Testimonies of Dwelling:

People with Physical Disabilities and [In]appropriate Housing In Calgary

Prepared by:
Debb Hurlock, PhD
Shannon Forsyth, MSW Student
Lori Bell, MSW Student
Urmil Chugh, MA, MEDes
Jennifer Hewson, PhD

Prepared With:
United Way
of Calgary and Area

Community Research Sponsors:

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**Research Team**
Debb Hurlock, PhD  
*Joint Appointment, Faculty of Social Work and United Way of Calgary and Area*

Shannon Forsyth, MSW Student  
*Research Assistant*

Lori Bell, MSW Student  
*Research Assistant*

Urmil Chugh, MA, MEDes  
*Assistant Director of Research, Centre for Social Work Research and Professional Development*

Jennifer Hewson, PhD  
*Director of the Centre for Social Work Research and Professional Development*

**Community Research Sponsors**
Accessible Housing Society  
Calgary Homeless Foundation

**Advisory Committee to Research Study**
Roy Smith, *Accessible Housing Society*

Mike Hambly, *Independent living Resource Centre of Calgary*

Ralph Hubele, *Supportive Living and Long-Term Care Branch, Alberta Seniors and Community Supports*

Sharyn Brown, *Calgary Homeless Foundation*

Katrina Milaney, *Poverty Reduction Coalition*
Quand les cimes de notre ciel se rejoindront
Ma maison aura un toit

When the peaks of our sky come together
My house will have a roof
(Bachelard, 1958)

“When the peaks of our sky come together” is a poetic metaphor for the combined care and action needed to ensure that each person has a “house” and a “roof”; a place of safety, shelter, and a place to call home.

Thank you to all of those who supported and participated in this research; you have all been instrumental in the peaks of our sky coming together.
CONTENTS

Introduction 5
   Questioning 5
   Dialogue, Hope and Action 6

Key Facts and Critical Questions 7
   Key Housing Facts in Calgary 8
   Key Facts of People with Disabilities 10
   Supports to People with Physical Disabilities: Immobilizing or Mobilizing? 13
   Adaptation for Accessibility or Maintaining Inaccessibility? 14
   Are we (Dis)abling our Support Workers? 16

Action Research and Housing Equity 17
   Action Research 17
   Principles and Promises for Accessible Housing 19

Language and Lenses: Stories of Their Own 25
   The Meaning of Home 26
   Adapting to Inaccessibility 27
   The (In)calculable Costs of Daily Living 30
   An Essential Marriage: Housing and Care 32
   Images of Accessibility 36

Power in Numbers 43
   Survey Approach 43
   Survey Results 44

What the Research Tells Us: A Fusion of Learnings and Images 59

Research to Action 62

References and Resources 64

Appendices 68
INTRODUCTION

....what is the state of dwelling in our precarious age? On all sides we hear talk about the housing shortage, and with good reason. Nor is there just talk; there is action too. We try to fill the need by providing houses, by promoting the building of houses, planning the whole architectural enterprise. However hard and bitter, however hampering and threatening the lack of houses remains, the real plight of dwelling does not lie merely in [only] a lack of houses. (Heidegger, 1971, p.161)

The “real plight” of the issue of housing and support care for people with physical disabilities in Calgary is multifaceted. It requires not only a seemingly simple solution of offering more accessible and affordable housing, but also a parallel questioning of the value systems that underlie our social policies and structures of housing and support care in Alberta.

Having accessible and affordable housing for people with physical disabilities is not only a pragmatic issue, but also an ethical one. Ethics derives from ancient Greek philosophy, with the root of “ethos” literally meaning “abode”, “dwelling place” and “the place from where we start” (Nussbuam, 1986). To address the issue of the absence of affordable and accessible housing, we begin by exploring the etymological meaning of ethics as introduced by ancient philosophy, which is about virtue and “goodwill towards others.” The issue of need for appropriate housing requires a collective effort, that no one person, or organization can solve alone. It requires the collective ethics of all to create action. Thus, dwelling is not only the place that we inhabit; it is also how we are in the world.

Houses are more than a structure when they become spaces where we “dwell.” They are places where we live out the architecture of the ordinariness and magic of our lives. Dwellings are places where there are “adequate supports to live a life of safety, security, and dignity.” (Alberta Disability Strategy, 2002, p.5). This research steps into dialogues that have already begun of the necessity of housing for people with physical disabilities and its contribution to “full citizenship.” The issue of affordable, accessible and appropriate housing for people with physical disabilities is one of provision that ensures housing support in order to live a life of “safety, security and dignity” (2002).

Questioning

“To ask a question means to bring into the open” (Gadamer, 1989, p. 363).

All action research begins with a noticing or questioning of something; a question yielded from a particular moment in which we are struck by inequalities and injustices. In 2006, the Accessible Housing Society (AHS) and the Calgary Homeless Foundation (CHF) initiated a dialogue with other allied stakeholders to address the question of inappropriate housing for people with...
physical disabilities. Their questioning of this issue began with an “intuitive knowing” from practice that the issues of inappropriate housing exits in Calgary. It arose from listening to persistent stories of people with physical disabilities and their struggles to find appropriate housing, and AHS’s growing wait list of people seeking accessible and affordable housing. AHS, in conversation with allied stakeholders, wanted to “confirm” their practical knowledge with primary research, and to “bring into the open” the issues of affordable and accessible housing for people with physical disabilities. The AHS and the CHF worked with the Faculty of Social Work, University of Calgary and United Way of Calgary and Area to explore more deeply the issue of appropriate housing and support care for people with disabilities.

Dialogue, Hope and Action

This research study speaks to the practical needs of dwelling, but also addresses issues of inequality and how this manifests in our social infrastructures, particularly when we are experiencing limited affordable and accessible housing. As Robinson notes, “true equality” is beyond physical infrastructures and lies in our social infrastructures:

True equality for the disabled means more than access to buildings and methods of transportation. It mandates a change in attitude in the larger social fabric---of which we are all a part---to ensure that they are no longer viewed as problems, but as holders of rights that deserve to be met with the same urgency we afford to our own. Equality puts an end to our tendency to perceive “flaws” in the individual and moves our attention to the deficiencies in social and economic mechanisms that do not accommodate differences. (Robinson in Herr et all, 2003)²

Thus, the data to support this study is interpreted from a wider social model (Hahn 1985; 1993, Brandt and Pope, 1997; Hahn 1993; Nagi, 1965; Pope and Tarlov, 1991; Verbrugge and Jette, 1994; World Health Organization, 1991), informed by a sociopolitical conceptualization of disability that perceives disability as not stemming “from individual limitation but from the failure of the social environment to adjust to the needs of people with differing abilities” (Jongbloed, 2003, p. 203).

The research offers a body of survey results, and narratives that speak to the limitations and possibilities of the physical environments and supports for people with psychical disabilities. Our intent is that this research furthers the dialogue and commitments noted for “full citizenship” as initiated in the Alberta Disability Strategy (2002) and significantly informs the current 10 Year Plan to End Homelessness in Calgary.³ Also, our hope is that the voices of people with physical disabilities, that their “testimonies of dwelling” offer words and images of the “social and environment component of disability” (Putnam, 2005, p.193) that will positively change perceptions that inform our social policies and systems in Calgary. We hope that the testimonies deepen people and policy makers’ consciousness of disability. Finally, our ultimate hope is that through this primary research, we enter a form of action and change so that people with physical disabilities have stable appropriate housing and supports.

² Mary Robinson was the United Nations High Commissioner for Human Rights from 1997-2002.  
³ www. www.endinghomelessness.ca
This quote is all too well known in Calgary right now: Issues of not having enough affordable and accessible housing; living in low income situations; caught between subsidies; and living within unhealthy home environments.

Within Calgary, the issue of affordable housing is rife with contradiction. Calgary and Alberta are national leaders in economic prosperity; however, we have people with physical disabilities living in impoverished conditions, and struggling to find stable affordable and accessible housing. For people living with physical disabilities in Calgary, and in which case, most have income support as the main source of income. For people who receive AISH, they are living on $1050.00 per month. With the high cost of housing in Calgary, this is not enough to afford housing. This is compounded by the issue of limited accessible housing available in Calgary that is located within an area in which in-home support care is available. These limiting factors then create situations in which people, like the research participant above, are living in unhealthy and unsafe environments, and are on the edge of being homeless.
**Key Housing Facts in Calgary**

*Erosion of Housing Affordability:*

- Increasing migration, low mortgage rates and economic growth coupled with increased labor and construction costs are sharply increasing the cost of housing.
  - In 2006, net migration totaled 31,223; in 2007, net migration is expected to reach 22,000 people (2007 Calgary Housing Outlook Conference).
  - The average year-to-date residential sale price in 2006 was $346,673, an increase of 38.17% over the year. CMHC forecasts that 2007 will close with homes at an average price of $418,000, representing a 19% annual increase.
  - Incomes have not been keeping up with skyrocketing housing costs. Despite the current boom economy in Calgary, average total family incomes grew by only 2% from 2004 to 2005 (Statistics Canada Income Trends in Canada 2007).
  - To be able to afford a 1 bedroom apartment in Calgary, a single person needs to earn a minimum of $15/hour (CHRA Minimum Housing Wage 2006), yet 103,500 Calgarians (25 yrs+) were earning $15 and below in July 2006 (Statistics Canada, Labour Statistics Division, Labour Force Survey 2006).

*Depleting Rental Stock:*

- The lack of supply is driving rents up and dramatically decreasing affordability.
  - Apartment vacancy rate reached a low 0.5% in October 2006 and is only expected to marginally rise to 1.2% in October 2007 (CMHC 2007 Calgary Housing Outlook Conference).
  - Calgary’s apartment availability rate shows that only 645 apartment units were available for rent in October 2006 (CMHC Rental Market Report 2006).
  - As result of condo conversions, Calgary’s rental apartment stock fell by 1,083 units in 2006, reducing the apartment universe by 2.6% to 40,333 units (CMHC Rental Market Report 2006). A further depletion is expected in 2007 (CMHC 2007 Calgary Housing Outlook Conference).
  - New rental construction in 2006 has only amounted to two projects totaling 148 units (CMHC Rental Market Report 2006).

*Increasing Homelessness:*

- The erosion of housing affordability and inability of lower skilled wages to keep up with skyrocketing costs has led to increasing homelessness.
  - Based on 2001 Canada Census data, 58,555 households are in need of affordable housing and 16,230 of them are at a very high risk for homelessness.

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4 This information was provided by the Poverty Reduction Coalition, 2007.
because they are low-income renters spending more than 50% of their household income on shelter (City of Calgary, Research Brief #03, 2004).

- Approximately 2,100 households on the Calgary Housing Company waiting list. Of those, between 200 and 350 are larger families, some of whom have to wait as long as two years for a unit depending on the type of housing they require (Calgary and Region Social Outlook 2007-2012).

- The 2006 City of Calgary Homeless Count enumerated 3,436 homeless people – an increase of 32% from the 2004 count. Also from 2004 to 2006:
  - The number of homeless persons on the street increased by 238%;
  - The number of homeless families increased by 39%; and
  - The number of homeless children increased by 40%.

- A 2002 Calgary Homeless Foundation study found that 50.2% of the absolute homeless were working full time, part time or occasionally.

**Accessible Housing in Calgary.**

- The top two reasons Calgarians with physical disabilities seek assistance from the Accessible Housing Society include (2006-2007):
  1. Inaccessible accommodations (35%)
  2. Unaffordable accommodations (28%)

- In the private housing sector, accessible apartment suites are being rapidly converted into condominiums:
  - The larger floor plans necessary for people with physical impairments to get around in their apartments results in attractive business opportunities for condo developers.
  - According to the Accessible Housing Society’s housing registry over 50 wheelchair accessible apartments (82 bedrooms) have been converted, over approximately the past ten years, into condominiums.
  - As a result, Calgarians with physical impairments are being evicted from their apartments and pushed into a housing market with a dwindling stock of accessible housing available for rent.

- People with physical impairments require specific accommodations in order for to be housed. These factors are often nonnegotiable for people with physical disabilities and they further drive up rental prices:
  - An extra bedroom or storage space is often necessary in order to store mobility devices (i.e. wheelchairs, walkers, medical equipment, etc).
  - In order to access the community (i.e. grocery shop, get to and from work, etc.), people with physical impairments must be situated closer to the core of the city to access public transportation.
  - Apartments on the ground floor or buildings equipped with elevators are necessary for people who cannot climb stairs.

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5 Information provided by the Accessible Housing Society, Calgary Alberta.
• Nearly half (49%) of the Accessible Housing Society’s clientele have an average monthly income of $1000 or less (2006-2007). This leaves the possibility of renting from the private sector virtually impossible for people with physical disabilities who cannot afford to pay the City’s average monthly rent of $1,037 for a two bedroom apartment unit (CMHC, Calgary Housing Outlook, Fall 2007).

Wheelchair accessible units in the City of Calgary:
(Based on Accessible Housing Society statistics)

<table>
<thead>
<tr>
<th>Non subsidized wheelchair accessible units:</th>
<th>Subsidized wheelchair accessible units:</th>
<th>Units with services attached (e.g. personal care services):</th>
<th>Wheelchair accessible suits for seniors</th>
</tr>
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<tbody>
<tr>
<td>- 4 bachelor</td>
<td>- 0 bachelor</td>
<td>- 2 bachelor</td>
<td>- 84 bachelor</td>
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<td>- 25 one bedroom</td>
<td>- 29 One bedroom</td>
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<td>- 39 two bedroom</td>
<td>- 68 two bedroom</td>
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<td>- 14 three bedroom</td>
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Key Facts of People with Disabilities

National, provincial, and local literature pertaining to people with disabilities commonly note the average low income of people with disabilities. However, a limitation in the literature is that there is minimal primary qualitative research and statistics focused on people with physical disabilities. Low income is a fundamental barrier in people with physical disabilities acquiring stable affordable and accessible housing:

Income Facts for People with Disabilities in Calgary:

• **21%** of *all* households or 19,920 households in Calgary (owner and renter) with the presence of disability in the household are in need of affordable housing because they have low-income and they spend more than 30% of gross annual income on shelter, compared with 18% of all Calgary households overall (City of Calgary, 2004a).

