

Disability and Dignity-Enabling Home Environments: Key Messages from an Ontario Study

January 28, 2011



University of Toronto
Joint Centre for Bioethics

Innovative. Interdisciplinary. International.
Improving health care through bioethics.

CONTACT INFORMATION

AUTHORS

Barbara Gibson, PhD, PT (Co-Principal Investigator)
Assistant Professor, Department of Physical Therapy, Faculty of Medicine, University of Toronto

Barbara Secker, PhD (Co-Principal Investigator)
Director, Education and Practice, University of Toronto Joint Centre for Bioethics

Frank Wagner, MA, MHSc (Co-Investigator)
Bioethicist, Toronto Central CCAC and University of Toronto Joint Centre for Bioethics

Debbie Rolfe, MHSc, MSW, RSW (Research Coordinator)
Lawrence S. Bloomberg Faculty of Nursing, University of Toronto

Bob Parke, MHSc, MSW, RSW (Co-Investigator)
Bioethicist, Humber River Regional Hospital

Bhavnita Mistry, MA (Research Coordinator)
University of Toronto Joint Centre for Bioethics

FUNDING

Canadian Institute of Health Research (CIHR), Fund # FRN 87367

FOR FURTHER INFORMATION

Barbara Gibson
Department of Physical Therapy
University of Toronto
160-500 University Avenue
Toronto, ON M5G 1V7
Tel: 416-978-1819
Fax: 416-946-8562
Email: barbara.gibson@utoronto.ca

EXECUTIVE SUMMARY

INTRODUCTION

In Canada where long-term care is primarily oriented to elderly persons and affordable accessible housing is limited, younger disabled adults* may be living in circumstances that do not meet their health needs, place undue burden on family members, and contribute to their social exclusion. The fundamental human right to live in circumstances that enable independent living and social inclusion is protected by international law including the United Nations Convention on the Rights of Persons with Disabilities¹. These rights have yet to be fully realized by member states including Canada.

CONTEXT AND PURPOSE

The purpose of this research was to explore the adequacy of home environments as enabling or disabling places that may or may not promote the health, well-being and social inclusion of younger adults (age 18-54) with significant mobility disabilities living in Ontario. 'Home environment' includes the home dwelling, the organization of the neighbourhood, and the provision of attendant services.

METHODS

An integrated design was used that combined qualitative interviews with normative ethical analysis in an iterative process. Twenty key informant interviews were conducted in Toronto and Thunder Bay, Ontario. Ten of these were conducted with health and social service policy makers, program administrators and discharge planners, and ten were conducted with younger disabled adults (ages 18-55) with mobility disabilities living in a range of circumstances.

KEY FINDINGS

1. The current situation denies disabled people's dignity and human rights

The data suggest that despite provincial commitments to 'enable individuals and families to live as independently as possible in the community and lead more productive, dignified lives'², policies and practices continue to focus narrowly on the basic physical needs of disabled people. Minimal consideration is given to how home environment is implicated in broader notions of citizenship, rights, dignity and social inclusion. Although services and programs exist to assist disabled people in accessing housing, transportation, attendant care, and other support

services, the lived reality is that many services and programs are insufficient, inadequate, variable, or unavailable. The availability, frequency, type and quality of attendant care emerged as at least as important as the features of dwellings and neighbourhoods in constituting a positive home environment for disabled people. Nevertheless, individuals often have to wait years to access public housing and/or attendant care programs.

2. Dignity is enabled through access to seven necessary conditions of home environments

* We use the term 'disabled people' rather than persons with disabilities in keeping with current usage in Disability Studies. Disability is not considered a condition of individuals as is implied by the phrase with disabilities, but rather something experienced as a result of prejudice, discrimination and social exclusion.

The paper outlines a framework for assessing the adequacy of home environments using *social dignity*^{3,4} as a guiding principle. The analysis suggests seven conditions - beyond the basics of shelter and personal care - necessary for a "dignity-enabling" home environment. These ideas are represented in a *Framework for*

Assessing Dignity-Enabling home Environments on p.10. The seven conditions are (access to): meaningful relationships; community and civic life; control and flexibility; self-expression; respectful care relationships; participation in school, work and leisure; and security and safety.

