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Title: Disability and Dignity-Enabling Home Environments

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Abstract

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 and contribute to their social exclusion. The purpose of this study was to undertake an ethical analysis of what constitute an 'adequate' home environment for adults with significant mobility disabilities. An integrated design was used that combined qualitative interviews with normative ethical analysis in an iterative process. Twenty interviews with 19 participants were conducted in Ontario, Canada with two groups: younger adults (ages 18 to 55) with mobility disabilities and 'decision-makers' who consisted of policy makers, program administrators and discharge planners. Data were analyzed using a critical disability ethics approach and processes of reflective equilibrium. Drawing on Nora Jacobson's [REF NEEDED] taxonomy of dignity and pluralistic approaches to social justice, the concept of 'social dignity' provides a lens for exploring the adequacy of home environments for disabled people. Analyses suggested seven threshold conditions necessary for a dignity-enabling home: the ability to form and sustain meaningful relationships; access to community and civic life; access to control and flexibility of daily activities; access to opportunities for self-expression and identity affirmation; access to respectful relationships with attendants; access to opportunities to participate in school, work or leisure; access to physical, psychological and ontological security. The results have implications for housing, health and social care policies, and

political reform. Social-dignity provides a normative ethical grounding for assessing the adequacy of home environments. The threshold elements outline specific dignity-enabling conditions that are open to further specification or elaboration in different contexts.

[Jacobson REF needed here]

Home is the place where I have choice, control, dignity, privacy, where I can socialize, entertain, people can come in. There's a certain sense of pride to it...and you have some flexibility about when you get up, when you're going to go to bed, what you're going to wear, how you're going to wear your hair, what you're going to eat. To me that's pretty simple.

Study Participant

In Canada where long-term care is primarily oriented to elderly persons and affordable accessible housing is limited, many younger disabled adults are living in circumstances that do not meet their health needs, place undue burden on family members, isolate them from peers and contribute to their social exclusion (Dyck et al., 2005; Hammell, 2004; Multiple Sclerosis Society of Canada, 2006; Secker et al., 2006). A critical shortage of accessible home environments 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 beds. 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 (Canadian Institute for Health Information, 2006). This is an ethical issue when policies and practices are unjustly perpetuating the exclusion of a particular group from meaningful social and civic engagement.

Questions regarding decent minimums in living arrangements for disabled people have normative ethical dimensions that have been under-researched. Deinstitutionalization

represents an important philosophical shift in state practices, but not all community-based homes are enabling. The physical layout of neighbourhoods and buildings can limit access to the community and confine disabled people to particular zones of interaction (Imrie, 2004). In Canada and elsewhere in the developed world, housing remains unavailable or inadequate with 'ghettoisation' in urban 'zones of dependence', often in unsafe neighbourhoods (Dear & Wolch, 1987; Gleeson, 1999). Disabled persons may be able to access their own adapted living spaces but not those of friends, neighbours or public venues (Gleeson, 1999). The constitution of the home environment thus has implications not only for physical health and psychological well-being, but also for engagement in work, social, and civic life.

The focus of this research was to explore the adequacy of home environments as enabling or disabling places that may or may not promote health, well-being and social inclusion. The home as a site of material and symbolic relations has been an increasing focus in the humanities and social sciences. Cultural geographers in particular have explored the 'geographies of home' (Blunt & Varley, 2004) and the varied ways that home mediates self-identities, inclusion and exclusion (Blunt & Varley, 2004; Blunt, 2005; Mallet 2004; Blunt & Dowling, 2006). Following Moss (1997), the term 'home environment' is used in this paper to conceptualize homes as complex sites of interaction that are more than particular physical dwellings. Home as a relational space is constituted through the mutually reinforcing and reciprocal relationship between people and place (Cummins et al., 2007). Home environments are thus not merely locales where interactions occur but places imbued with meanings and taken-for-granted rules that mediate interactions

(Casey, 2001; Cummins et al., 2007; Freund, 2001; Kelly, 2003; Kitchin, 1998). Home environments include all the actions and relations that constitute that space, including the organization of the neighbourhood and the provision of health and social services. While homes are often thought of as personal havens - revealed in phrases like 'home is where the heart is' - these characterizations have been widely critiqued as idealized notions of the home unrepresentative of the realities of many people's lives (Mallett, 2004; Wise, 2000). Home environments (whether residential or institutional) are thus potentially positive and enabling but are also possible sites of isolation or fear that could have significant effects on health and well-being and the ability to participate in social life (Dupuis & Thorns, 1998; Mallett, 2004; Blunt, 2005).

