supporting family member remarked on staff change:

In this last little while, quite a few have retired, right? They were some of the best gems. Hard to step into that position.

### Adapting to Change

Interviews with residents and their supporting members highlighted residents' thoughts, feelings, and opinions about their living situation, experiences, and the changes they've encountered while residing at the Manor. We found that residents appear to be content with their living situation, receptive to changes, and engaged in various activities that provide enjoyment and a sense of belonging.

Acceptance of changes: The residents seem to accept changes fairly well. They mention enjoying the changes in their room and seem content with the new bed. However, some expressed opposition to changes in room furniture. One supporting family member described reactions to changes to resident belongings:

We were talking about change. When "D" was here, they needed to have furniture for her provided by the family. So, my mom and I bought some lovely oak furniture for her room. And she had it until my mom passed away in '84. Okay, so we bought it prior to that. (And am I making you sad, "D"? I'm sorry.) And about four years ago, she moved to this new room. And so, when she was going to be moved, they were concerned that her furniture was getting old. And then, when the mop came by, it took the finish off the back. So, she needs new furniture. So, we bought this beautiful big chest of drawers and a nightstand. And when it came, I brought it in here, and we put it into her room and took out her old dresser, mirror, and nightstand. She was mad. She was very sad about the whole thing.

Residents of Kinsmen Manor also showed emotional attachments to staff who had retired or otherwise moved on. One resident acknowledged that staff changes have occurred during their time at the Manor, and she mentioned missing a particular staff member who left but she still maintained contact with that staff member through phone calls.

Supporting family members explained the residents are emotionally sensitive to changes and absences. It underscores the importance of clear communication and recognizing emotional responses within unique understandings of the world. They shared one example:

Another time she was really pretty mad at me because we are far away in winter. It was the first winter we went away; I wasn't there for Christmas. And "M," of course, took her home, and nothing was said. I guess nobody said anything about us. So anyway, we came and went to the family picnic. We always had a family picnic in June. So, we came to the family picnic, and we were sitting at the table, and she just ignored me. Every time you sat near her, she was just ignoring me. And then I said, "What's wrong?" She wouldn't answer. I think this is now only my own thought. "Did you think I died or something?" And she burst into tears.

These events indicate the importance of proper communication about the changes to make residents comfortable and prepared for changes.

### QoL in a Congregate Setting

Our goal was to understand resident perception of their QoL at Kinsmen Manor. We asked their opinions about the services, their daily assistance, the meals they receive, their recreational activities, and the medical treatments available to them. To measure the quality of these services, we used a five-point scale with pictures or emojis to ease answers. Nearly all residents were happy with their room at the Manor (See Figure 13).

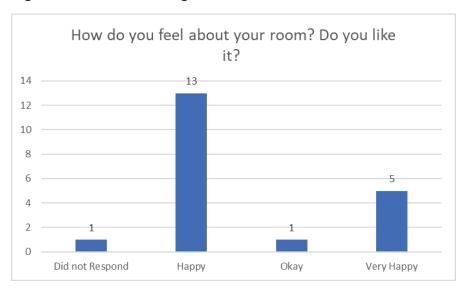


Figure 13. Resident Feelings About their Room at the Manor

When we asked about the meals provided at Kinsmen Manor, residents gave mixed responses from sad to really happy with the majority either happy or very happy (See Figure 14).



Figure 14. Residents' Feelings About the Food at the Manor

#### Available Recreational Activities

The variety of recreational activities at Kinsmen Manor contributes positively to the residents' QoL. These activities offer social interaction, entertainment, creative expression, and a connection to shared memories, enhancing their overall well-being within the facility's community. We asked the residents how they felt about available recreational opportunities at the Manor, and most of them answered they were happy or really happy with the activities, which is consistent with the response of non-residents perception. See Figure 15.

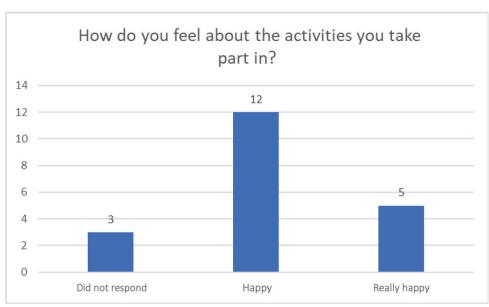


Figure 15. Resident Feelings about Manor Activities

### Personal Space and Privacy

We asked the residents about privacy and personal space to ensure their human rights. Residents reported that they feel their privacy is respected in their rooms. Their rooms are seen as their personal space where they can have privacy and control over who enters. With the help of the supporting family member, the researcher ensured that the residents understood this part. One interview has the following conversation, which supports residents' clear understanding of privacy:

*Researcher:* Do you feel your privacy is respected? Like your space?

Supporting Family Member (X): D, do you think you have your own private space?

Respondent: Yes.

Supporting Family Member (X): And now, can you describe what your private space is?

Where is your private space?

*Respondent:* Right here?

Supporting Family Member (X): Like, not in this room, so where is your private space?

*Respondent:* In my room

The responses were mixed about protecting privacy in this congregate setting. Although most residents re-confirmed in repeated questions that their privacy was protected and people usually knocked on their room before entering, some reported cases of people entering their rooms without permission, suggesting a breach of personal space. One resident responded to researcher probes in this way:

Researcher: Do you feel overall that people respect your privacy?

*Respondent:* No way.

*Researcher:* So, do people come into your room without asking permission?

Respondent: Yes, they do.

*Researcher:* Are they staff or residents?

Respondent: Other residents.

Researcher: So, they don't always respect your space.

*Respondent:* No.

Researcher: So, do you tell them?

*Respondent:* Talking to this wall.

Concerns were raised by other residents regarding the invasion of their privacy when they were not present. They conveyed a sentiment that their personal space is not honoured by others, as reflected in their negative feedback.

Respondent: No, no

Researcher: Not so much. Do people come into your room when you don't want them to?

*Respondent:* Yes. Especially since I am here now, they go around snooping in my room.

### Decision-making Capacity

We posed a question using a five-point Likert scale accompanied by pictorial emojis. We asked residents to rate their response to this question, "Can you choose activities as and when you want?" Most residents (n=14) replied that they sometimes could decide or choose their daily activities. The distribution is shown in Figure 16.

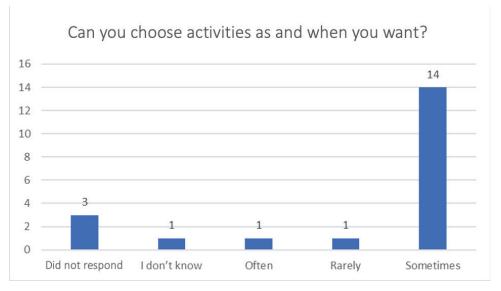


Figure 16. Residents' Opinion on Choosing Daily Activity at Kinsmen Manor

Even during our interview, one resident reported that they can sometimes engage in activities they enjoy, but there is often a significant delay before their turn. They mentioned waiting for months before being able to participate. Additionally, when going out, they noted encountering long lines and having to wait for their turn, such as when attending a hockey game:

Sometimes I can do the things that I like to do. It takes too long to come to my turn. It takes too long. A month, two months later. I have to wait for months. And when we go out, there is always a long line. I have to wait for my turn. When one moves on, then you can say.

