

8th Annual Stephan M. Salzberg Memorial Lecture

What constitutes a dignity-enabling home environment?

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Objective

- To review and discuss the results of a recently completed CIHR study examining the ethics of home and home/health care for younger disabled adults.



Overview

- ❑ Background
- ❑ Purpose
- ❑ Methods
- ❑ Results
- ❑ Analysis
- ❑ Limitations
- ❑ Implications
- ❑ Discussion



BACKGROUND

Study team

- Barbara Gibson – Co-Principal Investigator
- Barbara Secker – Co-Principal Investigator
- Frank Wagner – Co-Investigator
 - Bioethicist, Toronto Central CCAC
- Bob Parke – Co-Investigator
 - Bioethicist, Humber River Regional Hospital
- Debbie Rolfe – Research Coordinator
 - PhD (c) Lawrence S. Bloomberg Faculty of Nursing, UofT
- Bhavnita Mistry – Research Coordinator

Team's related work

Local Health Integration Networks (LHINs)

Building a True System

Ethics of LHINs: Implications for People with Disabilities and Chronic Illnesses

(2005) Secker et al., University of Toronto Joint Centre for Bioethics (white paper).



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Think Tank on Ethics for LHINs

Summary of the Discussion Forum Held on February 20, 2006

Ontario

Highly accessed

BMC Medical Ethics

BioMed Central

Debate

Open Access

Just regionalisation: rehabilitating care for people with disabilities and chronic illnesses

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Rationale

- ❑ Narrow focus on physical needs and activities of daily living (ADLs)
- ❑ Minimal consideration of how home environment is implicated in broader notions of well-being
- ❑ Unmet health needs, burden on family members, isolated from peers, social exclusion
- ❑ Ethical issues: respect for persons and social justice



Care 'options' in Ontario

- ❑ Private/family with Outreach Attendant Services+
- ❑ Direct Funding Program
- ❑ Supportive Housing Units
- ❑ Transition Units
- ❑ Institutions (e.g. long-term care facilities)



PURPOSE

Study: 'Adequate' home environments

Purpose: To undertake an ethical analysis of what constitutes “adequate” home environments for younger adults with significant mobility disabilities.

- *Good enough? Nice but not necessary?*
- *Ethical issues?*



Home environments

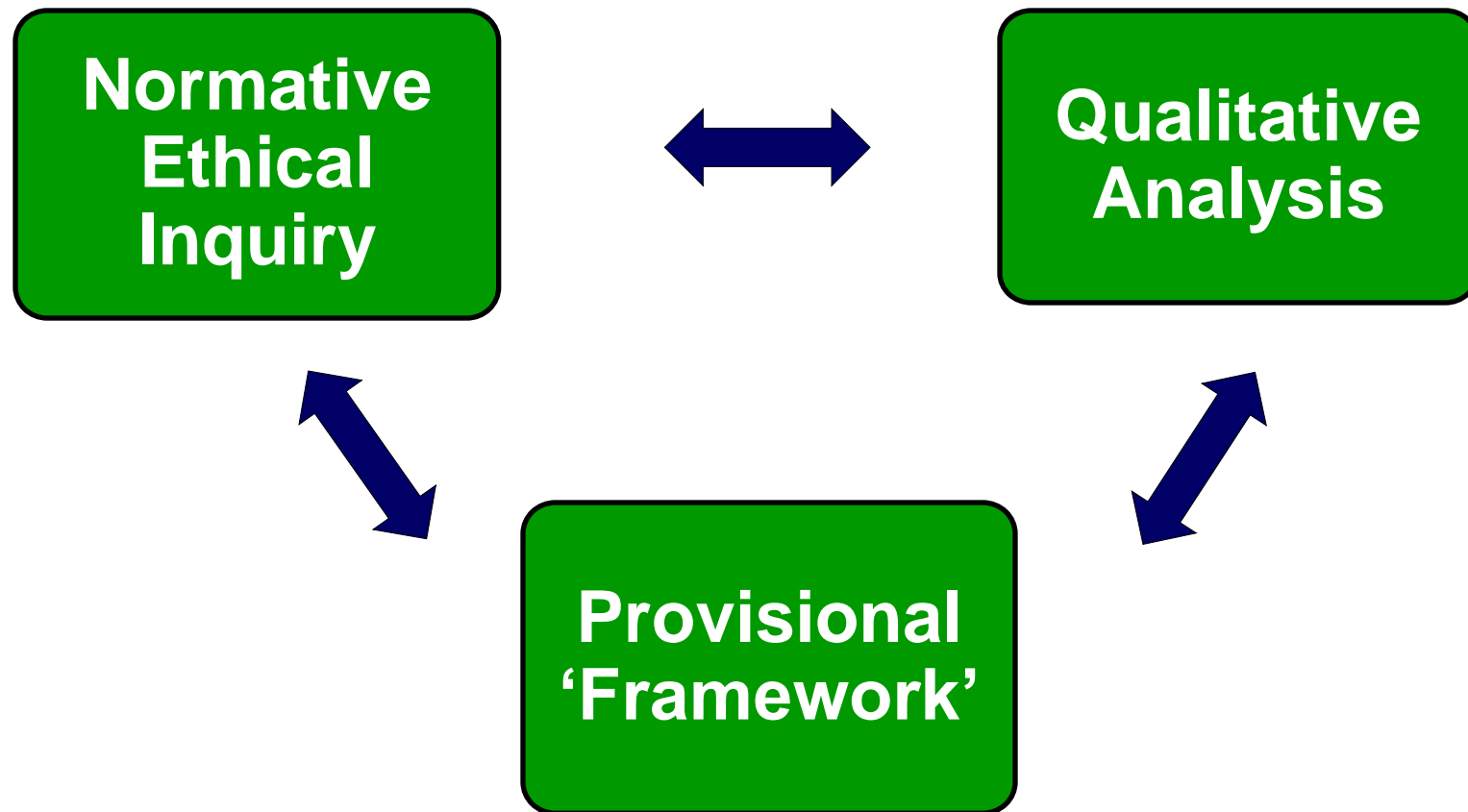
Circumstances, actions and relations that constitute that space, including the neighbourhood and the provision of home health and social services.