Critical Disability Ethics

Critical disability ethics is an emerging field at the intersection of disability studies and bioethics which asserts that policies and practices responsible for systematically excluding disabled people from participating in social life are morally wrong and must be addressed on multiple fronts (Kuczewski, 2001). Only recently has the field of bioethics begun to examine the ethical issues that affect disabled people in their daily lives (Waymack, 2001; Wendell, 2001). Drawing on social justice scholarship, our approach considers social exclusion and the systematic harms experienced by disabled people as more than problems of distributive justice and the rationing of scarce resources. Rather it highlights the complex multidimensional nature of disablement and calls for understandings of social justice that serve to integrate disabled people into the activities and relationships that make up the 'cultural, practical, and institutionalized conditions for

exercising capacities in a context of recognition and interaction' (Young, 1990, p.55).

Critical disability ethics thus aligns with particular feminist and pluralistic approaches to social justice that focus on affirmative material and institutional support in redressing the subordination of marginalized persons and on the elimination of harmful or exclusionary norms, practices and structures (Nussbaum, 2006; Sherwin, 1992; Sherwin, 1996; Young, 1990).

The aim of the study was to undertake an ethical analysis of what constitutes an 'adequate' home environment for younger adults (18-55 years) with significant mobility disabilities. Uniting empirical research methodologies with moral philosophical reflection grounded our ethical deliberations in the contextual realities of disabled people's lives (Sherwin, 1996). As described below, what emerged was a provisional framework that uses *social dignity* (Jacobson, 2007) as a test of the adequacy of home environments and maps out seven key conditions of home environment that are dignity-enabling. As we outline below, social dignity is a contingent form of dignity in that is related to how respect and worth are recognized and conveyed through prevailing social conditions and interactions.

Research Context

The study was conducted in Ontario, Canada where there are five main attendant care options, each associated with different living arrangements: 1) Outreach Attendant Services are publicly funded services provided in private residences and delivered by community agencies. 2) The Direct Funding Program is a publicly funded program, through which disabled people apply for funds to hire, train and supervise their own

attendants. Participants using Outreach or Direct Funding have capped hours of three to six hours per day of attendant care (CILT, 2010). 3) Supportive housing units (SHUs) provide attendant care services through non-profit organizations that are typically housed in a larger apartment building with accessible serviced units scattered throughout. The person receiving services rents accommodation from a building landlord (usually a non-profit housing corporation). Rents are geared-to-income (Social Housing Reform Act S.O. 2000). Direct funding and SHUs are severely stretched and waiting times can be several years (Ontario Community Support Association, 2008). 4) Public or private long term care homes - which are often considered the 'last resort' for disabled younger adults - provide 24-hour professional health care for residents. Finally, 5) Complex Continuing Care units provide similar 24-hour care in a hospital setting and are not considered long term residences. Nevertheless, people often live in these units for many years because of a lack of alternatives.

Methods

Ethics approval was received from the University of Toronto and participating Ontario health care organizations. The study utilized an integrated design that included qualitative interviews and normative ethical analysis (see 'Analysis' below) in an iterative process (Haimes, 2002; Sherwin, 1996). A purposeful sampling strategy (Miles & Huberman, 1994a) was used to identify key informants who would most likely be able to inform the analysis because of their immersion in the field.

All participants resided in one of two communities - one a large city and the other a regional/small urban centre. They were identified and approached through five community and health care organizations. Interviews were conducted with two groups, disabled adults and decision-makers. 'Decision-makers' were health and social service professionals including policy makers, program administrators, home care case managers, and discharge planners. 'Disabled people' were between the ages of 18 to 55 years, used a wheelchair for mobility, and required regular attendant care services at least twice a week. Six had congenital conditions (e.g., cerebral palsy, muscular dystrophy) and the remaining four had acquired conditions (e.g., spinal cord injury, multiple sclerosis). They were living in a range of circumstances including private homes with Direct Funding (3), SHUs (3), complex continuing care facilities (2), a university residence with direct funding (1) and a transitional living unit (1) - a temporary facility where individuals learn skills for living independently. Aggregate demographic details of participants are listed in Tables One and Two.

(Tables one and two ~ here.)

