Finding Our Way Home

Housing Options in Inner-City Winnipeg for People with Disabilities Who Are Dying

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CANADIAN CENTRE ON DISABILITY STUDIES

WINNIPEG INNER CITY RESEARCH ALLIANCE

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The personal experiences of living with disabilities were actualized for both authors of *Finding Our Way Home.* Deborah Stienstra lived with the death of her partner, Patrick Kellerman, as a result of complications from his disabilities in the middle of this project. His housing transitions in the last year of his life provided the catalyst for this research project and a personal reference point in listening to the stories of this project. Neither Deborah nor her partner anticipated his death so quickly. His wit and wisdom were missed in completing this project. Rhonda Wiebe underwent a rapid and dramatic deterioration of her vision due to complications of her disability during the last year of this project resulting in four eye surgeries and fundamental adaptations in order to accommodate new visual needs. Family and friends spent countless hours reading research materials aloud to her, typing and transcribing in order for the story of this project to appear on paper – thank you to all of you for your part in this journey!

Finally, and most importantly, our acknowledgements are extended to the people who participated in this research. These include both the service providers interviewed about their community involvements, and persons who spoke from direct life experience. It takes tremendous courage to talk about where you live and what you experience when you are anticipating the end of life. These people risked the significant vulnerability inherent in such conversations in order to share information with a researcher who was often a stranger. This research project could only be possible because participants were willing to take that risk in order to draw attention to the complexities of having disabilities, living in the core area of Winnipeg, and experiencing end of life issues. Some of these people have since passed away. We are committed to making this research an effective tool that can be used towards securing appropriate housing conditions so that those who are dying can be "at home" in the places where they live in inner city Winnipeg.

~ This project is dedicated to the memory of those who shared of their lives, but who are no longer with us. ~

EXECUTIVE SUMMARY

This project encompassed three pertinent social issues: the lack of safe, affordable, available and accessible inner city Winnipeg housing; the lack of supports available for people living in the core area experiencing end of life transitions; and the barriers encountered by people with disabilities. Each of these issues stands on its own as an important topic for research. Merging these three streams not only compounds issues but also brings forward new concerns that have, according to our research, never been identified before.

The approach used in researching and presenting the information for *Finding Our Way Home* was grounded in the understanding of disability as being the product of the interaction between people and their environments (O'Day and Killeen, 2002). The *Independent living* concept is based on the assumption that attitudes and perceptions about disability are not caused by a disease or impairment but through the interactions between persons within a larger social environment. Disability is self-declared; persons make this declaration in order to access services that will appropriately enhance their lives and help them achieve Independent living (Denson, 1988).

We identified five housing settings of participants for this project. These are:

Participants' own homes (private residences);

Transitional housing;

Independent living group settings;

Long term care facilities;

Acute care hospitals

Findings

1. People with disabilities living in the core area of Winnipeg are poor. People living in unsafe neighbourhoods have spent a lifetime exposed to more health risks than those with adequate incomes.

2. Many poor people with disabilities are of First Nations descent. If you are of First Nations descent and you live in the inner city, you are more likely to be poor, to have a disability, to live isolated and alone, and to die sooner than someone of European descent;

3. People with disabilities living in their own homes dwell in unsafe, inaccessible and inappropriate housing.

4. Women with disabilities in end of life transitions struggle with inadequate, unsafe housing and distinct support issues.

5. Participants experienced the lack of accessibility in all housing settings.

6. People in transitional housing had no other appropriate options.

7. People preferred Independent living group setting because of 24 hour access to self directed care.

8. People in long-term care facilities enjoyed socialization and security but not privacy, accommodation for families and independence.

9. Participants living in acute care hospitals did not experience emotional security or good physical care.

10. Home was more than a location; it was a setting where one's family and social circle gathered, and a restorative place that promoted well-being.

11. People with disabilities experiencing end of life transitions do not know where they will live when they die.

12. Housing, disability-related and palliative care service providers focused primarily on the limitations of their individual mandates, with few deep connections that merged the concerns of housing with the concerns of living and dying with disabilities in downtown Winnipeg.

13. Service providers faced considerable challenges relating to distinct disability-related needs, end of life issues, knowledge about First Nations cultures and issues, appropriate housing settings, and appropriate care for people with disabilities in the core area of Winnipeg.

14. People with disabilities can experience dying as a cyclical rather than a linear event.

Recommendations
The following recommendations are put forward to address many of the difficulties described by the people with disabilities living in the core area of Winnipeg who participated in this research. These recommendations are to be implemented by:
- Government and other agencies and individuals who provide housing;
- Government and other agencies that provide support services;
- Health care providers; and,
- Community advocacy groups.

1. INCREASE ACCESSIBLE HOUSING STOCK FOR PERSONS WITH DISABILITIES LIVING IN THE CORE AREAS OF WINNIPEG.

2. ENSURE PEOPLE WITH DISABILITIES HAVE ACCESS TO THE END OF LIFE SUPPORTS THEY REQUIRE IN THE HOUSING SETTING OF THEIR CHOICE.

3. PROMOTE INDEPENDENT LIVING SETTINGS FOR END OF LIFE HOUSING.

4. PROVIDE ACCESSIBLE TRANSITIONAL HOUSING FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES.

5. INCREASE PALLIATIVE CARE OPTIONS FOR PEOPLE WITH DISABILITIES IN CORE AREAS.

6. ENSURE HIGH STANDARDS OF CONDUCT BY PROFESSIONALS PROVIDING SERVICES TO PERSONS WITH DISABILITIES AND FIRST NATIONS PEOPLES.

1. INTRODUCTION

This project encompasses three pertinent social issues concerning core area housing, the lack of supports for people in end of life transitions, and the barriers encountered by people with disabilities. Merging these three streams not only compounds issues but also brings forward new concerns.

Disability advocates have produced literature supporting full citizenship, equal accessibility, autonomy and independence for persons living with disabilities. However, disability groups are only beginning to explore end of life transitions and the accompanying issues faced by people with disabilities. Healthcare professionals have written a great deal about palliative care for the general population. The Manitoba Centre for Health Policy released its report, *Patterns of Health Care Use and Cost at the End of Life*, in February, 2004 (Menec et al, 2004). The majority of health care users in Manitoba who are experiencing end of life are over the age of 65, and this is reflected in this report. Notable in the report, however, is the lack of analyses concerning the distinct needs of younger people with disabilities and First Nations persons with disabilities. *Finding Our Way Home* wants to make prominently visible the very people who have been invisible in previous research.

The development of appropriate and affordable housing stock for people with disabilities is gaining widespread attention. In April 2004 the Office of Disability Issues, Province of Manitoba, held a housing forum facilitating dialogue between disability groups, the Ministry of Housing and other provincial government departments. The participants recommended affordable, accessible, appropriate and safe housing in the core area of Winnipeg.

People with disabilities who are dying, however, find that safe, accessible, affordable and appropriate housing options in the core area of Winnipeg narrow very quickly. Two of the participants in our study had lived in substandard downtown hotels. Many people live in unsafe and inaccessible rental properties in the core area. Accessibility issues also prevail in transitional housing and families cannot be accommodated in that setting or in long term care facilities. Independent living group settings provide people with accessibility and autonomy, but are not set up as places where people can die. Participants in acute care hospitals experience loss of autonomy and dignity, racism, abandonment and despondency.

How and when people with disabilities die has an impact on where they die. The process of dying is often seen as a linear one – people gradually get sicker and lose more ability as they grow closer to death. This perception sees people traveling along a straight line going from one milestone to the next in one direction. However, participants in this study discussed the cyclical nature of dying for persons with disabilities. The onset of disability complications can bring persons to a critical brink where they are very close to dying, only to recover and eventually resume all the activities of daily living. This cycle might perpetuate itself many times. Each time the person experiences critical medical circumstances, death is a very real possibility. When one is living in this cycle, the linear trajectory of dying, and services arranged based on it are often irrelevant.

Almost half of the people interviewed as part of the research for *Finding Our Way Home* described themselves as First Nations, Inuit or Métis persons. This research strives to portray Aboriginal peoples' understandings of dying and death by including the important stories by First Nations and Inuit participants who shared their beliefs about the need for a sacred space to live and die in order to embark on their journeys home.

2. METHODOLOGY

2.1   Participants and service providers
We researched the *Finding Our Way Home* project by collecting qualitative data from interviews with 24 people with disabilities in the latter stages of their lives that were living in Winnipeg's core area. Thirteen people identified themselves as First Nations. Participants included mothers, fathers, grandmothers, grandfathers, single people, persons in committed relationships, First Nations people, immigrants, people employed, people living on social assistance, and individuals whose first languages were Salteaux, Cree, Dene, Inuit, Ukrainian, Polish or French. Translators were provided if requested.   The youngest participant was 27 years of age; the oldest was 83. Eight service providers who represented disability, First Nations disability-related, and palliative care organizations were also interviewed.

Although the data collected for this project was qualitative, quantitative information is represented with verbal descriptions that indicate numbers of persons or prevalence of responses as follows:

- a few = 2 to 5 participants
- many = more than 5 participants
- most = more than half (i.e. the majority) of the participants
- all = all participants

Interview questions were developed by the researchers and approved by the Canadian Centre on Disability Studies research ethics committee, the project partners, and the project advisory committee. We sent recruitment materials to a cross-section of disability and palliative care organizations, First Nations groups, community health centres, and individuals. Many of the participants came forward on the recommendation of trusted community advocates and health care workers.

2.2   Study Location

The parameters of the core area of Winnipeg, as established by the Core Area Initiative Project (1981), were provided by the Institute on Urban Studies, University of Winnipeg. The designations of this area include the electoral city wards of Burrows-Central, William Whyte, Centennial, North Main, Point Douglas, North and Central St. Boniface, Daniel McIntyre, St. Matthews, Wolseley, Spence, West Broadway, Central Park, South Portage, Broadway-Assiniboine, and River Osborne (City of Winnipeg 1981). *See Appendix 7.1 for map.*

2.3   Presenting information as a narrative

Disability is the product of the interaction between people and their environments (O'Day and Killeen, 2002). The approach used in researching and presenting the information for *Finding Our Way Home* was grounded in this understanding. Particular attention has been given to end of life transitions for people with disabilities that live in the core area of Winnipeg. The research is qualitative, and the experiences of the participants are the hub of the project's design. A thorough literature review is embedded in the report, with the stories of the people culminating each of the findings.

3. FINDINGS: Past and present research

"You played heroic, necessary games with death."
Adrienne Rich

> ➢   Disability is a social construct more than a condition based on physical or mental characteristics. Some people with disabilities are redefining themselves as members of a minority group needing protection of civil rights and accessible environments.
> ➢   There are links between housing and health. A pressing health issue is residential segregation determined by income, social class, race and ethnicity.
> ➢   Some participants received excellent home support care, others received inadequate care with significant health risks and still others received no care at all. Some people who stated they clearly needed home support refused it because of privacy issues and experiences with racial prejudice and disability related discrimination. More people in their own homes and in transitional housing received help from family or friends than from Home Care support services.
> ➢   People in Independent living group settings receive Home Care program dollars for attendant services.
> ➢   People living in long term care facilities stated their need for increasing support services played a critical role in their decision to move out of their communities and into institutional care.
> ➢   Home Care or institutional eligibility requirements, schedules and regulations can play a role in undermining individual self-determination.

3.1   Understanding disability

Disability is more than a condition characterizing an individual's limited functioning. Disability is also a construct arising out of the interaction between individuals and their surroundings. Traditional models based on providing cure or rehabilitation are the focus of a medical understanding of disability (O'Day and Killeen, 2002). Predominant in the Independent living Movement and important to the Disability Studies approach is the "Social Model" – the concept of disability as a social construct rather than a medical or pathological problem (Schaff, 1993). The social construction of disability underscores the reality that attitudes and institutions of the non-disabled are more of an impediment than certain biological characteristics (Asch and

Fine, 1988). This understanding of disability shifts the focus from rehabilitating the person with the disability to a new rights-based approach that concentrates on changing societal perceptions. Many people with disabilities are now redefining themselves as members of a minority group in need of civil rights protection and accessible environments. This understanding includes the recognition that individual citizens and society as a whole are enhanced by the presence of people with disabilities because they enable society to be more creative, diverse, and accepting of individual differences (O'Day and Killeen, 2002; Hahn, 1993).

The *Independent living* concept is based on the assumption that attitudes and perceptions about disability are not caused by a disease or impairment but through the interactions between persons within a larger social environment. Within this understanding disability is self-declared. Persons make this declaration in order to access services that will appropriately enhance their lives and help them achieve Independent living (Denson, 1988). The Independent living philosophy holds to the conviction that people with disabilities identify their needs for assistive services rather than be recipients of care giving (Schaff, 1993).

3.2 What is "home" to people with disabilities in end of life transitions?

> ➢ Home is more than a location; it is a setting where one's family and social circle gather, and a restorative place that promotes well-being.
> ➢ First Nations people with disabilities experiencing end of life transitions saw their homes as places where kinship connections, traditional foods and spiritual experiences should be located but where family breakdown, unsafe conditions and poverty can occur.

Shelter is a basic human need (Centre for the Advancement of Health, 2003). The term "home" is nuanced with meanings that journey along a continuum from the practical to the poetic. Home is a shelter – it is a place but it is also a state of being. This became clear when conversing with participants of Aboriginal descent. When First Nations and Inuit participants were asked to describe where they lived, they spoke of their kinship connections, traditional foods, spiritual experiences, and the breakdown of their familial structures.

The oldest participant in the study, an 83 year old Aboriginal elder, pulled a picture of a Canadian flag from a bag when it was explained to him that the project interviewer would talk to him about housing.

"Can you see anything wrong with this?" the elder asked, indicating the flag. The interviewer offered the suggestion, *"Red and white? The leaf, the living thing is red?"* *"Yes, yes!"* the elder responded, "*Years before anyone came to this country; our people were all living… so when Canada became what it is, they stole our leaf. This is our maple leaf in the first place. So what is this? [The outside stripes] are the white man, and [the leaf] is the red man. He can't escape."* When asked where he learned of the story of the flag, the elder replied, "*They're not actually my stories, they're the stories of my ancestors."*

Home for this man was not about location, it was about the destruction of his nation, and he used an image to convey his people's history of disenfranchisement and racial oppression.

Other participants also understood home to be more than a location. One of the characteristics participants saw as critical in terms of housing needs included availability. This was expressed by one participant as follows:
"In order for me to get into suitable and affordable housing, the doctors had to write letters and quite a few social workers had to get involved to get me in. I would have been on a 3 year waiting list."

Home was described as a setting where one's family and social circle could gather, and a restorative place that promoted well-being. One participant described her ideal home situation as:
"I need a lot of supports. I'd like to have a family member or someone [around] because they care about me. I need to have someone who's not going to pity me, who is going to respect me."

Another participant said:
"What would I like [in housing]? I don't [want to] have to deal with stairs. I guess mostly to have someone that…stays in the building who could know if [you] have a problem and check on you."

Links between housing and health are discussed in previous research. Housing is a basic human need both physically and psychologically. Housing provides shelter from the elements and protection against health

threats such as communicable and chronic diseases, and psychological and social stresses. It is also a source of identity. We identify and become attached to our homes. Housing is important because it is the place where a family/household establishes itself in society. Beyond the level of the individual home, housing is also important because housing units are set in relation to each other. Homes create neighbourhoods and communities which form the physical infrastructure of group life (Fullilove, 2003). Perhaps the most common concept of home is of a material, bounded place where our own activity spaces and those of people closest to us overlap. It is a place where we are accepted and affirmed as who we want to be. Home is also defined in terms of our roots, and is, therefore a cultural as well as a spatial place. Home is inseparable from the concept of identity" (Teather, 1999). Somerville offers an extensive collection of understandings of home that includes home as hearth implying the warmth and coziness that home provides to the body; home as heart emphasizing emotional rather than physiological security and health; home as privacy and the power to control one's own boundaries; home as roots meaning one's source of identity and meaningfulness. Furthermore, if we view home as an abode, then home can be anywhere that one happens to stay, whether that be a palace or a park bench. Finally, defining home as paradise is an idealization of all the positive forces of home fused together (as quoted in Chan,1999).

Housing affects the health of communities. One pressing health issue is residential segregation determined by income, social class, race and ethnicity. The reality in parts of Winnipeg is that poor people are living in some parts and rich people are living in others (Driedger, 1999). As early as the 1880s Winnipeg developed a clear pattern of residential segregation, with prosperous suburbs to the south along the Assiniboine River, and a shanty town in the north end. The long-term effects of this division have proved hard to erase. Today, the dispossessed still gather in the cheap housing just to the north of the business district. The reputation of this area has hampered attempts to reinvigorate the city centre.