• Of *all* households with the presence of disability in the household that are in need of affordable housing, **61% are “extremely low-income”** (City of Calgary, 2004a).

• 42% of all *renter* households (12, 010 households) and 12% of all *owner* households (7,910 households) in Calgary with the presence of disability in the household are classified as low-income because they spend more than 30% of gross household income on shelter (City of Calgary, 2004b).
• When broken down by renter household type, 51% of individual households, 34% of family households, and 19% of multi-family households with the presence of disability in the household are in need of affordable housing because they have low income and they spend more than 30% of gross household income on shelter (City of Calgary, 2004a).

• Among all households, with the presence of disability in the household in need of affordable housing, 47% fall into the primary needs group who spend 50% or more of gross income on shelter and 53% fall into the secondary needs group who spend 30-49% of gross income on shelter (City of Calgary, 2004a).

• From April 2005-March 2006, 31% of people who contacted the Accessible Housing Society’s Housing Registry were seeking new housing due to their current inaccessible accommodation; 90% of people needed adaptive housing; 46% of people had a monthly income of $701-$1000; and of the 83 placement referrals made, 76% required subsidized housing.

Income Facts for People with Disabilities in Alberta:

• The average total income for Albertans with disabilities ages 15+ in 2001 was $24,508. Nearly one in five had an income between $10,000 and $14,999.

• Women with disabilities are the most disadvantaged group in terms of income, earning on average a mere $18,633 annually. Both males with and without disabilities earn considerably more than women with disabilities.

• Many additional expenses are incurred for people with disabilities that must be paid out of pocket. Expenses such as medications, adaptive equipment, home modifications, and home services further deplete the income of people with disabilities. For some, these additional expenses can reach up to $25,000 annually. (Alberta Premier’s Council on the Status of Persons with Disabilities, Alberta Disability Strategy, 2002 as cited in Alberta Seniors and Community Supports, A Profile of Albertans with Disabilities: A Compilation of Information from National Data Sources, 2006).

Education

• Albertans with disabilities are disadvantaged in terms of education. For example, the high school dropout rate of men with disabilities is nearly one-third.

• Fewer people with disabilities complete university than people without disabilities. This is especially the case for females with disabilities, for whom only 12.7% complete university education, compared with 14% of men with disabilities and 19.9% of females without disabilities.

Employment

• According the Alberta Seniors and Community Supports 2006 document, A Profile of Albertans with Disabilities, 55.6% of Albertans aged 15-64 are active in the paid labour force. Between the ages of 25-54, employment rates reach 64.6%. Unfortunately, no
data has been collected to determine the rates of full and part time employment for people with disabilities.

- Albertans without disabilities participate in the paid labor force at a rate of 83.5%. This is 27.9% higher than Albertans with disabilities.

- Males with disabilities are more likely to participate in paid labour than females with disabilities (58.8% of males are employed versus 52.8% of females).

- Aboriginal adults with disabilities are almost twice as likely to be out of the workforce as Aboriginal adults without disabilities in Canada (Government of Canada, Office for Disability Issues, Advancing the Inclusion of Persons with Disabilities, 2006).

**Prevalence of People with Disabilities**

**In Calgary:**

- In 1996, there were 69,085 individuals in Calgary who reported having an activity limitation, accounting for 10% of the population. Of those individuals reporting activity limitations, 46% were over the age of 55 and 31% were over the age of 65 (City of Calgary, 2002).

- Children and youth also reported experiencing activity limitations, with 8% of persons with limitations being under the age of 14, while 7% were between the ages of 15 and 24 (City of Calgary, 2002).

- Individuals with activity limitations are more likely than the general population to be living as unattached individuals. In 1996 there were 17,775 individuals with activity limitations living as unattached individuals accounting for 26% of all people with activity limitations, as compared to 15% of the total population (City of Calgary, 2002).

- Unattached individuals tend to be at greater risk of poverty. 1996 Census data indicate that, 42% of unattached individuals in Calgary reported having low incomes compared to a rate of 21% for the total population. Unattached individuals with physical disabilities were at even greater risk of low income with 62% of unattached individuals with living in low-income households (City of Calgary, 2002).

- Individuals with physical disabilities are less likely to be employed full-time than those without physical disabilities. Of those with disabilities who worked in 1995, 41% were employed full-time, compared to 53.5% of those without disabilities. (City of Calgary, 2002).

- Women are least likely to work fulltime, with only 35% of women with physical disabilities who worked in 1995 working full time. Among those who were employed full-time, 13% reported low incomes, compared to only 8% of those without physical disabilities (City of Calgary, 2002).
In Alberta:

- Alberta’s total population in 2001, including children, adults, and seniors, was 2,830,280. Of this total, 354,740 people, or 12.5%, had disabilities.

- The likelihood of experiencing a disability increases with age. Of Albertans between the ages of 15-24, 4.4% had a disability in 2001. For adults 25-44 years of age, 7.8% experienced a disability; for adults between the ages of 45-64, 18.8% had a disability.

- Women are more likely to experience a disability until the age of 75, when the likelihood of experiencing a disability becomes roughly equal for men and women. Please refer to Table 1 to review gender differences in disability prevalence rates for adults aged 15-64 years.

Supports to People with Physical Disabilities:

**Immobilizing OR Mobilizing?**

At the very beginning of every effort to understand is a concern about something: confronted by a question one is to answer, one’s knowledge of what one is interpreting is thrown into uncertainty, and this causes one to search for an answer. In order to come up with an answer, the person then begins asking questions. (Gadamer, 2001, p. 50)

As we delved more deeply into the issues of appropriate housing, many questions emerged. We began with questioning how do support services assist people with physical disabilities to ensure that they have stable and safe housing? To understand the issue of housing, it was important to unsettle our own understandings of the support services available. The support programs and services for people with disabilities are intended to provide assistance to help people with disabilities to be independent and experience social inclusion. However, in analyzing the supports further, it is important to critically ask: do these supports help people to achieve quality of life, or do they assist in constructing a permanent low-income class of people with physical disabilities? These questions are not intended to perpetuate the dichotomous questioning of ‘either-or’ but rather are inviting people to think critically about the ways in which the system is intended to support people, and the values that the system is built upon. The issue of housing and care for people with physical disabilities is far too complex to reduce it to an ‘either or argument.’ However in the midst of complexity, there is a simple fundamental, which is people with physical disabilities have the right to safe, affordable and accessible housing.

**AISH is one of the main supports for people with physical disabilities.**

- Over 36,000 Albertans receive benefits from the Assured Income for the Severely Handicapped (AISH) program. Of these recipients, 45% (or 16,200 people) have a physical disability (Alberta Human Resources and Employment, 2007). Given that “the disability must severely limit the individual’s ability “to earn a living” and must be permanent” this leaves people with physical disabilities being primarily and solely...
dependent on AISH for the income. Thus, the AISH situates and constrains people with physical disabilities to living in low income situations; vulnerable to market rent increases (Alberta Seniors and Community Supports, 2007). Further, people relying on AISH are vulnerable to a transitory life, for many are moved and need to move several times as rents increase, or their rental accommodation is sold or codoized. If AISH recipients hold more than 100,000 in assets that are in longer eligible for AISH. Again, we ask the question: does AISH support or suppress? Is AISH a primary factor in supporting social equity of people with physical disabilities, or does it keep people with physical disabilities in low income situations?

_AISH Key Facts:_

- Eligibility for AISH is income tested, although the recipient may hold up to 100,000 dollars in assets (or $3,000 in liquid assets). This policy affects homeowners with disabilities and their families whose dwellings may be worth more than 100,000 dollars. Many families face the financial hardship of having to pay for the cost of the care of their loved one as well as maintaining a household. According to Alberta disability service providers, some families have resorted to separation or divorce in response to this policy (Alberta Disabilities Forum, 2007).

- In May of 2007, the Alberta government announced a 50 dollar increase per month towards monthly AISH payments. AISH recipients can now receive up to 1,050 dollars per month, or an annual income of 12,600 dollars - well below any Canadian measure of poverty.

- AISH benefits are not indexed to geographic regions, which affects many recipients' ability to rent at market prices. For example, in 2006, the average market rent in Calgary was $618 for a bachelor apartment, $781 for a one-bedroom apartment, and $962 for a two-bedroom apartment. AISH recipients can only afford a monthly rent of $315 (30 percent of gross monthly income). Thus, many AISH recipients depend on public and subsidized housing programs.

**Adaptations for Accessibility OR Maintaining Inaccessibility?**

_Residential Access Modification (RAMP) Program_

The Residential Access Modification (RAMP) Program provides grants for permanent modifications that “facilitate access into or movement within a home by a wheelchair user” (Alberta Seniors and Community Supports, 2007). Homeowners with disabilities may apply for the grant, or tenants in rental facilities may apply with a written letter of approval by their landlord. Temporary modifications are available for palliative applicants and people recovering from a temporary injury. Applicants must be Canadian Citizens or permanent residents of Canada.

Although it is important that this program is offered, the criterion to be eligible for the RAMP program does not take into account additional expenses as well as the increase in labor costs, and costs of living in Calgary. The ceiling of $5000 is helpful for minor renovations and adaptive devices, but not sufficient in adapting central areas of a home to the principles of universal design. Given that the ceiling was set in 1990, it is essential that income support services are increased to reflect the increases in living in Calgary. Thus, we ask: does the program truly help
people with physical disabilities to adapt their homes for full accessibility, or does it perpetuate people with physical disabilities living in inaccessible homes? Discouraged by the criterion to apply for RAMP, and insufficient amounts to ensure full accessibility in the home, some people find it easier to adapt to their inaccessible homes, which amplifies their disability in these settings, or can create unsafe living conditions.

- An applicant may receive a maximum of $5,000 for home modifications; only one wheelchair user per home may apply. The current $5,000 lifetime limit was set in 1990. Since the consumer price index has increased by 60% since that time, the $5,000 ceiling does not reflect the current costs for equipment, building supplies, and labor (Alberta Disabilities Forum, 2007).

- Applicants may only receive the RAMP grant once per lifetime. This does not address the changing needs of people with disabilities who may experience a change in disability or a need to move; nor does the program assist individuals with mobility issues who do not require a wheelchair.

- The total gross household income must be $35,900 or less (some child and spousal deductions are available). Unfortunately, this earning exemption does not account for the additional cost of disability related expenses that people must pay (e.g. vehicle modifications, specialized equipment, and families' loss of income) and leads to some individuals being forced to move inappropriately and prematurely into supportive living or long term care facilities or to face the physical and social isolation of living in an inaccessible environment (Multiple Sclerosis Society of Canada, Alberta Division; Canadian Paraplegic Association, Alberta; and the Alberta Committee of Citizens with Disabilities, 2007).

**Alberta Aids to Daily Living (AADL)**

The AADL program helps Albertans with a long-term disability, chronic illness or terminal illness to maintain their independence at home, in lodges or group homes by providing financial assistance to buy medical equipment and supplies. An assessment by a health care professional determines the equipment and supplies that an Albertan can receive through this program (direct quote from the Alberta Seniors and Community Supports website, 2007).

- Albertans pay 25 per cent of the benefit cost to a maximum of $500 per individual or family per year. Low-income Albertans and those receiving income assistance do not pay the up to $500 cost-share portion. This $500 figure is nowhere near the up to $25,000 per year medical expenses described in the Alberta Government's 2002 Alberta Disability Strategy report. Alberta Disability Forum members have suggested a number of gaps in AADL services including:
  - Lack of coverage for certain necessary items (e.g. medical gloves, lubricant and tubing for catheter, cloth leg straps, ceiling tracks for lifts, diabetic supplies, and hospital beds).
  - The extent of time that a person must wait before he/she can re-apply for certain items (e.g. one hearing aid per individual per 5 years).
  - Limited coverage for certain items (e.g. catheters).
  - Confusion among clients how decisions are made regarding which items are chosen to be put on/taken off the medical equipment list.
Limited flexibility in items offered. If the items offered on the medical equipment list are not most appropriate for the person’s type of disability, there is no recourse.

The need for ongoing feedback from clients regarding the effectiveness of the program and the degree to which the program helps them to meet their needs.

(Note: This section reproduced from the Alberta Disabilities Forum’s May 22, 2007 Letter of Priorities for the Hon. Minister Melchin).

Are we (Dis)abling our Support Workers?

Without in-home support care, for a person with a physical disability, affordable housing can be rendered meaningless. The need for the support can vary from basic housekeeping functions, to support for “rising and retiring”: helping a person into bed at night, and helping them in the morning to bathe and dress. The support care provided by homecare workers, personal care attendants, and community-based support workers is essential to creating accessible housing.

However, the profession of being a support worker to people with physical disabilities is not an easy one in Calgary. With 50% earning less than $30,000 per year, many of the people working in the field of community disability services are themselves living in low-income situations, which compounds their daily stress created by unfair working conditions. Calgary is experiencing a crisis in social community disability services, specific to recruiting and retaining staff. Factors contributing to this include low salaries, high-burn-out and case overloads. The practitioners in this field are also vulnerable, and marginalized by the larger systems that contribute to perpetuating their unfair working environments. Part of ensuring accessible housing means supporting and advocating for better working conditions for practitioners in this field.

Key Facts of Staffing Issues

- Many Albertans with Disabilities rely on disability support workers (e.g. homecare/personal care attendants). Alberta’s growing shortage of workers coupled with a booming economy and population have left many people with disabilities without the services and care necessary to meet their basic needs. Along with a lack of necessary services, this puts additional stress on family members and loved ones for the care of people with physical disabilities.

- The wages of disability support workers are simply not competitive in today’s market. According to the Who Cares? Alberta Campaign, There are 17,000 people who work in community disability services with close to 50% earning less than $30,000/year (2007).