A total of 20 interviews with 19 participants were conducted between November 2008 and January 2010. The average length of the interviews was 80 minutes. Ten interviews were conducted with decision-makers and 10 with disabled people. One participant was interviewed twice, to capture her views and experiences as a disabled person and as a decision-maker.

Analysis: All interviews were audio-taped, transcribed and analyzed for the identification of emerging issues using qualitative techniques of progressive coding, analytic memoing and constant comparison (Birks et al., 2008; Miles & Huberman, 1994b). Data collection and analysis proceeded simultaneously to allow for new information to be investigated in approaching subsequent interviews. Transcripts were imported into the NVivo 8.0 software program to aid the analysis. To enhance rigour (Kvale, 1996), three team members participated in the coding and detailed memoing procedures. Summaries were shared with the larger team who read all transcripts and contributed to monthly analysis meetings. Emerging themes informed the ethical analysis suggesting new issues for investigation and helping to identify conceptual relationships. All team members had graduate training in bioethics and included individuals from a variety of disciplines that spanned philosophy, geography, rehabilitation science, social work, health administration and clinical ethics.

The normative ethical analysis was grounded in the assumption that, to be just, a conceptualization of 'adequacy' must address physical, mental, and social well-being (WHO, 1948). This point of departure was refined, clarified and contextualized through the qualitative interviews and analysis using a process of reflective equilibrium (Daniels, 1996; Rawls, 1971; Sherwin, 1996). Reflective equilibrium is an established analytic method in bioethics that involves identifying a set of considered moral judgements reached in a similar case or a group of cases, formulating values and principles that account for them, testing the values on similar cases with contextual differences, and then

revising the values and theories until achieving coherence. In keeping with Sherwin's work on feminist reflective equilibrium (Sherwin, 1996), our deliberations were based on the practical concerns and real life experiences of individuals rather than on hypothetical cases. In keeping with this method, the team concurrently engaged with diverse conceptual readings in bioethics, political theory, disability studies and geography. In this way, the analysis involved proceeding 'up' from data to transdisciplinary theories and principles, as well as 'down' from theories and principles to data, in an iterative process. While theoretically robust, because the study was grounded in data gathered from a specific Canadian region, generalizability to other settings should be interpreted with caution.

Findings

Overview

The accounts confirmed that attendant care and housing policies and services primarily focused on the basic physical needs of disabled people with far less 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 means often had to wait years to access public housing and/or care programs. Access to basic attendant care services was a primary driver in housing and discharge decisions for both groups of participants, and severely circumscribed people's housing options.

Beyond meeting these rudimentary needs, 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. Consistent with the idea of home as a relational space, these conditions are not discrete but overlap in relation to an individual's contextual circumstances. They included access to: self-expression; safety and security; meaningful relationships; community and civic life; participation in school, work and leisure; respectful care relationships; and control, flexibility and spontaneity. 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*.

In what follows, we first introduce the notion of social dignity and then present the details of the conditions and how they are supported in the data. In the representative quotations, all names are pseudonyms followed by (DM) for decision makers or (DP) for disabled people.

Dignity as a Test of Adequacy

Our iterative analyses suggested that social dignity provides an organizing concept for understanding the adequacy of home environments. Dignity is a much overused and sometimes poorly delineated concept in healthcare and bioethics (Jacobson, 2007; Macklin, 2003; Riley, 2008). In order to make dignity a useful concept for explicating the study data and, more broadly, to provide a conceptual basis for evaluating the adequacy

of home environments, we relied on Nora Jacobson's (Jacobson, 2007; Jacobson, 2009) delineation of two main forms of dignity: human dignity and social dignity. In Jacobson's taxonomy, *human dignity* is described as the abstract, universal quality of value that belongs to every human being simply by virtue of being human. Related but distinct is *social dignity* which is generated in the interactions between and amongst individuals and groups. There are two types of social dignity, Dignity-of-Self, which is roughly akin to self-worth, and Dignity-in-Relation, which refers to the ways in which respect and worth are conveyed through individual and collective behaviour. Social dignity is thus related to how respect and worth are recognized and conveyed amongst individuals, groups and within social structures. Social dignity is contingent in that it can be violated or promoted at micro, meso and macro levels of interaction. Within this context, home environments are fluid sites of socio-material, political and interpersonal interactions that can enable or violate the dignity of individuals.