When it comes to daily life activities regarding choosing a dress or taking part in the activities, the supporting family members agreed staff members respect residents' opinions and give them options to choose from, helping residents to develop decision-making skills. One family member reported on a resident's support to choose what she wants each day:

She really does love jewelry. They let her choose every morning. They all set out different jewelry sets for her; she just has to choose.

When the activities include a large number of participants, the decision-making capacity of the residents of Kinsmen Manor may be compromised.

# Available Supports

We asked questions to learn about the available supports provided at Kinsmen Manor to improve the QoL of residents. The most repeated words are presented in Figure 17.

Figure 17. Available Supports for Residents of Kinsmen Manor



Residents frequently mentioned caregivers' immediate and helpful response when they requested aid or help. This sub-theme underscores the caregivers' quick and efficient reaction to residents' needs. One resident expressed it this way:

Yes, they helped all the time. Whenever I want to see a hockey game, they plan. The people with wheelchairs or walkers help them.

Some residents share positive experiences of receiving help and attention, while others mention instances where their preferences were not respected. In response to the question, "Do the staff pay attention when you need?", one resident responded:

Some of them pay attention, and some of them don't.

Another resident also supported this information. However, on a five-point Likert scale, we found that most residents agreed that staff listened to them seriously (Figure 18).



Figure 18. Residents' Opinion on Being Heard by Manor staff

Similar to non-resident views, the supporting family members during our resident interview expressed complete satisfaction. Most of the residents also agreed they got good attention and care when they got COVID. One supporting family member reported very good support:

Her nurse keeps in very good touch with us. We were not here when she fell. They phoned right away to let me know. And they phoned in the morning and the night. And you know I've got a phone call from her nurse at the hospital. I love that. It was like, I couldn't believe it.

#### Interpersonal Relationships

We uncovered beautiful connections between residents and their family members. A prevalent theme is the presence of friendships and positive interactions among the residents. Respondents desire to return to the Manor to engage in activities and connect with friends. There is a sense of anticipation and excitement related to social interactions and shared experiences. One resident expressed his excitement about moving with his friends to the new home:

Yeah. "C" is my best friend. He is going with me. "J" is also my best friend; he is also going with me.

Even the use of emojis to convey positivity reinforces the meaningful connections they have with fellow residents. They rated their relationship with the residents at Kinsmen Manor as mostly good or very good (See Figure 19).

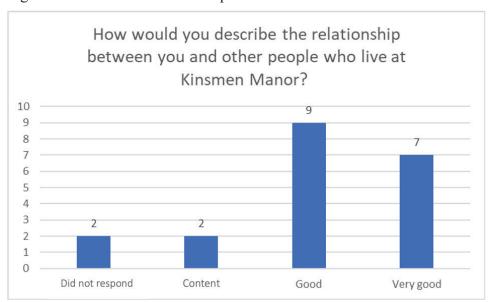


Figure 19. Residents' Relationship with Each Other

We observed strong emotional bonds among the residents. When describing their relationships with other residents, one individual who had recently experienced the loss of a friend expressed their sorrow. This respondent conveyed that they were not yet prepared to contemplate forming new friendships. The conversation between the researcher and the resident was as follows:

*Researcher:* How would you describe your relationship with the other people who live at the Manor?

Respondent: I haven't thought about it. I had a friend here; he passed away a week ago. On Saturday, at 5 am. "K"

Researcher: So, "K" was a good friend of yours?

Respondent: Yes. But he is up now in heaven.

Researcher 2: And what about the others? Do you have any other friends here?

Respondent: No. Not all.

Researcher: So, you only like some of them?

Respondent: I like a few of them. I like "R" and "J."

Researcher: So, who is your best friend?

Respondent: No one, not anymore.

Residents also find social support and companionship from the staff, particularly the kitchen staff. These interactions go beyond practical assistance and extend to emotional connections. Residents seek out staff members for conversations and companionship, highlighting the importance of these relationships in their lives. One respondent confirmed that importance:

When I need to talk, I go to the staff, to the kitchen staff. I went there, and I would have a coffee.

Besides the interpersonal relationship with staff and other residents, family members play a vital role in residents' lives.

#### House Environment

Nearly all residents said they were happy with all areas of Kinsmen Manor, although a few residents identified the large number of residents as a barrier to maintaining QoL at the Manor. One resident expressed frustration due to a disruptive party and emphasized the importance of peace and sleep:

One party keeps me awake at night. People made noise.

Another resident confirmed the impact of noise:

Sometimes, I went to my room and sat by myself. It's noisy here.

# The Impact of a Community-based Home on QoL

The respondents were generally positive and excited about moving to the new home. They discussed their hopes of having a private room, choosing the room's colour, and bringing along familiar belongings. They also anticipated enjoying the facilities and meals in the new home.

#### Improved Living Conditions

The conversations highlight various positive changes that the move is expected to bring: having a smaller, cozier space where individuals can live with close friends, thus fostering a sense of companionship. A quieter environment and more control over their life choices was also emphasized. When we asked what they hoped for in the new place, one respondent replied:

It will be quiet. And I can go out more. I would like to choose the things that I want myself. I'd like more friends and more people to visit me.

The move is associated with a sense of increased independence. Respondents mention being excited about not having others "boss them around" or having the freedom to go out when they want without restrictions. One resident said:

And nobody will be bossing me around. "You do that; you do that."

The respondents expressed enthusiasm about being able to personalize their new homes. They mentioned choosing colours and arranging their rooms. This sense of freedom to decide how they want to use their space emerged as essential for QoL.

### Increased Flexibility

From the interviews, we identified that new homes will offer individuals an increased sense of flexibility and the opportunity to engage in a broader range of activities. From participating in household tasks to enjoying outdoor spaces and pursuing personal interests, moving to a new home appears to empower these individuals with greater control over their living environments and activities. Respondents desired to spend time outdoors and engage in activities like working in the garden, barbecuing, and enjoying the yard. These activities represented a newfound freedom and flexibility that the new home offers. The most frequent activities they mentioned are presented in Figure 20.

Figure 20. Desired Tasks at New Home



Many individuals mentioned their eagerness to participate in household chores and responsibilities, such as cooking, cleaning, washing dishes, and doing laundry. This indicates a sense of ownership and a willingness to contribute to their living space in ways they may not have been able to before. One respondent said:

I like to help with dishes. Washing dishes, drying them, and putting them away in the cabinet. And I will sweep the floor and mop the floor. Just like the person does their job and I do my job.

Respondents expressed an interest in maintaining an organized and tidy living space. They mentioned enjoying activities like setting the table, washing dishes, and cleaning things. One resident expressed her dream about the new home:

I will put in flowers and plants. And I would put a cart in the lounge, in front. And I will put in the flowers. And I will put in the roses, yellow roses, blue roses, and pink roses.

The conversations reveal a positive outlook as individuals express excitement about moving to new homes, anticipating increased flexibility to engage in activities like cooking, gardening, and socializing, and personalizing their living spaces for improved living conditions.

# Impact on Relationships

Respondents express enthusiasm for living with new roommates, often friends or individuals they are comfortable with. They anticipate enjoying their company, sharing common spaces, and engaging in activities together. One resident commented that by staying in their room, they can enjoy their company without violating any privacy:

Researcher: And how about the roommates? Are they some of your special people?