DISABILITY AND DIGNITY-ENABLING HOME ENVIRONMENTS

INTRODUCTION

2010 has been a year in which great strides were made to make Canada more inclusive for disabled people. It began early in the year when a landmark Canadian Human Rights Tribunal ruling enshrined the rights of disabled voters to accessible polling stations. This was soon followed by Canada's ratification of the *United Nations Convention on the Rights of Persons with Disabilities* (the Convention)¹. The convention formally recognizes belonging or inclusion as one of our most fundamental human rights. At the provincial level, the first standard developed under the *Accessibility for Ontarians with Disabilities Act 2005 (AODA)*, customer service, comes into effect this year. Other proposed standards are being developed in the areas of transportation, information and communication, employment and the built environment, and are slated to be implemented by the year 2025⁵. With the passage of *AODA*, Ontario became the first jurisdiction in Canada to develop, implement and enforce mandatory accessibility standards.

In spite of this progress, however, Ontario continues to fall behind Japan, Sweden, Germany, Australia and parts of the United States when it comes to inclusion of disabled people⁶. In practice, this means that respecting the rights of disabled people remains a hit-and-miss affair in Ontario. In addition, the costs of this social exclusion impact significantly on the entire province because "large pools of untapped human capital" are not enabled to contribute

to Ontario's economy⁶. Nowhere is this more evident than in Ontario's healthcare and housing policies, which continue to focus narrowly on the basic physical needs of disabled individuals with minimal consideration of how home environment is implicated in broader notions of well-being and social inclusion.

The choice and availability of homes are closely aligned with the availability of attendant care services. In Ontario, there are four main attendant care options: a) Outreach Attendant Services; b) supportive housing units (SHUs); c) long-term care facilities; and d) the Direct Funding Program. In the latter program, disabled persons function as employers - hiring, training and supervising their attendants. Outreach Attendant Services are provided in private residences. It is funded through the Ministry of Health and Long Term Care and provided by a variety of community agencies. Participants using Outreach or Direct Funding have capped hours of 3 to 6 hours per day of personal care support⁷. SHUs are specialized supported housing complexes where publicly funded personal care services are continuously available. Those living in long-term care facilities or SHUs have access to 24 hours on call care, though the actual hands-on care may be three to six hours of care per day. All of these services are severely stretched and disabled people commonly wait for years to access attendant services⁸.

A critical shortage of adequate home environments affects disabled persons and their families, and also represents a major

financial issue for the health and social systems when persons who would be able to live in the community occupy costly institutional beds⁹. This places significant pressures on administrators and discharge planners who must balance the need to discharge patients quickly with the duty to find home environments that support individual health and well-being. Because long-term care is primarily oriented to elderly persons and affordable accessible housing is limited, younger disabled adults may be living in circumstances that do not meet their health needs, place undue burden on family members, isolate them from their peers, and contribute to their social exclusion. Persons with newly acquired or progressive mobility impairments may spend many months or years awaiting discharge from acute care, rehabilitation or complex continuing care facilities. For example, the Canadian Institute for Health Information recently reported that 18% of residents in Ontario hospital-based continuing care facilities were younger than 65⁹.

While deinstitutionalization has been a positive shift in the history of government responses towards disabled people, it is clear that not all community-based and 'integrated' homes are enabling. The physical layout of neighbourhoods and buildings can limit access to the community and confine disabled people to particular zones of interaction¹⁰. In Canada and elsewhere in the developed world, housing remains unavailable or inadequate with 'ghettoisation' in urban 'zones of dependence', often in unsafe neighbourhoods^{11,12}. Disabled persons may be able to access their own adapted living spaces but not that of friends, neighbours or public venues¹¹. The adequacy of home environments thus has political and ethical implications not only for physical health and psychological well-being, but also for social, occupational and civic engagement.