Conditions for an Adequate Home Environment: Participant Accounts

1. Meaning, Self and Self Expression

It has been well established in housing research that home is one of the fundamental places that gives shape and meaning to people's everyday lives (Dupuis & Thorns, 1998; Imrie, 2004; Mallett, 2004; Padgett, 2007). Notions of the home environment as a site of self-expression and personal meaning were reflected in participants' accounts. Decision-makers recognised the meaning and importance of home in their own lives and identified systemic barriers that denied these experiences of home to disabled

people. Disabled people told multiple stories of the meaning of home and the negative consequences of being denied their home-related needs.

A decision-maker working in a complex continuing care (CCC) facility related a story of how staff were instructed by management to discourage longer term patients from thinking of the facility as their home. Disabled people, however, may be living for years in these facilities if their health and personal care needs cannot be met in the community:

Mac(DM): 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.'

These comments resonated with the perspectives of Harry, a man in his 40's who had been living in a CCC facility for five years:

Harry(DP): 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.

Both comments suggest an institutionalized lack of recognition of the humanity of disabled people that disavows the relationships among dignity, self, and home. Persons living in these circumstances are effectively rendered homeless when they cannot make any claims to the spaces they occupy. The lack of recognition can have consequences for dignity-of-self, impeding self-expression and the formation of positive identities (Fraser 1995; Fisher, 2008; Fraser & Honneth, 2003).

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. Kate, a 21 year old who had recently moved out of her parents' home, put it this way:

Kate(DP): I guess I really like my own space. Like, I like having something. This is my home. I come home to, you know, here. And I like it.

Participants also relayed stories of home environments where they did not experience the same sense of ownership, belonging or self-expression. There were frequent references to constraints on decorating rooms and '*giving it my own style*' (Beth DP). In the following passage, Kate described how she experienced a loss of self when her attendants would not assist her to style her hair in a manner that she closely associated with her personal identity:

Kate(DP): Some people are picky about how their food is made, and how their bathroom stuff goes. And mine was my hair. Because to me, that's what makes me, me. ...And I was miserable. 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.

These passages demonstrate some of the myriad ways that dignity, worth and respect are conveyed in home environments. Dignity-of-self, the dignity that individuals attach to themselves (Jacobson, 2007), is threatened or diminished in settings where

individuals are denied the opportunities for self-expression and agency. Home environment is integral to the production of disablement both through the prevailing social and political relations and through the mundane everyday experiences of inclusion or exclusion (Gibson et al., 2007).

2. Safety and security

Safety and security were frequently raised in response to questions about the essential elements of the home environment. Safety concerns related to the competency of attendant care providers ('you're getting somebody out of the blue that hasn't worked with you. I wouldn't feel safe in that situation', Carol(DP)), the location of homes in neighbourhoods perceived to be unsafe ('high rise buildings that are filled with drug dealers and unsafe environments', Sayan(DM)), and the risks associated with not being able to obtain assistance during emergencies ('if I wasn't able to get to a phone I could just call out for help really loudly', Beth(DP)). Safety was identified by some decision-makers as a minimum threshold consideration for an adequate home environment:

Rhonda(DM): Some people like the idea of institutionalization because they feel safe. And I think safety and risk are the drivers to some degree.

In contrast to this comment, none of the disabled people in the study suggested that they would prefer institutionalization to living in the community. Rather, 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. ('When they

started taking me on tours of old age homes I was thinking, ‘No friggin way am I going to do this,’ Carol(DP)). Instead, living at home with sufficient support or in an SHU were described as having a good balance of safety and individual freedom - provided that the individual trusted the competency of the staff. Participants also suggested, however, that having ‘15 or 20 different people providing your care’ (Carol(DP)), as is often the case in SHUs, can be challenging and jeopardizes comfort and safety. Anne, who was in her 50s and living with a newly acquired disability, had recently moved into a SHU:

Anne(DP): (It is) really unsettling for some place that’s supposed to be your apartment, and you’re not able to know who’s going to be walking in the door to take care of you.

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. Lynn, a woman in her 50s, lived in a private home with direct funding but had spent many years living in SHUs and institutions:

Lynn(DP): 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. You should have some choice or control.