- Due to a lack of services, people with disabilities who are able to live in the community are being forced into already over-stretched hospitals, assisted living and long term care facilities. The Government of Alberta launched, in 2007, the Affordable Supportive Living Initiative is to provide affordable supportive living options to accommodate low and moderate income seniors and persons with special needs who require accommodation services in combination with health and personal care services to remain in their communities (www.seniors.gov.ab.ca/housing/asli/).
“Action Research seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities.” (Reason, *Handbook of Action Research*, 2001, p.1)

**Action Research**

This research is about many things, but ultimately it is about action. In this way, research is also a political event, in that the process and the result of the research are to build and lead to changes at three levels; individual, community, and system. This research is about change for the better for people living with physical disabilities in relation to appropriate housing and support care. This research involves many voices: those of the research team, community organizations, and people living with physical disabilities. Action research involves a “family of approaches” (Reason and Bradbury, 2001), thus this research emerges from three methods of gathering data to create knowledge: a survey, individual interviews, and a photo-voice focus group.

Action research is biased, which is essential to its paradigm. It is not intended to be objective, or distant. The topic of this research requires a “foreknowledge.” It requires some understanding, something that strikes us that we want to change. We are struck by the inequities faced by people living with physical disabilities. We are also struck by the perseverance and strength of those living within these inequities. In a broad context, action research is concerned with the “flourishing of individual persons and their communities” (Reason, 2001, p.1).

**Research Approach: Strengths of Hybrid Knowledge**

The differing paradigms of quantitative and qualitative within this study are seen as complementary. Each method and approach deepens our understanding of the living conditions of people with physical disabilities. With surveys, it is difficult to “capture the complexity of human experience, social life, or the interaction of human an environment systems” (O’Day, 2002). However, in conducting a survey, we are able to create a “benchmark” of datum of a group of people and their commonalities. Thus, creating this benchmark of datum for people with physical disabilities in Calgary is critical to building the case for action. However, the survey does not express the particulars of an individual’s experience. The qualitative research creates a rich description of particulars and how the unique conditions of a person’s life are impacted by the larger systemic and socio-economic environments.
“I really believe there are things nobody would see if I didn't photograph them.”
- Diane Arbus

The intent of combining interviews and a photo-focus group is to have the participants speak for and show of themselves so that we can hear, through their own voice and eyes, about the experiences of housing and care. This underpins much of the paradigm of qualitative research as it does not attempt to distance the researchers from the participants; in fact, we seek to reduce the distance. As well, the qualitative paradigm views the reality of people with physical disabilities as both contextual and socially constructed, and seeks to further understand the phenomenon of housing and care for people with physical disabilities (O’Day, 2002, Gadamer, 1989; Van Manen, 1994, Reason, 2001).

The photo-focus group drew from the principles of photo voice, which enables people to record and reflect on their strengths and concerns as a community, and to promote critical dialogue and creation of knowledge about community issues (Wang, 1997). A key learning in this is how difficult it is to access people who are marginalized through programmatic, systemic and environmental systems. When engaging marginalized populations in action research, being flexible and creative with different research approaches is vital to ensuring that they have the space to participate and to co-create knowledge with the researchers.

In preparing for the photo-focus, we realized that some of the participants are unable to take their own photos as they are unable to use their hands. A further reason for introducing photovoice is so that it can show us the lives of people with physical disabilities through their own lens. Photo-focus intends to be an even more accessible way of reaching and helping to create a space for the stories and experiences of marginalized groups. This population was unable to take pictures of their own, so members of our research team worked with participants to capture images of their lives.

Social Model of Disability

The approach of this research is founded on a plurality of theories, but mainly draws from the social model of disability, which also aligns with human-rights based approach. The social model of disability has its roots in the struggle of disabled people for the realization of their civil rights. It provides a way of understanding the disadvantages experience by people with impairments through the social, economic, and environmental barriers to participating in society (Burchardt, 2004). The social model of disability can be viewed in contrast to the individual model of disability, where limitations in functioning or participating in society are seen as a result of a medical condition and the best course of action is found in individual rehabilitation. This shifts the emphasis from the person to the environment, and that the “principal problems” of disability arise from an inaccessible or “disabling” environment, rather from the disabilities of the person (O’Day, 2002 and Hahn, 1985). The social model of disability asserts that the barriers experienced by people with disabilities are found socially, not individually, and that instead of changing the individual to fit or cope with society, systemic barriers must be reduced and social justice achieved to “treat” the disabilities experienced. For example, a person with a physical disability...
disability might feel depressed because they can no longer visit the residences of their friends and favourite restaurants. A medical individual “treatment” of the problem might be to provide counseling to the person to better cope with losing their mobility. A social or disability rights perspective “treatment” might be to advocate for greater accessibility of public buildings and private residences by lobbying for universal design and education to counter discrimination.

“Accessible Just Means It’s Smart Design”:
Principles and Promises for Accessible Housing

Ensuring that stable, affordable and accessible housing and supports are available for people with physical disabilities does not seem like a complex idea. However, beneath what seems a very simple solution, lies interconnected and multifaceted sets of beliefs, values, and ways of thinking that lead to what kinds of programs and services are offered.

There is no standardized definition of “accessible housing” in the literature or in Calgary housing services (e.g. the Calgary Housing Company or the Accessible Housing Society). However, organizations and municipalities adopt and define for themselves accessible housing. This may largely be a result of the subjective nature of “accessibility.” For example, some wheelchair users may be able to maneuver within a shower while others may require a wheel-in shower. However, there are some basic principles that must be upheld in order to ensure that an adequate stock of accessible housing is available for persons with varying levels of mobility. The adoption of standard definitions and/or a “typology” system of accessible housing could lead to greater direction and accountability in ensuring an adequate stock of affordable, accessible housing in Calgary.

The definition of affordable housing was approved by Calgary City Council in July 2002. The following definition is used by The City of Calgary for ongoing research and planning activities:

Affordable housing adequately suits the needs of low- and moderate-income households at costs below those generally found in the Calgary market. It may take a number of forms that exist along a continuum – from emergency shelters, to transitional housing, to non-market rental (also known as social or subsidized housing), to formal and informal rental, and ending with affordable home ownership.

Affordable housing projects are targeted to households with 65 percent or less of the area median income. In the city of Calgary, affordable housing initiatives would be targeted to those with a gross income below $37,621. For housing to be affordable, the Canada Mortgage and Housing Corporation has defined that a household should not
spend more than 30 percent of gross income on [rental] shelter costs. The highest priority for affordable housing are "core needs households" that spend more than 50 percent of their income on shelter costs. (The City of Calgary, 2002)

The language of “principles and promises” in this study is used deliberately in that the human rights-based principles are key to housing and support care for people with disabilities and need to inform the action that results from this research. Secondly, we say “promising” simply because we believe that this is a field that requires more growth and understanding in its practice to ensure that all people with physical disabilities are able to live a good and meaningful quality of life. Also, the notion of best practices should be read with caution, in that the concept and discourse is often absent of context, and context is key to action, and not attending to context in our research would not be staying true to the process of action research.

The following principles are congruent with the Social Model of Disability and have significant implications on the housing and care of people with physical disabilities:

**Universal Design:**

The model of universal design emerged from “barrier free” design. Barrier free design provides a level of accessibility for people with disabilities but also may result in stigmatizing or ‘separate’ solutions, for example, a ramp that leads to a different entry into a house or building. Universal design proposes solutions that help everyone, not just people with physical impairments. For example, parents pushing their children in strollers or an individual with a temporary injury may benefit from structures deemed “wheelchair accessible” such as sloped street curbs and wider doorways.

With the aging population in Canada, the principles of Universal Design have garnered increasing attention from builders and city planners. Alberta’s population is aging and for various reasons. There has been a 162% increase in the number of Albertans over the age of 65 since 1974, from 130,089 to 340,553 in 2005. In 2005, seniors aged 80 and over made up one quarter of all Alberta seniors, which is an increase from 21% in 1974. Projections suggest the estimation that between 2011 and 2021, the number of older adults will increase from approximately 410,000 to 627,200 which is an increase to 16% of the total population comprising of seniors. By 2031, it is projected that one in five Albertans will be over the age of 65 which will equal 880,000 seniors residing in Alberta. Further projections state that the aging of the population will be quite gradual until 2011. The rate of growth will then accelerate until approximately 2030 as the baby boomers begin to turn 65. Even though the rate of people turning 65 will decrease after 2030, the aging population will continue to characterize demographic trends in the decades that follow. In 2001, 44% of Alberta seniors reported having a disability where their activities of daily living were limited because of a health-related condition. Of the seniors who reported having a disability, 34% said that their disability was severe or very severe. Looking at the projections for an aging population is important in relation to disabilities because the possibility of a person living with or acquiring a physical disability increases as one ages; therefore, it is becoming increasingly evident that the need to plan for such an aging population is essential (A profile of Alberta Seniors Government of Alberta, 2007).
The principles, as articulated by the Center for Universal Design are as follows:

1. **Equitable use**: design is useful and marketable to people with diverse abilities
2. **Flexibility in use**: design accommodates a wide range of individual preferences and abilities
3. **Simple and intuitive**: use of the design is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level
4. **Perceptible information**: design communicates necessary information effectively to the user, regardless of ambient conditions or the user’s sensory abilities
5. **Tolerance for error**: design minimizes hazards and the adverse consequences of accidental or unintended actions
6. **Low physical effort**: design can be used efficiently and comfortably with a minimum of fatigue
7. **Space and size for approach and use**: appropriate size and space is provided for approach, reach, manipulation, and use regardless of the user’s body size, posture, or mobility

**Visitability:**

In 1986, a grassroots movement emerged in Atlanta, Georgia from the lack of federal legislation for accessible single-gamily homes (2007). Concrete Change, a project of the State-wide Independent Living Council of Georgia, defines visitability as, “a movement to change home construction practices so that virtually all new homes—not merely those custom-built for occupants who currently have disabilities—offer a few specific features that make the home easier for people who develop mobility impairments to live in and visit.” Visitability promotes the inclusion and social integration of people with disabilities into the community as a whole rather than isolating them in their own home, or forcing them into institutions. Three key features are promoted:

1. At least one zero-step entrance on an accessible route leading from a driveway or public sidewalk,
2. All interior doors providing at least 31 ¾ inches (81 cm) of unobstructed passage space and
3. At least a half bathroom on the main floor

The principles and design guidelines of Visitability have been advocated by Habitat for Humanity, who have been involved in building numerous ‘visitabile’ dwellings internationally (Concrete Change). In England, the adoption of lifetime homes (LTH) standards, similar to the standards of visitability, are likely to become mandatory for all newly constructed dwellings in the private sector by 2008 (Imrie, 2006). In the Alberta context, the City of Edmonton has been a leader in the development of “visitabile” affordable housing initiatives. Through their Cornerstones: Edmonton's Plan for Affordable Housing 2006-2011 initiative, 100 percent visitable and 10 percent adaptable suites in all new multi-family developments receive funding from Cornerstones. To date, the City of Calgary has not engaged in any ‘visitabile’ housing projects despite recommendations from Advisory Board on Services for People with Disabilities (ABSPD) who recommend changes to the 1997 Alberta Building Code, and all municipalities, to incorporate 100 percent visitability and 10 percent adaptable suites in all new multi-family developments (Canadian Centre on Disability Issues).
Adaptations

The importance of housing adaptations for people living independently has also been deemed invaluable to the health and well being of people with disabilities and their families. Heywood (2004) conducted 104 interviews with recipients of major housing adaptations and 164 postal questionnaires with recipients of minor housing adaptations in England and Wales. The findings suggest that “well-designed adaptations have beneficial, and/or preventative effects on both physical and mental health; and these benefits are long-term and extend beyond the disabled person to help the health of other family members” (p.129).

Examples of Costs for Adaptations

- 483,000 adults in Canada require adapted features in their homes. 26% of those individuals have none of their needed modifications and 11% have some but need more (Statistics Canada, 2004).

- For adults aged 25-64 with disabilities, 47% have an annual personal income below $15,000, compared with 25% of adults without disabilities (Statistics Canada, 2004).

- The time of construction is minimal. The cost of building a zero-step entrance is $150 and the cost of building wider doorways is $50 for the entire home. The Canadian Mortgage and Housing Corporation estimates the cost of installing reinforcements (to allow the future installation of grab bars) in washroom walls ranges from $50 to $90 ($38 to $68 U.S.)

- The Rowntree Foundation estimates that the cost of implementing visitable features at the time of construction is no more than 200 pounds ($365 U.S) When several visitable townhouse developments in Atlanta were built, the developer estimated that the costs of providing visitable features was no more than $25 per home.

- In contrast, retrofitting a home to accommodate visitable features is costly. Concrete Change estimates the cost of adding a zero-step doorway to a pre-existing home is $1,000 and the cost of widening a doorway is $700 per doorway. 12 The Canadian Mortgage and Housing Corporation estimates the cost of installing reinforcements in an existing bathroom is $530 Canadian ($400 U.S.). In Macon County, Georgia, the cost of retrofitting existing units for visitability ranged from an estimated $7,500 to $15,000, depending on the age of the unit.

Transportation

A key recommendation related to equitable mobility as stated through conversations with community stakeholders emphasized the importance of accessible housing close to public transportation (i.e. it is isolating to ‘place’ people with disabilities on the periphery of the city where they cannot access the community). Transportation and physical accessibility have been deemed integral aspects of community participation in the “quality of life” of people with disabilities (Fresher-Samways, Roush, Choi, Desrosiers, & Steel, 2003).
Person-Directed Services

Person-directed service models have emerged as important initiatives in improving the care of people with disabilities. A variety of person-directed service models exist, although the central tenant and value behind the models lie in their recognition that people with disabilities should have an active role in making choices that affect their day to day lives. The National Institute on Consumer-Directed Long-Term Services out of the United States (1996) describes this philosophy as recognizing the capacity of individuals to, “assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they receive” (as cited by Powers, Sowers, & Singer, 2006, p.66). This approach to service provision falls in line with a large body of research which has shown the importance of self determination, autonomy, and recognition of personal rights on the well being and health of all human beings.