PURPOSE

The purpose of this paper is to summarize the key

findings of a research study that applied an ethics lens to examine the question: What constitutes "adequate" home environments for younger adults with significant mobility disabilities? The research explored home environments as enabling or disabling places that may or may not promote health, well-being and social inclusion. 'Home environment' includes all the actions and relations that constitute that space, including the organization of the neighbourhood and the provision of health and social services¹³. Based on the analysis, we describe implications for housing, health and social care policies.

METHODS

The study combined qualitative interviews with normative ethical analysis in an iterative process. Key informants included both (1) disabled adults and (2) 'decision-makers.' 'Disabled adults' were between the ages of 18 to 55 years, had a physical impairment(s) that required the use of a mobility device such as wheelchair or scooter, and required attendant care services on a regular basis at least twice a week. 'Decision-makers' were health and social service professionals, including policy makers, program administrators, home care case managers, and discharge planners. All participants were based in either Toronto (n= 15) or Thunder Bay (n= 4).

A total of 20 interviews were conducted with 19 participants between November 2008 and January 2010. Ten interviews were conducted with decision-makers and ten with disabled people. One participant was interviewed twice, to capture her views and experiences as a disabled person and as a decision-maker. Demographic details of participants are listed in Tables 1 and 2. The 10 disabled people interviewed were living in a range of circumstances including: i) private homes, either independently or with family members, ii) supportive housing units (SHU) with on-site attendant care, iii) complex continuing care facilities, or iv) a transitional living unit (a facility where individuals learn skills for living

independently). Four of the individuals living in private homes received public funds through the Ontario Direct Funding Program. All interviews were audio-taped, transcribed and analyzed for recurring themes and the identification of emerging issues using qualitative techniques of progressive coding, analytic memoing and constant comparison¹⁴.

funds often had to wait years to access public housing and/or care programs.

The data strongly bore out the importance of attendant care in constituting a positive home environment for disabled people. The availability, frequency, type and quality of personal care available emerged as at least as important as the features of dwellings and neighbourhoods.

Table 1: Participant Characteristics: Disabled Adults

Gender	Living Circumstances	Age
7 Women 3 Men	3 Supportive Housing Unit 3 Private Home with Direct Funding 1 University Residence with Direct Funding 1 Transitional Care Unit 2 Complex Continuing Care Unit	18 – 55 years Mean = 39 years

Table 2: Participant Characteristics: Decision-makers

Gender	Position	Time in Current Position
8 Women 2 Men	4 Administrators of a Healthcare Organization 2 Government Administration 1 Director of Supportive Housing Unit 2 Discharge Planners 1 Director of a Service Organization	1 – 23 years Mean = 7.35 years

FINDINGS

Unmet Attendant Care Needs

The interviews confirmed that health and social policies and services continue to focus on the basic physical needs of disabled people with little regard for other aspects of health or well-being. Available housing options provided accessible physical shelter and attendant services to assist individuals with basic activities of daily living (ADL) such as dressing, eating, and hygiene. Nevertheless, individuals without independent

Both groups of participants affirmed that the availability of care was often the central driver in determining where and how people lived, and their perceptions of the quality of their home environments. Obtaining basic attendant services presented numerous challenges. Waiting times currently range between 4 to 10 years⁸ and participants confirmed that accessing Direct Funding was virtually impossible as wait times sit around 15 years. Those accessing Direct Funding had difficulty retaining staff because they could not compete with the salaries attendants received

in institutional settings:

I've written letters to the MPPs, because we really require more attendant care hours. I'm getting sick and tired of getting an attendant and training them, and they know what they're doing, and then at the end [they] drop out, for an old folks' home. And they pay 18 bucks an hour. Well, give me 18 dollars an hour, so I can compete.

(46 year old woman receiving Direct Funding)

Necessary Conditions for a Dignity-Enabling Home Environment

Home environments were described as highly variable and often deficient in a number of related areas. Not surprisingly, participants wanted more than shelter and assistance with ADL. From the data, we identified seven additional necessary conditions for an adequate home. These included access to: meaningful relationships; community and civic life; control and flexibility; self-expression; respectful care relationships; participation in school, work and leisure; and security and safety.