Respondent: Yes. There will be girls and boys.

Supporting Family member (x): And how many are going to be in there?

Respondent: Four people.

Researcher: Four people, including "M."

*Respondent:* I will be in my room. And they will be there in their own room. They will be in their room.

Many participants anticipate returning to their current living environments to visit friends, continue participating in activities, and maintain relationships with other friends. Some look forward to the opportunity to see familiar faces and enjoy the activities they've been engaged in. When the researcher asked about visiting back to Manor, one resident said:

*Researcher:* We've talked about things you'll bring from here. Will you look forward to returning to the Manor to visit friends and do activities?

*Respondent:* I will be working all the time here at the Manor.

#### Impact on Privacy

The discussions also centred on sharing common spaces such as kitchens, living rooms, and washrooms. Participants shared mixed sentiments about sharing these spaces with others, with some

expressing comfort and others having reservations. Although most of the residents said they were okay with sharing the common space and washroom with other residents, one resident was not okay with sharing space, clearly expressing a desire for enhanced space:

I want my room to be big, not small.

# Fear of Losing Service

Participants in the discussion exhibit a range of emotions regarding the upcoming move. While some express anxiety and uncertainty, fearing the unknown changes that the transition might bring, other participants display excitement and confidence, expressing no worries and a positive outlook toward the impending move. One resident expressed concern:

They will be too bossy. And when I go out, they will come with me.

Another resident expressed no such concern:

No worries. I am excited.

One participant brought up the issue of disability within the context of the move. She mentioned that some residents in their current setting have disabilities, possibly indicating concern about the new environment's ability to accommodate their needs:

But a lot of people here are disabled. Like I am one of the people who sit on chairs, who had wheelchairs/ Some people are blind.

Overall, while some expressed fears about changes in their living situation and services, others were more focused on the transition's potential benefits and positive aspects.

# **CONCLUSION**

Committed to a community-based service delivery, consistent with the paradigm shift in service delivery for people living with intellectual disabilities, Elmwood Residences Inc. in partnership with the Ministry of Social Services, Community Living Service Delivery (CLSD) is closing Kinsmen Manor and moving to a community-based home model in which residents live together in groups of four. Beginning in the fall/winter of 2023/2024, the transition from the congregate setting to community-based homes is motivated by literature showing improved health and well-being outcomes for residents of community-based homes, as well as aging infrastructure that no longer meets individual resident physical needs. The move to a community-based living model offers an important research, policy, and practice opportunity to examine the impact of living arrangements on people living with intellectual disabilities in Saskatchewan. It presents an opportunity to fill gaps in knowledge, to document what changes, how and why, and increase understanding of factors in and indicators of quality of life in order to better support those living with intellectual disabilities. This year one study is designed to establish baseline data in support of a longitudinal study pre- and post-transition to community-based homes.

This study importantly deploys a qualitative approach in order to build on existing literature and centre the voices, stories, hopes, fears, and experiences of those most impacted by the changes from their current congregate living environment and the upcoming transition to community-based homes. This research study aims to examine the impact of living arrangements on people living with disabilities in Saskatchewan and understand the residents' experiences, perspectives, and needs, concerns, and aspirations as they prepare to move to community-based living. This exploration is rooted in the existing body of research, which consistently shows improved health and well-being outcomes for residents with ID living in community-based homes but raises questions about the complexity and interdependence of factors and issues of causality as opposed to correlation. The study objective is to provide data that will help policy, program, and practice further improve the QoL of people with ID in Saskatchewan, while adding to the limited literature within the Canadian context.

Through in-depth interviews with both residents and non-residents, the study seeks to capture a holistic picture, focusing on areas such as personal development, self-determination, interpersonal relationships, social inclusion, rights, emotional and physical well-being, and material well-being. This qualitative approach aims to ensure that those most impacted by the upcoming transition are heard and given a say in the planning and implementation of the move.

Our findings reveal several key themes, such as social inclusion, recreational activities, choice, autonomy, and independence, and health and safety fundamental to the residents' well-being. The study highlights the adaptability of residents in the face of changes, such as institutional shifts and the challenges brought on by the COVID-19 pandemic. These changes, while often difficult, were met with resilience and a capacity to find comfort in new routines and environments.

Looking ahead to the transition to community homes, the responses from residents are mixed. While some express excitement about the prospect of more personalized living spaces and autonomy, others convey apprehension about losing familiar settings and support systems. While residents' satisfaction with the Manor's services is generally high, especially regarding recreational activities and medical facilities, the study also highlights the challenge of catering to diverse needs within a congregate setting. It is evident that while the residents of Kinsmen Manor are adaptable and value their independence and social connections, careful consideration must be given to the emotional and practical implications of transitioning to community-based living. The anticipation of enhanced personal space and autonomy in the new homes is a source of optimism, but the fear of losing familiar support systems must be addressed to ensure a smooth transition.

The next steps must involve clear communication, ensuring residents understand the changes and have their concerns addressed. Tailoring the move to account for individual preferences, particularly in terms of privacy and autonomy, is essential. It is important to maintain open dialogue, to listen attentively to the residents, and to make this transition as smooth and positive as possible and to build upon the sense of community and comfort that residents have come to value at Kinsmen Manor.

The study paves the way for future steps. Our research provides valuable insights for Elmwood Residences Inc. and key stakeholders involved in this transition. The findings emphasize the importance of a resident-centred approach in the move to community-based living. This aligns with the broader themes identified in our initial literature review, which highlighted the shift towards normalization and social inclusion models in the care of individuals with intellectual disabilities. Much like the critical disability studies of the 1990s began to reverse the trend of deinstitutionalization, our study reinforces the notion that improved QoL outcomes are attainable through community integration. Paying close attention to residents' social connections, their

autonomy in daily decision-making, and maintaining continuity in care and support, can support the ongoing movement towards enhanced autonomy and QoL for individuals living with intellectual disabilities.

In summary, this research not only highlights levels of satisfaction with the current state of living at Kinsmen Manor, but also offers a guideline for enhancing the QoL for residents as they transition to a new chapter in their lives. The findings from this study centring the unique needs and desires of residents will be beneficial and significant in shaping policies, caregiving practices, and potentially shaping community perception or understanding of these changes and the people involved.

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#### **APPENDIX A**





# Invitation letter to non-resident participants, Families, Caregivers, Manor board and staff, and other stakeholders

Study: Manor Transition Initiative: Outcome and Evaluation

<u>PI:</u> Dr. Isobel M. Findlay, Professor Emerita, Edwards School of Business, University of Saskatchewan; University Co-Director, CUISR; findlay@edwards.usask.ca; Tel: 306-966-2120

<u>Administrative Coordinator:</u> Joanne Hritzuk, Administrative Coordinator CUISR; joanne. hritzuk@usask.ca; Tel: 306-966-2121

<u>Student Researcher:</u> Shirmin Bintay Kader, graduate researcher, Community Health and Epidemiology and CUISR, University of Saskatchewan; byp019@usask.ca; Tel: 306-966-2120

You are invited to participate in an Interview for a research study entitled Manor Transition Initiative: Outcomes and Evaluation. Community-University Institute for Social Research (CUISR), University of Saskatchewan, is conducting the study funded by Elmwood Residences Inc, a Saskatoon community-based organization, that provides a residential home for 30 individuals living with intellectual disabilities. As a part of its commitment to a community-based service delivery model, Elmwood is closing Kinsmen Manor and moving to a community-based home model. The impact on residents' quality of life of the move from the congregate setting to a community-based living model is the focus of this research. The research has been reviewed and approved by the Behavioural Research Ethics Board at the University of Saskatchewan.