All participants interviewed for this project lived in the core area of Winnipeg. Participants were asked to specify which of 5 housing settings best described their homes. The 5 settings determined for the project were:

Their *own home,* a term referring to private residences (houses or apartments) either owned or rented by the participant or a family member of that participant.

Transitional housing, a term that refers to temporary places of residence designed for persons in health crises who are homeless, who are waiting for placement in a more permanent facility, who live in hospices, or who need to live in the core area of Winnipeg in order to have access to medical treatment not available in their home communities. *Transitional housing* in this study consisted of medical boarding houses, rehabilitative housing, and hotel rooms.

An *Independent living housing cluster*, which describes housing designed for persons with physical disabilities. Such clusters are governed by the belief that each tenant is committed to the common goal of contributing to the maintenance of the housing on an ongoing basis. These homes are set up as individual apartments within a larger group setting. Every tenant within the cluster has a right to self control, a free and independent life style, and self management. *Independent living clusters* strive to integrate those adults who have demonstrated capacity to govern their own affairs into suitable living environments within the larger community. The two principal components necessary to achieve this goal are permanent housing and permanent, shared support services (Ten Ten Sinclair Housing, 2004).

Long term care facilities described in this study provide 24-hour professional nursing services to eligible individuals who can no longer manage independently at home with family support and/or community services like Home Care. Long term care facilities are mandated by the Winnipeg Regional Health Authority (WRHA) to provide: personal care, physician services, basic medical supplies, food and nutrition, medications, activities/recreation, access to occupational, speech-language and physiotherapists, housekeeping, laundry/linen services, and access to transportation. Eligibility is based on a comprehensive multidisciplinary assessment conducted through the WRHA Long Term Care Access Centre and the Panel Review Board. The residential charge for Personal Care Home services is based on the income of the resident and ranges from

$25.40 to $59.30 per day (WRHA, 2004). This can be waived through an in house appeal process. A Request for Waiver will be considered by Manitoba Health if: the resident has a spouse residing in the community; both the resident and the spouse are not eligible for Old Age Security or other income assistance; if their combined income is less than an amount specified by Manitoba Health; and if they have dependent children (Manitoba Health, 2004).

The term *acute care hospital* indicates those facilities where patients have been assessed as requiring the level of health care services that can only be provided in an acute setting. The length of an acute care hospital stay in Manitoba is defined as being between one and 59 days. This term excludes long term and rehabilitation hospitals (Manitoba Centre for Health Policy, 2004).

Participants were asked how long they had lived in their current housing situation. Those in their own homes had the greatest permanence in terms of stay; the majority had been in the same home between 1 - 8 years. Patients in acute care hospitals had the shortest stays, between 0 - 6 months, although these participants had repeated hospital stays of a month or more. People in transitional housing tended to stay less than one year, whereas in Independent living group settings and long term care facilities the range of stay varied from less than 6 months to more than 7 years. Two persons in an Independent living group setting had the longest stay of all participants in the project, having lived in that setting for more than 20 years.

The majority of participants who lived in their own homes were provided housing by the Manitoba Housing Authority (MHA). The MHA was incorporated in 1992 as an agency of the <u>Manitoba Housing and Renewal Corporation (MHRC)</u> to function as the property management arm of the Housing Division providing service to Manitobans of low and moderate income, including those with specialized needs. The range of MHA housing includes apartments, townhouses, duplexes and single household dwellings. Rental rates are based on a rent-geared-to-income ratio of 27% of the household income for one to five bedroom apartments. Rental rates for studio apartments are based on a rent-geared-to-income ratio of 25% of the household income (Manitoba Family Services & Housing 2004).

3.3 Living in the core: looking for safety, security and sanctuary

"I'm living in Manitoba Housing right now… The other tenants in the building were knocking on my door harassing [me] and asking for cigarettes and money and drugs…It's just come to the point where I have to move. Manitoba Housing management won't do anything about it. They said it's a police matter. So, I called the police, but the police won't lay charges because they say I'm not being physically attacked. And then I was physically attacked."

~ Project Participant

> ➢ Safety is a major issue for people living in their own homes; despite this most want to stay in that setting.
> ➢ People in transitional housing had no other appropriate options. Families could not be accommodated.
> ➢ People preferred Independent living group settings because of 24 hour access to self-directed care.
> ➢ People in long-term care facilities enjoyed socialization and security but missed privacy, family and independence.
> ➢ People in acute care hospitals were unhappy and despondent. Living in this setting didn't ensure emotional security or good physical care.

Having a safe, affordable and quality home is important for maintaining health, but it is not just the house itself that needs to be safe. The community in which one lives must be safe, as well. A strong social infrastructure that nourishes and supports the life of the community is important. Many neighbourhoods are trapped in poverty, in part because the community's social life, institutions and relations have weakened. A well-functioning community – regardless of socioeconomic level - provides an environment within which its members are able to establish standards of behaviour that reflect the values of the group and advance its common goals (Hughes, 2000).

Social service agency providers canvassed Winnipeg core area communities in 1999 to determine the major issues faced by the residents who lived there. Beth Hughes, speaking on behalf of this project at a presentation to the Manitoba Professional Planner's Institute, stated,

"We figured that childcare would be the major issue since nearby childcare centres were filled. We were wrong. The issue was safety. Residents were not safe on their streets" (Hughes, 2000).

Psychological well-being and emotional security provides a sense of safeness or sanctuary for people experiencing illness in end of life transitions. Palliative care, often understood as "comfort care," focuses on physical and psychological comfort, maximizing quality of life for the patient. A physician's reassurance that a patient will not be abandoned in a time of physical and emotional suffering is instrumental in relieving anxiety and providing care (Ahronheim, 1996). Critically ill participants close to the end of life in this project experienced neglect, isolation, and shame because they were ill. They required comfort in order to feel safe.

🏠 Personal physical safety was the greatest factor that influenced the housing choices for participants living in their own homes. The reputation of a neighbourhood and its residents played a key role in determining if participants chose to move into a given housing setting. Almost half of those persons living in their own homes had experienced physical assault or the threat of a physical assault. The same number stated it was easier not to have any kind of a relationship with neighbours. Harassment, noise, intoxicated behaviour, littering of drug paraphernalia and liquor bottles, vandalism, neglected children who required attention, and racial tensions were all problems participants living in their own homes had with their neighbours. Being in an end of life situation was, according to participants, already psychologically draining. Fearing for one's safety only compounded this stress.

🏠 Some participants reported they had to stay away from substance abusers in order to feel safe. One participant described it like this:

"I don't want anybody to know my address…Somebody will come if you tell the address where I'm staying. Only three people know where I'm staying. Too many people ask me where I'm staying, or do I have a phone, and they bother me…. That's when my sugar goes up and down."

🏠 Participants described prior events in their lives where they had endured violence or harshness from others with addiction issues. They did not feel safe as long as either those familiar to them or strangers who were under the

influence of drugs or alcohol were close by. In some instances, participants were in recovery and stated they needed to eliminate the option of substance abuse from their immediate surroundings.

Infestations of cockroaches, mice, and other vermin interfered with the sense of well-being people had in their own homes.

Participants reported poor or no building security, inadequate lighting at entrances and in hallways, and hazardous stairways in apartment buildings.

Some participants did not want strangers to come into their homes to provide much needed support services. A community advocate explained,
"We are very private people. We don't want strangers coming in and out of our homes looking around."

Despite fears for safety, most participants who lived in their own homes stated their housing circumstances were their preferred choice. Persons living in their own home appreciated their privacy and the comparative quiet when contrasted with previous hospital stays. People liked private kitchens and bathrooms. One participant largely restricted to being indoors because of a medical condition reported that the MHA provided her with a larger apartment in order to help alleviate considerable claustrophobia.

Some participants liked their neighbourhoods because they were close to public transportation, services, conveniences and an adult day program. They were concerned, however, that many of these same services are closing in the core areas of Winnipeg (Osborne Village Development Plan, 2002; Tamarack Community, 2004; Cambridge Credit Union, 2004; Rostecki, 1972), making access to such amenities and conveniences more difficult, and increasing transportation costs. Participants reported such closures had negative impacts on their wellbeing and the levels of satisfaction they experienced regarding the places where they lived.

Most people living in transitional housing stated they had no choice but to live in that setting because their previous housing setting was either too far removed from medical services or could not accommodate their disability-

related needs. Those living in transitional housing wanted distance from substance abusers. They also experienced problems with noise, theft, harassment, and racial tensions. Most of these issues did not occur between residents of the transitional housing but with neighbours who lived in those areas.

Factors that had a negative impact on the emotional security and sense of well-being of people living in transitional housing included dealing with unfriendly support staff, having no choice as to where they could live while receiving medical treatment, and isolation from support networks.

Mobility barriers such as stairs and an absence of grab bars threatened participants' physical safety. Issues that made participants feel unsafe included the lack of flexibility in Home Care and other caregiver schedules. This inflexibility made it difficult for caregivers to respond to participants' fluctuating physical needs.

Tranquillity, having a private bathroom, the appearance of the living quarters, and the close proximity to amenities provided participants living in transitional housing with emotional security and a sense of well-being about their housing.

Participants housed in Independent living settings made no complaints about theft, harassment, assault, noise, intoxicated behaviour, neglected children, racial tension, or littering of liquor bottles, etc.

Some participants reported experiencing discrimination towards persons with disabilities from neighbours who lived in the same apartment building as the Independent living group setting. Participants experienced a loss of emotional security and well-being when they encountered prejudicial attitudes encountered in hallways, lobbies and elevators.

All participants living in Independent living clusters stated their housing circumstances were their preferred choice. Emotional security and group cooperation were pivotal factors in creating the community cohesion and trust that formed the management foundation for this kind of housing.

The most important positive aspect for tenants living in Independent group settings was the knowledge that they could get assistance at any time of the day or night. Access to 24 hour a day care provided a sense of physical safety and emotional wellbeing for participants who chose to live there. They also valued the quality of staff who worked there (staff are hired by a tenant management team.) All participants interviewed enjoyed the locations and appearances of their homes.

Participants interviewed expressed their preference for living in a co-operative setting rather an institution. When participants felt they were able to control who came into their homes to provide care, and when they could direct that care themselves, they felt more autonomous and experienced greater emotional wellbeing. One participant described it as follows:

"I like [the Independent living group setting]. We share the attendant staff. The thing that has kept me here is the immediacy. I had a problem and...I was able to have a staff person come almost immediately to look after my needs. If I were living [elsewhere]…I might have had to wait an hour or so before somebody got to me."

Those participants in institutional care felt that the need for privacy affected their emotional well-being. Only one person in a long term care facility had a private room. When asked what it was like to live with other people in a long term care facility, one participant said,

"We just got to learn to live with one another. It's just a matter of how you look at other people. Nobody's perfect…you just look to this side and look to that side and go on."

Some participants wanted their long term care facility to feel like a home for everyone who lived there. One resident reported that she regularly visited others in the facility.

Some participants from cultural minorities who lived in long term care facilities experienced racial tensions and discrimination by facility. When residents felt disrespect for themselves and their property by staff persons or

other residents, they found it more difficult to live in a long term care facility. One participant stated,

"I was very displeased with the way they were treating my property. But if I say too much, they won't come help me anymore. I would do it myself, if only I could!"

Other participants said they felt insecure and fearful of their physical safety as a result of incidences of theft, harassment, and physical assault that occurred between residents in those settings.

Only one person described a long term care facility as a preferred choice; the remainder expressed that it was the best of a limited number of options. A number of participants living in long term care facilities felt that as their need for support services increased, they needed to move out of their communities and into institutional care. They cited that the time lags that occurred between calls for personal or medical care and having staff arrive at participants' homes was too long and, in some cases, life-threatening. This added stress for participants and their informal care-givers. It had the potential to render staying in one's own home with home support a situation that took away independence and sometimes jeopardized health.

"Sitting in the back yard on a nice day and…having the ability to talk to family and friends were...some of the things done at home."

One participant described the transition from living in his own home to living in a long term care facility,

"But there was always an additional stress as to whether Home Care attendants were going to remember to come or whether they were going to come at times that were convenient."

Living in a long term facility in these kinds of circumstances was regarded as a way of regaining some self-determination.

Long term care providers noted that residents can become upset when someone is close to death because it's *"hitting close to home."* One service provider of group homes for adults with cognitive disabilities described the challenge of helping people who remain behind when someone dies. This service provider also stated that there was virtually no

bereavement counselling available geared to adults with cognitive disabilities. Sometimes staff people used grieving material created for children, but this was not appropriate. Some group home residents have lived together for years and find the death of a household member very upsetting and confusing.

No participant wanted to live in an acute care hospital. No one viewed this as a home, but felt this was the only choice they had in order to accommodate their medical needs. All participants in acute care hospitals had roommates. Privacy was not specifically stressed as being important, but one participant requested the project interview be conducted in a different room. One participant remarked,

"I don't talk to my roommate and he doesn't talk to me."

No one had made friends in the hospital. Participants were unhappy and, at times, despondent.

Living in an acute care hospital does not ensure good physical care or emotional security.

"When I pull that button, you know, where it flashes for [hospital staff] to come, they'll say, 'Just a minute', and they're gone for half an hour," one person reported, *"When they come in [after] you keep ringing it, you know they're angry. You can feel it."*

The same participant commented that he hadn't been bathed for many days.

"I'm angry…It's just that I need help to get into bed or out of bed and get washed up because for about 2 weeks they didn't wash me…One of the workers said it was written down that they did wash me. They never did."

Participants in acute care hospitals reported attitudes of discrimination against people with disabilities held by healthcare providers. A patient facing an amputation described the disgust he sensed hospital staff had for his affected limb.

"They don't want to touch it, and I lose patience with them. If you're going to do [your job] and you don't want to touch it, get the hell out of here."

Many participants in the *Finding Our Way Home* project feared for their personal safety. This was most common among people living in their own homes, and decreased in a continuum for those in transitional housing, and to an even lesser degree for those in Independent living clusters, and finally into institutional and hospital care. In contrast, the need for emotional well-being was most common for people in hospitals. Privacy was important for the emotional well-being of those in long term care institutions. The more meta-physical needs, that is, the desire for a sense of sanctuary and well-being, were mentioned less often by people living in Independent living group settings, transitional housing and their own homes.

3.4   Living and dying in poverty

> ➢   Poor people who live in unsafe neighbourhoods are not as healthy as people with adequate incomes
> ➢   Extreme poverty rates among Aboriginal peoples, non-permanent residents and visible minorities, persons with disabilities, lone-parent families and unattached individuals are evident in most communities.
> ➢   Lack of affordable, acceptable, safe housing in the core area is the most prominent unmet need identified by project participants and service providers.

Residential environments, homes, neighbourhoods and communities, play an important role in health. Poor people who live in unsafe and under-resourced neighbourhoods are not as healthy as people with adequate incomes who live in safe, affordable housing. Neighbourhood designs are important as they can affect choices about exercise and other health promoting activities. Not having access to affordable housing and being homeless can lead to increased health risks. Unaffordable rent is associated with inadequate nutrition and growth. People living in substandard housing are at higher risk for asthma, burns and other types of injuries (Centre for the Advancement of Health, 2003).

Indicators of social class such as income, education, and occupation are associated with death rates and variations in life expectancy (Epp, 1986; Truman and Trueman, 1995; Mustard et al, 1997). Socio-economic status affects people's chances of survival as well as of becoming ill. Being in the lowest household income group is predictive of death before the age 75 (Statistics Canada, 1997). The National Population Health Survey of 1994-5,

shows an inverse relationship between income and hospitalization; the poor are more likely to be hospitalized than the rich (Wilkins and Park, 1997). The poor in Canada have a considerably lower health status than higher income groups (Manga, 1990).

The now defunct National Housing Act demonstrated the significant connection between public health, including Home Care programs, and housing (House of Commons, 1985). This Act encouraged federal, provincial and municipal partnerships to build accessible, low-income housing in Canada. The result of its demise is that new housing of this kind has all but disappeared. Although private investors have built apartments with space and amenities, these units are generally too costly for those who need them most. Serious consideration needs to be given to resolving the current problem in order to support Independent living arrangements as well as the delivery of cost-effective Home Care services where necessary (Shapiro, 2002).

Cultural background can be associated with life expectancy and rate of death. Aboriginal peoples continue to have lower life expectancy and higher rates of death than non-Aboriginal populations, with greater occurrences of diabetes, tuberculosis, meningitis, AIDS, suicide, homicide and accidents (Herring et al, 1995). These patterns may be the result of isolation, poverty, social marginalization and disorganization, and substance abuse (Trovato, 2001).