Furthermore, our normative ethical analysis suggested that each of the conditions could be further understood in relation to how its presence or absence enabled or violated individual *social dignity*. Social dignity is related to how respect and worth are recognized and conveyed amongst individuals, groups and within social structures³. The normative ethical analysis is described in further detail in a forthcoming paper.

Each of the conditions is described below with representative quotations from the study participants.

1. Meaningful Relationships: The ability to form and sustain personally meaningful relationships with family, friends and pets.

Sustaining meaningful relationships included the ability to both give and receive care. Participants discussed the importance of living within proximity to loved ones, maintaining social roles as parents and spouses, a sense of community, and the importance of the ability to maintain relationships with friends when moving to a new location. Sustaining and forming relationships was dependent on flexibility and availability of attendants, institutional and care policies, the design of living spaces and arrangements of neighbourhoods including transportation options. A number of participants spoke of the importance of keeping pets and kinship bonds with another living creature. Some attendant job descriptions, however, explicitly excluded tasks associated with pets such as refilling feeding dishes.

Housing is good if you make that housing a home. And to have people around that care and that are going to help you out. Instead of just being like, nobody talks to you... it is very important to have a social group that you feel a part of. I should be able to reach out around me and make friendships.

(42 year old man living in a Complex Continuing Care Unit)

People get very, very lonely, if they're not going to work or they're not going to school or they don't have family in town. You should be able to go out with your friends and have a beer if you want. And friends maybe will take on that role, but you have to be put in a situation where you can develop those friendships, and where those friendships are supported. I don't think we're doing a really good job at that stuff. Because we're still in a minimalist mode.

(Director of Disability Service Organization)

2. Community and Civic Life: Access to community and civic life through accessible socio-material environments.

Both the physical and the socio-cultural features of the neighbourhood and community emerged as health- and dignity-promoting or damaging. The connection disabled people described with their surrounding community, such as proximity to places that fostered social engagement (accessible restaurants, parks, coffee shops) and places that facilitated the instrumental aspects of daily living (grocery shopping, banking) enhanced their living experiences. Reputation of the area as a 'good' or 'bad' neighbourhood also affected individuals' morale and sense of belonging. Proximity to friends and families was also a concern as individuals were often forced to move to neighbourhoods or cities far from their home communities in order to assess independent living options.

We've been moderately successful in creating opportunities for people with physical disabilities to live in the community. We haven't provided as good an access for people to actually actively participate in community living.

(Government Program Consultant)

3. Control and Flexibility: The ability to exert a reasonable degree of control over one's daily activities including choice, flexibility and spontaneity.

Participants discussed how day-to-day life required the scheduling of multiple tasks with attendants. This scheduled and routinized life resulted in a lack of spontaneity, flexibility and choice that might otherwise be possible. Particularly in supportive housing, but also to a lesser extent in direct funding or outreach attendant care models, participants suggested that deviating from the schedule required

significant planning and energy and could create problems which limited social participation.

I stay pretty localized within this apartment... Being in a totally institutionalized building you really feel cut off. And it takes a grand effort to overcome that. It can be done, and I'm sure people do it, but it just takes a lot of effort.

(55 year old woman living in a SHU)

4. Self-Expression: The ability to access opportunities for self-expression and identity affirmation. This includes the ability to feel a sense of ownership and belonging and make choices in the design of the home space and expression of personal styles.

The interviews powerfully suggested an institutionalized lack of recognition of the humanity of disabled people that disavows the relationships among dignity, self, and home. Disabled people in the study discussed experiences of their home environments that both supported and constrained self-development and self-expression.

The importance of having a place of one's own was a pervasive theme across the accounts regardless of whether the space was owned or rented, or was an allocated room or shared space within a facility. Decision-makers identified systemic barriers that denied these experiences of home to disabled people and rendered them psychologically homeless.