3. Ability to Sustain Meaningful Relationships

Sustaining meaningful relationships includes the ability to both give and receive love, care and support. Participants discussed the importance of living within proximity to

loved ones, maintaining social roles as parents and spouses, acting as a host, having a sense of community, and maintaining relationships with friends when moving to a new location. 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. Participants also described barriers to parenting and narrow policies that assumed disabled people did not have families. Carol lived in a private home, but for many years she and her husband had lived in SHUs while raising their children. Although (with government intervention) she eventually found an SHU to accommodate her needs, at the time she became pregnant the SHU where she was living refused to provide nurturing assistance:

Carol(DP): You were expected to be living by yourself and to be single...I negotiated with the government, I said, 'It's not babysitting, I'm going to be directing. It's more like nurturing assistance.' He said, 'We think that this can be done within what attendant services are all about. We can just negotiate for some extra hours for you.' So I went to (SHU) and asked, 'Would you be willing to do this?' And they wouldn't do it.

The ability to maintain or form new friendships was also described as severely circumscribed by the arrangement of homes and communities. For example, young people wanting to move out on their own for the first time could find that the only SHU available was on the other side of the city. Without the ability to drive and with limited transit options, friendships and family relationships were increasingly difficult to maintain. The following two passages from Kate (transitional living unit) and Harry (complex continuing care unit) reflect these challenges:

Kate(DP): I made a sacrifice by coming here. Because I see less of my friends because I'm here now and it's hard for them to take the car and convince their parents to let them drive over here.

Harry(DP): 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, like, nobody talks to you... it is very important to have a social group that you feel a part of, instead of just being an individual in an individual apartment. I should be able to reach out around me and make friendships.

Decision-makers recognized the importance of the ability to maintain and form social relationships and that the available options for disabled people were inadequate:

Cheryl(DM): 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.

In her reference to a 'minimalist mode', Cheryl, who had many years of experience working in a community based disability organization, suggested that only the most basic needs of disabled people were being addressed.

The potential for social isolation described in the accounts suggests a violation of the social dignity of disabled people both on an individual and group level. Isolation and marginalization not only affects an individual's sense of self-worth, but disabled people as a group may be systematically denied their collective dignity when they are treated only according to their physical needs in a 'minimalist mode'. Conceived of in terms of

their personal care needs only, disabled people are denied the opportunity to give and receive love, and to contribute to the lives of others as parents, friends, children, relatives, social supports and care providers.

4. Access to community and civic life

Closely paralleling the issues related to sustaining relationships were broader issues of citizenship and the ability to participate in community and civic life. Both the physical and the socio-cultural features of the neighbourhood and community emerged as 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 neighbourhood as a 'good' or 'bad' also affected individuals' morale and sense of belonging:

Kate(DP): The apartments are beautiful. I'm so upset that they were so nice and they ended up being in such a crap location. It's just horrible...because you can't go anywhere. It literally traps people in.

Participants described the tradeoffs they faced when choosing between different home options and locations. Private homes usually allowed more choice and flexibility, and permitted young or newly disabled people to stay in their existing homes with loved ones. Living 'at home', however, could have a number of disadvantages. Suburban neighbourhoods organized for automobile use with long distances to shopping and

service areas were seen as less accessible and participants described how neighbours' homes were not wheelchair accessible decreasing their 'visitability':

Carol(DP): I wouldn't be able to get into any of my neighbours' houses, like there's no visitability there, so they have to come and visit me.

Dawn, a woman in her 20s who was living on her own for the first time in supportive housing, discussed the advantages of moving out of her parents' home in the suburbs:

Dawn(DP): In the suburbs, I rely on my mother for drives even to the bus station. In the city I have a lot more freedom to do what I want when I want. I think it's really a better place for someone with a disability to live ...I can pretty much get anywhere I want easily.

Two decision-makers, both of whom had long term experience in disability policy, discussed the limited success of programs and policies aimed at deinstitutionalization and integrating disabled people into the community. They suggested that people living in private homes or SHUs may experience a similar degree of social isolation compared with living in an institution. In other words, some of the objections to institutionalization have not necessarily been resolved through community living. Participants discussed that living outside of an institution did not in and of itself afford people opportunities to leave their homes, interact in their communities, or participate in social and civic life. One participant, Cheryl, called this 'filing for dead type of integration' suggesting that disabled people are placed in a home situation ('filed') and then forgotten about (as if 'dead') with little support for their ongoing welfare. Jeffrey said the following:

Jeffrey(DM): 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.