Poverty increased throughout Canada in the 90s, and concentrated poverty occurs in the core areas of Canadian cities. The general population growth in metropolitan areas grew 6.9% between the years 1990 – 1995, but poor populations grew by 33.8%. The second highest population group to experience poverty in Canadian cities is Aboriginal peoples (the first being refugee claimants, foreign students, and foreign workers). Fifty-six percent of all First Nations people live in poverty, as do 36.1% of people with disabilities (First Nations and others). Poverty rates are higher among women than men. Extreme poverty rates among Aboriginal peoples, non-permanent residents and visible minorities, persons with disabilities, lone-parent families and unattached individuals are evident in most communities. This suggests there are real barriers preventing sufficient income (Lee, 2000).

Poverty is not simply a problem for people who have fallen on hard times. Its scope is much wider and should be a concern for all Canadians. Poverty rates are indicators of the health of citizens and the state of institutions (Lee, 2000).

Lack of affordable, acceptable, safe housing in the core area was the most prominent unmet need identified by both project participants and service providers. People living in their own homes and in transitional housing talked about issues entrenched in financial hardship, such as lack of adequate funds for food, clothing, transportation, and safe housing. No one resided in a home that they owned. The majority of apartments rented were made available through the Manitoba Housing Authority (MHA), and one of the participants lived in a co-operative housing situation.

The need to provide for basic requirements lessened for people living in Independent living group settings, and decreased even more as interviews progressed to persons who were more entrenched in institutional care. This continuum demonstrates the correlation between living as independently as possible and experiencing the most immediate effects of poverty, or living in an acute care hospital where all basic physical needs are provided, but there is an extreme loss of self-autonomy.

All participants who lived in their own home were dependent on income security. Many participants reported that Income Assistance did not provide an adequate amount for rent, so money from the welfare cheque was used to top off the rent. One participant stated,

"There aren't that many options because the housing costs more than what social services will allow you and they take that extra income off your budget that you need."

This meant participants had fewer funds for food, clothing, transportation, over-the-counter medicines, telephones, and incidentals.

Sometimes landlords of private housing stock took advantage of extra income received by renters for disability expenses. One person reported that when the landlord discovered the participant was receiving additional disability support through Income Assistance, the rent was raised to match the amount provided by Income Assistance. No disability-related adaptations were made to the property with this increase in rent. Another

had lived 4 years in a location that switched landlords three times. Each new landlord raised the rent, but none of these increases resulted in repairs, including those that involved safety hazards.

"I fractured [my] ribs slipping on the stairs," this participant related, *"And one day I was trying to get the water [to] go down my sink and …the pipe broke. It was a cold winter, and I couldn't fix it and the water kept squirting out, hot water that I couldn't touch…Finally somebody turned it off. It was steaming hot up there, and I had to go to sleep with my carpet all wet. They never touched [the carpet], so I had to go someplace else until my carpet dried."*

Living in poverty makes physical safety and emotional security even harder to attain.

🏠 People with disabilities experiencing end of life situations encountered obstacles in obtaining their own homes. Persons with HIV/AIDS and those with same gender sexual preferences also experienced prejudice from property management and others that made obtaining housing difficult. Obstacles encountered included:

- Property management not showing up for appointments to view apartments. This was prohibitive for participants with extreme fatigue;
- Social Assistance refusing to cover moving costs (one participant had to give away all his belongings because he couldn't afford to move them); and,
- Property management wouldn't return damage deposits even though tenants stated they weren't responsible for any damage.

🏠 Other housing condition problems included:

- The need for outstanding repairs;
- Filthiness;
- Bad plumbing;
- Poor security;
- Overcrowded facilities;
- Building temperature;
- Poor storage space;
- No or inadequate laundry facilities;
- Poor access to health care facilities; and,

- Poor air quality.

[icon] All participants who lived in transitional housing were recipients of income assistance. They acquired their housing through Manitoba Health. None of them stated specifically why their economic standing had a bearing on their housing situation, but did see this dependence as a factor influencing their housing choices. One participant explained,

"Medical services gave me about 4 months to stay in a [medical] boarding home. That's why I have no other choice. I have to go to this place. There's no other place."

[icon] Several persons from transitional housing were required to travel to different offices collecting various kinds of documentation in order to receive Income Assistance despite the fact that they were in intensive medical treatment.

"I went to get this document today," one participant described, *"I went [to an office on] Main Street… and there they told me [I had to put my name] here…so I went over [to another place] and that lady said you need separation documents [or] I can't put your kids here, just you…I thought I was going to get my welfare today and that lady worker said, 'You have to erase your husband's name,' and she needs more documents."*

This participant was receiving dialysis a minimum of three times a week. A non-governmental advocacy organization was helping to ease this process because Income Assistance did not offer any help.

[icon] One participant had been homeless prior to entering into transitional housing.

"Sometimes I slept in the garage," he related. A community advocate, speaking on his behalf, added further to his story. *"He came here and told me he had burns on his leg. He said he didn't have a place to sleep so he went and made a makeshift home for himself by the river and made a fire. It got cool through the night, and because he didn't have proper feeling in his*

leg [due to a disability-related condition], he didn't know he had burned his leg. He burned it quite severely."

Another participant had been hospitalized for seven months.

"When I was in Rehab…the landlord got some people to move in [to my apartment] because he heard that I was dead. He told CPP and they cut off my disability pension. I was…coming home on a weekend pass… so when I unlocked the door…to my amazement somebody else was living [there]…That's what I seen in my own house. Then I phoned the police and she phoned the police…and the police come around and say, 'Who's renting this place?" And I said, 'I do,' and she said, 'I do,' and then the landlord comes over. 'You're dead! You're dead! You're dead! You're dead!' [He said] pointing at me. I asked him for my stuff. Some of the stuff I lost I can never replace, like my grandparent's pictures from the 1800s…and the outfit I wear for powwows. Friend's pictures are gone. Family pictures are gone. They forced me up to a point where I just about committed suicide."

Poor temperature control and overcrowded facilities were problems for people living in transitional housing.

Economic limitations did not play any role in the housing choices of participants who lived in Independent living clusters. These tenants were on provincial disability allowance or the Canada Pension Plan (CPP), hence, housing costs were covered by government.

Participants living in Independent living group clusters did not report any poor housing conditions.

Economic limitations were not factors for those in long term care facilities or acute care hospitals. When asked if housing costs were covered by the Canada Pension Plan, one participant took the opportunity to say,

"I don't have CPP because I've never worked a day in my life. I graduated and then I never got work. I have epilepsy – it was like discrimination."

Poor temperature control was one poor housing condition reported by participants living in long term care institutions.

Participants living in acute care hospitals did not describe any immediate financial concerns. Basic needs are to be provided by the hospital. However, they described their previous living circumstances. First Nations persons spent their early years (childhood to young adulthood) in rural and remote Aboriginal communities, but had lived in the city for a significant length of time prior to experiencing end of life transitions. One had lived in a downtown hotel prior to being hospitalized.

Two conditions of poor housing in acute care hospitals were inadequate laundry facilities and uncomfortable building temperatures.

Many people interviewed were poor. According to the Participation and Activity Limitation Survey which collected information about persons with disabilities (Statistics Canada, 2001), the average yearly income of men and women with disabilities was $21,964.00 compared with the average yearly income of men and women without disabilities, which was $28,499.00. Discussion about financial hardship was prominent in many interviews. The role of poverty in the lives of people with disabilities living in the core area was also acknowledged by service providers involved with this project. One stated:

"The lack of affordable, acceptable housing is loud – it's just screaming. [We need] housing that is suitable – not just hospital rooms and nursing homes."

3.5   Housing challenges: accessibility and other basic needs

> ➢ The majority of participants living in their own homes were not housed in accessible settings.
> ➢ People chose to live in transitional housing in order to accommodate disability-related needs, proximity to medical treatment, and access to non-medical services. Not all transitional housing is accessible.
> ➢ People living in Independent living group settings experienced some problems with staff flexibility and site accessibility.

> ➢ People chose to live in long term care facilities and acute care hospitals in order to accommodate disability-related needs and access medical treatment. Not all facility aspects were accessible.

Residential segregation has several different types of health consequences. The array of available resources changes as the characteristics of neighbourhoods change, and what is taken for granted in one area may not be accessible or available in another (Centre for the Advancement of Health, 2003). People with disabilities need to be included in the planning of neighbourhood upgrading and re-sourcing in order for these neighbourhoods to be accessible and available to them.

A home is a place of identity. It is a manifestation of one's power to choose, to exercise autonomy (Gilson and Netting, 1997). The National Association of Social Workers (United States) conceptualized the notion of "aging in place" for people with pre-existing disabilities who are growing older. Residential settings are guided by policies and goals that promote self-determination, the least restrictive environment, the value of the home and the quality of life (Gilson and Netting, 1997). Proponents of the social theory of disability and the disability rights movement hesitate to blend gerontology with disability, but coalition building between various interest groups has provided affordable and supportive housing for all segments of the population, including people with disabilities experiencing deterioration (Pynoos and Parrott, 1996).

Finding Our Way Home participants listed the influences affecting their residential choices, and the barriers they encountered in obtaining this housing.

🏠 Less than half of those living in their own homes stated accommodation needs played a role in determining where they lived. Other accessibility factors that influenced their housing choices were:
- Proximity to available medical services;
- Access to transportation; and,
- Access to non-medical services (banks, libraries, shopping, and laundry facilities); and Independent living group settings.

🏠 The majority of participants living in their own homes were not housed in accessible settings. None of the participants owned the property where they lived, and most were dealing with financial hardship and end of life physical conditions that made modifications difficult.

🏠 Accessibility problems for this group included:
- Lack of grab bars;
- Lack of railings in hallways and stairways;
- Slippery floor tiles;
- Poorly attached carpet;
- Poor lighting;
- Stairways with no elevators;
- Lack of functioning automatic doors for entrances into buildings and individual apartments;
- Snow and debris on outdoor walkways; and,
- No air conditioning (critical for certain health conditions).

🏠 All tenants who lived in Manitoba Housing Authority apartments reported poor air quality. Those persons with respiratory issues struggled with significant dust and other impurities in the air. One participant with emphysema stated that despite signs posted in hallways and the foyer, other tenants continually smoked in these areas. She described the cigarette smoke as "*hitting her lungs like a brick wall.*"

🏠 A critical incident occurred when emergency medical services personnel did not have an entrance key to a MHA building. This resulted in a significant delay before a participant could be taken by ambulance to the hospital for acute care.

🧳 Accessibility factors that influenced housing choices for participants living in transitional housing were:
- Accommodating disability-related needs and medical conditions;
- The need to be near medical treatment; and,
- Access to non-medical services (banks, libraries, shopping, and laundry facilities);

Not all participants lived in accessible settings. Accessibility problem areas included:

- A lack of grab bars;
- A lack of railings;
- Stairways and no elevators;
- Lack of access to telephones for wheelchair users;
- No or poor access to transportation;
- Slippery and un-cleared sidewalks leading to and from entrance ways; and,
- Tenants with fatigue issues were required to collect documents from different locations around the city as part of the admission process.

Accessibility factors that influenced the housing choices of participants living in Independent living group settings were:

- Accommodating disability-related needs and medical conditions;
- Access to transportation;
- Access to non-medical services (banks, libraries, shopping, and laundry facilities);

None of those in Independent living clusters considered close proximity to healthcare facilities as important in their choice of housing locations. Having home supports and accessible housing greatly reduced their dependence on medical services. One participant who was adjusting to a new daily medical procedure said,

'They help me with [the procedure]…if I would need more help I'd be assessed by…Community Therapy Services…and that way it gets built right into the schedule."

Independent living group settings were considered accessible, with some exceptions:

- Elevator frequently needs repair;
- Kitchen units were too high for persons using wheelchairs to have access to dishes, etc.; and
- Stoves were not accessible for persons in motorized chairs.

Proximity to work (paid or volunteer employment) was only a factor for people housed in Independent living group setting. Most participants who lived in this situation had jobs outside of their homes.

Accommodating disability-related needs and medical conditions and the need to be near medical treatment influenced the housing choices of participants living in long term care facilities.

A participant from a long term care facility lived in an environmentally controlled room with lighting and television operated by remote.

Inaccessible elevators, exit doors and main floor washrooms were problems for persons living in long term care facilities.

Participants living in long term care facilities wanted the capacity to visit between residents, access to enjoy the facility grounds, and entertainment programs provided to residents. Characteristics that contributed to positive experiences within this housing setting included proximity to family outside the facility, nice bedrooms, visiting areas where residents could entertain family members, access to private telephones, and the caring staff.

Accommodating disability-related needs and medical conditions and the need to be near medical treatment influenced the housing choices of participants living in acute care hospitals.

Acute care hospital rooms were considered inaccessible because participants in wheelchair were required to remove prosthetic legs in order to turn around.

3.6 "I could sure use the help:" support services

"I could sure use the help, but [support staff] has to understand how you feel inside. That's why I tell them I'm not there as a …job they just do, just a place of work. There's no compassion. The worker just comes in and…gets it over with, and then out. That's not what I am. I am not a piece of furniture, but…that's the way they make me feel."

~ Project Participant

> ➢ Some participants received excellent home support care, others received inadequate care with significant health risks and still others received no care at all.
> ➢ Some people who stated they clearly needed home support refused it because of privacy issues and experiences with racial prejudice and disability discrimination.
> ➢ More people in their own homes and in transitional housing received help from family or friends than from Home Care support services.
> ➢ People in Independent living group settings received Home Care program dollars for attendant services.
> ➢ People living in long term care facilities stated their need for increasing support services played a critical role in their decision to move out of their communities and into institutional care.
> ➢ Home Care or institutional eligibility requirements, schedules and regulations can play a role in undermining individual self-determination.

The Home Care program in Manitoba was established in 1974 to help people live at home, remaining independent for as long as possible, thereby avoiding or delaying the need for individuals to go into long term care facilities. The mandate of the current Winnipeg Regional Health Authority Home Care program is to:

- Provide effective, reliable and responsive community health care services to support Independent living;
- Develop appropriate care options with clients and/or their families; and,
- Facilitate admission into long term care facilities when living in the community is no longer possible.

Home Care services include**:**

- Personal care;

- Nursing,
- Counselling/Problem Solving;
- Household assistance;
- Respite/Family Relief;
- Occupational Therapy Assessment;
- Physiotherapy Assessment;
- Referral to other agencies;
- Coordination of internal and external services in the community;
- Assessment for long term care and specialty services (Adult Day program, Companion Care program and Supportive Housing program).

Individuals must be Manitoba residents, registered with Manitoba Health, require health services or assistance with activities of daily living, require service to remain safely in their homes and require more assistance than available from existing supports and community resources in order to qualify for home support services (Winnipeg Regional Health Authority, 2004).

Some *Finding Our Way Home* participants reported excellent home support care. Others received inadequate care that involved significant health risks. Still others received no care at all. Some people who stated they clearly needed home supports nevertheless refused them because of privacy issues and experiences with racial prejudice and judgemental Home Care staff. One example of this reticence involved a participant who did not want to deal with the condemnation of outside support providers because of her use of marijuana for medical purposes.

Although all participants in our study were experiencing end of life transitions, and a number of them have died since the interviews took place, none of them spoke about receiving palliative care services. Palliative care services are designed to alleviate suffering for patients with life-limiting illnesses and their families by improving the availability of and access to quality palliative care in the Winnipeg Community. Palliative Care works closely with Home Care, Cancer Care Manitoba, Hospice & Palliative Care Manitoba, and others to provide expert end of life care in a variety of settings including home, personal care home, hospice, outpatient clinics, acute care inpatient units, and intensive care units (WRHA, 2004).

A drawback in current palliative care programming in Winnipeg is its inability to provide 24 hour home supports. The Health Canada report, *"Decision-*

Making: Home or Long Term Care?" discusses the differences in policies that lead people to choose institutional care rather than to remain at home (Health Canada, 2001). A similar national palliative Home Care demonstration project noted that the lack of access to 24 hour Home Care was a reason for the poor uptake of palliative Home Care (Shapiro, 2002). "We don't make Home Care easy enough," states Harvey Chochinov, a Winnipeg psychiatrist who holds the Canada Research Chair in Palliative Care at the University of Manitoba, "Only an estimated 5% [of Canadians] will receive integrated, interdisciplinary care that is aimed at lessening physical, emotional, and psychosocial suffering" (Chochinov, 2000).

Participants in our research gave details about their support needs and services. These are described by housing setting as follows:

Persons living in their own homes required:
- Medical care;
- Personal care (occasional or daily);
- Food preparation;
- Light housekeeping
- Foot care; and,
- Blood pressure monitoring.