The purpose of this study is to examine the impact of living arrangements on the quality of life of residents of Kinsmen Manor. We are inviting you to share your experiences and perceptions of their living arrangements, including supports and activities, plans and schedules for the transition, and their impact on residents' goals and needs and overall quality of life. If you agree to participate, you can help us to establish baseline data and quality of life indicators in support of a potential longitudinal study (subject to funding) following the transition to community-based homes.

We will conduct up to twenty **face-to-face interviews** lasting approximately **60 minutes** with families, caregivers, Elmwood staff and board, and other stakeholders following an interview guide

prepared by the researchers. The interview will be conducted in a private room at Kinsmen Manor, Elmwood Residences, following all public health measures (if allowed). If in-person gatherings are not permitted, you may choose to participate in a password-protected Zoom meeting. If you agree, we will record the interview which will be transcribed by the CUISR research assistant who has signed a confidentiality agreement.

Participation in this study is voluntary. You do not have to answer any questions that make you uncomfortable. Your name and information will remain confidential, unless you choose to be acknowledged in the publication. You can ask to stop recording and withdraw from the study at any time (up to one month after your interview) without any penalty. Your choice to participate or not in the study will have no impact on access to services or how you are treated. The results of the study will be given to the funders and published by CUISR.

Please feel free to communicate with the research team for more information. If you have questions or if you wish to participate, please contact Dr. Isobel M. Findlay at 306-966-2120 or findlay@edwards.usask.ca.

Your time and interest in this study are very much appreciated.

Sincerely,

Dr. Isobel M. Findlay and Shirmin Bintay Kader





#### **Contact Letter for Residents**

## **Study title: Manor Transition Initiative: Outcomes and Evaluation**

You are invited to take part in a study funded by Elmwood Residences Inc. and conducted by Community-University Institute for Social Research (CUISR) to tell us about your quality of life at Kinsmen Manor and the move to a home in the community with some of your friends. **Quality of Life** means how you feel about your life, your home, your relationships, the supports in your life, your health and your goals. The research has been reviewed and approved by the Behavioural Research Ethics Board at the University of Saskatchewan. We hope to talk to all residents at Kinsmen Manor and to up to 20 family members, caregivers, Elmwood staff and board, and other interested people.

We want to find out how you feel about your quality of life at Kinsmen Manor and the move to a new home with three of your friends starting in the fall of 2023. Talking to us will give you a chance to share what it is like to live at Kinsmen Manor, how good your life is, your goals and needs, the people who help you, what supports, and activities, what you enjoy or not, and how they affect your quality of life. If you agree to talk with us, you will help us understand what matters to you and what is important in your life. Your answers will also help people like government develop policy and programs to support your and other residents' quality of life. Please ask any questions you have about the study and what will happen next.

You are welcome to have a support person with you. A **support person** could be a family member, guardian, or appointed advocate. If you have any support needs, or if you want to bring anything that will help you feel more comfortable, you can talk with your support person.

If it is safe for us to meet in-person, we will come to Kinsmen Manor and talk with you. Our conversation will last for **up to 60 minutes**. We will talk with you in a private room so other people cannot hear us talk. If you agree, we will record our conversation so that we can listen to the recording of you talking. The CUISR research assistant (who has signed an agreement not to tell anyone about what you say) will prepare a copy of what you say that you can add to or change. If you want to have someone with you as you read the copy of what you said, you will be able to have a support person with you.

It is your choice to agree to talk to us or not. You don't have to answer any questions you don't want to. You can let us know if you want to take a break or stop talking to us or stop recording. You can stop talking at any time and you can ask to talk again in a second conversation. You may withdraw from the study at any time (up to one month after our conversation) without anyone being upset with you. Your choice to participate or not in the study will not change the services you receive or how you are treated and cared for.

The results of the study will be presented to the funders, the disability and broader communities and published in a report and plain language summary that will be given to the funders. We will not share your name or any other information in any of our presentations, summaries, or reports or articles unless you want people to know.

You are welcome to contact the research team for more information. If you have questions or wish to participate, please contact Dr. Isobel M. Findlay at 306-966-2120 or findlay@edwards.usask.ca.

Your time and interest in this study are very much appreciated.

## Researcher(s):

**Dr. Isobel M. Findlay**, Professor Emerita, Edwards School of Business, University of Saskatchewan; University Co-Director, Community-University Institute for Social Research (CUISR); findlay@edwards.usask.ca; telephone: 306-966-2120

**Shirmin Bintay Kader**, Masters Graduate Student, Community Health and Epidemiology, University of Saskatchewan; Research Assistant, Community-University Institute for Social Research (CUISR); byp019@usask.ca; telephone: 306-966-2120

**Comfort (Remi) Kusimo**, Research Coordinator, Community-University Institute for Social Research (CUISR); remi.kush@usask.ca; telephone: 306-966-2136

**Joanne Hritzuk**, Administrative Co-ordinator, Community-University Institute for Social Research (CUISR); joanne.hritzuk@usask.ca; telephone: 306-966-2121

#### APPENDIX B





#### **INTERVIEW**

Participant Consent Form

Study Title: Manor Transition Initiative: Outcomes and Evaluation

**Principal Investigator:** Dr. Isobel M. Findlay, professor emerita, Edwards School of Business, University of Saskatchewan; University Co-Director, Community-University Institute for Social Research (CUISR); findlay@edwards.usask.ca; tel: 306-966-2120.

**Student Researcher:** Shirmin Bintay Kader, Masters Graduate Student, Community Health and Epidemiology, University of Saskatchewan; Research Assistant, Community-University Institute for Social Research (CUISR) byp019@usask.ca; tel: 306-966-2120

**Research Coordinator:** Comfort (Remi) Kusimo, Research Coordinator, Community-University Institute for Social Research (CUISR); remi.kush@usask.ca; telephone: 306-966-2136

<u>Administrative Co-ordinator:</u> Joanne Hritzuk, Administrative Coordinator, Community-University Institute for Social Research (CUISR); joanne.hritzuk@usask.ca; tel: 306-966-2121

## **Purpose of the Research:**

The purpose of this study is to examine the living arrangements and quality of life of the 30 people living with intellectual disabilities at Kinsmen Manor, Elmwood Residences Inc. It will be carried out by the Community-University Institute for Social Research (CUISR). As a part of its commitment to a community-based service delivery model; Elmwood is partnering with the Ministry of Social Services, Community Living Service Delivery (CLSD), to close Kinsmen Manor and move to a community-based home model in which residents live together in groups of four. This transition starting in the fall of 2023 is motivated by (a) best practice literature for residential service delivery showing improved health and well-being outcomes for residents and (b) aging infrastructure that no longer meets individual residents' needs. The move from the congregate setting to a community-based living model is the focus of this research. Your involvement in the research is an opportunity for you to tell us about your perspective on the impact of living arrangements at Kinsmen Manor on

residents. This will give us opportunity to complete the following:

- To examine the change in quality of life experienced by residents as a result of the move
- To understand the process by which the change in quality of life occurred
- To provide data that will help policy and program further improve the quality of life of people living with intellectual disabilities
- To establish baseline data and quality of life indicators in support of a potential longitudinal study (subject to funding) following the transition to community-based homes
- To fill an important gap in Canadian disability research

You will be asked questions on a range of topics such as the potential impact of this move on resident quality of life, the supports and schedule needed for optimal results.