5. Participation in school, work or leisure

Access to community life included the ability of the home environment to support participation in work, recreation, or school when desired. The timely availability of transport was a key issue, as was access to attendant care outside of the home. A community-based decision-maker spoke broadly about the relationship between home environment and participation:

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

Programs and services that assisted individuals to access work and school were praised. In the following passage, Dawn discussed the advantages of a program that provided her with housing and attendant care while attending university:

Dawn(DP): You live here and they have on-site attendant care, and it's just basically about testing what independence would feel like if you weren't living with your parents. How would you do cooking, how would you do laundry, whatever you think you need to work on, you can work on here with a staff that's willing to support you.

In contrast, Carol spoke about how transportation barriers impeded her ability to compete for work:

Carol(DP): 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?'

Participants living in colder climates also discussed the impact of weather on the ability of people to get out of their homes in the winter:

Abdul(DM): The transportation is available but some mornings here it's minus 28 and lots of snow. Snow is a huge issue in a wheelchair, and snow removal. You see a lot of people out in their scooters and wheelchairs in the summertime, but you don't tend to see too much in the winter.

These comments suggest that, 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 life and the demoralizing effects of being 'filed for dead'. Enabling the dignity of individuals requires the opportunity 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.

6. Respectful care relationships

The data strongly bore out the importance of relationships with attendants in constituting a liveable home environment. While all participants spoke about the importance of attendant care services, disabled people spoke less about resource issues than decision makers, and more about interpersonal relationships with attendants, the need for consistency in staffing, and the need for services beyond basic ADL.

Participants spoke about negative attitudes of some attendants and how this affected their mental health and wellbeing. 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, particularly in SHUs. Both Anne and Beth had recently moved into their first SHU. Anne moved because of progression of her acquired condition. Beth, a young woman in her 20s with a congenital condition, had moved out of her parents’ home for the first time:

Anne(DP): It’s a very, very powerful position that an attendant has...They’re the ones that are in this strong position of power because you depend on them. And they kind of abuse that position.

Beth(DP): 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?

These comments reflect how the commodification of care, inherent in the attendant care relationship (Davies, 1994), is experienced by care recipients. Disabled individuals have

to qualify for care, purchase care, and risk that carers could go on strike, which places them at constant risk for losing their independence and security. Interactions risk losing the human sense of ‘caring about and for’ and may be easily reduced to a set of services and work products (Gibson et al., 2009; Thomas, 1993). Both disabled people and their attendants can experience violations to their dignity in these situations. In the accounts, decision-makers more often acknowledged the mutual vulnerability of the attendants and disabled persons:

Jeffrey(DM): You’ve got one vulnerable group which is a very low paid staff group,...largely could be people that lack training, maybe immigrants, whatever, they’re not making a lot of money. Then you’ve got another disempowered group which is people with physical disabilities that largely may not be employed, and they’re being told, ‘You have to direct your own care.’

7. Control, Flexibility and Spontaneity

The lack of control and choice in daily life was another pervasive theme in the accounts. 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 control that might otherwise be possible. Particularly in SHUs, 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 that limited social participation:

Beth(DP): I would say in terms of attendants, first of all, what’s needed is flexibility, with the understanding that we like to go out, and that we are like other people.

Jeffrey(DM): If the organization makes it feel like it's extraordinarily difficult for me (as a disabled person) to not come home at the time I said I was going to come home at, or the leaving time is different, or have friends over and reschedule a booking so that I'm not disturbing the middle of the social activity because the attendant's coming in. Those are the things probably that conspire against, or support somebody.

Discussion: Dignity-Enabling Home Environments

This research began with the question, 'What constitutes an adequate home environment for younger adults with mobility disabilities?' Our analysis suggests a provisional answer: 'An adequate home environment is one that enables and promotes social dignity by providing access to seven essential conditions'. These ideas are schematically represented in Figure 1. Our analysis is consistent with pluralistic approaches to social justice that insist on the importance of *capabilities*, that is, what people are actually able 'to do and to be' as central requirements of a life with dignity (Nussbaum, 2001; Nussbaum, 2006; Nussbaum & Sen, 1993; Sen, 1993).