Most service providers and people with disabilities would likely agree that the client or consumer is the best expert in their own needs and should ultimately direct the decisions which dictate their housing and care. The Government of Alberta, in principle, has committed to upholding person-directed service models. The Supported Living Framework, published in 2007, states that current and future supportive living developments should be based on the following principles:

1. Supportive living options recognize the individuality of each resident and his or her changing needs
2. Communities will strive to have a range of supportive living options that can meet the service and affordability needs for local residents wanting to stay in or near their own communities (p.2).

Promising Practices

The following table provides examples of promising practices in the provision of housing and care for people with physical disabilities living independently in private residences and group settings, and residing in long term care facilities.

The promising practices outlined here have been extracted from the academic literature in the area, “grey literature” such as government reports, and conversations with community stakeholders throughout the research process.
# TABLE ONE: PROMISING PRACTICES FOR HOUSING AND CARE

<table>
<thead>
<tr>
<th>Independent Living in the Community</th>
<th>Transitional Housing and Independent Living in Group Settings</th>
<th>Long Term Care Facility Living</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Increase the stock of available housing across a continuum of models and needs (i.e. homes for individuals and families, group homes, and long-term care homes).</td>
<td>➢ Increase the stock of transitional housing and group homes.</td>
<td>➢ Increase the stock of available housing across a continuum of models and needs</td>
</tr>
<tr>
<td>➢ Ensure structural accessibility of public facilities</td>
<td>➢ Ensure universal design principles in facilities.</td>
<td>➢ Ensure structural accessibility of public facilities</td>
</tr>
<tr>
<td>➢ Provide accessible public transportation</td>
<td>➢ Provide accessible public transportation</td>
<td>➢ Provide accessible public transportation</td>
</tr>
<tr>
<td>➢ Availability of quality care services – the same home care worker, set times, reduce wait lists, 24 hour availability for emergencies</td>
<td>➢ Address staffing shortages</td>
<td>➢ Address staffing shortages</td>
</tr>
<tr>
<td>➢ Ability to ensure basic needs are consistently met through adequate income supports and affordable housing</td>
<td>➢ Availability of quality care services – the same home care worker, set times, reduce wait lists, 24 hour availability for emergencies</td>
<td>➢ Spaces and rooms for visiting family members and friends</td>
</tr>
<tr>
<td>➢ Opportunities for home ownership</td>
<td>➢ Spaces and rooms for visiting family members and friends</td>
<td>➢ Respect the privacy of residents</td>
</tr>
<tr>
<td>- Adequate income</td>
<td>➢ Ensure availability of options for when moving out of “transitional” housing</td>
<td>➢ Provide private rooms and bathrooms</td>
</tr>
<tr>
<td>- Ability to own a home and continue to receive health benefits and AISH. Opportunities for ongoing home modifications i.e. increase funding to the RAMP Program and reduce waitlist</td>
<td>➢ Continuum of options</td>
<td>➢ Immediate assistance</td>
</tr>
<tr>
<td>➢ Consumer controlled services</td>
<td>➢ i.e. group home or private apartments with 24 hour care when needed</td>
<td>➢ Respect and support of self advocacy</td>
</tr>
<tr>
<td>- Opportunities for choice</td>
<td>➢ Flexibility of care to accommodate disabilities which fluctuate in severity</td>
<td>➢ Provision of care services based on individual needs</td>
</tr>
<tr>
<td>- Individualized services</td>
<td>➢ Nice location – a sense of “ownership,” community, and pride in one’s home</td>
<td>➢ i.e. opportunities for more frequent bathing if desired</td>
</tr>
<tr>
<td>- Individualized funding</td>
<td>➢ Availability of 24 hour care for emergencies</td>
<td>➢ Age appropriate accommodations</td>
</tr>
<tr>
<td>➢ Reduce Isolation</td>
<td>➢ Nice location – a sense of “ownership,” community, and pride in one’s home</td>
<td>➢ i.e. young adults with disabilities generally prefer to live with their own age group</td>
</tr>
<tr>
<td>➢ Supports so people can live independently for as long as possible</td>
<td>➢ Daily activities and leisure opportunities</td>
<td>➢ Access to the community</td>
</tr>
</tbody>
</table>
Very few stories are narrated either to idealize or condemn; rather, they testify to the always slightly surprising range of the possible.

– John Berger

…listening like that
becomes part of the story too,
just as I am added when I tell it,
as anyone will be, each version
a journey that carries us all along,
as the shards of pottery, carefully labeled
and carried up through layered villages
flesh out more hands
than the two that made them.
-Bronwen Wallace

*The People Who Shared Their Stories*

Eight individual conversational interviews were held with people with physical disabilities. Each person is unique in his and her own experiences of living with a physical disability. The individuals have varying continuums of experiences of housing and they varied in nature of disability, and ranged in age from 30 – 58. Some of the individuals were born with a disability and others reminded us of the fluidity and unexpectedness of disability, as they became disabled through an accident or progressing disease. Some of the individuals live independently in the community with support, some live without support, some live in-group homes, and some live in long-term care facilities. This variety of contexts created more “layered” experiences and helped us to better understand the commonalities of their experiences of disability, and the environments they live within.

Four individuals participated in a photo-voice focus group. They attended a meeting to share and discuss their photos, and one individual captured images of her experience through photos and writing, however she was unable to attend the group.
"To Live Comfortably and at Peace":

The Meaning of Home

For our house is our corner of the world. As has often been said, it is our first universe, a real cosmos in every sense of the word. (Bachelard, 1964, p.58)

The word home is very subjective. It can mean many different things to people, and evoke different sensibilities. The word home can be traced to multiple uses and meanings from the 1600’s onwards. Primarily, when tracing the history of the word home, it connotes “dwelling” “residence” and “world.” This is similar to Bachelard’s notion that a house is our “corner of the world” or our piece of the world and part of how we show up in the world. The word ‘shelter’ can be traced to 1585, and means “structure affording protection”, evolving from the word “shield.” In this study we questioned the meanings of words, such as house, home, shelter, living spaces; all words that convey how one might feel about the space they live in, and learning that they are seeking, at the very least, to be shielded from the hardships of life, and seeking to create a “home.”

We talked with research participants about what home means to them. They shared that home is something very simple, a space that is easy to get around, a place where people can feel at peace. One woman, who is now living in a long-term care facility, said that a home is a place “to live comfortably and at peace with ourselves in comfortable housing.” She continued on to say that “Home brings back….home with my parents and my siblings, where we lived very comfortably, not a thing to worry about, nice beds, nice blankets, good food….just a very comfortable space where you can do whatever you want to feel safe.”

Another man, living in group home, spoke of the simplest structural changes that would make a home for him:

I don’t want some mansion in the mountain, just something that is affordable and accessible, and has you know, like a laundry room in the apartment or house so that we don’t have to carry laundry around.”

(Research Participant, 2007)

His notion of home is very structural, and speaks to the simplicity of the environment that would create a home for people living with physical disabilities. Also, having these structural changes would enable him to live in the community and not a group home, and to be able to care more for himself, and rely less on support care.
Another man living in a group home setting, linked the essentiality of support care with the meaning of home: “...it's all about the care and finding the proper care and there is a shortage of that right now...it's hard for me to do things on my own...mentally I am as independent as I can be but physically, I rely on other peoples various types of assistance.”

A young woman, with severe physical disabilities living in a long-term care facility, shared what home means to her, and how home was really based on family, in particular, her mom and dad:

> [Home is] living with my mom and dad. I know this is going to sound weird—strange—it's hard to believe, but that was the most freedom that I've ever had. And I had privacy, and I mean, to me that was my best...the only two places I've lived are in the group home for 6 years and then I lived here and I’ve lived here for almost 5 years. And I went to having minimum privacy at the group home to having absolutely no privacy [here]. (Research Participant, 2007)

In summary, the research participants articulated the particulars that make a home for them:

- Peace
- Safety
- Affordable
- Accessible (for example a laundry room in the apartment, wheel in shower, a practical kitchen)
- Support care in the house
- Family
- Freedom

If we return to the idea of a house as a piece of our world, then an important question to ask, is how do the homes of the people with physical disabilities reflect their worlds? If they are living in inaccessible and unsafe spaces, how might this impact how they see themselves and how they see the world? There are links between health and housing, and further more, creating more segregation through residences being determined by income, social class, race and ethnicity (Stienstra and Wiebe, 2004).

“I'd climb the steps on my stumps”:

Adapting to Inaccessibility

Rather than adapting to accessible homes, most people interviewed were adapting to the inaccessibility of their homes. In meeting with individuals with physical disabilities, a theme that emerged through most of the conversations was a desire to “not complain” or a fear of speaking out for fear that they may lose what they have:

...because I fall down the stairs a lot..I try really hard not to but I still do. I don’t always tell the health care workers because I don’t want to end up on the streets either. The outside is not accessible to get in and out. My parking is definitely not accessible the bathroom is just a tub, but there are bars in the tub, so it's not like accessible to get in. I still have to climb in and out. And, then the cupboards are really high so if I am trying to
do things in the cupboards sometimes my legs will give out. (Research Participant, 2007).

Parallel to these themes is also the resilience and perseverance of those we interviewed. As researchers, we continually live in the tension of not imposing how we think “they should be living” and respecting their sense of perseverance, with the recognition that these environments are inadequate for their abilities; and as one of our participant’s shared with us, with a laughter that comes from hind-sight: “I feel so dumb and stupid. I never realized how horrible [it was]...just used to surviving by day.” Thus, this interpretation is informed by a human-rights based perspective and Nussbaum’s capacities approach to living. The common thread between these two is that everyone is entitled to a space, and home environment that is safe, affordable, and is a place in which they can thrive independently, and as members of collective societies. What we ask then, is if these home environments help people to live to their maximum capacity? Also, because the context of our study is people with physical disabilities, our participants had full cognitive capacities.

From the survey results, we learned that almost 76% of survey respondents are living on less than $25,000, per year. Most of the people we interviewed are also living in low-income situations. This creates a variety of stressors for people with physical disabilities, as they are susceptible to market fluctuations, and may have a landlord or property owner who will sell the property or increase the rent. This mitigates the ability to create a safe and stable home. One woman, who now lives in a long-term care facility, reflected on her experiences of continually needing to move and the role her children played in helping to find their home:

The hardest part was when we lived in Bowness. I think he just sold the building...it was like--- it was this little apartment building about six suites I think....and he said he sold it but we have to move so my kids and my oldest daughter helped us look, look, look nowhere to find a family house so we went to Dover and my daughter was driving around and this was urgent, this was an emergency, all we could find was this townhouse in an area—it was [an] older townhouse and the paint was kind of rusty outside but when I went in it was very clean, well painted, and stuff like that. So we moved in there but, it’s not even accessible at all. When I think about that, I don’t know how I can live like that for four years. There were about 6 steps and a platform, and then about another six steps. And I would take a bath or shower every other day and my oldest son, he’s 31, he lived in the one bedroom upstairs, and then my daughter lived downstairs, and my youngest son who lived down in the basement there was a bedroom suite…. (Research Participant, 2007)

In this excerpt, we see how a woman with a physical disability and her family, living in a low-income situation are susceptible to the changing market conditions. The landlord decided to sell the building, thus displacing the family. The family was in an “emergency” situation, and without knowing supports are available, the family became the caretakers, which aligns with the survey respondents.

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Nussbaum, Martha C. (2000) *Women and Human Development: The Capabilities Approach* (Cambridge University Press, Cambridge). Analysis of the study is informed by Nussbaum’s capability approach, which is a conceptual framework for evaluating social states in terms of human well-being. For example, poverty is seen as “Capability-deprivation.” Similar to rights-based approach it advocates that each person has the right to develop capabilities in ten areas: life; bodily health; bodily integrity; senses, imagination, and thought; emotions; practical reason; affiliation; other species; play; and control over one’s environment.
results that almost half of the respondents rely on family for informal care. The children, literally and metaphorically, would “watch” their mother’s back. Whether it was finding an affordable home, supporting her while she climbed the steps on her stumps, or dumping her urine from a pail:

[I would climb the stairs] just to have a bath. But then to pee—I still pee—well many years—I’m very independent I can transfer myself onto the washroom toilet and pee, bowel movement like that…I used to pee in this pail, and then my son would spill it, but I put a lot of…Pine sol [in it]. And, it’d sit in the corner by the door and my son would spill it before bedtime and then if my son is sleeping or when it’s not really cold, when I have to have a bowel movement I’d used to go to a 7-11 close by—from here to the traffic lights….just to have a bowel movement.

(Research Participant, 2007)

This particular narrative, helps us to understand how homes are inaccessible to people. Consistent with the results of the survey, people most often reported that bathrooms and kitchens were inaccessible and were the most important rooms to be accessible as they contribute to a greater sense of independence. Like the woman in this narrative, she prides herself on being independent and able to transfer herself onto a toilet. But, constantly having to climb a set of stairs on your stumps, is a reminder of her disability.

These narratives bring to life the social model of disability. They live in environments that are inaccessible, and the inability to engage in particular functions, because of their inaccessible environments is a constant reminder, or continuous construction of their disability:

If a particular environment offered all of the resources a particular individual required to perform a task or activity, no disability would exists. Thus there is balance in which individual capabilities and environmental supports are in congruence…if a person’s abilities and the environment’s attributes are compatible, there is no disability” (Putnam, 2005, p. 189.)

Most of the people we interviewed are very resilient in their ability to create ways of adapting themselves to their inaccessible homes or environment. Although this demonstrates their resilience and courage to dwell in inappropriate spaces, it also amplifies their disabilities, and may also progress their disability depending on the physical stressors of continually adapting to the environment.

Often not wanting to complain, but seeing themselves as being independent and having a sense of agency, many people with physical disabilities found their own ways and routines within their homes. Although a testament to their persistence, it raises concerns as to what happens if their disability worsens, thus increasing their risk for accidents. One man we spoke with, now living in a group home, shared with us that he never lived in an accessible unit in Calgary. Again, this narrative illustrates how people adjust and become acclimatized to their environments.