#### **Procedures:**

- You are invited to participate in one of up to 20 In-depth face-to-face interviews (recorded if you agree) at Kinsmen Manor, Elmwood Residence; 2012 Arlington Avenue, Saskatoon; SK S7J 2H5. It will take approximately 60 minutes to complete. We will conduct this interview in a private room following the attached interview guide—and following all public health measures (if allowed).
- We are taking all safety precautions to reduce the risk of spread of COVID-19, including temperature check, use of PPEs for researchers and participants throughout (disposable masks will be provided), sanitizing of surfaces and shared items, hand washing, physical distancing, etc.) and expect you to follow public health directives as well.
- We will ask questions about coughs or other symptoms, travel, and contacts with people with COVID-19.
- If you or researchers answer "yes" to any of these questions, the interview will be postponed.
- The research team members adhere to the USask vaccine mandate and are fully vaccinated to reduce the risk of spread of COVID-19.
- You may choose to participate by telephone or by a password-protected Zoom meeting. The
  USask agreement with Zoom ensures that all data will be routed through servers in Canada.
  You may choose to use or turn off video. You may ask for the recording to be turned off at
  any time without giving a reason.
- Please note that, when interviewing from home, the researcher(s) will interview from a location where they cannot be overheard and will make no unauthorized recording. To the extent possible, you are also requested to maintain the privacy of our conversation on your end and make no unauthorized recording of the interview.

- If you agree, we will tape the interview to ensure the accuracy of the record. If you do not agree, the researcher(s) will take field notes. The interview will be transcribed by the CUISR research assistant who has signed a confidentiality agreement.
- Please note no guarantee of privacy can be made with any of the online videoconferencing platforms currently in use.
- Once the interview has been transcribed a copy will be sent to you if you choose for your final approval. You have a deadline of two weeks to respond and return any transcript revisions. You can add, alter, or delete information from the transcript as you see fit within the given period. A reminder email will be sent to participants after one week. If there is no response by the deadline, it will be assumed that participants accept the transcript as sent to them.

Please feel free to ask any questions regarding the procedures and goals of the study or your role.

#### **Funded by:**

This study is funded by Elmwood Residences Inc.

#### **Potential Risks:**

There are no anticipated harms from participating, although sharing your perceptions could stir emotions or cause some stress. If any question make you feel uncomfortable and cause stress, you may choose not to answer. If your discomfort persists, we can refer you for counselling at Kinsmen Manor or you may access counselling from Family Service Saskatchewan at counsellingconnectsask. ca. Please bear in mind researchers' duty to report to the appropriate authorities if any abuse or neglect is disclosed.

#### **Potential Benefits:**

Participants often appreciate the opportunity to be heard through a research study. Your answers and perspectives will help us understand what supports and living arrangements will enable residents to have the best quality of life outcomes. Your answers can facilitate policy and program decision making I support of optimal outcomes. We cannot promise that changes will happen, but by sharing your perspective, you will help people understand more about factors shaping resident quality of life.

#### **Confidentiality:**

• The data will be presented in aggregate form, so that it will not be possible to identify individuals. We will remove all personal data before the analysis. This means that any

direct quotes, opinions, or expressions will be presented without revealing names. To further protect confidentiality, only the research team will have access to the study data. We will share the final report and findings with our funder and it will be published by CUISR. Your identity will remain confidential, unless you choose to be acknowledged in the publication. Your contact information will be coded in the master list which will be stored separately from the data collection. We will destroy the master coding sheet once we analyze the data and integrate findings into the draft report (likely within two-three months of interviews).

- Your confidentiality may be limited, however, by the naming of Kinsmen Manor in the report, by the small population on which the study draws, by recruitment procedures, and by choosing in-person interviews at Kinsmen Manor.
- Confidentiality will also be waived if any abuse or neglect is disclosed. Researchers have a duty to report any such disclosures to authorities.
- The privacy policy of Zoom Video Communications, which hosts the Zoom platform, is available at https://www.zoominfo.com/about-zoominfo/privacy-policy

#### **Storage of Data:**

All recordings and transcription will be stored on the PI Dr. Findlay's password-protected laptop (with a back-up on OneDrive-University of Saskatchewan) in a locked CUISR office for five years after publication. Access to files and raw data will be restricted to the research team. After five years after publication, the data will be destroyed permanently and beyond recovery.

#### **Right to Withdraw:**

Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort up to one month after the interview.

Your choice to participate or not in the study will not impact your employment or relationship with your employer or residents of Kinsmen Manor or how you or they are treated.

## Follow up:

To obtain results from the study, please contact CUISR by phone (306-966-2121) or by email (cuisr. oncampus@usask.ca) or visit our website https://cuisr.usask.ca. A summary of the findings will be available March 2023.

## **Questions or Concerns:**

Contact the researcher(s) using the information at the top of page 1;

This research project has been reviewed and approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free 1-888-966-2975.

#### **Consent:**

# *Option 1* – SIGNED CONSENT

opiion 1 Started Contactive	•		
have had an opportunity to ask	questions and my/ou	nd understand the description provided ar questions have been answered. I consume the form has been given to me for respect to the constant of	sent to
Name of Participant	Signature		
Researcher's Signature			
A copy of this consent will be le	eft with you, and a co	copy will be taken by the researcher.	
<i>Option 2</i> – ORAL CONSENT			
	ng the participant's c	es having read and explained this Conconsent, and the participant had knowled	
Researcher's Signature			
I consent to audio recording of a	my interview	Yes No	_
I would like to review a transcri	nt of my interview	Ves	





#### **INTERVIEW**

Resident Consent Form

Study title: Manor Transition Initiative: Outcomes and Evaluation

<u>Principal Investigator:</u> Dr. Isobel M. Findlay, professor emerita, Edwards School of Business, University of Saskatchewan; University Co-Director, Community-University Institute for Social Research (CUISR); email: findlay@edwards.usask.ca; telephone: 306-966-2120.

**Student Researcher:** Shirmin Bintay Kader, Masters Graduate Student, Community Health and Epidemiology, University of Saskatchewan; Research Assistant, Community-University Institute for Social Research (CUISR); email: byp019@usask.ca; telephone: 306-966-2120

**Research Coordinator:** Comfort (Remi) Kusimo, Research Coordinator, Community-University Institute for Social Research (CUISR); remi.kush@usask.ca; telephone: 306-966-2136

<u>Administrative Co-ordinator:</u> Joanne Hritzuk, Administrative Coordinator, Community-University Institute for Social Research (CUISR); email: joanne.hritzuk@usask.ca; telephone: 306-966-2121

## What is the study about?

This study is about how you feel about where you live and your quality of life at Kinsmen Manor. **Quality of Life** means how you feel about your life, your home, your relationships, the supports in your life, your health and your goals.

We will talk with residents, families and supporters, staff and board members, and others. We will ask questions about how good your life is, your goals and needs, the people who help you, what supports and activities you enjoy or not, and what is important in your life.