More people received help from family or friends than from Home Care support services.

Participants left their homes and went to health care facilities for medical treatment.

People in transitional housing required:
- Medical care;
- Personal care (occasionally or daily);
- Food preparation;
- Light housekeeping;
- Foot care;
- Blood pressure monitoring;
- Physiotherapy;

- Dietary management;
- Continual standby attendant care;
- Social worker.

More people received help from family or friends than from Home Care support services.

Participants went for medical treatment to health care facilities.

People in Independent living group settings required:
- Medical care;
- Personal care (daily);
- Food preparation;
- Light housekeeping;
- Continual standby attendant care.

Independent living group settings are contracted to receive Home Care program dollars for attendant services.

People living in long term care facilities required the following supports:
- Medical care;
- Personal care (daily);
- Food preparation;
- Light housekeeping;
- Foot care;
- Blood pressure monitoring;
- Physiotherapy;
- Dietary management;
- Continual standby attendant care.

A number of persons living in long term care facilities stated their need for increasing support services played a critical role in their decision to move

out of their communities and into institutional care. The time lags occurring between calls for personal or medical care and having staff arrive at participants' homes were too long, and in some cases, life-threatening. The fear that Home Care wouldn't be able to come due to weather, etc. added stress for participants and their informal care givers. Further difficulties developed if Home Care couldn't accommodate household schedules but arrived at a time convenient for the workers. All of these problems made staying in one's own home with home support a situation that took away that person's independence and sometimes jeopardized health. Living in a long term facility was therefore regarded as a way of regaining some self-determination.

Participants received personal care and medical treatment within the long term care facility setting.

People living in acute care hospitals required the following supports:
- Medical care;
- Daily personal care;
- Food preparation;
- Light housekeeping;
- Foot care;
- Blood pressure monitoring
- Dietary management;
- Continual Standby Attendant Care

Participants received personal care and medical treatment within the acute care hospital setting.

Participants also outlined care needs or levels of service they were not currently receiving. House cleaning and personal care were dominant needs that were either totally lacking or only partially met.

One of the components of depending on others for personal care is a loss of control. Home Care or institutional eligibility requirements, schedules and regulations can play a role in undermining individual self-

determination. One participant living in a long term care facility expressed it this way:

"One of the consequences of coming into an institution like this is an expectant and concomitant loss of privacy…and the only way to really address that is to be…completely comprehensive about describing your needs, your desires, and wishes. Now they attempt to accommodate all of these. There is recognition on my part when you're in an institution like this you sort of have to run your life according to the institution's needs and rules. They only have so many staff people to deal with so many residents."

Persons living in their own homes were most likely to need laundry and light housekeeping, whereas those participants in long term care facilities and hospitals needed additional personal care.

Those participants living in long term care facilities and hospitals were frustrated because they had to depend on staff for personal care. Feelings of isolation and fear over struggles with pain management and the loss of body functioning were described in many interviews throughout the project. Participants' social circles tended to shrink as they progressed further into end of life; for some, support staff was their only contact. One participant described interactions with acute care hospital staff as follows:

*"There are some nurses that are very friendly and some nurses they just do their work, and those are the nurses I get into an argument with, the nurses that figure they know how I feel, and I tell them, '**I know** how my body feels, you don't…Basically I said, 'I'm nothing but a number to you people…you smile yet it doesn't reach your eyes, so don't bother smiling at me if it doesn't reach your eyes."*

Problems with support staff described by participants in long term care facilities and acute care hospitals included waiting for long periods of time after signalling for help, gruffness and insensitivity on the part of workers who didn't understand the correlation between loss of body function and loss of dignity, poor hygienic care, and staff charting that certain tasks had been done when the participant knew these tasks had been neglected.

One participant who lived in her own home described her concern for those in a different situation from her own experience, stating:

"I really worry about people who are aging who live in group homes because they have mental illness or mental disabilities. They have no one working there who has counselling training. They just have staff who look after basic needs – and not even that sometimes. Sometimes these people are just warehoused. And if you're aging and forgetting your meds they don't even always have staff give the meds. There can be no supervision so people get confused and take the wrong stuff. And then the residents may not always say something's wrong. Staff don't always really care about them – it's a job, that's all."

Meal preparation, increased wheelchair assistance, light housekeeping, personal care and oxygen provision were home support needs participants anticipated in the coming year. Some also stated that their future needs depended on changes in their medical condition.

Participants found it difficult to discuss their futures, and answers were often accompanied with a flood of emotion. It was hard for some participants to talk about the need for increased support. One person welcomed the question as an opportunity for her to take stock of her situation in order to plan for the future, but the majority of participants indicated it was not easy to think of the days ahead. They described their experiences of energy fluctuation – some days were better than others. One participant made this comment:

"Sometimes at this point in my illness I just get too sick to clean, perhaps 2 weeks at a time where I don't clean up. But I have enough energy now."

Participants had concerns about the impact anticipated home supports would have on their daily routines and their independence. One participant in transitional housing who hoped to return to a MHA apartment following medical treatment described these concerns:

"I thought maybe have a homemaker come in five days a week and then leave me alone. But it's hard to say what they want. What you want is different from what [Home Care] wants, and they've got the rules and you have to follow them. You're being treated like a little kid again."

Participants living in long term care facilities and acute care hospitals also had concerns about anticipated increased dependence, loss of physical capacity and loss of autonomy.

3.7   Living lonely: Isolation

"Just look outside, there's people walking around smiling, laughing and walking and what about you? You're sitting here and you wish you were out there. See? The isolation again comes down on you."
~ *Project Participant*

"To be vulnerable and isolated is the matrix of disaster."
~ *Willard Gaylin, MD*

> ➢ Loneliness can be medically significant and even life-threatening.
> ➢ Disability can be perceived as being sentenced to the isolation and loneliness of a social outcast.
> ➢ The relationship between physical independence and loneliness is important, as independence represents control and ability to choose, as well as the ability to accomplish daily activities and fulfill social roles.
> ➢ Life is most vulnerable at its beginning and its ending. People who are dying experience profound loneliness because of awkard, distant relationships between friends, families, and caregivers of dying persons.
> ➢ Many people with disabilities dying in the core area of Winnipeg live alone and experience profound isolation and loneliness.

It is hard to define loneliness because it is a subjective experience, much like chronic pain. One researcher described it as *a gnawing distress without any redeeming features* (University of Missouri, 2001). Anecdotal evidence suggests loneliness can be very medically significant and even life-threatening. Such pre-existing medical conditions as heart disease, diabetes and arthritis get significantly worse when a person feels lonely. In the case of heart disease, the statistical impact of loneliness on health and well-being appears to be equal to the impact of smoking a pack of cigarettes a day (University of Missouri, 2001).

Disability, unlike culture or race, has not traditionally created communities wherein people customarily look to one another to create intimacy and family (Asch and Fine, 1988). Disability can be perceived as being sentenced to the isolation and loneliness of a social outcast (Kent, 1988). Despite all the knowledge acquired concerning the relationship between loneliness and mental/physical health among diverse populations, few empirical studies

examine loneliness among people with physical disabilities, and even fewer are likely to include those who are living within the community. Physical barriers constitute important obstacles to the social integration of people with visible physical disabilities; they are faced with social realities that differ from those who do not have disabilities, thereby verifying the existence of a relationship between loneliness and variables associated with physical disability (Hopps et al, 2001).

The relationship between physical independence and loneliness is important, as independence represents control and ability to choose, as well as the ability to accomplish daily activities and fulfill social roles. Within this framework, physical independence is related to social participation and integration (Hopps et al, 2001). Pitonyak observes that many people who receive social services are profoundly lonely. Much of their suffering results from isolation, not disability. When people are connected to a social network they are generally happier, healthier, and better able to adjust to life's ups and downs. The benefits of any medical therapies and interventions cannot be sustained in the absence of meaningful relationships (Pitonyak, 2003).

We also know that life is most vulnerable at its beginning and its ending (Chochinov, 2000). People who are dying can experience profound loneliness because of the awkward, distant, evasive relationships that develop between friends, families, and caregivers of dying persons (Barnard, 1998). Discussions about death and dying are often avoided in Canadian social contexts. When a family member becomes critically ill, other family members respond with avoidance or even revulsion. Many family and friends are unable to support the dying person or each other during the dying process (Northcott et al, 2001). Historically, many people died at home, and those who lived with them were thoroughly involved in the daily process of dying. The shift to have people die in hospitals removed that daily contact, and contributed to making death an isolated experience for the patient, and a frightening mystery for family and friends. Perspectives on dying will be inadequate as long as they remain technical, clinical and institutional (Kellehear, 2001).

Psychiatrists who treat depression in dying people try to understand why some patients might lose the wish to go on living. The dominance of depression among people who are dying is a predictor of a desire for death, including an interest in physician-assisted suicide (Wilson et al, 2000; Chochinov et al, 1995; Breitbart, 1996). Although depression and pain play

prominently in people's wishes to commit suicide, concerns such as being a burden to others, loss of sense of purpose, meaning and hope, and loss of dignity all emerge as significant forces that can move patients to wish for a hastened death. Healthcare providers need to honestly engage with these issues – and conceive of ways to expand, if not step well outside of a too narrowly defined model of end of life care. This need for a broader, more inclusive view of palliative care is further supported by the observation that symptoms contributing to psychological distress and existential concerns are even more prevalent than pain and other physical symptoms, among those with life-limiting conditions (Chochinov, 2002; Portenoy et al, 1994).

The Institute of Medicine, in a report entitled, *Approaching Death: Improving Care at the End of Life* (Field et al, 1997) identified professional perspectives of quality supportive care as including:

- Overall quality of life;
- Physical well-being and functioning;
- Psycho-social well-being and functioning;
- Spiritual well-being;
- Understanding the patient's perception of care; and,
- Family well-being and functioning.

Clearly, from the vantage point of professionals and patients, acknowledging and addressing issues connected with meaning, purpose and dignity needs to be included within the realm of quality end of life care.

Many people with disabilities dying in the core area of Winnipeg live alone. Participants described frequent feelings of isolation and loneliness. Less than half of those interviewed lived with one or more family members, a roommate, or an intimate partner. One married couple participated in the research. One single parent had some of her children with her as the remainder of her family could not be accommodated in her housing setting. Another participant resided too far from a medical institution that housed his under-aged daughter with disabilities to visit her regularly. No one living in their own apartment, in an Independent living group setting, in a long term care institution, or in an acute care hospital lived with their own children, although a participant from a long term care institution identified having children under the age of 18 living elsewhere.

🏠 Participants described what they had in common with those neighbours and residents who lived near them. The majority of people who lived in their own homes reported they had little in common with those around them.

🏠 Being close to people of the same cultural and linguistic group was not reported to be a factor for most participants.

💼 Participants living in transitional housing had very little interaction with their neighbours, so they knew of no commonalities.

💼 One participant who came directly from a northern reserve was a single parent unable to bring all her children with her into transitional housing because of space constraints. She included the need for her school-aged children to obtain an education as a form of home support. These children provided their mother with such home supports as personal care, light house-keeping and some food preparation.

💼 Participants living in transitional housing were concerned about the strain such settings placed on familial relationships due to lack of privacy, lack of space, the inability to provide furniture, etc. for comfortable visiting, and the compliance required to meet the needs of other residents in such facilities.

💼 Changes in the participants' health conditions had a negative impact on previous relationships of some of those persons interviewed. One person described the onset of end of life as an experience of isolation and loss of worth. He described his perception of how others viewed him as follows:

"You're a cripple, an invalid that can't help himself. So, they totally ignore you."

💼 Other participants living in transitional housing experienced isolation because many in their social circle had already died. One person interviewed stated:

"I don't have too many friends. They're all dead from sugar diabetes, they're all gone. Everybody dies – my dad, grandpa, [and] son. I've got more friends on the other side now."

Those living in Independent living group clusters and long term care facilities had considerably more in common with others who lived in these settings, including having similar ages, levels of disability, and interests.

The majority of people living in Independent living group settings described the relationships they had with other tenants as being friendly, or at least on the level of acquaintance.

Some participants living in Independent living group settings talked about one instance when another tenant within the cluster had died at home. Arrangements had been made between housing management and WRHA Home Care in order to supplement staff for increased support needs. The other tenants felt ambiguous about this arrangement because increased staff demands had an impact on their own care needs. Participants stressed that any time this kind of event occurs in the future, careful planning would need to be strategized in order to cover fluctuating care needs for dying persons without sacrificing the regular care routines of other tenants. This was a time of emotional difficulties for members of the housing cluster.

The majority of people living in long term care facilities described the relationships they had with other tenants as being friendly, or at least on the level of acquaintance. Two persons interviewed were members of the residents' council in their institution. One resident reported that she regularly visiting others in the facility. If she ever missed a visit, people would wonder why she hadn't come to see them. Making newcomers feel welcome was an important task; the participant described it as follows:

"It's like a little brother or sister. They… come[s] into the Centre and it's our duty, you could say that – to welcome them, [to]   make   them   feel cheerful and have friends."

However, a younger person in a long term care facility described feelings of isolation from other residents due to differences in age, level of education, and interests.

"I find," said one participant, *"that I am more highly educated than most people here… There is the age difference [as well]. This place is predominantly seniors…I have achieved a great deal…as a consequence most of my recreational activities are cerebral. And you know, most people here I find are interested in sitting down and playing cards or watching TV or talking and…the type of television or radio that I would listen to or the type of conversation that I would engage in [is] really different than theirs."*

A common concern among those living in long term care facilities was the strain such settings placed on familial relationships due to lack of privacy, lack of space, the inability to provide furniture, etc. for comfortable visiting, and the compliance required to meet the needs of other residents in such facilities.

"I have accommodated my living circumstance to facilitate the disability," stated one participant. *"My preferred living arrangement would, of course, be with my children and my partner. Unfortunately…both of us have recognized that although we didn't want it, it was a necessity that I consider moving into an institution. There are problems with living at home that put stress on both the person with disabilities and on anybody who is providing support for that person."*

Some participants who lived in long term care institutions stated one of the reasons they chose that housing setting was because they wanted to be close to people of the same cultural and linguistic group.

Some participants felt that limitations in home support, etc. meant they had no other options but to live in long term care institutions.

"The reality," said a younger participant who had been separated from his family *"is I do not like living here. But I dislike the necessity of my being here."*

A number of participants felt isolated from the outside world. One person described:

"I feel fenced in. I'm on the perimeter, watching things pass by. They built a high fence around the yard, and I can't go around anymore."

Further indications of this sense of disconnection lay in the reason people were in a facility rather than with the facility itself. One person stated the worse aspect of living in a long term care facility was not the building or the staff, but his concern for who was going to take over a family farm. In this way, the ordinary irritations of every day life were not the focus for participants. One said:

"You are removed from society at large and you have been relegated to a functional place where you are no longer going to engage in any activity that is going to be of consequence. I mean, I'm not [even] helping raise my children."

Participants who lived in acute care hospitals were the most demoralized of any people involved in *Finding Our Way Home* research. One person laid waiting for a limb amputation; the other had multiple amputations and required other treatment because of end organ failure. Both found the hospital to be a lonely, friendless place. One had ongoing clashes with healthcare staff, stating that he felt his dignity was continually at risk. His loss of physical capacity made his situation very difficult, but when he described his future fears about further amputation, he couldn't imagine making yet another set of psychosocial and physical adjustments.

"If that [another amputation] happens, I might end up going home," he told the researcher. When asked what "going home" meant, he explained he would stop all treatment.

"I know I'm not going to last very long…but I'm tired of getting all these run-arounds with the government and the people that are supposed to help, saying, 'you have to do this,' and 'you have to do that,' and 'we have to assess you.' ..How in the hell do [they] know when they have 2 feet and are in their big offices, and then they decide for me?"

He wanted to direct the course of his own life, and this included where he lived and who took care of him. The lack of feasible housing options that

provided full accessibility, healthy social connections, and the restoring of his dignity had driven him to a state of hopelessness.

3.8 A Glimpse into the journey: First Nations perspectives on end of life transitions

Death comes to us in many ways.
It is in a broken flower,
In a carrot we eat,
Or in a small child.
Death is ugly and beautiful.
It is useful and wasting.
It is tragic and happy.
It is in everything and
It is everything.