Secondly, this narrative speaks to the issue of the need for combined affordability and accessibility:

I never lived in one unit that was accessible…I lived in all apartments and houses that I used the…I don’t know what the program it was for the government at the time, but I was able to get ramps built at houses that I had and apartment buildings that I lived in as long as they had an elevator and I could get in the door then I was fine…you know, the bathrooms certainly weren’t accessible no wheel in showers, but at that time, I was able to transfer I could the shower transfer to a bench seat,
transfer back onto my chair...And the cupboard space, the kitchen wasn't set up for wheel chairs at all but I used the cupboards that I could and the stuff I didn't use that often I put up high. I couldn't get out to the patio or balcony because the register was always in the way. But I made out good. I have no complaints. I would go back into it if it was affordable. I would go back into a regular apartment now. The main issue is affordability and the main issue is homecare. (Research Participant, 2007)

Similar to the other narratives, this narrative is a testament to the perseverance of people with disabilities to live in inaccessible homes. As one of the research participants noted, “as long as they had an elevator” he could handle the remaining challenges, such as not being able to access his patio or balcony. What may be perceived as a minor barrier in structure has a significant impact on the quality of life for a person with a disability. During the photo-voice focus group, one of the participants explained how his deck is his “window to the world.” He went on to share how access to his own balcony is key to people with physical disabilities, as it is a space to get “fresh air”, to be outside and feel part of the world. Access to balconies was often noted as an important structural feature that contributed to creating a sense of home.

“Just Surviving: Day by Day…”:
The (In)Calculable Costs of Daily Living

To me it's a dump, but it’s three bedrooms, they take dogs, and it’s what I can afford and actually my rent has skyrocketed. I was paying $700/month, and I just got notice that it is going up to $1045.00. (Research Participant, 2007)

This narrative from one of the women we interviewed was not unusual. For people with a physical disability, whose main source of income is income support, they are often living in low-income situations, and are often renting, unable to afford a mortgage on their home. For people with severe disabilities living in a long-term care facility, most of their AISH goes directly to the long-term care facility, and as some of the research participants shared with us, they often have about $200.00 left for personal spending. They often use the money to purchase everyday toiletries. One participant shared, “if it’s a good month I can afford to go to a movie.”

Another woman we interviewed, living in the community without any formal care, shared with us a detailed breakdown of her finances to show how challenging it is to live on income support.

She noted that she received $945.00 in AISH, and $650.00 in rent subsidy. The rent subsidy began in September 2007. She also has $400.00 that she and her husband get from a border renting out a room in their home. This research participant is married with three grown children, and six grand children. So, their total income is $1995.00, and their expenses are $1,879.00 leaving $116.00 per month cash. Their rent is $1200.00, and their utilities on average are $400.00 per month. Then there are expenses for phone, cable, and food.

This woman also captured images of how her home is inaccessible (the photos appear on the following page). She has a severe disability and uses a walker now but is waiting for a
wheelchair. She contends, once she has a wheelchair, she will not be so “trapped or house bound.”

In images 1 and 2, the research participant captured images to show us how the rooms are inaccessible. She noted that the bathroom does not have a walk in tub or shower. The toilet she raised herself. She noted that under the counter of the bathroom sink there is no space for wheelchair access, so she would not be able to access the sink. In reference to the RAMP program, she noted that “for what little government funding there is, it takes several months to four long years to even get approval and to receive equipment grants and such to readapt an apartment or most homes. Thus, this is how the housing shortage starts” (Research Participant, 2007).

Image #1

Image #2

Image #3

Image #4

Image 3 is of the walker she is currently using, as she waits for a wheelchair. She uses this walker inside the house wherever she can, and outside the house.

Image 4 shows how under the kitchen skin there is no wheelchair access, and the galley kitchen is a very narrow space. Also, for people in wheelchairs, stoves can be dangerous, as well as too high. All the doorways in the home are too narrow for a wheel chair, as well as there are stairs leading into the house.
**Preparing to be Homeless**

Most homeless people do not live on the street. More than 80% of Canada's homeless are improperly housed or on the verge of eviction. Some of the research participants we spoke with who are living in the community are in low income situations and are concerned, month to month, with not being able to afford the home they are renting and that they are very close to being homeless. One woman shared with us that she is “preparing to be homeless”, and believes that being homeless is an inevitability for her:

…so once all is said and done, and I know this will come in my life, I will end up homeless. And once I am homeless, I will no longer have an address to get a disability pension so then I will qualify for welfare, then I will qualify for low rental housing and then I will qualify for all those things. But I will have to wait until I am homeless before I can do that. (Research Participant, 2007)

For this woman, being homeless seems like it will create more possibilities for her as she is currently caught between subsidies, in that she can barely afford to live on her income now, but yet she does not qualify for subsidized housing. This invites critical questions of access to subsidy for accessible housing, and if the criterion is a realistic reflection of the high cost of rental accommodation in Calgary.

Some of the research participants wanted to work to supplement their income, but are unable due to their disability, or the deduction to their income support will render them unable to support themselves:

…actually with my income if I do get a job down the road then whatever I make they will deduct it off my income so that just gives me absolutely no drive to work just because I am scared, like don’t; get me wrong, I like to work but at the same time I am just scared that if I get a job then say something happens, like I get a pressure sore so something like that and I have to take like months off work right, then I am scare that I will have no income unless my insurance company says they will start my income back or whatever…so it gives me no ambition to work. (Research Participant, 2007)

**An Essential Marriage:**

**Housing and Care**

I’m dependent on other people for my care, even though a place may be accessible and I may be able to move into it; it would be pointless because I don’t have the care, so that’s why self-managed care is so important for people who can do it. (Research Participant, 2007)

Through the survey results, we learned that almost 44% of respondents rely on informal care, with 56% relying on formal care. This underscores a main theme through this research that

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12 www.raisingtheroof.org/lrn-hh-index.cfm
affordable housing is meaningless without support to the people within the homes. In addition, support is integral to people living in-group homes and long-term care facilities.

Research participants shared with us how integral care is to all aspects of living, such as maintaining employment. One of the research participants shared how the "chain of care events" can unfold smoothly, or can be detrimental, depending on the quality of care:

And I think jobs give you a lot of self worth. You know, whether it be volunteering for 10 hours a week or working, you know nobody says you have to work 60 hours a week, but I think everyone could do something, but again that also depends on stable health, stable transportation, and then stable home care supports, and then it's happily ever after….I literally can’t get into bed myself, so when you look at the chain of events that have to go right for me to be at work and earning a living, and a good living where I am now giving back to the community. Whereas, if one of those things weren’t in place I am just another sad number of the 40-50% of people with a severe disability that don’t work. And then, it’s a vicious cycle, you don’t have money, if you don’t have money you don’t eat well, you can’t afford the roast beef dinner,…and then your health just spirals and the perfect storm that can affect people with disabilities—I mean you literally can’t take care of yourself if you don’t have these supports in place. (Research Participant, 2007)

Currently, in Calgary, there is an on-going challenge to recruit and retain people to work in the community care field. It is important to recognize the conditions within which many of the practitioners are working, and how the shortage of casework is creating severely stressful working conditions. Also, some of the research participants living in group care settings could be living in the community, but they are able to find and afford support care:

When I first had my accident, I was living at home and I had a caregiver come in and it was good. They were easy to get, the funding was there, there were lots of people available and as time progressed, then I came here (group home and of course you have all your care. You have all your meals, you have all your laundry, and you have everything available. Moving out into the community, it was good at first you know, and then there is no homecare available. They don’t have the staff to send up to you at different times of the day and evening and you need that…so that’s how it’s changed over the years. (Research Participant, 2007)

Care is a Family Affair

The high rate of informal care identified in the survey results was further contextualized by interviewees. Many people rely on family to provide their care support. Often, this can lead to family caregiver burnout. People who are caregivers are not only spouses, but often grown children of a person with a disability:

I receive nothing in home, I do everything myself. My daughter was living at home up until three weeks ago and she moved out on her own. She was the last one here but the mold was really effecting her so it was better for her to just go and move to an apartment until the landlord gets the mold resolved….I am not really sure I can get into an accessible housing, It is easier to get into a one bedroom than a two bedroom and would need two bedrooms with her. So, my daughter did a lot of it. She did the vacuuming and laundry of the other stuff….she helped with the groceries and cooking and now that she is not here, I do it myself. (Research Participant)
Recognizing that sons and daughters are filling the roles of support care for their mothers and fathers also speaks to the need to ensure that affordable and accessible housing accommodates people with physical disabilities and their families. We learned through the survey, that 10.3% of respondents have children who are still dependents. Also, this connects with the research participant who shared that her children would take on the role of seeking other affordable housing in the city each time she had to move. Another participant shared with us how he recognized it would be too hard for his father to support him, so he moved into a group home:

After my accident I moved back home for short period of time because we lived in a split level house and I could come in the back door and I could access my bedroom but I couldn’t get to the kitchen. I couldn’t get to the middle floor. I could get to the laundry room and the bathroom and that was it, so I just couldn’t stay there, I mean I could ask Dad to lift me up all those steps. And so the best situation was to move out. (Research Participant, 2007)

Dignity

Dignity is important to people with physical disabilities and support care assists people in maintaining their dignity. It is a reality that people with physical disabilities are often completely reliant on others for their care. One research participant spoke of how he was frustrated and "maxed out" on the concept of "maximizing independence." He described that although there are certain features of a home and technology that can assist people with physical disabilities to be able to take care of themselves, they still need some level of support care. For people with less severe physical disabilities, depending on how accessible their home is, their need for care is not as high. If they have an accessible bathroom, kitchen and laundry rooms, they can often care for themselves. For people in long-term care settings they too need continuous care, as they are unable to live alone in the community without a constant personal care attendant. One of the women told us about her frustration of living in a long-term care setting:

Because they look at you in a place like this they seem to look at me like they don’t really treat me like a person...there’s people here that talk down to me because they enjoy flaunting their power over you. And there are many glitches in the system. And because I am like, you see, all my life, I’ve been brought up and everything to believe that I’m just a normal person. Just like anybody else....So as people they’re nice---it’s nothing personal---but the care they provide sometimes doesn’t provide the privacy and the respect you deserve.

I’m happy to get away from here (get teary eyed and pauses). And sometimes, I get sad, like when I go home to my mom and dad’s for dinner, I’m happy to go there, but have to remember after dinner sometimes I get sad because I have to come here. (Research Participant, 2007)

Dehumanization is what one research participant described as what can happen as a result of living in inappropriate group or long term care environments. In these environments, the support care is central to their quality of life. The buildings are often accessible in terms of wide
doorways, technology, and elevators, but they are not able to offer everyone a private room. Having a private room in a group living space was something all research participants longed for, recognizing that privacy was a key factor in maintaining dignity. One of the research participants spoke about how his care is “ideal”, and that by having assisted and self-managed care, he is able to live well:

It's sort of like the golden handcuff apartment because what is so nice about having that assistant on staff is that I wanna go home tonight and go to bed at 7:30 pm—ok call them up and they will help you get into bed or do whatever you need at 7:30, but if you want to go out and come home at three in the morning, you can do that too. Where as when you get out into the community, you got to deal with the person one-to-one.

I really have the best of both worlds because I am on self-managed care where I get a pool of funds each month to hire my own attendants. And then I get to use the accessible housing services at night. You could line up every quadriplegic or paraplegic in this province and I probably have the best situation right now. (Research Participant, 2007)

The internal self worth of people with physical disabilities is often subject to the external and internal influences that alter how much control a person can have over his or her own life (Putnam, 2005; Hahn, 1998). Also, the degree and ability to which someone can perform skills for themselves and their ability to accomplish certain task in their own home, contributes to their self-worth and value (Putnam, 2005). Support care assists people with physical disabilities to have control of their lives and their homes.
“Living Like a Rock-Star”:

Images of Accessibility

“Your photography is a record of your living, for anyone who really sees.”
- Paul Strand

Through images captured by participants involved in the photo-voice focus group, we are able to see into their worlds, and their homes. Whether living in the community, a group home, or a long-term care facility, these images show us how particular aspects of their home create accessibility and contribute to their sense of social inclusion. They all shared photos with each other, helping them to see how others were living and to garner ideas of ways they can make their spaces more accessible.

Location, Location, Location
The images emphasized the importance of location of the home, within the city, and within a community. In particular, participants spoke of how important it is for them to have green space to access, and to have home features such as a deck or a patio. These spaces were seen as vital to their well-being. Also, one of the participants noted that it is important to be close to amenities or shopping malls, as he would just “roll on down” to the mall he lived near.

Technology
Technology is vital to creating an accessible home. All participants captured images of their “workspaces” or their computers. Their computers were seen as their way of staying connected with people, and current issues, as well as taking courses for school. Also, having computer skills was seen as a significant skill set for employment.

Kitchen, Bed and Bath
Other common images photographed were bathrooms and kitchens. Participants shared how the smallest of details could help them to be more independent within their own homes. Examples of these are the lifts to place them in bed, a seat in the shower, a convection microwave oven, and door levers rather than round handles.