We will also ask about how you feel about the move from Kinsmen Manor starting in late 2023 to a community-based home where you will live with three of your friends. We will ask you what your hopes, needs, and goals are as part of this move to your new home.

These conversations will help your team learn how to support you for the best quality of life outcomes.

#### What is involved?

- You are invited to talk to us in a conversation in a private room at Kinsmen Manor that will take about **60 minutes**. We will follow all public health measures (if allowed).
- We are taking all safety precautions to reduce the risk of spread of COVID-19, including temperature check, use of PPEs for researchers and participants throughout (disposable masks will be provided), sanitizing of surfaces and shared items, hand washing, physical distancing, etc.) and expect you to follow public health rules as well.
- We will ask questions about coughs or other symptoms and contacts with people with COVID-19.
- If you or researchers answer "yes" to any of these questions, the interview will be postponed.
- We will be collecting personal contact information that we must retain for 14 days in
  order to follow up with you and/or conduct contact tracing if you may have been exposed
  to COVID-19 at the research site. Contact information will be kept separate from data
  collected for the study; after 14 days it will be destroyed securely.
- The research team members adhere to the USask vaccine mandate and are fully vaccinated to reduce the risk of spread of COVID-19.
- You are welcome to have a support person with you. A support person could be a family member, guardian, or appointed advocate who will be asked to maintain your confidentiality. If you have any support needs, or if you want to bring anything that will help you feel more comfortable, you can talk with your support person.
- You may also ask us to schedule our conversation over two sessions.
- If in-person gatherings are not permitted, interviews will be conducted via password-protected Zoom meetings where the researcher will be in a place where other people cannot hear us talk. This is to protect your privacy. If you have any hearing impairments, we will provide audio captioning for the zoom meeting. Please note, USask's agreement with Zoom ensures that everything is stored in servers in Canada. Here is a link to Zoom's privacy policy: https://explore.zoom.us/en/privacy/
- Please note no guarantee of privacy can be made with any of the online videoconferencing platforms currently in use.
- If you agree, we will tape record this conversation. You can ask for the recording to be stopped at any time. If you do not want us to tape record, the researchers will take notes. The researchers (who have signed an agreement not to tell anyone about what you say) will prepare a copy of what you say and send it to you/ your support person. You or your support person can add to or change the copy within two weeks of getting it.

• We will send you or your support person an email to remind you after one week. If you do not respond by the end of two weeks, we will consider that you accept the copy as sent.

Please feel free to ask any questions about what is involved in the study.

## **Funded by:**

Elmwood Residences Inc.

## **Potential Risks:**

There are no known risks to taking part in this study, although sharing your story could cause some anxiety and/or stress. You may answer only those questions that you want to answer or feel comfortable answering. And you don't have to take part if you're not sure. Your access to care and services will not be affected if you don't take part. And if you become upset because of the questions, you can get counselling at Kinsmen Manor, or you may access counselling services from Family Service Saskatchewan at counsellingconnectsask.ca. Please bear in mind researchers' duty to report to the appropriate authorities if you disclose any abuse or neglect.

## **Potential Benefits:**

Participants often appreciate the opportunity to be heard through a research study. Your story and answers will help us understand what matters to you, your goals, and needs, and help advise on what supports and living arrangements will help you to live your best life. We cannot promise that changes will happen, but by sharing your story, you will help people understand more about what is important to you.

#### **Confidentiality:**

Your name or any other information that could identify you (consent form, recording, or written copy of our conversation) will not be shared with anyone outside the research team. They will be stored safely and separately by the researchers. The results of the study (in the form of a formal report) will be given to the funders and published by CUISR. We will not put your name in our report. The report will say "one person said". We will also not include in the report anything you share that might identify you because it is unique to you.

Your confidentiality may be limited by the naming of Kinsmen Manor in the report, by the small population on which the study draws, and by recruitment procedures.

If a support person is present, they will be asked to keep the conversation confidential and not repeat anything that is discussed.

Confidentiality will also be waived if any abuse or neglect is disclosed. Researchers have a duty to report any such disclosures to authorities.

Your contact information will be given a code number in the master list of residents being interviewed which will be stored separately from the information you share. We will destroy the master list once we analyze and include findings into the draft report (likely within two-three months of interviews).

## **Storage of Data:**

All recordings and transcription will be stored on the Principal Investigator, Dr. Findlay's, password-protected laptop (with a back-up on OneDrive-University of Saskatchewan) in a locked CUISR office for a period of five years after publication. Access to files and raw data will be restricted to the research team. After five years after publication, the data will be destroyed permanently and beyond recovery.

#### **Right to Withdraw:**

- *Right to withdraw* means that it is your choice whether you talk to us or not and you don't have to answer any questions you don't want to. You may ask to have the recording turned off and can stop talking with us at any time and you do not have to explain why. You can ask to finish talking with us in a second conversation. No one will be upset with you. You can withdraw up to one month after we talk with you.
- Whether you agree to talk with us or not will not change the services you receive or how you are treated and cared for.

#### Follow up:

We will send you a short summary of the results of the study, which should be available March 2023. To get the full report, please contact CUISR by phone (306-966-2121) or by email (cuisr. oncampus@usask.ca) or visit our website https://cuisr.usask.ca.

#### **Questions or Concerns:**

Contact the researcher(s) using the information at the top of page 1;

This research project has been reviewed and approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free 1-888-966-2975.

Appendices					
Consent:  Permission to audio record the converge a written copy of the converge and the co		Y		No	
– SIGNED CONSENT/ASSENT					
Consent means that you give perm Your signature below indicates, or provided and that you give your co	tells others, t	hat you h			1
I have had an opportunity to ask q participate in the research project.		•			
Name of Participant	Signatur	e		Date	
Name of Support Person (if applicable)	Signatur	е		Date	
Researcher's Signature	 Date				
ORAL CONSENT/ASSENT					
I explained the research to the part of my knowledge, the participant consented/assented to participate.	-		• `	**	
Name of Participant	Name of	Support p	oerson (if ap	plicable)	

**74** 

University of Saskatchewan

#### **APPENDIX C**





## **Non-Resident Interview Conversation Guide**

## **Manor Transition Initiative: Outcomes and Evaluation**

Mark	Steps to be covered before the interview
a.	Explain purpose of interview –
	The purpose of the interview is to collect information about the resident living arrangements at Kinsmen Manor and impact on Quality of Life (QoL) and their needed supports, their dreams and fears about vthe move to community-based homes of four people. This information will help us understand better the impact of living arrangements on people's QoL.
b.	Go over the interview consent guidelines –
	Explain that whether or not they participate will have no effect on the service residents are getting at Kinsmen Manor or how they are treated. We will not tell anyone about their responses.
	If they agree to recording of the conversation, they can ask for the recorder to be turned off at any time; they do not have to answer a question if they don't want to; they can finish the interview at any time for whatever reason with no penalty for choosing to end the interview.
	They may withdraw up to one month after the interview.
c.	Sign the consent form —
	If they agree to participate, get the individual to sign the forms and give them a copy for their records.