~ Chief Dan George

> ➤ The greatest densities of Manitoba's First Nations Peoples live in the downtown core of Winnipeg.
> ➤ If you are of First Nations descent and you live in the inner city, you are more likely to be poor, to have a disability, to live isolated and alone, and to die sooner than someone of European descent.
> ➤ First Nations people with disabilities are more likely to live in sub-standard housing and encounter physical barriers within their housing.
> ➤ The historical circumstances of colonization have had devastating effects on Aboriginal cultural identity and social framework, shifting the responsibility for support of the dying person from the kin group and community-based support networks to specialized care provided by professional staff.
> ➤ Current models of palliative care have evolved with little input from indigenous communities.
> ➤ First Nations people experience cultural attitudinal barriers that deter them from seeking outside assistance such as Home Care. Assessments of needs are often not completed without pressure by First Nations Advocacy groups.
> ➤ Many Aboriginal people are not aware or don't understand what they can access in terms of home supports and other assistance.

> ➢ One solution to conflicting cultural values concerning end of life decision-making and care for the dying is cultural brokerage; embracing various health and healing systems together in ways of greatest meaning and benefit for the person dying.

Hearing the voices of Manitoba's First Peoples was a critical concern of this project. Winnipeg's Aboriginal population is estimated at a number upwards of 55,755 people. The greatest density of this population is located in the downtown core (Aboriginal Council of Winnipeg, 2003). Aboriginal peoples need housing which provides the necessary supports and safety in a manner appropriate to their cultural traditions. First Nations, Inuit and Métis participants often referred to the abuse and cultural undermining they suffered within predominantly white institutions. The historical circumstances of colonization in Canada have had devastating effects on Aboriginal cultural identity and social framework with implications for current healthcare practices.

If you are of First Nations descent and you live in the inner city, you are more likely to be poor, to have a disability, to live isolated and alone, and to die sooner than someone of European descent. According to virtually every available indicator, health issues are a more pressing priority for First Nations peoples than others (Assembly of First Nations, n/d). Manitoba Centre for Health Policy Statistics indicate that the Manitoba First Nations population has twice the premature mortality rate of the overall Manitoba population and that Aboriginal people living in northern areas have better health status compared with those living in such southern locations as Winnipeg (Manitoba Centre for Health Policy, 2002). Statistics Canada indicates 17.6% of Manitobans are disabled, but 25.8% of Aboriginal Manitobans are particularly affected with one or more disabilities (Full Citizenship: A Manitoba Strategy on Disability, Province of Manitoba, 2000). First Nations people with disabilities are more likely to live in sub-standard housing and encounter physical barriers within their housing. Households of First Nations people with a disability experience higher forms of socio economic disparity in terms of low income, high unemployment, and greater dependency on social assistance (Elias and Demas, 2001).

One of the ironies in researching housing options for Aboriginal peoples in the core area of Winnipeg is the paradox located in the traditional understanding of what it means to "be home." First Peoples were nomadic for ten thousand years. They carried their homes with them. In the pre-

contact era, the Cree, Sioux, Ojibway, Dene and Inuit Nations were nomadic tribes who had no permanent stationary homes but lived in portable structures. They survived by following the buffalo and caribou herds. The Métis were also nomads with no real property who took part in the summer buffalo hunt (The Heritage Community Foundation, 2000). Decisions made by Aboriginal peoples about living locations, hunting, family structure, spiritual practises, and even life and death were made within the context of kinship and clan (Wiebe, 1973.)

Historically, dying and death would have been a common life event for native persons, and this greater visibility of dying and dead people occurred in smaller, more intimate communities than urban centres such as the core area of Winnipeg. Dying people frequently participated in preparing for their own death by invoking deities, calling together their families, and making other preparations. If a healer was not able to help a person heal, then the healer's role was to call upon the spirits to help the dying person in the journey to the afterlife (Carter, l973). The belief that native souls revisited their loved ones supports the understanding of death as a natural part of the life cycle for First Nations people. Morton describes the self-perception of the First Nations peoples as being one with nature, not masters of nature, grief and mourning accompanied the loss of community members, but death was a common, expected, accepted, visible and spiritual event (Morton, 1997). Turner-Weeden explains a First Nations perspective of death and dying as follows:

Our Native peoples believe we pass over into the Spirit world, where we are met by ancestors who have passed on before us. We, as Native peoples, believe our spirits live on. When our time arrives to meet our Makers, many have fear and doubt. They know what this world is like, but they don't know what the other world is like. As we prepare to pass over, we believe our Creator lets us know our work here on earth is coming to an end. We must relinquish our tasks and make way for new growth and ideas (Turner-Weeden, 1995).

A First Nations service provider interviewed for the *Finding Our Way Home* project described Ojibway and Cree perspectives on dying as follows:

"Individuals in that [end of life] stage never look towards the end, because that's one thing I know; our people are more day-to-day people. Those things are far from being part of our decision-making. When it comes to our people thinking about the end, we don't think about, well, this is where I want to be buried and this is how I want to be buried. It just comes to that point in

time when we know that we're close to meeting our Creator once we've decided, you know, this is near so I'm going to tell a family member or whomever. But if death comes suddenly, those things are not as important for us to decide - the what or the where."

First Nations contact with Europeans and their hospitals-based management of terminal illness has shifted the responsibility for support of the dying person from the kin group and community-based support networks to specialized care provided by professional staff (Kaufert, 1997*).* The presence of Europeans in the nineteenth and twentieth centuries was disastrous for Aboriginal peoples who were decimated by epidemics, warfare, and the destruction of their ways of life and economies. Aboriginal cultures differ from religious and cultural groups that draw on scripture and textual foundations for their ethical beliefs and practices. Traditional Aboriginal ethical values generally emphasize holism, pluralism, autonomy, community- or family-based decision making, and the maintenance of quality of life, rather than the exclusive pursuit of a cure *(*Ellerby, 2000).

The relationship between the ethno-centric approach of Western medicine and the power this gives health professionals over patients becomes more pronounced during times when critical health decisions must be made. Current models of palliative care are fundamentally western in approach and have evolved without input from indigenous communities (Prior, 2000). Clinical ethics in themselves may be based on Western philosophical traditions.   Ethically-based decisions regarding the health of cultural minorities may ignore diverse perspectives, resulting in culturally insensitive decisions and overall health policies (Kaufert et al, l998; Shanahan and Brayshaw, l995; Davis, l996; and Hallenbeck, et al, l996). For Aboriginal patients who must travel south to get treatment, hospital-based management of terminal illness has shifted the responsibility for support of the dying person from the kin group and community-based support networks to specialized care provided by professional staff (Kaufert, 1999). Physical re-location of the patient, often without accompanying members of the family, means that death occurs in the alien cultural environment of the urban hospital (Kaufert and O'Neil, 1995).

One solution to conflicting cultural values concerning end of life decision making and care for the dying is to establish what Pickett calls a cultural brokerage (Pickett, 1993). This concept takes place between health care professionals, patients, and their families that involves actively exchanging

information about belief systems. The health care worker must be aware of her/his own framework of values, beliefs, and practices. Clarke goes further with the concept of a cultural broker: "A cultural broker is someone who has skill in visualizing two or more health and healing systems simultaneously and putting them together in ways of greatest meaning and benefit for the client" (Clarke, 1978). Kaufert et al developed a cultural brokerage plan for health care teams working with the terminally ill. To be able to be a competent "cultural broker," one has to be aware of ones own attitudes and beliefs and of the effect these can have on patients and their families. Communication skills must be developed that elicit the patient's framework of values, attitudes and beliefs. Effective negotiating skills are then required to find common ground on which to build a mutually agreed-upon care plan. All members of the health care team must develop these skills and learn to be flexible and creative. Only by fostering an open, non-threatening relationship and by specifically asking the necessary questions are health care teams able to work effectively in supporting terminally ill patients and their families (Kaufert et al, 1998). Care of patients approaching death involves the whole healthcare system — but may need, from time to time, palliative care specialist input, including specialized cultural competence (Lickiss, 2003).

There is under representation of cultural minorities, such as Aboriginal groups in palliative care programs. Healthcare staff can be frustrated because they can't provide the kinds of holistic care desired by patients of such minority groups. There is a tendency for health care staff to have ethnocentric beliefs about the superiority of western health standards and little awareness of cultural differences (Eve et al, 1997; Kaufert et al, 1998).

Twenty four persons participated in the *Finding Our Way Home* research project total; of these 13 identified themselves as being of First Nations, Inuit or Métis descent. Five were women, and eight were men. Five First Nations persons lived in their own home, 4 lived in transitional housing, 1 each lived in an Independent living cluster and long term care facility, and 2 lived in an acute care hospital.

One participant who came directly from a northern reserve was unable to bring all her children with her into transitional housing because of space constraints. This meant her family was divided at a time when she as a parent was in an end of life transition. The location where this individual lived was neither near the children's school nor their peers; therefore, they were unable to attend school. These children were described as having to cope

with separation from their siblings, living with a parent in an end of life situation, and contending with social isolation.

A number of First Nations persons reported prior experiences with cultural attitudinal barriers. This prevented them from seeking outside assistance such as Home Care. According to Health Canada, First Nations and Inuit peoples are significantly underserved in terms of Home Care services. Federal initiatives measuring the home support requirements of urban and remote Aboriginal communities found the type of model used in a community is far less important than how well the model fits with the community's needs (Shapiro, 2002). Findings in our project echoed those of the Federal initiative. Applying a framework designed for the general population does not necessarily meet the distinct social and health needs embedded deep within First Nations cultures. A First Nations community advocate expressed this dilemma as follows:

"One of the things you're going to find with individuals that come through our doors is that they have to pretty well be falling apart before they find the help they need…it's a lot to do [with] our culture because we are very private people. We don't need people coming in and out of our homes, looking around."

First Nations persons expressed their reluctance to acknowledge home support and medical needs. Advocates stated assessments of participants' needs were often not completed without considerable advocacy and pressure from community groups. Furthermore, many Aboriginal persons were not aware or did not understand what they could access in terms of disability accommodations, home supports and other assistance.

Service providers were asked about the challenges they experienced as organizations in meeting the needs of First Nations peoples. Representatives of the First Nations disability organization explained that providing effective support went considerably beyond the expected models of service delivery. They stated there needed to be understandings of traditions that were generations old. These included an appreciation of the impact of traditional clan structures, healing practises, kinship patterns, and the impact of colonization, cultural degradation and residential schools on contemporary First Nations persons. Being ready to die and finding a sacred space in which to die was stressed as being far more important than making material funeral arrangements. First Nations disability service providers were governed by these understandings of death and dying. No set protocol of

service delivery was established. The organization tried to meet each individual's distinct needs in order to help them prepare themselves for dying.

3. 9   Challenges for women

"Today, gradually, sometimes not easily, I begin to understand my body is still in charge of my life process and has always been. It is still taking good care of me, but it has always had two jobs; to make sure that I live and to make sure that I die. All my life it has been as busy with my dying as my living."

~ Barbara Macdonald
(*Look Me in the Eye, 1983*)

> ➢ Women with disabilities experiencing end of life transitions in the core area of Winnipeg feel obligated to assume care-giving responsibilities for others despite their own critical medical circumstances. Healthy women who provide care for others experience deterioration of their physical and emotional well-being, stressors related to constant responsibility, and social isolation. This is compounded considerably for women who are already unwell.
> ➢ Women with disabilities in end of life transitions struggle with poor and inadequate housing conditions.
> ➢ Feeling unsafe is a significant concern for women living in their own homes or in transitional housing.
> ➢ Financial problems compound other issues relating to housing for women with disabilities in end of life transitions. Women experienced difficulties with the provincial Income Assistance program, particularly when applying for disability benefits.
> ➢ Advocacy plays an important role for women with disabilities who want to acquire, modify or even keep suitable, safe and affordable housing. Forced choices pit independence against health. Advocacy is essential so women are not forced to accept a house because of its affordability rather than its suitability to life with disabilities.
> ➢ Women are concerned if they remain in their own homes, this places heavy burdens on families.

The total number of participants in *Finding Our Way Home* involved 24 individuals with disabilities experiencing end of life transitions living in the

core area of Winnipeg; of these, only 8 were women. All participants were volunteers, and many came to know of the project through information dispersed to the public or by word of mouth. The scope of this research has not determined why almost twice as many men as women came forward to provide details in what was often a very vulnerable time in their lives, but this warrants further exploration. Four women participants lived in their own homes, one lived in transitional housing, two lived in an Independent living group setting, and one lived in a long term care facility.

Many of the housing needs of women who participated in *Finding Our Way Home* were not distinct from those of the men interviewed for this study. Feelings of vulnerability in unsafe neighbourhoods, financial stress that prohibited people from living in appropriate housing, the need for appropriate accommodation for disability-related limitations, the need to be close to transportation to access medical and other services, and the need for a quiet place to rest were voiced equally among genders.

What was different were the additional care-giving responsibilities that women in end of life transitions felt obligated to assume. Despite critical illness, one woman had responsibilities to look after underage children, another after an ailing parent, one lived with a roommate who was sicker than she was, one made daily rounds in the long term care facility where she lived to make sure other residents were okay, and another, despite serious illness, acted as a community advocate for those who were unable to articulate concerns for themselves. The impact of these care-giving responsibilities varied from woman to woman. Some found a sense of purpose in helping others, and were nourished by the positive feedback they received when they interacted with people in circumstances similar to their own. The obligation to make sure others' needs were met appeared to be a crushing responsibility for others. This was most evident in the case of a single mother with school aged children.

The Prairie Women's Health Centre of Excellence conducted research concerning the health of informal care-givers in Manitoba in 2000 (Hawranik and Strain, 2000). Forty one percent of the informal care-givers participating in that study rated their health as very good, while 51% indicated their health was pretty good. Less than 1% stated their health was poor or very poor. This contrasts significantly with those women participants who were providing care for others while experiencing end of life transitions in *Finding Our Way Home.* Hawranik and Strain reported that despite the overall very

good health among women informal caregivers in their study, many experienced:

- A deterioration of health during the time they were providing care;
- A psychological toll that care-giving placed on them;
- A continual anxiety and concern because they could never take a break from the constant responsibility regarding the safety and health of the person for whom they were caring;
- A gradual process of losing ties with other people because of the time care-giving took and the energy it demanded; and,
- Additional pressures because these care-givers had to act as gatekeepers, mediators and advocates for the person requiring their help (Hawranik and Strain, 2000).

Given these stressors faced by women participants of the Hawranik and Strain study who were generally in very good health, it is easy to understand the level of strain care-giving puts on women care-givers from the *Finding Our Way Home* research that were themselves facing serious illness or debilitation.

Women with disabilities in end of life transitions struggle with poor and inadequate housing conditions. Safety was named as a priority for women living in their own homes or in transitional housing. One woman had received a death threat; others felt it imperative to live in housing that was not near people with substance abuse issues or sex trade workers. Vandalism was a problem, and women chose to be socially isolated as a way of being less visible and less prone to abuse within their communities. One participant described living in her apartment building as follows:

"Well, I guess it's safe…if I don't bother anybody."

Another woman said,

"I don't talk to my neighbours. They say, 'hi,' to me; I say, 'hi,' back. That's the extent…before, when I've gotten to know my neighbours, they took advantage of me and I was too sick to work but I wasn't so sick that I couldn't take care of their kids type thing."

This woman described how she needed to protect herself from feeling obligated to care for the children she thought were being neglected in other households close to her own home.

The lack of fully accessible housing was experienced by women in their own home, in transitional housing, in Independent living group settings and in long term care facilities. Entrance doors into apartment buildings and long term care facilities weren't accessible, although some women made repeated appeals to building management to have that changed. Independent living group settings were also not fully accessible. One participant reported:

"I can't reach my cupboards. We had to buy our own china cabinet so we can reach our dishes…and we can't cook very well. We can't reach the stove elements."

Financial problems compounded other issues relating to housing for women with disabilities in end of life transitions. There is a dilemma inherent in applying for Canada Pension Plan monies; because CPP is granted on a one-time basis, if an applicant should recover to the point where she is able to work, she not only loses her pension, but cannot re-apply if her health deteriorates. A number of women participants and service providers described difficulties with the provincial Income Assistance program, particularly when applying for disability benefits. One woman who was critically ill and awaiting surgery explained:

"[Income Assistance] don't seem to understand the disability of people, because a number of times I've talked to my worker and I try to tell her something about my disability and then she turns around and says, 'That's not our policy,' like she's working [for] policies, not people with disabilities."

A community advocate echoed these concerns:

"The attitudes [of Income Assistance workers] are some of the things I don't understand when it comes to [a woman with disabilities in end of life transition]…She was expected to walk to her worker's office and I called her worker and said, 'How can you possibly expect this woman to walk over there? She is suffering from pneumonia, she has shortness of breath.' I explained all these things and [the worker said], 'You're not a doctor.' I said to her…'I'll have to deal with your supervisor,' and the minute I mentioned that she [did] an about face."