It's very important to have a home. I haven't had a home in a long time, so it's very hard for me to remember anything about having a home.

(42 year old man in Complex Continuing Care)

I was so depressed the first month I moved in here. I felt ugly and gross and they were taking away everything I worked so hard to achieve, like the way I wanted to look, and how I wanted to be.

(21 year old woman in SHU)

They said: 'Don't tell them this is their home anymore. You have to give them this message. This is the hospital, this is not their home.'

(Social Worker in Complex Continuing Care Unit)

5. Respectful Care Relationships: Access to opportunities to receive care within respectful relationships with attendants.

The data strongly bore out the importance of relationships with attendants in constituting a liveable home environment for disabled people. Participants spoke about negative attitudes of some attendants and the effects on their mental health and well-being. They shared stories of humiliation, helplessness, depression and the desire to 'escape' from particular attendants. These stories highlighted some of the complexities of the power relationships between attendants and disabled people, and reflected the commodification of care that is inherent in the attendant care relationship¹⁵. Disabled individuals had to qualify for care, purchase care, and risk that carers could go on strike which placed them at constant risk for losing their independence and security. Both the caregiver and care receiver risked objectification in the relationship – the attendant seen as proxy 'arms and legs' and the disabled person as the object of labour¹⁶.

Sometimes when a whole bunch of problems pile up that's when my self-esteem goes down, and that's when I get a little depressed as well. Sometimes I report (the attendants) but it depends on the manager, because I feel like what's the point of reporting them if nothing will get done?

(27 year old woman in an SHU)

Because if I had just been on my own in an accessible apartment, I wouldn't have been able to survive. I had to have the services to go with it...I never thought we'd live in a house because the services were always attached to apartments, and you have to live in the apartment building to get the service.

(50 year old woman receiving Direct Funding)

6. Participation in School, Work and Leisure: Access to opportunities to participate in school, work and leisure.

Community participation included the ability of the home environment to support participation in work, recreation or school. Programs and services that assisted individuals to access work and school were praised. The timely availability of transport was a key barrier, as was access to attendant care outside of the home.

If you're relying on attendant services, and you know, you can't get the help you need when you need it, you can't get to work when you need it, and you can't do the things you need to do when you need them. And if you're not regenerating at home, you don't have as much to give to work or leisure or other things that drain your energy level.

(Senior Manager, Rehabilitation and Complex Continuing Care Facility)

Teachers were getting their foot in the door by doing supply teaching. And transportation was very difficult; you had to give five days advance request for a ride. So I knew that a school board couldn't call me up and say, 'Could you fill in for Ms. M. today because she's sick?'

(50 year old woman receiving Direct Funding)

7. Security and Safety: Access to security and safety including physical safety, psychological security and a sense of personal continuity.

Security and safety were amongst the most frequently discussed issues raised in response to questions about the essential elements of the home environment. Safety concerns related to the competency of attendant care providers, the location of homes in neighbourhoods perceived to be unsafe, and the risks associated with not being able to obtain assistance during emergencies. Safety was identified by decision-makers as a minimum threshold consideration for an adequate home environment. Professionals working in health care organizations particularly expressed a duty to ensure an individual's safety above all other considerations. None of the disabled people in the study, however, suggested that they would prefer institutionalization to living in the community. Institutionalization in a long-term care facility was frequently cited as a worse-case scenario both by those who had lived in these environments and by others who feared the possibility. Instead, SHUs with on-site 24 hour attendant care services were often described as having a good balance of safety and individual freedom, provided that the individual trusted the competency of the staff. Safety was of high

importance to the disabled people we interviewed, but was not necessarily their first priority. They suggested that safety concerns needed to be balanced with other concerns including freedom, choice and control over daily activities.

When they started taking me on tours of old age homes I was thinking, 'No friggin way am I going to do this,'

(50 year old woman receiving Direct Funding)

It has to be safe, there's a certain minimum safety and security that has to go with that, but not so much so that you're dominated by that, or controlled by that, or restricted by that.