Mark	Steps to be covered before the interview					
d.	Explain what will happen to information from our conversation –					
	All the information will be put together into a report about resident QoL. The report will be shared with funders and made public. The goal of the research is to establish baseline data and quality of life indicators in support of a potential longer study (if we get the funding) following the transition to community-based homes. We will share a plain language summary and infographic with all of the participants as well as a final report to be published on the CUISR website.					
Intervie	w Guide (TURN ON THE RECORDER IF PERMISSION IS GIVEN)					
e.	Getting to know the individual					
	Ask the individual for a general brief overview about themselves, their role and relationship to Kinsmen Manor residents.					

#### Domain 1:

#### **INDEPENDENCE:**

#### 1. Personal Development:

- a) Can you tell me about changes that residents have experienced in their time living at Kinsmen Manor?
- b) Can you tell me how residents have handled those changes?
- c) What do you think are important factors in or measures of their Quality of Life (QoL)? Here I want you to think about their life, their friends at Kinsmen Manor, the supports in their life, their health and their goals.
- d) How would you rate the quality of supports provided by Elmwood Residences based on their day-to-day care?

Very High Quality	High Quality	Average Quality	Low Quality	Very Low Quality
----------------------	--------------	-----------------	-------------	---------------------

e) How would you rate the quality of residents' diet?

Very High Quality	High Quality	Average Quality	Low Quality	Very Low Quality
----------------------	--------------	-----------------	-------------	---------------------

f) Can you rate Kinsmen Manor available recreation activities?

Very High Quality	High Quality	Average Quality	Low Quality	Very Low Quality
----------------------	--------------	-----------------	-------------	---------------------

g) What about their medical treatment facilities?

Very High Quality	High Quality	Average Quality	Low Quality	Very Low Quality
----------------------	--------------	-----------------	-------------	---------------------

- h) Do you think the move from Kinsmen Manor to a community-based home will enhance the choices and opportunities for residents? Please explain.
- i) Do you think the residents of Kinsmen Manor are excited about the move to community-based homes?
- j) Do they also have fears about the change?
- k) How would you describe your perception of the overall "Quality of Life" of the residents of Kinsmen Manor?

Really Good	Good	Okay	Not very good	Really bad
-------------	------	------	---------------	------------

## 2. Self-determination:

- a) What recreational activities are most important to the residents of Kinsmen Manor? Could you explain how you think those activities have affected the quality of life of the residents?
- b) How do the residents of Kinsmen Manor decide the daily activities? If they do, please explain how (Circle one).

Always	Often	Sometimes	Rarely	Never
--------	-------	-----------	--------	-------

- c) Do residents decide when and with whom they share activities?
- d) How do you think that their deciding or not impacts their quality of life?
- e) Do you think moving to community-based homes will increase the opportunities for deciding or selecting the daily activities?

#### Domain 2:

#### **SOCIAL PARTICIPATION:**

## 3. Interpersonal Relationships:

a) What is your perception of the relationships among the residents of Kinsmen Manor?

Really Good	Good	Okay	Not very good	Really bad
-------------	------	------	---------------	------------

- b) How do you think moving to community-based homes will impact their relationships? Please explain how.
- c) What supports have you found most beneficial for the residents of Kinsmen Manor? Do you think those supports will be adequate or not to support them through the move to community-based homes?
- d) Do you think residents of Kinsmen Manor will get help more promptly and effectively at community-based homes?

#### 4. Social Inclusion:

a) In the last 12 months how often did you visit or interact with the resident/ loved one personally or virtually at Kinsmen Manor?

I didn't visit once in past 12 months	1-3 times	4-12 times	More than 12 times
---------------------------------------	-----------	------------	--------------------

b) During your most recent visit, did staff at Elmwood Residences welcome you and engage with you in meaningful ways?

Yes	Somewhat	No
-----	----------	----

- c) Do you think moving to the community-based home will increase the number of your visits? If yes, can you explain why?
- d) Do you feel the residents of Kinsmen Manor will miss their fellow residents and/ or staff members after moving to a community-based home? If yes, what might be done to reassure and address any concerns?

## 5. Rights:

- a) How important do you think it is to bring a human rights perspective to resident living arrangements and quality of life? Please explain
- b) Do you think at Kinsmen Manor resident privacy and rights (Like sharing washroom, proper sleeping arrangement) are well preserved? (Explore: General rights)
- c) Do you think the rights and privacy can be improved by moving to community-based homes?
- d) Do you think the move will overall have a positive impact on resident QoL?

#### Domain 3:

**WELL-BEING:** (Explore: Quality of Life at Kinsmen Manor)

#### 6. Emotional:

a) How do you feel about the resident's bedroom or suite at Kinsmen Manor?

Really Happy	Нарру	Content	Sad	Really Sad
--------------	-------	---------	-----	------------

- b) Do you believe that the resident likes their room at Kinsmen Manor?
- c) How do you feel about the meals/ food provided for residents?

Really Happy Happy	Content	Sad	Really Sad
--------------------	---------	-----	------------

- d) Do you think the quality of the food and services can be improved?
- e) Do you think moving into a community-based home will increase the resident's involvement in household activities in a good way? Please explain.

## 7. Physical:

- a) Do the residents get good attention from the staff or caregivers at all times?
- b) Do you think that moving to a community-based home will increase the quality and number of services or not? Please explain.

#### 8. Material:

a) How do you think the residents of Kinsmen Manor are impacted by sharing washroom facilities with other residents?

- b) Are there difficulties Manor residents face in the congregate setting that could be improved by the move to a community-based home?
- c) Is there anything else you would like to add regarding resident quality of life that we have not touched upon yet? Can you think of any specific needs that are not addressed currently?

## Wrap up:

Thank you for taking the time to talk to me/us today. We will be analyzing and integrating interview findings in a report. If you have requested, we will send you a transcript of the interview to review and make changes. Thanks, and have a good day.





## **Resident Interview Conversation Guide**

## **Manor Transition Initiative: Outcomes and Evaluation**

Mark	Steps to be covered before the interview
a.	Explain purpose of interview –
	The purpose of the interview is to collect information about how you feel about where you live at Kinsmen Manor, your feelings about the move to a new home with three of your friends starting in the fall of 2023, and the impact on your <b>Quality</b> of Life (QoL). QoL means how you feel about your life, your home, your friends, the supports in your life, your health and your goals. This conversation will help us understand better what supports you and your friends need for the best QoL outcomes.
b.	Go over the interview consent guidelines –
	Whether or not you agree to talk with us will have no impact on the services you receive or how you are treated or cared for. We will not tell anyone about what you say.
	You are welcome to have a support person with you. A support person could be a family member, a friend, or staff. If you have any support needs, or if you want to bring anything that will help you feel more comfortable, you can talk with your support person.
	If you agree to recording of the conversation, you can ask for the recorder to be turned off at any time; you do not have to answer a question if you don't want to; you can stop talking with us at any time and you don't have to explain why. Nobody will be upset with you. You can withdraw up to one month after the conversation. This is about your voice, your stories, to help get the support you and your friends need.

Mark	Steps to be covered before the interview
c.	Sign the consent form —
	If you agree to talk with us, you (or your support person) will sign the forms and you will get a copy to keep.
d.	Explain what will happen to information from our conversation –
	All the information will be put together into a report that will be made public. The report will tell your own and your friends' stories about what is most important for your quality of life. We might be back to talk to you again (if we get the funding) following the move to community-based homes. You will get a short plain language summary that tells your stories.
Interview	w Guide (TURN ON THE RECORDER IF PERMISSION IS GIVEN)
e.	Explain that we will start by getting to know you.
	We will start by getting to know one another and asking you to tell us a bit about yourself (e.g. age, family contact, friends, likes and dislikes), before asking about your time at Kinsmen Manor and what has made it good or not.