The advocate was then able to secure transportation to appointments for the ill woman, and delivery of her medical prescriptions. Although the end results of this encounter with the Income Assistance program were satisfactory, this anecdote illustrates the difficulties encountered by women

with disabilities who are in end of life transitions when they interact with government mechanisms designed to act as a social safety net.

Two thirds of respondents in a random survey of Canadians who identified themselves as living with disabilities stated that they needed assistive devices or help with everyday activities (Cossette, L. and Duclos, E. 2002). This proportion is slightly higher for women; the number of men who identified themselves as living with disabilities was 12.4% compared with 17.5% for women. Nearly one third of this group reported they needed but did not have adequate housing accommodations.

The Women's Housing Action Team (Alcorn et al, 2004), studied the housing realities and requirements for women living with disabilities in Victoria, BC. Their findings indicate women living with disabilities experience significant difficulties finding affordable, safe and suitable housing. Participants commented that the daily work of living with disabilities becomes even more difficult if one is not living in a place that "*is your home that nourishes your soul.*" Keeping a private, safe home becomes more difficult if there are too few people or services to assist when necessary. Women living with disabilities struggle with the unknown implications of fluctuations in their illness, capacities and requirements. They also struggle with a keen sense that their entitlement to their housing requirements are increasingly tenuous in times of cuts to public services, pressures for everyone to find gainful employment, and expectations that housing markets be profitable.

Alcorn et al stress the important role of advocacy for women with disabilities who want to acquire, modify or even keep suitable, safe and affordable housing. Affordability is not just the cost of the housing; it includes the costs that are required to live with disabilities. Participants spoke of the forced choices that pit independence against health. Advocacy is essential so women are not forced to accept a house because of its affordability rather than its suitability to life with disabilities. Providing this assistance and advocacy is not an extra, but an essential, not favours but requirements. Women with disabilities do not want to depend on others for the basics in their lives (Alcorn et al, 2004).

There is considerable diversity in the housing needs of women with disabilities. Besides affordability and safety, few women share all of the same specific requirements or wants. Housing requirements cannot be separated from the person, and need to be individualized. Flexibility is

essential in all policy and planning. Disability is not generic. Housing solutions, therefore, cannot be generic (Alcorn et al, 2004).

Popular belief assumes a common agenda between old women and women with disabilities; the stereotype holds that all old women are disabled and all women with disabilities may as well be old (Healey, 1993). This stigmatizes and marginalizes both groups, even within the feminist community. Both groups share social invisibility and oppression; ageism and ableism drive old women and women with disabilities to distance themselves from each other. This plays out in housing options – women with disabilities don't want to be warehoused with those who are old; and the old don't want to be labelled as disabled. When old age and disability are viewed as abnormalities rather than normal life conditions, options for housing and other aspects of daily living quickly narrow to situations only offered within medical settings (Healey, 1993).

The long term care trajectory for older women with disabilities often begins with the use of Home Care services to meet personal and housekeeping needs, followed by a period of homecare with short stays in a long term care facility, and then a permanent move to an institution (Mehdizadeh, 2002). Women who are not married or involved in a long term relationship are more likely to move to an institution, and do so at a younger age. Of these, less than 50% experience cognitive impairments that make living in their own homes a risk. The majority of women living in long term care facilities only experience physical disabilities and require assistance with activities of daily living (Mehdizadeh, 2002).

Only half of the women participants in *Finding Our Way Home* lived in their own homes, and none of them reported experiencing cognitive impairments. Women participants were concerned that if they remain in their own homes, this would place heavy burdens on family members. In at least one instance, this was the reason a woman chose to be in an institutional setting where she experienced less independence than remaining in the community.

Women with disabilities, according to Alcorn et al, need housing that is:
- Affordable and takes into account the extra costs of living with disabilities;
- Safe so that women can live free from physical and emotional harm both in their homes and in their communities;
- Adequate and customized to meet their basic needs of daily living;

- Reflects their values about healthy living. This includes the capacity to have pets, room for visitors, natural light, and space for doing home rehabilitative exercises, hobbies and home-based employment.

Women participating in *Finding Our Way Home* had similar housing needs to those identified by Alcorn et al. They wanted affordable housing, more room, ramps, accessible doors, clean air quality, safety, more home supports, a place for their pets, a place for their families, quietness, access to services, cleanliness, and assistance with personal care that respected their dignity.

3.10   Finding a place to die

"Theoretically [I'd die in a place where I get to call the shots] if I were comfortable. I mean, if the hospital would keep me more comfortable and I would be in less agony, then that's the place I would want to be, but if I was just waiting for my time to run out, all things being equal, I'd rather be at home."

~ Project Participant

"They have what they call the 'shaking tent'. [The] medicine man is in there and he performs…he brings in everything and everybody….all the last things that people in their desires come tell. [They] disclose whatever there is to be disclosed."

~ Project Participant

> ➢ The majority of people from transitional housing and Independent living group settings expected to move to a long term care facility if their physical condition deteriorated further.
> ➢ Others were more ambiguous about future plans. Someone in an acute care hospital stated if one more amputation was required, he would simply unplug himself from life-sustaining treatment and *"go home."*
> ➢ People with disabilities may understand the nature of dying as being more cyclical than linear. The onset of disability complications can bring persons to a critical brink where they are very close to dying, but then they can recover and eventually resume all the activities of daily living. This cycle might perpetuate itself many times.
> ➢ Some participants did not tie their end of life housing preferences to specific physical locations but rather to the quality of care and relationships they anticipate experiencing in certain settings.

> ➢ Making the context rather than the location the priority in choosing a place to die was articulated most clearly by participants of First Nations descent.
> ➢ Some people hoped for housing settings that don't currently exist. These included completely environmentally controlled accessible downtown apartments and Independent living group settings with a palliative component managed so people could make end of life transitions with increased care needs while retaining self-autonomy and the capacity to stay at home.

Finding Our Way Home participants were asked what length of time they anticipated living in their current housing situation. This was a probe into what plans people made for the future. Some participants provided direct answers. The majority of people from transitional housing and Independent living group settings expected they would need to move to a long term care facility if their physical conditions deteriorated further.   One person who rented an apartment and two from long term care facilities said they would stay where they were until they died.   Others provided more ambiguous answers. One participant from transitional housing answered, *"Not long,"* but gave no indicators as to where the next move would be. Another person in an acute care hospital answered the question by stating if one more amputation was required, he would simply unplug himself from life-sustaining treatment and *"go home."* Moreover, some participants did not connect this question with morbidity, but stated they were looking for better housing options, and would move as soon as these became available.

This ambiguity may be the result of a number of difficulties. Both the project Advisory Committee and those who designed the research questions stressed the importance of practicing sensitivity regarding the difficult subject matter this research entailed. It was agreed that at no point would researchers push participants to declare details about their end of life situations that could result in emotional discomfort or trauma. Given this imperative, the questions posed were, "How much longer do you think you'll live in your current housing setting?", "Do you anticipate an increase in your support needs?" and "Would you like to live somewhere else?" These questions left flexible openings so participants could choose what they wanted to discuss about where they'd be living when they die. The question, "Where are you going to die?" was never explicitly posed. Participants were aware of the nature and purpose of the project; they knew it involved hearing the stories of people who were in end of life transitions, but they also were

informed that they could answer questions in ways that were appropriate for them. This included having the right to refuse to answer questions.

A second theory about the ambiguous answers some participants offered pertaining to where they would die may be linked to the linear nature of the question itself. Planning **where** you are going to die involves having a pretty good idea about **when** you're going to die. The project interviewer (herself a person with a life-threatening disability) introduced a concept to a couple of participants in the very latter stages of the interview phase of the project. This concept involved looking at the cyclical nature of dying for persons with disabilities. The onset of disability complications can bring persons to a critical brink where they are very close to dying, but then they can recover and eventually resume all the activities of daily living. This cycle might perpetuate itself many times. Each time critical medical circumstances are experienced, there is a very real possibility that the person may die. Living in this cycle makes the more linear trajectory of what is understood to be "palliative" more difficult to apply. This concept did not originate with project participants, but those with whom it was discussed agreed that they had *"been around that loop type thing"* themselves.

Some participants did not tie their end of life housing preferences to specific physical locations but rather to the quality of care and relationships they anticipated experiencing in certain settings. When asked where she'd like to live, one participant said she'd like to stay in her own home as long as possible because her landlord understood and was empathetic about her health circumstances. One participant stated that an acute care hospital would not be an option because of previous experiences with dignity issues:

"I have no control over my bladder. When I was in the hospital they didn't give me anything for that and when I was on a stretcher I pissed myself…when they saw that they treated me like shit. You know, if you're in the health care profession, patients do that…it's not our fault that we're sick."

Making the context rather than the location the priority in choosing a place to die was articulated most clearly by participants of First Nations descent. Aboriginal traditions embracing a holistic understanding of death and dying have been discussed earlier in this research. Representatives of a First Nations group told *Finding Our Way Home* project staff that one very important story to include in this research involved the circumstances of an older Aboriginal man who was incarcerated and then placed in a downtown "drunk tank" because he had no where else to go. His friends knew he was

dying, and made urgent appeals to have him moved to an apartment. Within hours of being given his own place, his friends reported that he was finally able to die. Advocates in that situation stressed repeatedly to the *Finding Our Way Home* project interviewer the importance for First Nations peoples to have their own safe, sacred space to die. This space was described as a departure point, *"That person leaves to [go] to the spirit world,"* and a place of reckoning and reconciliation, *"They disclose what ever needs to be disclosed,"* rather than as a specific physical setting or locale.

A number of participants indicated they were hoping for the creation of housing settings that did not currently exist. One such setting involved a fully accessible downtown apartment that could be completely environmentally controlled (i.e. lighting, heating, water, computer, television, doors, drawers and cupboards operated by remote control.) A number of participants discussed another alternative – the creation of Independent living group settings that incorporated a palliative component. These were described as needing to be managed in such a way that persons could make end of life transitions with increased care needs and appropriate staffing while retaining self-autonomy and the capacity to stay at home.

Some First Nations persons in their own homes in the core area of Winnipeg had been relocated there in order to be nearer to medical services and accommodations not available to them in their communities in northern Manitoba. This move to the city did not necessarily mean participants accessed these medical services. One participant described his lack of contact with his physician as follows:

"My doctor is moving so I don't know where that is…I don't know and besides I live close by the hospital now and there's an emergency. They'll take somebody there."

This same participant appeared to be very ill, but when asked where he would want to live if he got "really sick," he said, *"I would rather be home [up north]."*

Participants living in transitional housing saw their circumstances as temporary. Most commented that they felt they had little choice except to stay in that situation for the time being. Many found it difficult to think about the future. A participant who had previously been homeless found making

day-to-day decisions a considerable adjustment, and did not describe long term plans when health deteriorations might require housing changes.

People in transitional housing did not want to stay there. One person in critical health circumstances expressed a strong desire to move out of the downtown hotel where he was being housed and receiving daily Home Care because he wanted to live with a close friend he trusted. This participant died a few weeks after the interview. Another participant was optimistic despite serious illness, stating, *"Well, down the road I am hoping that my life situation gets better."* When the interviewer asked where this participant would live if his health deteriorated further, the participant stated he did not want to stay in transitional housing, but did not elaborate further on a housing preference. Context took priority over location; this participant expressed the importance of companionship and care over living in a specific locale.

One person who frequently stayed at a downtown AIDS hospice appreciated the care offered in that kind of transitional housing setting, but found the lack of privacy and the circumstances of being with others who were very sick with the same medical condition psychologically difficult:

"All the services there were good, but the privacy issues – everybody [was] looking over my shoulder. I like to eat in private but we all had to eat around the table and I [would] just eat and run because I couldn't stand it. It's not that I don't have compassion for people who are sick, but when they get to that stage of AIDS, I can't really take it…They get really cantankerous. If I was really sick I'd be grateful if anyone came and helped or even visit[ed] if I was at that stage."

Both participants and service providers in Independent living Group settings discussed the difficulties of housing tenants with palliative needs. At the time of the interviews, this had occurred once before. Providing someone whose death was imminent with care based on the principles of Independent living was seen as an important and positive option for people with disabilities. The practical implications of making palliative care available was difficult, however, because of unpredictable urgent needs, scheduling difficulties and the legal implications once a tenant was no longer competent to make care decisions.

Persons living in long term care facilities stated that being located close to friends and family played some part in determining which institution would become their home when they are dying.

Participants interviewed in an acute care hospital were undergoing significant changes to their sense of independence and well-being. Both were in acute, end stages of their disabilities. Both stated there was nothing good about their living situations; both described their lack of independence, and one person reported he had not been bathed in 2 weeks. One was despondent, and the other told the interviewer he would refuse life-sustaining treatment if one more negative manifestation of his disability were to occur. When asked if they anticipated moving somewhere, one participant did not answer and the other talked of "going home" by refusing treatment and "not lasting very long."

4. PUTTING THEORY INTO PRACTICE

4.1 Providing services to people with disabilities in the core area of Winnipeg who are dying

"Once a person is dying, as a culture, as a society, we really, really have to expand our views as to what that means. We don't think enough about that. It's not a priority – care for the dying."

~ Service Provider

Inter-Agency cooperation
One objective of the *Finding Our Way Home* project was to discover the kinds of connections different organizations made with each other, and to measure the impact of these connections on people with disabilities living in the core area experiencing end of life transitions. Service providers from palliative care and disability organizations were interviewed, and information was obtained from representatives of the Manitoba Housing Authority regarding provincial government housing policies and practices (*see Section 3.2)*.

It was difficult to find service organizations whose mandates encompassed the triad of issues concerning:
- Safe, affordable, accessible housing in the core area;
- Appropriate and adequate support services for people with disabilities; and,
- Resources that met the complex needs people encounter when facing end of life transitions.

Housing, disability-related and palliative care organizations each focused primarily on the limitations of their individual mandates, with few if any deep connections that merged the concerns of housing with the concerns of living and dying with disabilities in downtown Winnipeg.

Disability related organizations reported they used "Information and Referral" programs to build bridges between themselves and other community groups at the municipal, regional, provincial and national levels.

Independent living group service providers reported that they connected with other organizations as specific needs arose. One particular liaison with the

WRHA (Winnipeg Regional Health Authority) Home Care palliative team was put in place in one instance to meet the needs of an individual who was dying.

Informal connections with other disability organizations, including advocacy groups, were ongoing.

Accessibility
Service providers were asked if their organizations were accessible to people with disabilities that lived in the core area. Most representatives from disability organizations stated their agencies were wheelchair accessible; however, some activities held outside of agency buildings were not. Alternate formats for materials were supplied in the form of cassette tapes, large print, or supplying reading and scribe services.   American Sign Language (ASL) was readily available for one organization for consumers with hearing impairments, and could be arranged with advance notice by other disability-related service providers.

Efforts were made by hospice care providers to remove barriers to participation in their organization, and there was intent expressed to learn more about accessibility. People with visual disabilities or literacy needs were provided with volunteer readers, large print and scribe services. ASL interpreters were also used. Vehicles with easy access and seats that permit passengers to lie down were used to transport patients. All meetings were held in accessible locations. The organization worked in conjunction with mental health services to assist patients with emotional and psychological difficulties. Volunteers offered companionship and support, but did not become involved as part of the team addressing complicated mental health issues.

Roles of service providers
Long term care facility service providers described their institutions as playing a dual role - they provide housing for persons with disabilities, but are also often places where people die. They provide emotional, spiritual and physical support, friendships, and palliative care. Long term care facilities work with hospitals and the WRHA to provide appropriate medical services for patients. If required, staff will consult with any available sources to serve tenants and patients. Behaviour therapy is available for those residents of long term care institutions with mental health issues.

Hospice and palliative care organizations provide community public education on palliative care, advocacy for dying persons and their families, volunteer visitors for patients and their families, volunteer bereavement services, and professional consultations regarding end of life care and bereavement.

A disability organization representing First Nations people assisted dying persons through advocacy services that involved obtaining housing, income assistance, Home Care and disability supports. This organization also provided sobriety support for persons with disabilities in end of life transitions who were dealing with addiction issues.

Disability-related organizations reported they did not offer specific programming for people who were in end of life transitions; however, they did provide advocacy, peer support, and information and referral services for anyone with a disability. One service agency that provided group housing for adults with cognitive disabilities stated that when residents reached a palliative stage, they were transferred out of the care of the group homes and into medical facilities.

Services for First Nations persons
Service providers were asked to describe if they had specific services for First Nations peoples with disabilities. Independent living group setting management hired qualified persons as staff. This included Aboriginal attendants for First Nations tenants.