(Moss, 1997)



METHODS

Integrated design

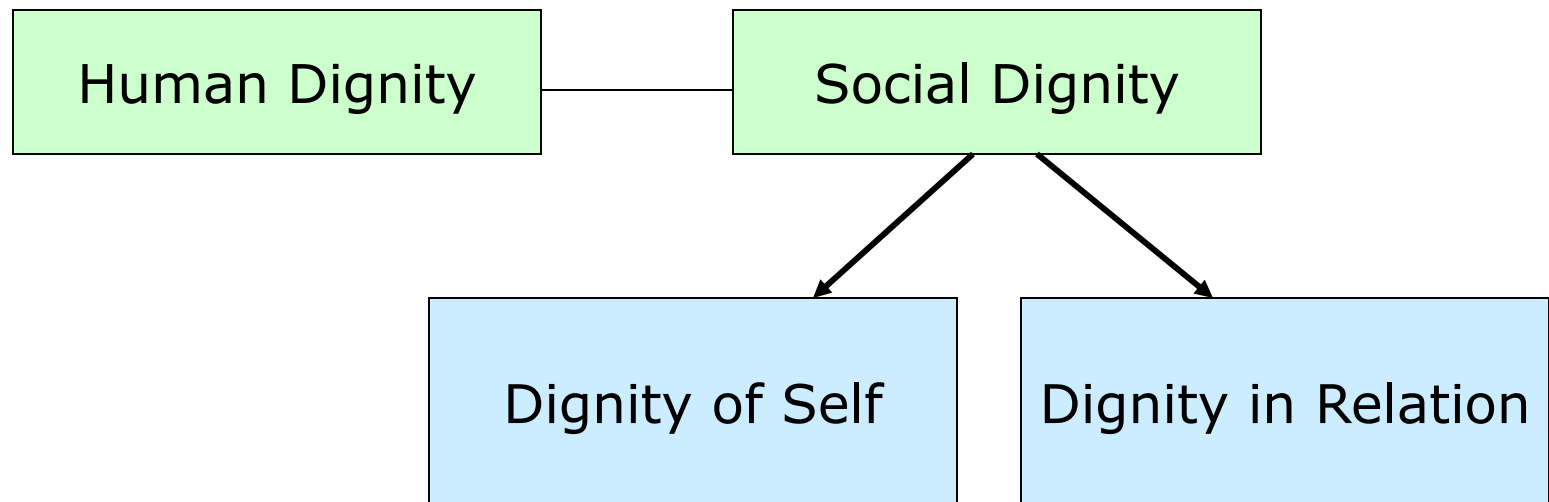


Critical disability ethics approach

- ❑ Policies and practices that exclude disabled people from social life are morally wrong
- ❑ Exclusion is more than a problem of distribution of resources
- ❑ Nature of disablement is multidimensional (social, cultural, personal, political)
- ❑ Uncovering, examining and eliminating exclusionary practices and structures is necessary