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13 Paul Strand was an American photographer and filmmaker who helped establish photography as an art form in the 20th century.
“Your deck is like your window on the world”

This is one of the best features of my apartment. It’s taken from inside the room out onto the patio, where I spend a lot of time in the summer. The patio doesn’t look like much. I’ve got some plants, and trees, stuff like that. But I love that deck. It gives you open space, and access to the world. For the first 5 years, I was a pretty stubborn guy and used a manual chair, and couldn’t get out onto the deck by myself. They are building apartments and condos now with small decks that are inaccessible and stuff like that. To me, for a person with a disability, your deck is like your window on the world. I love my deck. I would not trade it for a high-rise condo. (Photo-voice Participant, 2007)
That’s a shot of the view from outside my window. I spend a lot of time there in the summer. It’s a good thinking spot. You can look out over the pond and let your mind wander. (Photo-voice Participant, 2007)

Those are my flowers. I actually took that picture. It took me half an hour to take it. I plant them. They have a rooftop program. My friend helped me plant stuff. My mom helped me water them. I take care of them the best I can. (Photo-voice Participant, 2007)
There is a cut out underneath the sink, so I can put my bottles underneath there, wash my hands, that sort of thing. My convection microwave oven...that’s probably one of the best inventions ever made. In that I can heat up stuff, so not only can you cook stuff, but you can reheat dinners and stuff. So, it’s a great use of space, and just an easy fix instead of putting in a regular oven. Because I always worried about getting burned. The only thing that is inaccessible is the paper towel, I haven’t figured out how to rip off the power towel yet. (Participant laughing...). What’s cool too, is you notice the U-shaped handles on the cupboards, they’re prefect because I can hook my fingers in and then open them. (Photo-voice Participant, 2007)
This is an electric door. This is really important too because it allows me freedom. I have a remote control for the door. It’s excellent because you don’t need any keys. It’s nice to come in a barrier free entrance. Without that door I have to wait for somebody. Without the remote I was waiting outside like a lost puppy until someone came along. (Photo-voice Participant, 2007)

There’s my shower. To me that’s great because when I was first hurt, you got one shower a week at the hospital. This is my roll in shower. I have my hand-held shower so I can shower myself and do different things. I have an assistant who helps me, and then I’m good to shower, and it’s just great because I shower everyday, which is perfect. Ya, just a simple chair, and a handheld shower makes a big difference. (Photo-voice Participant, 2007)
I could never work keys very well, and so this is a code key door, which is awesome, between the remote control door [to get into the building] and the code key, it's awesome.

And if my care attendant is ever ill, they don’t need a key, I just give them the code key. It’s another one of those things that’s designed to help us [people with disabilities] and that’s useful for the general public. And, that lever handle is really important too, because if that was a door knob, I couldn’t open it. This is a $200 dollar fix...I had to pay for that as well. (Photo-voice Participant, 2007)
This is a shot of my office, which is great. There’s a hand crank, and what’s cool is if I use my manual chair I can crank it lower, or if I use my electric chair, I can crank my desk higher. Again, wheel chairs hate legs. So with this desk it almost has no leg room, or a spot where legs are in the way.

I really think now is the best time, in the history of the world, to be a disabled person. With electronic controlled blinds, a computer that can make your place hot or cold, if you can work the computer you can do a lot of jobs in today’s society. I think if someone had no computer skills, and was disabled, that would be the first investment you make, and it’s going to make the rest of their lives easier. (Photo-voice Participant, 2007).

That’s just a shot of my workspace. It allows me to work. It allows me to do my school work, it writes letters. I can use the voice recognition. I got my speaker phone. Without the advancement in technology, whatever it may be, whether it is a computer, a speaker phone, an ipod, without it, there would be no independence for people with disabilities. (Photo-voice Participant, 2007).

The computer can do everything, go anywhere, do anything. I talk to friends, I send e-mails, I’m on facebook and I look up all this stuff and I look up things on You Tube. I’m always doing different things on the computer now. When I’m on the computer, I can do anything. I can go anywhere, look up anything, read everything. Everything is accessible, everything is in front of me. (Photo-voice Participant, 2007)
"... for disability-related surveys, return rates range from 15 to 30 percent and typically do not exceed 50 percent." 14

The housing literature has identified a need for survey research on ‘special needs’ housing to go beyond identifying unmet needs and move towards identifying principles to inform policy development and the provision of services. Means (1996) has stated that, “the challenge faced by ‘special needs’ housing surveys is how to ensure the ‘facts’ uncovered are used in such a way as to support aspirations to independent living” (p.208).

The survey offers a “snapshot” of people with physical disabilities and the issues of appropriate housing and care. The results below are the descriptive results of the survey. Because this is a convenience sample, caution should be exercised to not generalize these findings to the overall population. However; these learnings do provide significant insights into the collective profile of people with physical disabilities, and the complexity of appropriate housing and care for people with physical disabilities, and implications for improving programs and policies that will lead to the betterment of housing and care.

**Survey Approach**

- The purpose of the survey was to collect information that would help us to better understand the suitability of the living and support care conditions for people with physical disabilities. The survey was categorized into three main areas: demographic information, housing information, and support care.

- The survey is a convenience sample (Participants come from a variety of sources, and were selected according to the criterion that they are: physically disabled, and between the ages of 18-65). This survey is not generalizable to the overall population, and was conducted in order to begin to build base-line data/understanding of this population in relation to housing and care needs; and secondly, to understand some of the common traits of this population in order to inform recommendations for action to enhance the living conditions and housing options and care support for people with physical disabilities.

- Participants were surveyed across a variety of living environments including:
  - Living independently (without care)
  - Living independently with care
  - Group Homes
  - Long-term Care

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A total of 129 surveys were returned. 10 could not be counted because the respondents were over the age of 65. 286 surveys in total were distributed.

2-levels of response rate:
- 42% overall response rate
- 64% response rate if surveys distributed to one of the institutions surveyed were not included. Only 1 survey out of 100 was returned and it was returned after the cut-off date of August 22\textsuperscript{nd}. To adhere to ethical guidelines we have considered these 100 surveys in our response rate.

Surveys were administered via mail, on-line, telephone, and in-person.

**Survey Results**

The following draft report uses the American Psychological Association (APA) conventions of \textbf{N} for the total sample (129) and \textbf{n} for any and all sub-samples that are selected either deliberately or because of non-responses. Thus, for each test and computation the sample size (or sub-sample) has been indicated by the symbol \textit{n}. In this context it is considered to be the valid sample for a test. The valid sample is the sum of participants who responded to the question and those participants for whom the question did not apply. Thus, each question has a unique \textit{n}.

**Gender**

\textit{n=119}

![Gender Chart](chart.png)
The majority of respondents were aged 45-59, with the next significant grouping being 25-44. The age group targeted for this survey was 19 – 60 years of age.

Although the majority of the respondents are Caucasian, there is an increasing diversity among people
with physical disabilities in Calgary. The seemingly low demographic of different ethnicities may have implications for research and creating different ways of engaging other populations within the disability community.

The average length of time respondents indicated that they were disabled was 11 years. This is a reminder of the fluidity of disability, and for people not born with a disability, some developed a disability early in life, sometimes as early as twenty and within their forties.

*Other Disabilities (33%—arranged thematically)*
- Epilepsy
- Muscular dystrophy
- Spinal bifida
- Spinal cord injury
- Traumatic brain injury
- Mobility issues with arms and legs due to paralysis

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**Nature of Disability (n=119)**

- MS: 36.1%
- Other: 33%
- Stroke: 11.8%
- Rheumatoid Arthritis: 10.9%
- Cerebral Palsy: 8.4%
- Sight Impairment: 7.6%
- Paraplegic: 6.7%
- Quadriplegic: 5.9%
- Hearing Impairment: 2.5%
- Amputee: 1.7%
The high rate of unemployment is consistent with the provincial statistics. There may be many reasons for the unemployment. We heard, through the qualitative research, people want to work, but are unable because of the detrimental impact it has on their income support. More than half of the respondents' income support is derived from AISH, and if they were to work, this would mean reducing the financial support that is received through AISH, as well as a loss of the comprehensive medical benefits.
Of the 11.80% of the respondents who are employed, the majority are working part-time.

Of the respondents, 38.7% have completed post-secondary education. Contrasting this with the high rate of unemployment shows that there are people with disabilities with a variety of skills and knowledge, who do not have opportunities to be employed. Creating ways for people with disabilities to be employed support social inclusion as well as additional income. However, research shows that most people are unemployed because their income support will be reduced, and given the fluidity of disability and the development of related issues (for example bed sores), there may be periods where people would be unemployed, thus the loss of benefits and income render employment to be very undesirable.
73% of respondents indicated that their annual income is less than $25,000 per year. Of the people living on $25,000 per year or less, 74% of them are receiving AISH, and 26% are not receiving AISH. For The City of Calgary, affordable housing initiatives are targeted to those with a gross income below $37,621. Therefore, we know that the majority of the people surveyed are spending most of their income on housing. The increase in rental costs, with the lack of increase in support of funding for people with physical disabilities perpetuates and maintains their low income to the point that any unanticipated expense could render them unable to afford their homes.
People with physical disabilities may experience related mental health conditions, such as depression. Also, brain related traumas or injuries, can create dual disabilities of cognitive and physical. This speaks to the importance of understanding the unique and complex conditions of a person’s life and the specific housing and care supports they require.

With more than half of the respondents receiving AISH, this means their income is $1050.00 per month, and that many of the respondents are living in very low income situations.

With the “other” category, respondents indicated that their other sources of income include:

- CPP and disability
- Private pensions
- Personal investments

People with physical disabilities may experience related mental health conditions, such as depression. Also, brain related traumas or injuries, can create dual disabilities of cognitive and physical. This speaks to the importance of understanding the unique and complex conditions of a person’s life and the specific housing and care supports they require.
Only 39 people responded to this question out of 119. We can infer that the remaining 80 respondents are not in a relationship. Of those that indicated that they are in relationships, nearly 90% of them are married. Of the respondents in a relationship, 5.7% are in same sex relationships.

A small number (15.3%, 18 of 118) of respondents currently have dependents, and of this cohort only 10.3% (11) dependents are children. It is important to remember that people with physical disabilities have families and children they are caring for. This has implications for the kinds of affordable housing needed for people with physical disabilities and underscores the importance of having a continuum of choice for affordable and accessible housing.
The majority of respondents are living in the community. This means nearly 55% of survey respondents are living in their own home. Of these, nearly 30% are living in the community without formal support. Also, through our research we learned that there are people living in long-term or group care settings because they cannot afford to live in the community, or cannot find the support care needed to help them live independently in the community.

Other:
- Living with parents
- Mount Royal college residence
- Living in a townhouse with sister and her family
- Living in a truck
- Living with daughter, her fiancé their baby and two men in the basement
Most respondents agreed that their current residence is “suitable” for them. Although the survey attempts to capture this, we recognize that “suitability” can be a very subjective concept. This response can lead to many interpretations, as we learned through the interviews that people do not want to “complain.” There is a high level of “just surviving” or feeling of complacency with their surroundings and not knowing that there are alternatives. There was also fear expressed to the researchers that if they speak out they will lose what they currently have.

If yes, why it is suitable?

Major themes of why residence is suitable:

- **Home space is physically accessible**—often wheelchair accessible.

- **Care**, both informal and formally
  - “Because I can manage my scooter in the house which does not prevent me from carrying on my normal day.”
  - “I can move around in wheelchair at home, able to feel independent.”
  - “Excellent caregivers, ramp access to home, open space, easy to move around, bathroom and kitchen adopted for needs.”
  - “Home is built to make things accessible for me. Good husband—I’m lucky.”
  - “I am capable of caring for myself with help from my wife.”
  - “I currently live in a mobile home that we purchased new and adapted to make it suitable for me. We replaced the carpet with vinyl flooring and put a protective coating on the lower part of many walls. We put in a porch lift for the scooter and the wheelchairs and ramps at the door to make egress and access easier. Lately we put in a porch door holder that holds the door open when we go through. Whatever modifications are necessary, my husband is able to do the work and if the item is costly then we search to find a way that we afford it. We also changed the tub to a wheel-in shower and attached some railings for me to use. I use a shower stool to wash my hair and take showers and I’m able to transfer from the chair to the stool with help. He also put an extension on the toilet so I can transfer there from my wheelchair.”
  - “I only require a few hours of homecare assistance each day. Living independently in the community is best for both my social life and personal piece of mind. Group home
settings are poorly staffed, quite often with untrained caregivers who do not care nor meet one’s specific needs. Independent living and hiring one's own staff rectifies this and gives one a greater sense of autonomy.

- “My building is wheelchair accessible; I live on the main floor and right beside a major shopping centre and Wal-Mart, which I can scooter over to for shopping. This enables me to keep my independence somewhat.”
- “My care works great. I get help in the morning for about 15 minutes - showering dressing, etc. Then I get afternoon help as needed (meals, cleaning, etc)... then about 1/2 an hour to get put into bed and wash up.”

If no, why is it not suitable?

- **Home is not fully accessible** due to issues of stairs, inaccessible kitchen and bathroom
- **Need for care** to relieve family from time to time (respite)
- **Affordability**
  - “Need an elevator—stairs are difficult, I would also benefit from accessible features in bathroom.”
  - “Not accessible— [have] just a regular apartment. Kitchen and bathroom unusable—can’t do laundry, can’t cook.”
  - “Parents are finding my care to be too much.”
  - “Personal homecare not consistently available in Calgary’s current climate. I need further home modification (Ceiling lift installation) in order to meet my needs without PCA.”
  - The cost of living is always going up. I need to share accommodations in order to be able to live.
  - [I live] in an old basement, very substandard, no kitchen or air circulation.”
  - My basic needs are met, but ideally I’d be at home with my husband.”
  - “My current living situation does not meet my needs in that it does not provide the care I need. It does not allow me to fully participate in the community.”
  - “My wheelchair cannot fit in the bathroom, no access for me to enter from the front of the house. Always have to be dropped in the back which is okay if it is not snowing or raining, if so, that mud goes directly form the alley to my house.”
  - “Truck not much of a place to live! Does not feel safe staying in shelters. Has a lot of meds and needles for diabetes that got stolen at the shelters—feels safer sleeping in truck.”
  - “We have a 2 storey house. I can no longer do the stairs by myself.”
Examples of formal care provided by respondents:

- Accessible Housing Society
- Calgary Health Region/Homecare
- Calgary Home Support
- Community Access worker
- Food Bank
- Seals
- MS Society
- Self-managed Care
- Long-term Care facility
- Calgary Family Services

Examples of informal care provided by respondents:

- Friends
- Husband: “husband does everything.”
- Wife
- Mom
- Daughter: “My daughter shops for me and finds food that’s easy to prepare.”
- Parents: “my mother takes my laundry weekly and does it at her house. In Strathmore. My brother comes over a couple of time a month to help with housework and shopping.”
More than half of the respondents indicated that their care has stayed the same over the past two years.