Some disability organizations had First Nations people on staff, and bridge-building efforts between the disability and Aboriginal communities are an ongoing process. The First Nations disability organization had all programming and services geared to that sector of the population.

The palliative care service provider stated that on rare occasions Aboriginal volunteers have met their Aboriginal clients. Volunteers were also provided with cultural awareness training concerning Aboriginal traditions.

4.2 Challenges for service providers

Lack of knowledge about end of life issues
Disability-related service providers stated that although staff knowledge about living with disabilities was extensive and often drawn from life experience, the knowledge base about end of life issues was weak.

One challenge for long term care facility service providers involved helping residents and their families understand the meaning of palliative care. Residents and their loved ones were described as sometimes thinking palliative care just meant leaving someone in a bed to die. The facility stressed the importance of recognizing that a different branch of nursing care was required in such situations.

Providing an appropriate setting for people with disabilities who are dying
Another problem in long term care facilities arises because many rooms are double occupancy – noise problems from oxygen machines and other increased activity can be disturbing for roommates. One service provider stated,
   "This is someone's space, someone's home, and there's no privacy for the physical little day-to-day things right at the end of life."

Independent living and end of life transitions
The Independent living group housing service provider stated their organization had only once offered services to a person with disabilities living in the core area of Winnipeg who was dying. This service had been an inter-agency cooperative effort done in conjunction with the WRHA Home Care palliative unit. The Independent living group housing staff was in no way responsible for making any decisions on behalf of the dying tenant. An understanding had to be established between the tenant, Home Care, and the Independent living staff that specified if the tenant was found unconscious, the IL staff would call emergency services. The Independent living staff did not want any responsibilities concerning the upholding of Do Not Resuscitate Orders, Advance Healthcare Directives or living wills. Providing this service was described as an extraordinary circumstance. The principle of Independent living is based on the capacity for tenants to self-direct; in other instances, when a tenant no longer has that capacity, they move out of the housing cluster.

Those involved in managing Independent living group settings stated providing services for people in the last stages of life was very challenging. Historically it wasn't in the mandate of the organization to work with people who were dying and stipulations of government funding did not allow tenants to plan to die in this setting. The one time when someone with palliative needs died in an Independent living group setting, very careful planning had to occur between IL housing cluster management and the WRHA Home Care palliative team. The representative from this service provider stated that neither the housing management nor the Home Care program is very comfortable in providing highly medicalized care in this setting. The service provider raised the issue of cost factors, stating that government and the public are increasingly recognizing that it's less expensive for people to remain in their own homes than to be hospitalized when they die.

Providing Appropriate Care for First Nations Peoples

Service providers were asked about the challenges they experienced as organizations in meeting the needs of First Nations peoples. Representatives of the First Nations disability organization explained that providing effective support went considerably beyond the expected models of service delivery. They stated there needed to be understandings of traditions that were generations old. These included an appreciation of the impact of traditional clan structures, healing practises, kinship patterns, and the impact of colonization, cultural degradation and residential schools on contemporary First Nations persons. Being ready to die and finding a sacred space in which to die was stressed as being far more important than making material funeral arrangements. First Nations disability service providers were governed by these understandings of death and dying. No set protocol of service delivery was established. The organization tried to meet each individual's distinct needs in order to help them prepare themselves for dying.

Service providers from disability and palliative care organizations recognized the need to know more about First Nations cultures and issues. Challenges for Independent living group settings included dealing with racial stereotypes on the part of both parties during conflicts between First Nations peoples and other cultural groups.

Long term care providers also talked about misconceptions and prejudicial views that interfered with service delivery. Biases held by individual

residents against First Nations persons were often a challenge, but as residents got to know one another, these issues sometimes resolved.

4.3   Gaps in service and unmet needs

Lack of affordable, acceptable, safe housing in the core area was the most prominent unmet need identified by service providers. Palliative care service providers saw a need for increased volunteer services. More public education regarding: palliative care; the importance of emotional support; and pain management are also required. People often wait too long before coming into palliative care; this makes developing relationships and support systems difficult. Fully accessible, free-standing hospices need to be built in all areas of Winnipeg.

Lack of services for First Nations people
Long term care providers did not have specific services for First Nations persons with disabilities experiencing end of life. Challenges for service providers of palliative care included having very little visibility within the Aboriginal population. Several questions arose for the service provider, including the need to ask why more First Nations people weren't reflected in the population served, and how palliative care services could be more accessible to diverse populations.

Palliative care as middle class phenomena
Challenges for service providers of palliative care included having very little visibility in the core area. One stated:

   "*Owning your own home and having a healthy caregiver are critical in order for persons to die at home.*"

Palliative care organizational models of assessment don't work well for people without phones or who live in rooming houses. Several questions arose for service providers. Once again, providers noted that core area people weren't reflected in the population served, and asked how palliative care services could be more accessible to diverse populations. Service providers also stated that suburban hospices such as Jocelyn House were not accessible physically nor are they socially geared for people with disabilities who live in the core area. The inference was that hospices and home palliative care were middle class phenomena.

Lack of resources
The development of a model of Independent living that also offered care for end of life transitions was suggested by both participants and service providers throughout the project. No such place exists now.

Long term care providers noted the shortages of palliative care unit beds in downtown hospitals, and the lack of staff and resources for a population base that will grow as baby boomers age.

None of the disability organizations had therapeutic counsellors on staff to help consumers face the complexities of end of life transitions. Some, however, offered one-on-one peer support, support groups, sobriety counselling and informal support.

Lack of understanding about distinct disability-related needs
Service providers from disability organizations identified the gap in understanding about the distinct needs of persons with disabilities at any stage of life. Information and Referral programs require more information about issues regarding death, dying and disability. This would be important for the core area, but the gap exists everywhere.

Staff and volunteers of the hospice and palliative care organization were not provided with disability awareness sensitivity training.

The limits of traditional models of palliative care
The most dominant message embedded in literature concerning end of life transitions concerns pain management, psychological adjustments inherent in facing death, the importance of creating an environment of dignity for the dying, and the spiritual well-being of dying persons and their families. The Institute of Medicine, in its report, *Approaching Death: Improving Care at the End of Life* identified appropriate quality supportive care services by professionals for people who are dying as including:
- Overall quality of life;
- Physical well-being and functioning;
- Psycho-social well-being and functioning;
- Spiritual well-being;
- Patient perception of care; and,
- Family well-being and functioning (Field and Cassels, 1997).

Prior research suggests the most important domains of supportive care for dying patients include:

- Receiving adequate pain and symptom control;
- Avoiding inappropriate prolongation of dying;
- Achieving a sense of spiritual peace;
- Finding meaning in life;
- Relieving burden; and,
- Strengthening relationships with loved ones (van der Maas et al, 1996, Moadel, 1999, Meier et al, 1998).

What is not noted in the above and much other palliative literature is the recognition that psychological distress and existential concerns are not only symptoms for dying people, but, as repeatedly articulated by *Finding Our Way Home* participants, also the results of living in poor, unsafe housing with inadequate services, racist and able-ist discrimination, and the abject misery of social isolation. These degradations in themselves are de-moralizing and life-limiting conditions, and are only compounded with the added stress of facing end of life transitions. Clearly, an engagement of these issues is required by housing, disability and medical service providers in order to conceive ways of expanding what appears to be a too-narrowly defined model of end of life care for people with disabilities living in the core area of Winnipeg.

4.4   Recommendations: Instigations for positive change

The following recommendations are put forward to address many of the difficulties described by the people with disabilities living in the core area of Winnipeg who participated in this research.

1.   INCREASE ACCESSIBLE HOUSING STOCK FOR PERSONS WITH DISABILITIES LIVING IN THE CORE AREAS OF WINNIPEG.

1.1 We recommend the:

- **Minister of Family Services & Housing for the Province   of Manitoba,**
- **Manitoba Housing Authority,**
- **City of Winnipeg, and**

- **Other relevant groups**

Develop appropriate, available, accessible housing stock that allows persons with disabilities experiencing end of life transitions to live in private dwellings that are safe and suitable to accommodate supportive family and friends.

1.2 We recommend the **Canada Mortgage and Housing Corporation** promote the Residential Rehabilitation Assistance Program (RRAP) and the Home Adaptations for Seniors' Independence (HASI) program to landlords and homeowners so that disability-related adaptations are funded.

1.3 We recommend the

- **Minister of Family Services & Housing for the Province of Manitoba**
- **Housing Committee of the Manitoba League of Persons with Disabilities, and**
- **Other appropriate community groups**

Monitor the development of accessible, affordable, appropriate and safe housing for persons with disabilities.

1.4 We recommend the **Minister of Family Services & Housing for the Province of Manitoba** conduct formal evaluations of accessible housing stock and make results of these evaluations available to the public on a bi-annual basis.

2. ENSURE PEOPLE WITH DISABILITIES HAVE ACCESS TO THE END OF LIFE SUPPORTS THEY REQUIRE IN THE HOUSING SETTING OF THEIR CHOICE.

2.1 We recommend the:
- **Minister of Family Services & Housing for the Province of Manitoba,**
- **Minister of Health for the Province of Manitoba,**
- **Winnipeg Regional Health Authority Palliative Care Unit,**
- **Winnipeg Regional Health Long Term Care Authority, and**
- **Winnipeg Regional Health Authority Home Care Program.**

Provide adequate palliative, personal, medical and other supports so that persons with disabilities living in the core area in end of life situations can

choose the housing settings that are most appropriate for themselves and their families/support circles.

3. PROMOTE INDEPENDENT LIVING SETTINGS FOR END OF LIFE HOUSING.

3.1We recommend the:
- **Minister of Health for the Province of Manitoba**
- **Minister of Family Services & Housing for the Province of Manitoba**
- **Winnipeg Regional Health Authority Palliative Care Unit**
- **Winnipeg Regional Health Authority Home Care Program**
- **Independent Living Resource Centre,**
- **Fokus Housing, Incorporated,**
- **Ten Ten Sinclair, and**
- **Other Independent Living group housing clusters**

Discuss and promote the Independent living principles within a palliative context to the disability community.

3.2 We recommend the:
- **Minister of Family Services & Housing for the Province of Manitoba,**
- **Minister of Health for the Province of Manitoba,**
- **Winnipeg Regional Health Authority Palliative Care Unit,**
- **Winnipeg Regional Health Long Term Care Authority,**
- **Winnipeg Regional Health Authority Home Care Program,**
- **Fokus Housing Incorporated and**
- **Independent Living Resource Centre**

Work together to develop Independent living group settings that accommodate the increasing personal and palliative care needs of persons with disabilities who are making end of life transitions.

4. PROVIDE ACCESSIBLE TRANSITIONAL HOUSING FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES.

4.1 We recommend the:
- **Minister of Health for the Province of Manitoba**

- **Minister of Family Services & Housing for the Province of Manitoba**
- **Winnipeg Regional Health Authority Supportive Housing Division**
- **Hospice and Palliative Care Association of Manitoba**
- **Dial-a-life Housing and**
- **Other pertinent organizations involved in the administration and development of transitional housing**

Develop fully accessible, safe transitional housing that accommodates family/support circle visitation, privacy, and immediate availability.

4.2 We recommend the **Minister of Family Services & Housing for the Province of Manitoba** provides appropriate funding for not-for-profit organizations that administer transitional housing so all sites are made fully accessible.

4.3 We recommend the:
- **Minister of Family Services & Housing for the Province of Manitoba and**
- **Child and Family Services of Winnipeg**

Provide case management that ensures the children of residents in transitional housing have the opportunity to remain with their parents.

5. INCREASE PALLIATIVE CARE OPTIONS FOR PEOPLE WITH DISABILITIES IN CORE AREAS.

5.1 We recommend the:
- **Minister of Health for the Province of Manitoba**
- **Minister of Family Services & Housing for the Province of Manitoba and**
- **Hospice and Palliative Care Association of Manitoba**

Develop a broader mandate to address the distinct social needs of people living in the core area who require hospice and palliative care options.

5.2 We recommend the:
- **Manitoba Housing Authority,**
- **Winnipeg Regional Health Authority Palliative Care Unit,**
- **Winnipeg Regional Health Authority Home Care program,**
- **Hospice and Palliative Care Association of Manitoba**

- **Groups representing poverty concerns,**
- **Groups representing First Nations peoples,**
- **Groups representing ethnic minorities**
- **Groups representing persons with HIV/AIDS and**
- **Consumer-based disability organizations**

Work together to gain a fuller breadth of perspectives concerning the needs of people with disabilities in the core area of Winnipeg who are dying.

6. ENSURE HIGH STANDARDS OF CONDUCT BY PROFESSIONALS PROVIDING SERVICES TO PERSONS WITH DISABILITIES AND FIRST NATIONS PEOPLES.

6.1 We recommend the **Policy and Program Development department of the Employment and Income Assistance program of the Province of Manitoba** develop mechanisms to effectively ensure high standards of professional practice and respectful treatment of persons with disabilities, including persons of First Nations descent are followed by Manitoba Employment and Income Assistance workers.

6.2 We recommend the establishment of an independent ombudsperson and a Fair Practises Office within the **Employment and Income Assistance Program** that would assist persons applying for and/or receiving income assistance in appeal processes and other disputes with the Income Assistance program. The ombudsperson and the Fair Practises Office should be highly visible and accessible.

6.3 We recommend the**:**
- **Winnipeg Regional Health Authority Home Care Program**
- **Winnipeg Regional Health Authority Primary Care Program**
- **Manitoba Government General Employees' Union and**
- **Manitoba Nurses' Union**

Develop mechanisms and educational opportunities to effectively ensure that high standards of professional practice and respectful treatment of persons with disabilities, including persons of First Nations descent are followed by primary healthcare and home care workers.

6.4 We recommend the:
- **Winnipeg Regional Health Authority Home Care Program**

- **Winnipeg Regional Health Authority Primary Care Program**

Make information concerning the existence of the Appeal Panel for Home Care and in-hospital patient ombudspersons highly visible and accessible.

6.5 We recommend the**:**
- **Minister of Health for the Province of Manitoba and**
- **Minister of Housing & Family Services for the Province of Manitoba**

Evaluate the effectiveness of these mechanisms and educational opportunities and make the findings of this evaluation available to the public within a three year period.

6.6 We recommend the **Manitoba Government General Employees' Union** develop mechanisms that ensure Home Care workers are safe and can provide services in all settings, including high risk neighbourhoods in the core area of Winnipeg.

5. CONCLUSION

We undertook the *Finding Our Way Home* project knowing we were exploring issues that lay in uncharted waters. We were aware of three pertinent social issues: the lack of safe, affordable, available and accessible inner city housing; the lack of supports available for people living in the core area of Winnipeg experiencing end of life transitions; and the barriers encountered by people with disabilities. We knew that each of these issues was an important topic for research on its own. But we had a hunch that there were people who were caught in a complex maze that encompassed housing in Winnipeg's core, struggling with end of life transitions, and living with disabilities. We did not know who these people were, where we could find them, and if they would come forward. They seemed invisible – unidentified on the streets, under-represented in community-based advocacy and service groups, and certainly not noted in existing research literature. But there were enough clues to convince us these people existed. Previous research, personal experience and the connections we had with various community groups had informed us that:

- People with disabilities tend to be poorer than those without disabilities;
- The downtown area of Winnipeg houses people of lower economic standing;
- The highest concentration of First Nations people is in the downtown core;
- Aboriginal people are more likely to have disabilities and illness than those of European descent;
- Poorer people tend to die sooner; and,
- There are issues of safety, accessibility and affordability in Winnipeg's core area housing stock.

Our hunch led us to some important discoveries. The assumptions we made were fairly accurate. But we were also surprised, and some of our assumptions were overturned.

We were surprised by the kinds of people who came forward to participate. There were more men than women willing to talk about housing circumstances and end of life transitions. Half of the participants were of Aboriginal descent; a representation we had anticipated as highly unlikely given the mistrust between First Nations peoples and predominantly white

institutions and the fact that the researcher conducting interviews was not a woman of colour. And, we found people willing to talk about the highly personal existential quandaries they were facing. As researchers and as an advisory committee we had struggled with the question of evoking information about people's views on life and death. We wanted to be sensitive when talking to participants about death because discussions of that nature can be emotionally difficult and socially taboo. We spent hours and countless emails coming to a consensus about the wording, "end of life transitions" for the participant recruitment material. Participants did come forward; some talked about death, and others talked about survival in a city where they lived in substandard housing and just wanted to avoid the street violence all around them.