(54 year old woman receiving Direct Funding)

KEY MESSAGES

1. The current situation denies disabled people's dignity and human rights

Home-related policies and practices that systematically deny disabled people opportunities to participate in social and civic life, pursue familial roles, maintain friendships or pursue work and leisure violate the collective dignity of disabled people and deny them their fundamental human rights. These rights are enshrined in international law including the United Nations Convention on the Rights of Persons with Disabilities which was recently ratified by Canada. Signatories are required to ensure that disabled people 'have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement', and have access to 'community

support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community'¹ (Article 19). Similarly the Ontario's Human Rights Code¹⁷ recognizes the universal right to equal treatment for all persons and identifies the prevention and remedy of discrimination as one of its purposes. Dignity is the central principle framing both the Ontario Human rights Code and the Convention and provides a lens to assess the adequacy of home environments that can be specified to a set of necessary conditions.

The study results demonstrate the many ways that provisions to uphold these rights have not been fully realized in Ontario. Disabled people continue to experience severely limited choices or no choice of living arrangement. They may be forced to move to receive care, be "placed" somewhere that contributes to their isolation, or may even feel that they have no home. Personal assistance may be meeting basic physical needs, but combined with other barriers in the social and built environment, most often falls short of supporting social inclusion or preventing isolation.

While community integration programs and policies of the last few decades have done much to decrease the isolation of disabled people, much more needs to be accomplished. Moving people out of institutions does not in and of itself address exclusion from community and civic life and the demoralizing effects of being 'filed for dead' as one participant called it. Enabling the dignity of individuals and securing their human rights requires providing opportunities to engage in meaningful relationships, activities and occupations outside of the four walls of a dwelling. Persons cannot be considered integrated in their communities when the opportunities to engage in community life are severely limited or require extensive efforts to overcome.

2. Dignity is enabled through access to seven necessary conditions of home environments

Our analysis suggests seven conditions - beyond the basics of shelter and personal care - necessary for a "dignity-enabling" home environment. These ideas are represented in Figure 1 in the form of a values framework wherein social dignity is the test of adequacy, and the seven conditions describe the elements that enable social dignity.

By identifying a provisional list of threshold conditions we are not suggesting that each is relevant to every disabled person. For example some individuals will not be interested in participating in school or work. Nevertheless the data strongly bore out that home environments should provide equality of opportunities on par with the standards afforded to non-disabled people. Care, housing and planning policies thus need to recognize the rights of disabled people to, for example, participate in social life and maintain security of person as per other citizens. Furthermore, fulfillment of one of the conditions should not require sacrifice of another. For example, access to a safe and secure environment should not require sacrificing the ability to sustain meaningful relationships.

Importantly, the conditions are meant to reflect a provisional minimum set of necessary criteria for an adequate home environment. These criteria are provisional because the study sample was not extensive and was limited to two Ontario communities. Further exploration and research could no doubt provide further insight into how the elements apply in different contexts or what additional elements may be warranted. However, nothing on the list is meant to be considered 'nice to have' but, rather, all are necessary conditions for an adequate home environment, required of a just society that affirms the dignity and human rights of its citizens. Canada's ratification of the Convention is consistent with this imperative. Societal recognition of the rights of disabled people is reflected - or not - in housing and care policies and procedures which send clear messages about the value of disabled persons, assumptions about what they can or should be

doing, and what kind of home disabled persons need/should have. Both the policies regarding the space and the circumscribed work/interactions in the space have potential to enable dignity.

CONCLUSIONS

The task of this research was to provide an analysis of what constitute an 'adequate' home environment for adults with significant mobility disabilities. It began with the assumption that safety, an accessible space, and the provision of basic ADL care were the only minimums currently operating. These assumptions were confirmed by participants' who acknowledged that while

conditions had improved, there were still a number of changes needed to address the social marginalization of disabled people. We have outlined seven conditions that could begin to form the basis of a guideline for policies and practices to secure the human rights of disabled people. These conditions are knit together by a principle of dignity whereby adequate home environments enable the social dignity of persons through promotion of the conditions. The conditions emerged from analysis of data grounded in the experiences of people located in a particular time and place and thus are open to revision, expansion and further specification in other contexts.