Nussbaum's 'capabilities approach' sets out the threshold capabilities she argues are central to the requirement of a life of dignity. Amongst others, these include the ability to have good health, freedom of movement, to form attachments, to be treated as a 'dignified being', and to exercise control over one's environments (Nussbaum 2006, p 76-78). Nussbaum argues that the capabilities provide precision to the language of human rights and make clear the positive obligations of societies to provide supports beyond non-interference. She has articulated the application to justice for disabled people in terms of how prevailing conditions enable their capabilities (Nussbaum, 2006; pp 96-223). *Contra* approaches that focus on economic productivity, she suggests that all persons have a claim to support in the 'dignity of human need itself' (Nussbaum, 2006,

p.160). The need for care, she suggests, is one aspect of dignity rather than something to be contrasted with it, and does not preclude access to the prerequisites of a good human life.

Consistent with a capabilities approach, the conditions we outline for an adequate home both help to flesh out the concept of social dignity and rely on social dignity as a guide to their realization in specific contexts. In other words, with each of the conditions we can ask 'what would be a way of establishing a home environment that is minimally compatible with social dignity?' and 'how would each condition be operationalized in different contexts?' The conditions are not meant to be necessarily discrete and will overlap or manifest differently in different contexts. The use of a clearly defined and delimited conceptualization of social dignity, however, provides a means for mapping out how contingent forms of dignity, i.e. those that are not inviolable, can be promoted or violated through the structures, processes and interactions of home environments. Furthermore it avoids many of the common problems inherent in ill-defined or undefined usages of dignity that in effect render it almost meaningless (Macklin, 2003; Riley, 2008).

(Figure 1 ~ here)

By identifying a provisional list of necessary conditions we are not suggesting that each is relevant to every disabled person, but rather that an individual should have access to each of the conditions if they so desire. For example, some individuals will not be interested in participating in school or work, but it is still necessary to provide the means

for disabled people to pursue these options. The data strongly bore out that home environments should provide equality of opportunities on par with those afforded to non-disabled people. Care, housing and planning policies thus need to recognize the rights of disabled people -as citizens - to, for example, participate in social life and maintain security of person. Furthermore, because these are necessary conditions, fulfillment of one of the conditions should not require sacrifice of another. So, for example, access to a safe and secure environment must not require sacrificing the ability to sustain meaningful relationships.

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 ('the Convention'; United Nations, 2006). A comprehensive analysis of our findings in relation to the Convention is beyond the scope of this paper. Nevertheless given its recent ratification by Canada and its focus on promoting dignity, it is worth commenting on the provisions directly related to housing and care. The Convention states that its driving purpose with respect to disabled people is 'to promote respect for their inherent dignity' (Article 1, p.4). Its provisions require 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’ (Article 19).

The study results provide examples of the many ways that these provisions have yet to be fully realized in Ontario. While deinstitutionalization has been a positive shift in the history of practices towards disabled people, our results provide examples of how not all community-based and ‘integrated’ homes are enabling. Furthermore a recent report from the Ontario Community Support Association (2008) identifies that programs such as Direct Funding and Outreach Attendant Services provide inadequate hours of service and are severely underfunded. As of 2008, over 700 people are on wait lists for attendant services and/or supportive housing. Wait times officially range from 4 to 10 years but are likely longer if factoring in the number of persons who do not bother to apply. The report suggests that disabled people in Ontario continue to experience severely limited choices, or no choice, of living arrangements. Our findings provide examples of those who could not access or claim a permanent home and how they were effectively rendered materially and psychologically homeless and vulnerable to the vagaries of the system and where they would be ‘placed’. Furthermore we heard from decision makers how people in Ontario may be forced to move to receive care or to make trade-offs between maintaining important relationships and pursuing independent living. Personal assistance was for the most part meeting basic physical needs but, combined with other barriers in the socio-material environment, often fell short of supporting social dignity.

Importantly, the ‘conditions’ in Figure 1 are meant to reflect a provisional minimum set of criteria for an adequate home environment emerging from this study. They are

provisional because further exploration and research would no doubt provide further insight into how the elements apply in different contexts or what additional elements may be warranted. However, none of these conditions is meant to be considered merely ‘nice to have’; rather, all are presented as necessary 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 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 they need/should have. The broader social context thus gets acted out in the relations of a given home space. Both the policies regarding the space and the circumscribed work/interactions in the space have potential to enable or violate dignity.

Conclusion

The task of this study was to undertake an ethical analysis of what constitutes an ‘adequate’ home environment for adults with significant mobility disabilities. We have outlined a number of provisional basic conditions that might form the basis of a guideline for policy and practice. 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 particular time and place and, thus, are open to revision, expansion and further specification in other contexts. Further exploration of this provisional framework across multiple locales and with a wider sample is warranted.