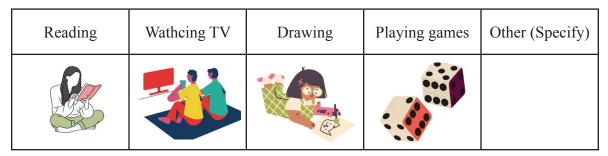
## Domain 1:

#### **INDEPENDENCE:**

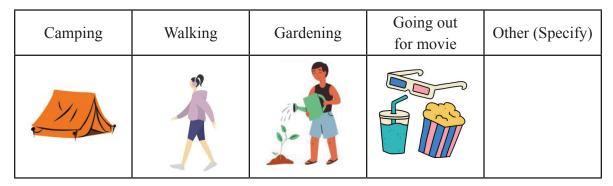
## 1. Personal Development:

- a) Can you tell me how long you have been living at Kinsmen Manor?
- b) Do you find there have been many changes during your time at Kinsmen Manor? (Explore their living experience at Kinsmen Manor) If so, please explain what changes were good for you and what not
- c) Can you share what kind of activities you take part in here? (Circle appropriate options, multiple responses are possible), Such as-

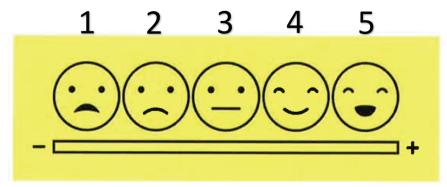
#### **Indoor:**



## **Outdoor:**



How do you feel about the activities?



Moods: Really sad - Sad - Content - Happy - Really happy

- d) How do you feel about the move to living in a new home in which you will live together with three or four of your friends from Kinsmen Manor?
- e) What are you excited about? Is there anything you are worried about?
- f) How do you feel about the chance to choose what your new home will be like, what your own room will look like, what stuff you'll put where in your new home?

- g) Are there things that you have at Kinsmen Manor that you would like to have in your new home?
- h) Will you look forward to activities and seeing your friends and supports at the Manor still?
- i) Can you tell me about the things you would like to do in your new home? Have friends and family over to visit? Eat when you want to? Help at home? Garden? Laundry?

## 2. Self-determination:

a) How do you feel about the activities you take part in? (Circle one)

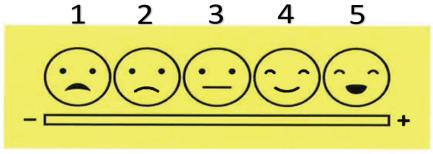
			-	99
Really happy	Нарру	Okay	Sad	Very sad
1	2	3	4	5

Can you tell me who decides the daily activities? If you decide, how does that make you feel? If it is not you, do you like that? Do you want to do anything different?

b) Can you choose activities as and when you want? If yes, how: (Circle one)

Always Often Sometimes Rarely Never
-------------------------------------

- c) Are some activities more important to you than others? Can you tell me which you enjoy the most or the least?
- d) Can you tell me about your life here? How do you feel overall?: (Circle one response)



Moods: Really sad - Sad - Content - Happy - Really happy

e) Do you think moving to community-based homes will increase the opportunities for deciding or selecting the daily activities?

#### Domain 2:

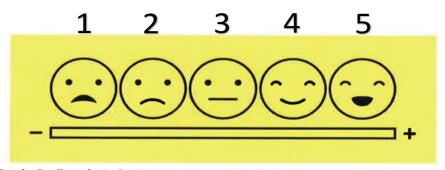
## **SOCIAL PARTICIPATION:**

## 3. Interpersonal Relationships:

a) How would you describe the relationship between you and other people who live at Kinsmen Manor?

			P	99
Really good	Good	Okay	Bad	Really bad
1	2	3	4	5

- b) Can you tell me who means the most to you, who are your best friends, and why?
- c) How do you feel about the support you receive from staff at Kinsmen Manor?



Moods: Really sad - Sad - Content - Happy - Really happy

- d) Do you feel that the staff and caregivers are taking good care of you?
- e) Tell me about a time that you asked for help to do something that mattered to you. Did you feel staff understood your goals or wishes and helped you? (Explore: relationships with staff and caregiver)
- f) Do you think you will enjoy your relationship with your roommates even more in your new home?

#### 4. Social Inclusion:

a) Do you enjoy doing things with the other residents of Kinsmen Manor?

				99
Very much	A lot	Okay	Not very much	Not at all
1	2	3	4	5

- b) How often can you talk with your family members? (Explore: having a normal life) (Exclude for three residents, who have no family members)
- c) Do you enjoy visitors? Can you tell me about that?
- d) Who do you talk to when you have any questions, dreams, or concerns? (roommate, family member, staff member, friend)
- e) Do you feel the staff members listen to you and take your opinion seriously at Kinsmen Manor? (Explore: to be accepted by others)

Always	Often	Sometimes	Rarely	Never

## 5. Rights:

- a) During your time living here, do you think you have privacy? (Like sharing washroom, proper sleeping arrangement, information sharing). (*Explore: General rights*)
- b) Do you think moving to your new home will protect your privacy and rights better?
- c) Do you have any fears about moving from Kinsmen Manor to a smaller house?

## Domain 3:

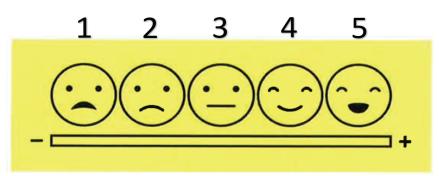
**WELL-BEING:** (Explore: Life at Kinsmen Manor)

#### 6. Emotional:

a) How do you feel about your room? Do you like it?

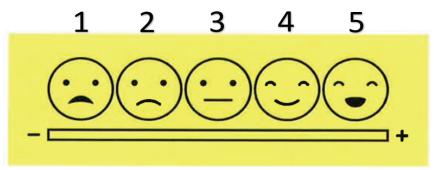
				99
Really happy	Нарру	Okay	Sad	Very sad
1	2	3	4	5

- b) What do you want your bedroom to look like at your new home? (Provide examples: Colour of your room)
- c) How do you feel about the facilities (gym/living room/ program area/ dining room/ bathroom) in the rest of Kinsmen Manor?



Moods: Really sad - Sad - Content - Happy - Really happy

d) Can you tell me about your meal experience? Do you like it?



Moods: Really sad - Sad - Content - Happy - Really happy

## 7. Physical:

- a) Do you feel you get good care from staff whenever you get sick?
- b) Do you feel you can get better care with moving into your new home?
- c) Can you access/see a nurse when you need support with your health?

#### 8. Material:

- a) Do you feel any discomfort with sharing washrooms with the other residents at Kinsmen Manor?
- b) Moving to a smaller house will allow you to share the washroom with a few friends. How do you feel about that?
- c) Can you think of anything you need and would like in your new home?
- d) Is there anything else you want to share with us?

## Wrap up:

Thank you for taking the time to talk to me/us today.

The next thing we are going to do for this study is to write down what you said during the recorded conversation (if it was recorded). If you have asked for it, we will send you a written copy and you can make changes, or add or remove information.

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