FIGURE 1: FRAMEWORK FOR ASSESSING DIGNITY-ENABLING HOME ENVIRONMENTS

Adequate Home Environment = Dignity-Enabling Realized Through Seven Conditions:	
1. Meaningful Relationships	<p>Access to personally meaningful relationships with family, friends and pets</p>
2. Community and Civic Life	<p>Access to community and civic life through accessible social and material environments</p>
3. Control and Flexibility	<p>Access to a reasonable degree of control over one's daily activities including choice, flexibility and spontaneity</p>
4. Self-Expression	<p>Access to opportunities for self-expression and identity affirmation, including choices in the design and adornment of one's home space and body</p>
5. Respectful Care Relationships	<p>Access to opportunities to receive care within respectful relationships with attendants</p>
6. Participation in School, Work and Leisure	<p>Access to opportunities to participate in school, work and leisure activities</p>
7. Security and Safety	<p>Access to security and safety, including physical safety and psychological security</p>

REFERENCES

1. United Nations. Convention on the Rights of Persons with Disabilities. New York: United Nations; Resolution A/61/106 of 6 December 6 2006.
2. Government of Ontario, Ministry of Community and Social Services. Ontario disability support program - income support directive preamble. www.mcscs.gov.on.ca/en/mcscs/programs/social/directives/directives/ODSPDirectives/income_support/0_1_ODSP_ISDirectives_preamble.aspx. Accessed November/2010.
3. Jacobson N. A taxonomy of dignity: A grounded theory study. *BMC International Health and Human Rights*. 2009;9(3):1-33.
4. Jacobson N. Dignity and health: A review. *Social Science & Medicine*. 2007:292-302.
5. Ministry of Community and Social Services. Ontario's accessibility laws and standards. <http://www.mcscs.gov.on.ca/en/mcscs/programs/accessibility/OntarioAccessibilityLaws/index.aspx>. Accessed November 2010.
6. Kemper A, Stolarick K, Milway J, Treviranus J. Releasing constraints: Projecting the economic impact of increased accessibility in ontario. Toronto, Canada: Martin Prosperity Institute; 2010: http://martinprosperity.org/media/ReleasingConstraints_June22.pdf.
7. Centre for Independent Living in Toronto (CILT). Attendant services overview. <http://www.cilt.ca/overview.aspx>. Accessed November 2010.
8. Attendant Services Advisory Committee, Ontario Community Support Association. Unleashing attendant services: Enhancing people's potential, reducing wait times in acute and long-term health care. Toronto, OCSA; July 2008.
9. Canadian Institute for Health Information. Facility-based continuing care in Canada, 2004.2005: An emerging portrait of the continuum. Ottawa: CIHI; 2006.
10. Imrie R. Disability, embodiment and the meaning of home. *Housing Studies*. 2004;19(5):745-763.
11. Gleeson B. *Geographies of Disability*. London: Routledge; 1999.
12. Dear MJ, Wolch JR. *Landscapes of Despair: From Deinstitutionalization to Homelessness*. Princeton: Princeton University Press; 1987.
13. Moss P. Negotiating spaces in home environments: Older women living with arthritis. *Social Science and Medicine*. 1997;45(1):22-33.
14. Miles MB, Huberman AB. *Qualitative Data Analysis: An Expanded Sourcebook*. Vol 2nd. Thousand Oaks: Sage Publications; 1994.
15. Davies K. The tensions between process time and clock time in care-work: The example of day nurseries. *Time & Society*. 1994;3(3):277-303.
16. Gibson BE, Brooks D, DeMatteo D, King A. Consumer-directed personal assistance and 'care': Perspectives of workers and ventilator users. *Disability & Society*. 2009;24(3):317-330.
17. Human rights code, R.S.O. 1990, c. H.19 .