Concept of dignity

- Nora Jacobson (2007, 2008, 2009)



Qualitative interviews

1. 10 Decision Makers: Policy makers, program administrators and discharge planners
2. 10 Disabled Persons: Adults (Ages 18 -55) with mobility disabilities living in a range of circumstances

Toronto and Thunder Bay



Qualitative interviews

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

Qualitative interviews

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

RESULTS

Dignity-enabling home environments

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. You always go home, and you own it, ownership. And you have some flexibility about, you know, when you get up, when you're going to go to bed, or what you're going to wear, how you're going to wear your hair, what you're going to eat. (DP, Study Participant)

Self-expression

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.' (DM in CCU)

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. (DP in CCU)

Self-expression

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. (DP in TCU)

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. (DP in THU)

Safety and security

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

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. (DP w/ DF)

Safety and security

(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 walking in the door to take care of you. (DP in SHU)

You're getting someone out of the blue that hasn't worked with you. I wouldn't feel safe in that situation. (DP w/ DF)

Meaningful relationships

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. (DM)

Meaningful relationships

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. (DP in CCC)

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 care and convince their parents to let them drive over here. (DP in TCU)

Meaningful relationships

You were expected to be living by yourself and to be single...I negotiated with the government, I say: '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 the (SHU) and asked, "Would you be willing to do this?' And they wouldn't do it. (DP w/ DF, previously in SHU)

Community and civic life

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

(DM)

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. (DP in SHU)

Community and civic life

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. (DP in SHU)

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. (DP in University Residence w/ DF)

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

Participation in school, work, leisure

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?' (DP w/ DF)

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 the scooters and wheelchairs in the summertime, but you don't tend to see too much in the winter. (DM)

Participation in school, work, leisure

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. (DM)

Respectful care relationships

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. (DP in SHU)

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... I feel like what's the point if nothing will get done? (DP in SHU)

Respectful care relationships

You've got one vulnerable group which is a very low paid staff group ...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.' (DM)

Choice and flexibility

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. (DP in SHU)

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 that probably conspire against, or support somebody. (DM)



ANALYSIS

Dignity-enabling home environments

Provisional framework

**Adequate =
Dignity-Enabling**

Through access to seven necessary conditions:

**Self-expression
Safety and security
Meaningful relationships
Community and civic life
Participation
Respectful care relationships
Control and flexibility**

Dignity-enabling home environments

Realized Through Seven Conditions

Self-Expression

Access to opportunities for self-expression and identity affirmation

Security and Safety

Access to security and safety – physical, psychological, ontological

Meaningful Relationships

Access to personally meaningful relationships with family, friends and pets

Community and Civic Life

Access to community life through accessible social and material environments

Participation in School, Work and Leisure

Access to opportunities to participate in school, work and leisure activities

Respectful Care Relationships

Access to opportunities to respectful relationships with attendants

Control and Flexibility

Access to choice, flexibility and spontaneity in daily activities

Main messages

1. All persons need more than physical accessibility and personal care to thrive
2. Current policies and practices that focus on instrumental needs may not respect disabled people's dignity and human rights
3. Engaging those most affected is a key part of enabling dignified lives
4. An adequate home environment is one that enables and promotes social dignity by providing access to seven essential conditions

Limitations

- ❑ Representativeness of the interview sample?
- ❑ Generalizability not a goal of qualitative research
- ❑ Conclusions need to be interpreted based on contextual similarities and differences
- ❑ Provisional framework needs to be specified

Implications

- ❑ Implications for housing, health and social care policies, political reform
- ❑ Provisional framework (7 necessary conditions)
 - Could inform basis of guideline for policy and practice
 - Could be further revised/expanded/specified in different contexts to help assess/evaluate whether home environments are dignity-enabling
- ❑ Further research needed across multiple locales and with broader sample
 - Consider general principles of UN Convention on the Rights of Persons with Disabilities

Acknowledgments

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For more information

- <http://www.jointcentreforbioethics.ca/research/disability.shtml>
 - Full Report
 - Research Study Highlights

- BE Gibson, B Secker, D Rolfe, F Wagner, B Parke, B Mistry (2012), Disability and Dignity-Enabling Home Environments. *Social Science and Medicine*. 74 (2)
<http://www.ncbi.nlm.nih.gov/pubmed/22142787>

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