We had made no assumptions about the importance of safety. We had anticipated participants would want to discuss housing costs or the failure of the medical system to provide them with adequate health care. But the issue of safety loomed large, particularly for people living in their own homes and in transitional housing. People are more worried about being beaten up and robbed than they are about suffering a long, painful death. They need to be vigilant to survive the streets, and strategies for well thought through palliative planning aren't even in the picture.

Another assumption that proved to be ungrounded was the supposition that people had clear ideas about the places where they wanted to die. We anticipated descriptions of certain physical settings with particular amenities and comforts. Some participants described vague geographical designations like, *"I'd like to be up north,"* but most described a context in which to experience end of life transitions rather than a locale. People wanted to be near loved ones who would offer them care and comfort and spiritual reconciliation. People, particularly First Nations people, wanted to *"go home,"* so that where they died was a departure point, not a destination.

Another assumption we made was steeped in age-ism. Put plainly, we anticipated many of the participants would be old. Palliative and other medical literature certainly seemed to suggest that the overwhelming number of people dying were old. Housing settings such as long term care institutions seem geared for an elderly population. We discovered that the people falling between the cracks are not old. We talked with people who have young minds with young interests and social needs who are housed in settings designed for those a generation or more older than themselves. Not

only do they have the difficulty of facing an end of life transition, but they do so in the context of social isolation.

The final assumption worth reviewing is the one often held about the nature of dying itself. Several times in this report the concept of dying as cyclical rather than linear is discussed. Regrettably, we twigged into that too late, and only raised this idea with a few participants at the end of the interview stage of the research. The conceptualization of being well, then getting critically ill, then being at the brink of death, and then recovering is worth exploring further. Personal experience leads to the conclusion that if you get very ill and then get better, people either doubt the seriousness of your illness or the integrity of your recovery. Recognizing this cycle could have profound effects on housing, healthcare, and home supports for people with disabilities facing end of life transitions.

This project leaves us with further questions.
1. Many participants relied upon non-government advocacy organizations regarding core area housing options. **Why aren't people with disabilities who are experiencing end of life issues receiving case management informing them of their future housing needs?**

2. Many First Nations participants who clearly needed home support services refused them. The Manitoba Home Care program is designed to be universal. **What is the missing link that would make home support services more acceptable and accessible for native people?**

3. First Nations people are transported from northern remote communities to Winnipeg in order for them to access medical services not available to them at home. They move into substandard, inaccessible and unsafe housing in the downtown core and lose contact with healthcare providers. **Why is there this breakdown in connection, and how can it be remedied?**

4. Participants in all five housing settings experienced issues of inaccessibility and lack of accommodation regarding disability-related needs. **Why is accessible housing stock not available for people with disabilities? Why are institutions and other organizations such as medical rehabilitation transitional housing, Independent living group settings, long term care facilities and acute care hospitals not fully accessible?**

The College of Family Physicians of Canada, in its submission to the Romanow Commission on the Future of Health Care in Canada, posed the question,

"*Will health care continue to be a central Canadian value? Will Canadians see a need to augment and strengthen our commitment to the core principles and values of accessibility, portability, universality and comprehensiveness embodied in the Canada Health Act? If these core principles are to be upheld, Canadians must recognize the need for fairness and equity, trust and choice within our medical systems.*"

After concluding this research, we agree with the validity of this question because it addresses the important connection between healthcare and housing that has been apparent throughout the *Finding Our Way Home* project. The core values of *accessibility, portability, universality and comprehensiveness* need to be applied to the implementation of any housing situation in the core area in which people with disabilities experiencing end of life transitions live. They are citizens who have the right to expect safety, security, and an environment that provides them with a sense of well-being.

They need this so they can find their way home.

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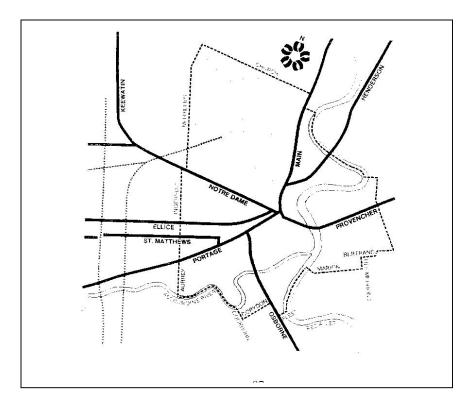
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7. APPENDICES

7.1   Map of study area

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7.2 Interview Guide for Participants
CANADIAN CENTRE ON DISABILITY STUDIES
Finding Our Way Home: Housing Options in Inner-City Winnipeg for
People with Disabilities Who are Dying

1. Tell me about the place where you currently live.
   Where do you live? (e.g. What neighbourhood? What street?)
   What kind of a place is it?
   > *If necessary, ask the following probe questions to determine which of the following options best describes the participant's current housing:*

   Is it a house you own or rent?
   Is it an apartment?
   Is it accessible transitional housing?
   Is it permanent Independent living group housing?
   Is it a long term car facility?
   Is it a hospital?
   > *Note to interviewer: This list may not be exhaustive (e.g. it is possible that some participants may live in hotels, rooming houses or be homeless.)*

   How long have you lived there?

2. Do you live with other people or by yourself?
   If participant lives with other people: Who lives with you?
   > *Note to interviewer: Answers to the above question may include support persons such as attendants. Some participants may find this question intrusive (e.g. social assistance recipients who may not want to disclose that they are in a shared living situation). If a participant declines to answer or seems reluctant, move on to Question 3.*

   > *Note to interviewer: If a participant who lives in a multi-unit building answers that she/he lives with other people, probe to determine if the "other people" (a) share the participant's apartment/unit or (b) live in other apartments'units of the building. If it's the latter, ask:*

   Tell me about the other people who live in [name of apartment, residence, facility, hospital].
   Do many of the other people have things in common with you? (e.g. similar age group, other people with disabilities).
   Do you have neighbours that are your friends?

3. Do you require any home supports for things like medical treatment, food preparation?
   > *If yes:* Tell me about them. Who helps you with those kinds of things?
   >> Do you have any support needs that aren't currently being met?
   >> Do you foresee any changes in your home support needs over the next year?

   > *If no:* Do you have any home support needs that aren't currently being met?

Do you think you may require home supports in the next year?

4. How did you come to live where you're currently living?
Was it your preferred choice? Was it the best of a limited number of choices? Did you feel like you had no choice or were forced to live there?

Was your physical or mental condition a factor in your choice?
   If yes: How did it influence your choice?
   Note to interviewer: Some study participants may have disabilities that are unrelated to their deteriorating health (e.g. a person who has cancer and uses a wheelchair – or is blind, hearing impaired, etc. – for reasons unrelated to the cancer.) For persons who say that their physical or mental condition influenced their choice, probe to determine what physical or mental condition(s) they are referring to.

Did the availability of home support services play a role in choosing to live where you're living now?

Did your social circumstances influence your choice? *Probe:* Social circumstances could be things like money, needing or wanting to be near friends, family, medical services, public transportation or other people who speak the same language.

Did you get or seek advice from a government or other agency?
   If yes: What organization(s) did you consult?

Did you encounter any obstacles to finding, choosing or buying/renting/keeping/being admitted to where you currently live?
   If yes: What obstacles did you encounter?

Where did you live before you moved to where you live now?

5. Do you pay your own mortgage/rent?
If no, how is your housing paid for?
Do you get any government financial assistance to pay your mortgage/rent?

6. How satisfied are you with living at your current home?
What is the best part about where you live?
What is the worst part?
How much longer do you think you'll live there?
Would you like to move to live somewhere else?
   If yes: Where would you like to move?
Do you want to move to a different location, a different kind of housing, or both?
Do you think you will move to [the place participant named]?

7. Do you experience any obstacles related to your physical or mental condition9s0 where you currently live?

If participant has difficulty thinking of obstacles, ask about the following obstacles:
- Access to human supports;
- Physical accessibility;
- Technological barriers;
- Attitudinal barriers;
- Transportation.

Interviewer note: See interviewer note for question 4.

8. Those are all my questions. Is there anything else you would like to add?

7.3   Interview Guide for Service Providers
CANADIAN CENTRE ON DISABILITY STUDIES
Finding Our Way Home: Housing Options in Inner-City Winnipeg for
People with Disabilities Who are Dying

1.   What services does your organization provide to people who are dying in Winnipeg?

2.   What role do you play in the services that your organization provides to people who are dying in Winnipeg?

3a.   Are there any specific services that your organization provides to people who are dying who live in inner-city Winnipeg?
3b.   Are there any specific challenges related to providing services to people who are dying in the inner-city?

4.   Do people with disabilities in the inner-city have access to these services?
If yes: Does that apply to all the housing arrangements that people with disabilities who are dying may be living in?

   Probes: Does that apply to people with disabilities who live in:
   - Their own houses or apartments?
   - Accessible public housing?
   - Permanent Independent living group settings/
   - Long term care facilities?
   - Hospitals/

5.   What does your organization do to make these services accessible to people with disabilities who are dying in inner-city Winnipeg?

6.   Do people with disabilities have the same access to these services as people without disabilities?
If yes: In what ways do people with disabilities have less access to these services?
Even if the participant answers "yes", probe for common barriers.
Does your organization provide sign language interpretation when providing services to deaf people who are dying?

   Do consumers ever have to travel to your organization to access services?
If yes: Do people with disabilities ever have difficulties getting from their homes to your site?
Is your site accessible to people who use wheelchairs?
Does your organization make all of its print materials available in other formats, such as large print, Braille, etc.?

Do you provide scribes or note-takers for persons with physical, learning or other disabilities who have difficulty writing? What about readers to assist people who can't read?

Are people living with mental health issues or psychiatric disabilities provided with counselling?

7.   Does your organization experience any challenges or barriers that make it difficult for you to support people with disabilities who are dying in inner-city Winnipeg?

8a. Are there any specific services that your organization provides to First Nations peoples who are dying who live in inner-city Winnipeg?
If yes: What are those services? Are they tailored to people from different First Nations?

8b. Are there any specific challenges related to providing services to First Nations peoples who are dying in inner-city Winnipeg?

9a. In what ways, if any, does your organization work together with other organizations that provide services to people with disabilities who are dying who live in inner-city Winnipeg?
If yes: What organizations? In what ways do you work with them?

9b. In what ways, if any, does your organization work together with disability organizations on broader disability issues?
If yes: What organizations? In what ways do you work with them?

10. Do you think there are any gaps or unmet needs in services for people with disabilities who are dying in the inner-city?
If yes: Do you have any ideas or suggestions for ways of filling those gaps or meeting those needs?

11. Those are all of my questions. Is there anything else you would like to add?

7.4 Consent Form

Informed Consent Form (People with Disabilities)
Informed Consent Form (Parents, Guardians, Substitute Decision-Makers)

You are being asked to participate in a research study. Before you decide whether or not you want to consent to participate, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do. You may ask questions by contacting the researchers at the addresses, telephone numbers, or email addresses listed later in this form.

What is the purpose of this study?

The Finding Our Way Home project is a study of the current and future housing needs of people with disabilities who are in the latter stages of their lives and live in inner-city Winnipeg.

Who is doing the study?

The study is being conducted by the Canadian Centre on Disability Studies (CCDS) in partnership with Fokus Housing and the First Nations disAbility Association (FNDA). Deborah Stienstra (Associate Professor of Politics, University of Winnipeg) is the principal investigator and Rhonda Wiebe is the Research Associate. The study is funded by the Winnipeg Inner-city Research Alliance (WIRA).

What will I be asked to do if I consent to participate in the study?

You will be asked to talk with the researchers in [month] 2003, either in a one-to-one interview lasting 30-60 minutes or by attending a focus group meeting with 3-5 other people that will last approximately 2 hours. You will also be asked to review a draft report of the study's findings and give your comments, suggestions, or concerns to the researchers. You may do this by attending a meeting where the study's draft findings will be present and discussed, by mailing or emailing written comments to the researchers, or by talking with the researcher(s) in person or by telephone.

What information will be collected?

If you agree to participate in the study, the researchers will ask you questions about where you live, any personal, medical or palliative care supports you receive in your home, how satisfied you are with your current home, and any obstacles or difficulties you experience where you live. The researchers will also be talking to people who work for governments and other agencies that provide personal, medical, or palliative care services to people in their homes. The questions the researchers ask these people will be about their organizations' programs and policies. The researchers will not ask them about the situations of specific individuals who receive services from them. The researchers may also ask you for permission to talk to other members of your family. We will not discuss your housing situation with anybody else unless you give us written permission to do so.

What will the information be used for?

The information will help the researchers identify the housing needs of people with disabilities who are dying. It will also identify any gaps in the policies and programs of organizations that provide supports to people who are dying in various housing settings.

A report on the findings of the study will be written at the end of the project. All study participants will receive a summary of this report. Information about the study will also be posted on the websites of the Canadian Centre on Disability Studies (http://www.disabilitystudies.ca). There will also be verbal presentations about the study at conferences.

The researchers hope that the findings of the study will lead to changes that allow people with disabilities to have greater choices of where to live as they approach the end of their lives. We also expect that the research will lead to changes in the policies, programs, and services of governments and their agencies that provide supports to people with disabilities who are dying.

What are the risks of participating in the study?

There is a possibility that some of the questions asked during the interview or focus group meeting may make you uncomfortable or cause you to remember unpleasant experiences. In focus group meetings, there may be disagreements between participants. If you feel uncomfortable at any point during the study, you may stop participating temporarily, or withdraw from the study permanently. You will be provided with information about where you can receive counselling or advocacy in cases where the need arises.

What are the benefits of participating in the study?

You may learn about different housing options or personal, medical and/or palliative services. The information you provide may lead to more or better housing options or services for people with disabilities in the latter stages of life.

Can I stop participating?

Yes. If you consent to participate in the study and later change your mind, you can stop participating at any time. You can refuse to answer any particular question or you can stop participating permanently. If you wish to stop participating permanently, contact one of the researchers listed at the end of the form and tell them you want to withdraw your consent.

What steps will be taken to keep information confidential and anonymous?

The researchers will take notes and use a tape recorder during the research. After the interviews and focus group meetings, a transcriptionist will type your answers. Your name will not be included in the notes, on the consent tapes, or the interview transcripts. Your name will not be included in any reports or presentations about the study without your written permission. Any unique characteristics that might lead someone to identify you will not be reported without your written permission. Examples of such characteristics may include a rare disease or condition, the name of a building or organization.

Original notes, transcripts, audio tapes and computer discs will be held in a locked filing cabinet and will only be accessible to members of the research team. The study data will be destroyed by shredding or other means 3-5 years after the study is complete.

What if I have questions?

If you have questions about the study, please contact Deborah Stienstra (Principal Investigator) or Rhonda Wiebe (Research Associate) at the Canadian Centre on Disability Studies:

Canadian Centre on Disability Studies
56 The Promenade
Winnipeg, MB R3B 3H9
Tel. (204) 287-8411
TTY: (204) 475-6223   Fax: (204) 284-5343
E-mail: ccds@disabilitystudies.ca

If you have any questions or concerns about your rights as a participant in the study, or the ethics of the study, you may contact any of the following:

Dr. Raj Dhruvarajan
Chair, Ethics Review Sub-Committee
Canadian Centre on Disability Studies
56 The Promenade
Winnipeg, MB R3B 3H9
Tel. (204) 287-8411
TTY: (204) 475-6223   Fax: (204) 284-5343
E-mail: ccds@disabilitystudies.ca

Dr. Ken Gibbons
Department of Politics Ethics Chair
University of Winnipeg
Winnipeg, MB R3B 2E9
Tel. (204) 786-9387
E-mail: k.gibbons@uwinnipeg.ca

Dr. Laura Sokal
Chair, Senate Committee on Ethics in Human Research and Scholarship
Department of Education
University of Winnipeg
Winnipeg, MB R3B 2E9
Tel. (204) 786-9915
E-mail: l.sokal@uwinnipeg.ca

What should I do if I want to provide my consent for another person to participate in this study?

Signing your name below indicates that you consent for the person named below to participate in the study. Your signature also indicates you have read the information in this agreement, have had a chance to ask any questions you have about the study, and you have been told that you can withdraw your consent at any time. You have been given a copy of this agreement.

If you provide your consent for another person to participate in the study, an assent agreement will be used to inform that person about the study in simple language or, if she/he is not able to read, the study will be described verbally. If he/she does not want to participate, he/she will be excluded from the study.

_____
Name of participant (please print)

_____
Name of participant's parent, guardian or substitute decision-maker (please print)

_____
Address

_____
City   Province   Postal Code

_____   _____
Telephone   Email address

_____   _____
Signature of Participant   Date

Limitations or conditions of participation:
_____
_____

_____   _____
Signature of project staff as witness   Date