Future research that examines housing/care provisions across jurisdictions in relation to the general principles of the United Nations Convention on the Rights of Persons with Disabilities would also be valuable.

Despite the importance of the home environment, to date there has been very scant research examining the ethics of home environments for disabled people and even less focusing on younger disabled adults. Furthermore, to our knowledge there are no existing ethical frameworks to guide related policies and practices. The exclusion of younger disabled adults from social participation is linked to the availability, organization and location of home environments. The problem of finding appropriate home environments is an issue of social justice that also represents a major financial issue for the health care system when persons who are able to live in the community occupy costly institutional beds. Framing home environment as an issue of social justice, rather than solely as an issue of distribution of scarce resources, helps ensure that the rights of disabled citizens are foregrounded in health and social policy debates. A decent minimum living standard needs to recognize each person's humanity and right to a life with meaning, purpose and dignity.

In addition to the substantive findings, the study also has conceptual and methodological implications. Conceptually, it contributes to a growing body of scholarship in geography exploring the spatial dimension of health (Curtis & Jones 1998, Imrie, 2007; Cummins et al., 2007; Popay et al 2003; Kearns & Moon, 2002), and the complex ways the micro-geographies of home environments are integral to experiences of illness and disability

(Dyck, 2005; Imrie 2004; Moss 1997). At the intersection with disability studies is an exploration of the spatialized body as a point of departure for considering disability (Gleeson, 1999; Imrie & Edwards 2007, Gibson et al 2007, Imrie, 2004; Freund, 2001; Kitchin, 1998). Our study adds to these ideas through the identification of an empirically-grounded normative principle of social dignity that helps to delineate conceptions of the good in relation to health and home environments.

Methodologically, the study builds on an emerging literature examining the integration of empirical and normative approaches to research problems of social justice and ethics (Borry et al., 2005; Haimes, 2002; Hedgecoe, 2004; Hunt & Carnevale 2011; Ives & Draper, 2009; Parker, 2007; Sugarman, 2004). Bioethicists are increasingly interested in how empirical work contributes to moral deliberations (Haimes, 2002) and concurrently there has been a call for social scientists to acknowledge the implicit normative dimensions of their work and to re-engage with moral philosophy (Sayer, 2009). The study provides an exemplar of research that combines empirical and philosophical analyses to address normative ethical questions. It also raises further issues for discussion and debate. These include prevailing questions of representativeness of sample and the transferability of normative guidance to other contexts. If contextual details are important to normative ethical deliberation, as we believe, then conclusions need to be interpreted in light of contextual similarities or differences. Nevertheless, we suggest that mindfulness about the extent of generalizeability should not preclude making supported, albeit provisional, normative claims regarding the conditions that promote or deny human flourishing.

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Table 1: Participant Characteristics: Disabled Adults

Pseudonym	Living Circumstances	Gender	Age
Anne	Supportive Housing Unit	F	55
Beth	Supportive Housing Unit	F	27
Tom	Supportive Housing Unit	M	53
Carol	Private home with direct funding	F	50
Lynn	Private home with direct funding	F	54
Marie	Private home with direct funding	F	46
Harry	Complex continuing care unit	M	42
Kevin	Complex continuing care unit	M	23
Dawn	University residence with direct funding	F	18
Kate	Transitional care unit	F	21

Table 2: Participant Characteristics: Decision-makers*

Pseudonym	Position
Cheryl	Director of a service organization
Jeffrey	Government administrator
Gloria	Government administrator
Jennifer	Director of a Supportive Housing Unit
Abdul	Discharge planner
Dina	Discharge planner
Alex	Administrator at a hospital/healthcare organization
Stephanie	Administrator at a hospital/healthcare organization
Rhonda	Administrator at a hospital/healthcare organization
Mac	Administrator at a hospital/healthcare organization

*Further details are not provided to protect anonymity

Fig. 1 Conceptual Framework: Dignity-Enabling Home Environments

Disability and Dignity-Enabling Home Environments

Research Highlights:

- Home-related programs focus on disabled people's basic physical needs with little regard for other aspects of well-being.
- An adequate home environment is one that enables social dignity through seven required conditions of access.
- This study of programs in Canada outlines a framework for establishing home environments that are minimally compatible with social dignity.