When asked to elaborate on how the respondent rates the care, the following themes emerged:

- **Substantial role of informal caregivers providing care: spouse and family are main support:**
  - “Have had to take care of myself, homecare came twice but now my daughter does most of my care and still hasn’t been able to work (daughter) since my injury”
“I spend most of the time caring for my mother, plus with four to six migraine attacks per month, she then cares for me. I take care of all her medical/homecare needs as well as weekly visits to our doctor.”

“Knowing each other’s (husband’s) hidden handicaps better, we’re able to aide each other as much as we can whenever necessary.”

“My care hours assessed for have been doubled but hours of formal care provided is but a fraction of the assessed need identified by the Home Care coordinator. My wife has had to quite the work force to provide the personal care I require.”

- Organization and systemic interconnected issues create barriers to accessing support care:
  - Need for better system support for support care workers
  - scheduling, inconsistent care workers, thus not being able to develop relationship with care workers;
  - shortage of care workers,
  - unable to afford self-managed care.
    - “Prefer managed homecare to agency homecare, Not a different person coming in every day. Regular homecare doesn’t pay staff enough money.”
    - “My needs are usually met. But I am finding it hard to find caregivers in the community. Their hourly rate of pay they want is much higher that I can pay them.”
    - “.the facility that I live in does not cater to the specific needs of a young active adult. I share a room with another woman and pay rent of $1300.00 a month. We only get four showers a month and the staff is unable to work around our schedules. We get the same care as one who is in a vegetative state.”

Benefiting From a More Accessible Environment

![Bar Chart]

33.9% respondents indicated that they are on a wait list for accessible housing. Of the 43.4% of respondents who indicated they would benefit from a more accessible environment, the following ways were identified:
With a more accessible environment, people would have greater independence within and outside of the home:
- “A wheel in shower would be wonderful, personal hygiene would be easier, would be able to cook again with a lower counter”
- “The unit I have is wonderful! It has a wheel-in-shower, but it has no oven, closets, bathroom cabinets, or any storage what so ever!???”
- There are 2 steps out to the patio, and 2 steps out the front entrance. The fridge is so small it hardly holds staples, let alone extras. I love it though and hopefully they’ll soon build the ramp for access to the street!! Then I could access the shops, ect on my own.”
WHAT THE RESEARCH TELLS US:
A FUSION OF LEARNINGS & IMAGES

1. Essential Connection of Accessible, Affordable Housing AND Support Care
   - Accessible housing must be instrumentally connected to support care. It is important to continually language these concepts as intrinsically connected, and to shift the discourse from just housing to housing and support. People with physical disabilities require supportive care in order to live well within their homes. In the planning for and creation of accessible and affordable housing, it will be critical to involve health and social services. We learned that the more a home is physically accessible, the less need there is for intensive support care, because the individuals’ capability is expanded to care more for themselves.\(^\text{15}\) For example, being able to do their own cooking (having an accessible kitchen, and appliances), doing their own laundry, and having an accessible bathroom for bathing.

   Integral to having support care is ensuring that a fair and supportive working environment is maintained for practitioners in this field. Calgary is experiencing a crisis in this field, and is part of the reason some people with physical disabilities cannot remain in their homes. Fully accessible and affordable housing cannot be achieved without attending to and improving the situation of recruiting and retaining practitioners in this field.

2. On the Edge of Homelessness
   - 73% of respondents indicated that their annual income is less than $25,000 per year. Of the people living on $25,000 per year or less, 74% of them are receiving AISH, and 26% are not receiving AISH. For The City of Calgary, affordable housing initiatives would be targeted to those with a gross income below $37,621. Therefore we know that the majority of the people surveyed are spending most of their income on housing. The increase in rental costs, with the lack of increase in support of funding for people with physical disabilities perpetuates and maintains their low income to the point that any unanticipated situation could render them unable to afford their homes.
   - 46.2% of respondents of the survey are not living in an accessible housing space, thus we know that this sub-group could be at risk of homelessness. Further, interviews described the inadequate conditions that some people are living within; yet without any other choices for affordable and accessible housing they remain within their inaccessible and inadequate homes. Should their disability progress or their care support be reduced, this group will be at a serious risk of homelessness.

   o Low Income and Poverty: A high number of people rely on AISH for their income. Most of the respondents are living on less than $25,000 per year. Based on the survey and interviews, we learned that people are living in unsafe and unhealthy housing spaces. This invites the question of how large

\(^{15}\) Nussbaum, Martha C. (2000) *Women and Human Development: The Capabilities Approach* (Cambridge University Press, Cambridge). Analysis of the study is informed by Nussbaum’s capability approach, which is a conceptual framework for evaluating social states in terms of human well-being. For example, poverty is seen as “Capability-deprivation.”
is this group, and to what degree are they living in unsuitable home environments, and secondly, how do we reach and support this group?

- **Inadequate and Unsuitable Housing:** Many people are already living in situations that are not accessible, but are indicating that this is “fine” and “do not want to complain”.

3. **The Need for Choice: creating a continuum of accessible and affordable housing**
   - We learned that a continuum of housing exists for people with physical disabilities, however traversing this continuum is challenging. There appears to be significant gaps in the continuum and a lack of choice for people to choose where they would like to live, because of the shortage of affordable, accessible housing and supportive housing (i.e. group homes, long term care). It is important to offer a robust continuum of choice for people with disabilities, including apartment buildings with integrated support, age-appropriate long-term care centres and group homes, and affordable housing for families. For example, several younger adults are inappropriately placed in long-term care centers for seniors because it is the only space available. Also, there are people with physical disabilities, and single parents who have a disability that require a home for their children as well.

4. **Discerning the Discourse of “Suitability” and Accessibility”**
   - 63% of respondents indicated that their residence is *suitable*, and 46.2% indicated that they do not live in an accessible space, and 43.4% indicated that they would benefit from a more accessible environment. Combined with the learnings from the interviews, we also know that individuals are living in unsuitable and inaccessible home environments, but are unaware of what options are available to them for accessible housing. Also, with marginalized populations, systemic oppression can be internalized, and thus they do not recognize or believe that they deserve a more appropriate living space. Many of the respondents do consider their place suitable, even though it may not be accessible. This could also be due to the high level of informal support (43.6%) that enables individuals to continue to live in their inaccessible spaces. This also demonstrates the strength of this population as they persevere under very challenging conditions.

5. **Informal care is a major support system for people with physical disabilities, and there is a shortage of formal care (in particular home care nurses, and personal care attendants)**
   - Almost 43.6% of survey respondents indicated that their main source of support is informal care. Most of the informal care is provided by spouses, as well as children supporting their parents. The implication of this is, why is there a high level of informal care for people with physical disabilities, and how is this affecting their quality of life? Also, with a reliance on informal care comes an increased stress on families, as we do not see the growing need for formal services, because people are increasingly taking on informal care because they have no choice. There is a shortage of formal support, and what kind of culture of care is being created under some of the limitations of low salaries, and shortage of staff, and secondly how is this impacting professionals, and people with physical disabilities?
6. Hearing from the Unheard and Unseen: Creating a Space for People with Physical Disabilities

- People with physical disabilities is a hard population to access because some are in structured facility settings, and others are isolated in the community. In addition, the more structured settings are bound by systems of care that are difficult to move through, thus when do ethical processes become a power over a marginalized group, or when is it in place to protect them? A key learning from this study is how do we continue to include the voices and perspectives of people with physical disabilities in understanding the issue of housing? We encountered several challenges in accessing to this population for surveying and interviewing. In addition, we included a photo-voice focus group in our research approach as a way to bring image and voice to the unseen ways people with physical disabilities are living. Most of the participants in this focus group did not have the physical capacity to take pictures of their own lives, and required assistance to do this. To ensure that people with physical disabilities are included in the development of accessible housing, requires a concentrated effort and collaboration with community-based organizations that are working with this population.
The following recommendations outline how the research can continue to move into action. It is recommended that the process of unfolding the recommendations follow the spirit of action research. Thus, it is vital to ensure that the process includes community-based agencies, academics, people with physical disabilities, and coalitions or people who can influence policy.

1. **Ensure that a percentage of all new affordable homes in Calgary incorporate the principles of universal design.** The research shows that there are minimal costs to create homes with universal design. Universal design benefits all populations, not only people with physical disabilities. For example, a single mom with young children who is using a stroller, or a senior who is struggling with mobility issues.
   - Universal design is a key concept that could inform the 10 Year Plan to End Homelessness in Calgary, and to ensure that a portion of the accessible units being built meet universal design principles. To ensure consistency, it is recommended that the City of Calgary, as a municipality adopt a universal design policy in order to make the city truly accessible and inclusive of all people. This would ensure that new buildings, parks, environments would be designed to be used by all people.
   - When affordable and accessible units are being built, it is important to take into consideration the location, and to ensure that the homes are close to amenities, or close to malls.
   - Ensure a continuum of choice in affordable housing for people with physical disabilities such as living independently in the community, or creating more group homes for people with severe physical disabilities. Group homes within the community setting offer a less institutional environment.

2. **Ensure a Continuum of Choice of Affordable and Accessible Homes.** In Calgary, there is a lack of sufficient “options” in living arrangements and care services i.e. long wait lists for housing and care and little choice when options arise. People with physical disabilities have differing housing needs depending on their situations and the severity of the disability. Key aspects to consider are:
   - Affordable housing for families
   - Age appropriate group homes located within communities
   - Age appropriate private rooms for people with severe disabilities who need to live in long-term care settings. Short staffed and under-funded personal care agencies and services. I.e. research has indicated that residents in assisted living facilities overwhelmingly prefer private rooms (Kane, Baker, Salmon, & Vealzie, 1998 as cited in Ball et al., 2000). The crowding and wait times of Long Term Care facilities in Alberta frequently render this desire unfeasible.

3. **Increase funding amounts for modifications and adaptations to create accessible homes for people with physical disabilities.** Due to the low number of accessible and affordable homes in Calgary, many people with physical disabilities are living in homes that are inaccessible, yet cannot afford to modify their homes. There is a need to increase funding for modification support programs and to decrease the wait time for...
home adaptations. Also, streamlining or simplifying the application process will make the funding more accessible.

- Technology is a vital aspect of an accessible home for people with physical disabilities, and it is important to ensure there is support for technology. Whether this is funding to assist with the purchasing of a home computer, or computerized features such as remote control door. These features help to support integration supports integration and reduces isolation of people with physical disabilities.

4. **Ensure that the development of new affordable and accessible housing is done in coordination with support services.** From the research, we know that affordable and accessible housing is meaningless without the support care (Means 1996). Part of what makes a home accessible is the support care that is offered within the home. Without the support care, many people with physical disabilities cannot live in their own home. Lack of community-based care services which reach beyond the provision of basic needs i.e. availability of counseling services, opportunities to access the community for reasons other than medical appointments, and services which facilitate socialization and connections in the community

5. **Develop a local collective voice and action plan in regards to the issue of housing and care for people with disabilities in Calgary.** There are several existing mechanisms that the action committee could link to. This committee could be part of the Premier’s Council on Disabilities, or could be a committee that forms out of the community impact work by United Way of Calgary that is focusing on people with disabilities. Thirdly, the committee could also be linked to the Calgary Homeless Foundation.

6. **Engage in more qualitative research for people with physical disabilities.** There is minimal qualitative research in the field of people with physical disabilities in the area of housing and care. There is a need for innovative research and creative ways of accessing this population so that they can participate fully in research.
REFERENCES AND RESOURCES


City of Calgary. (2004b). Housing affordability in Calgary, by sex, for households with the presence of disability in the household. Research Brief #17, 1-29.


A) PROJECT ADVISORY GROUP
B) KEY TERMS AND DEFINITIONS
C) SURVEY QUESTIONNAIRE
D) INTERVIEW GUIDE
E) CORE REQUIREMENTS OF AN ADAPTABLE DWELLING UNIT
F) CERTIFICATE OF ETHICAL APPROVAL
APPENDIX A: PROJECT ADVISORY GROUP

The research team met with the Project Advisory Group through monthly meetings. This process ensured that the representative community agencies informed the research process and learnings. The Project Advisory Group is also a vital link to the client population, which has multiple barriers and can be challenging to access.

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Roy Smith</td>
<td>Accessible Housing Society</td>
</tr>
<tr>
<td>Mike Hambly</td>
<td>Independent living Resource Centre of Calgary</td>
</tr>
<tr>
<td>Ralph Hubele</td>
<td>Supportive Living and Long-Term Care Branch, Alberta Seniors and Community Supports</td>
</tr>
<tr>
<td>Sharyn Brown</td>
<td>Calgary Homeless Foundation</td>
</tr>
<tr>
<td>Katrina Milaney</td>
<td>Poverty Reduction Coalition, United Way of Calgary and Area</td>
</tr>
</tbody>
</table>
APPENDIX B: KEY TERMS AND DEFINITIONS

Physical Disability
“Any degree of physical disability, deformity, malformation, or disfigurement that is caused by injury, birth defect, or illness. This includes but is not limited to, epilepsy; paralysis; amputation; lack of physical coordination; visual, hearing, and speech; impediments; and physical reliance on a guide dog, wheelchair, or other remedial appliance or device” (Calgary Health Region, 2005, p. 25).

Accessible Housing
There is no standard definition of accessible housing; however, discussion regarding the topic often includes the following: safe, affordable, and barrier-free physical spaces for people who experience mobility issues (AHS).

Universal Design
“The design of environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design (Multiple Sclerosis Society of Canada, Canadian Paraplegic Association & Alberta Committee of Citizens with Disabilities, n.d., p.5).

Barrier Free Design
“A building and its facilities can be approached, entered and used by persons with disabilities” (Multiple Sclerosis Society of Canada, Canadian Paraplegic Association & Alberta Committee of Citizens with Disabilities, n.d., p. 5).

Assisted Living and Supportive Housing
There are many definitions of ‘Assisted Living’ and ‘Supportive Housing’. Neither of these terms is protected in Alberta and can be used by housing operators at their own discretion. In the broadest sense, they both refer to the combination of housing and services in a residential setting. The services that are included in the rent or otherwise available for purchase vary from building to building” (Alberta Seniors and Community Supports, 2007, p.9).

Designated Assisted Living/ Designate Supportive Living/ Designated Supportive Housing
“The term ‘designated’ refers to spaces within a supportive living facility where there is a contract between a regional health authority and a housing operator. Under the contract the facility operator provides health and support services based on assessed need. The regional health authority, in collaboration with the operator makes decisions regarding the admission and discharge. Regional health authorities differ in terms of their target populations for these spaces, types and availability of health care staff, and the services the operator must provide as part of the contract” (Alberta Seniors and Community Supports, 2007, p. 10).

Long-Term Care
A long-term care center offers a range of residential, personal and health services to people who are elderly, disabled or chronically ill and who need 24-hour care. They also provide a number of health care supports like day programs, respite and rehabilitation services to people who still live in their own homes. In the past, long-term care centers were known as auxiliary hospitals and nursing homes (Calgary Health Region, 2007).
Community Living or Independently Living
Community living or Independently Living “includes people who live in their own homes, including but not limited to single family dwellings, apartments, and condominiums” (Alberta Seniors and Community Supports, 2007, p. 3).

Supportive Living
“Supportive living is both a philosophy and an approach for providing services within a housing environment. It provides a residential setting where people can maintain control over their lives while also receiving the support they need. Buildings and common areas are specifically designed to meet residents’ needs and to support their safety and security…supportive living options can serve the needs of a wide range of clients who need support to live as independently as possible…However, there are also limits to what supportive living can provide. For example, individuals who have complex care needs and require access on a 24-hour basis to a registered nurse may not be appropriately accommodated in supportive living” (Alberta Seniors and Community Supports, 2007, p. 2).

Personal Care Home
Personal care homes provide personal assistance, supportive services, lodging and meals to one or more adults aged 18 and over who are not related to the operator. In personal care homes the emphasis is on helping residents with daily activities, rather than treating them for medical conditions.

• The Calgary Health Region has approved 24 such residences across the city each with three to six beds. Approved homes have to meet regulations, for example nutrition has to follow Canada’s Food Guide and the homes have to be equipped with smoke detectors. There are also homes that are not approved by the Calgary Health Region. It should be noted that among these there are variations in the physical environment and services offered.
• Personal care homes that provide accommodation and services to four or more individuals are required to obtain a license under the provincial Social Care Facilities Act. Homes with fewer than four residents are not covered by this legislation and do not require a license (Calgary Health Region, 2007).

Personal Care Services
“Includes assistance with the activities of daily living (e.g. bathing, personal hygiene, grooming, dressing, toileting), assistance with therapeutic regimes (e.g. range of motion, medication assistance and reminders, simple wound care), simple bedside care (e.g. mouth care, turning, application of lotions), therapeutic interventions for behavior management and maintenance of health records” (Alberta Seniors and Community Supports, 2007, p. 8).

Group Home
A small supervised residential facility, as for people with disabilities, in which residents typically participate in daily tasks and are often free to come and go voluntarily (Medical Dictionary, 2007).

Low Income
“Refers to persons living in households with incomes below the relevant Low Income Cut-off (LICO) as established by Statistics Canada and as reported in the 1996 Census” (City of Calgary, 2002, p.6).
**Suitable Housing**
“Meeting health and safety standards, as well as a level of support that meets the needs of potential residents” (Multiple Sclerosis Society of Canada, Canadian Paraplegic Association & Alberta Committee of Citizens with Disabilities, n.d., p. 5). Low-Income Households range from having a gross annual household income of $0 to $37,621.

**Affordable Housing**
Is defined by the City of Calgary as adequately suiting the needs of low-and moderate-income households at costs below those generally found in the Calgary market….affordable housing projects are targeted to households with 65% or less of the area median income [which is $37,621]. For housing to be affordable, the Canada Mortgage and Housing Corporation have defined that a household should not spend more than 30% of gross income on [rental] shelter costs.
Thank you for sharing your time.
If you require any assistance completing this survey, please phone Debb at 220-7281.

Your input is very important for helping us to better understand the suitability of your living and support care conditions. The questions you answer will help us to gather information so we can improve accessible housing and care support for people with physical disabilities. By completing the survey, you will help us gain a better understanding of the housing and care needs of people with mobility issues in Calgary.

Your decision to complete and return the questionnaire will be interpreted as an indication of your consent to participate. Please note that in no way will this affect any supports that you are currently receiving. This survey will take about 10-15 minutes to complete.

### SECTION ONE: Demographic Information

The following questions provide background information about you.

1. **Gender:**
   - Female
   - Male

2. **Age:**
   - Under 18 yrs
   - 18-24
   - 25-44
   - 45-59
   - 60-65
   - 65+

3. **Ethnicity:**
   - Caucasian
   - Asian
   - African
   - Aboriginal
   - Hispanic
   - Other (please specify) ____________

4. **What is the nature of your disability?**
   - Amputee
   - Cerebral Palsy
   - Multiple Sclerosis
   - Rheumatoid Arthritis
   - Stroke
   - Paraplegic
   - Quadriplegic
   - Hearing Impairment
   - Sight Impairment
   - Other (please specify): ____________

5. **Have you been diagnosed with a:**
   - Mental health condition
   - Development disability
   - Both
   - Neither

6. **What type of mobility device(s) do you use?** *(Check all that apply.)*
   - Electric Wheelchair
   - Manual Wheelchair
   - Scooter
   - Cane/Crutches
   - Walker
   - Other ____________
7. How long have you been disabled? ____________________________ years

8. Are you in one of the following types of relationships?
   □ Marriage:   □ Same-Sex  □ Heterosexual
   □ Common Law: □ Same-Sex  □ Heterosexual

9. Do you have dependents living with you?
   □ Yes  □ No
   9 a. If yes, how many? ____________
   9 b. Are these dependents your children? □ Yes  □ No

10. Are you currently employed?
    □ Yes  □ No
    10 a. If yes: □ Full time  □ Part time  □ Contract/ Seasonal

11. Are you a postsecondary student? (For example, at the University of Calgary or SAIT.)
    □ Yes  □ No
    11 a. If yes: □ Full time  □ Part time

12. What is your highest level of education?
    □ Did not complete high school  □ High school diploma  □ Some postsecondary
    □ College Diploma/ Certificate  □ Bachelor’s degree  □ Graduate degree

13. What are your primary sources of income? (Check all that apply.)
    □ Employment  □ Self Employment  □ Employment Insurance (EI)
    □ Worker’s Compensation  □ AISH  □ Social Assistance
    □ Financial support from family  □ Other (please specify)______________

14. Please check your annual household income:
    □ Less than $25,000  □ $25,000 - $49,999  □ $50,000 - $74,999
    □ $75,000 - $99,999  □ $100,000 - $149,999  □ $150,000 and over

SECTION TWO: Housing
Information
The following questions will ask about your current living arrangements and housing needs.

15. What is your current living arrangement?
    □ Independently  □ Independently with care  □ Long-term care
    □ Group home  □ Emergency shelter  □ Other (please specify):____________________

16. Is your current living arrangement suitable for your needs? □ Yes  □ No
16 a.  If yes, why?

______________________________________________________________________________

______________________________________________________________________________

16 b.  If no, why?

______________________________________________________________________________

______________________________________________________________________________

17.  Are you on a waiting list for accessible housing?  
    □ Yes  □ No

17 a.  If yes, how long have you been on the list?  ____________ months.

18.  Do you live in an accessible housing unit?  
    □ Yes  □ No

19.  How long have you lived at your current address?  ________________ years.

20.  Who do you live with?
    □ Roommate/friend(s)  □ Parent(s)  □ Family (e.g., siblings)
    □ Partner  □ Alone  □ Other (please specify):  ________________

21.  If you have housemates, why do you live with this person/these people?  (Check all that apply.)
    □ Financial need  □ Support/personal care they provide
    □ The house is accessible  □ Personal choice
    □ Other (please specify)  ________________

22.  Please rate the accessibility of your current home:
    □ Not at all accessible  □ Somewhat accessible  □ Fully accessible

23.  Do you have a pet?  
    □ Yes  □ No

23 a.  Do you require the services of an animal to assist you (e.g., a Seeing Eye dog)?
    □ Yes  □ No

SECTION THREE:  Care/Support Services

The following questions will ask about the care and support services you receive

24.  Please check the personal care activities you receive:  (Check all that apply.)
    □ Dressing  □ Bathing  □ Cooking
    □ Cleaning  □ Taking medication  □ Other (please specify):  ___
25. **What kind of care do you receive most often?** *(Check only one)*

- [ ] Formal – e.g., Home Care provider
- [ ] Informal – e.g., Family/Friends

25 a. **If formal care, through which agency or service provider(s) (e.g., Home Care, the Canadian Paraplegic Association, etc.)?**

________________________

25 b. **If informal care, who provides it to you (e.g., Partner, Parent, Friend, etc.)?**

________________________

25 c. **In the past 2 years, have your total hours of care:**

- [ ] Stayed the same
- [ ] Increased - by approximately _______ hours per week
- [ ] Decreased - by approximately _______ hours per week

26. **Please rate how well your current level of personal care meets your needs:**

- [ ] Not at all
- [ ] Somewhat
- [ ] Most of the time
- [ ] Completely

26 a. **Please elaborate on how you’ve rated your current level of personal care:**

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

27. **Are you aware of where to turn if you need additional care support?**

- [ ] Yes
- [ ] No

*(For more information on supports available in Calgary, please refer to attached community resource sheet)*

28. **Would you benefit from a more accessible living environment?**

- [ ] Yes
- [ ] No

29. **How would you benefit from a more accessible living environment?** *(Check all that apply.)*

- [ ] Would be able to do my own personal hygiene (e.g., bathing)
- [ ] Would cook for myself
- [ ] Would obtain/maintain employment or studies
- [ ] Would have greater opportunities for socialization
- [ ] Other (please specify):

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Thank you for sharing your time
APPENDIX D: INTERVIEW GUIDE

Interview Guide:
Housing and Care Needs of People with Physical Disabilities

Name: ________________________________
Date: ________________________________
Interviewee: __________________________
Place of Interview: ____________________

Background Info:
Tell me about your experience of having a disability (the nature and cause of disability, how long, and the particulars of his/her life).

Experience of Housing
1. How would you describe your home?
   • Probe for accessibility: what makes it a “home,” how does it contribute to independence, sense of well being etc.
   • Also probe for how the home does not contribute to their well-being if it is not “appropriate”—(want to get at how housing affects quality of life)
   • Probe about their history in relation to housing—if they have had to move around, so we can understand if there is any continuum of “choice.”

2. What would your “ideal” home be like? (Is there anything missing that could make things easier, or better?)

Experience of Support Care:
1. Probe: Identify what kinds of care they receive and from whom.
2. What is your experience of support care? How has it helped you, or how has it hindered?
3. Ask them to discuss the relationship of support services with housing (ask them for their thoughts, perceptions, and experiences of care and possible relationships between the two.)
APPENDIX E:  
CORE REQUIREMENTS OF AN ADAPTABLE DWELLING UNIT

An ADAPTABLE DWELLING UNIT refers to a unit that has been designed to allow for alterations to make the dwelling consistent with the principles of barrier-free design.* (anticipated date of approval: January 2008).

CORE REQUIREMENTS:

General Application:

- 1.5 m or greater turning radius in all areas of a dwelling unit (including entries and laundry) (3.8.3.8.)
- Entry/egress doorways – 800 mm minimum width in fully opened position (3.8.3.3.(1)(a))
- Zero grade thresholds

Bathrooms:

- 1 500 mm X 900 mm accessible shower (3.8.3.13.(1)(a)) with 13 mm lip
- Backing for grab bar installation (19 mm plywood or alternate material of equal strength)
- Lavatory sink with knee space beneath (3.8.3.11.(1))
- Lavatory drainpipe shall be offset (3.8.3.11(1))

Kitchens:

- Height adjustable sink
- Height adjustable stovetop
- Height adjustable upper cabinetry
- Varied counter heights (at least 2 static) or height adjustable counters to allow for flexibility
APPENDIX F:
CERTIFICATE OF ETHICAL APPROVAL

MEMO

CONJOINT FACULTIES RESEARCH ETHICS BOARD
U/S Research Services
Main Floor, Energy Resources Research Building
3512 - 33 Street N.W., Calgary, Alberta T2N 1Y7
Telephone: (403) 220-3782
Fax: (403) 289-0693
Email: bonnie.scherrer@ucalgary.ca
Tuesday, May 8, 2007

To: Debbie A. Hurlock
Graduate Division of Educational Research/Social Work

From: Dr. Janice P. Dickin, Chair
Conjoint Faculties Research Ethics Board (CFREB)

Re: Certification of Institutional Ethics Review: Understanding the Housing and Care Needs for People with Physical Disabilities

The above named research protocol has been granted ethical approval by the Conjoint Faculties Research Ethics Board for the University of Calgary. Enclosed are the original, and one copy, of a signed Certification of Institutional Ethics Review. Please note the terms and conditions that apply to your Certification. If the research is funded, the sponsor should be notified, and the original certificate sent to them for their files. The copy is for your records. The Conjoint Faculties Research Ethics Board will retain a copy of the Certification on your file.

Please note, an annual/progress/final report must be filed with the CFREB twelve months from the date on your ethics clearance. A form for this purpose has been created, and may be found on the "Ethics" website, http://www.ucalgary.ca/research/compliance/ethics/renewal

In closing let me take this opportunity to wish you the best of luck in your research endeavor.

Sincerely,

Bonnie Scherrer
For:
Janice Dickin, Ph.D., LL.B., Faculty of Communication and Culture and Chair, Conjoint Faculties Research Ethics Board

Enclosures (2)