

There's No Place Like Home: Dignity-Enabling Home Environments for Disabled People

What was the purpose of this study?

This study examined the question:
What constitutes 'adequate' home environments for younger adults with significant mobility disabilities?

What is a 'Home Environment'?

Home environments include not only a physical dwelling but all of the circumstances, actions and relations in the space. It includes neighbourhood spaces and the provision of home health and social services.

Why was this study important?

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 needs, place undue burden on family members, and contribute to their social exclusion.

This is an ethical issue when policies and practices unjustly exclude disabled people or contribute to other physical, psychological, or social harms. A detailed analysis of the ethical issues in home environments had not been previously undertaken.

What were the methods?

Ten qualitative interviews were conducted with disabled persons, ages 18-54, with mobility disabilities; and ten with health and social service policy makers, program administrators and discharge planners ('Decision-Makers'). We then conducted an ethical analysis of the issues.

What were the results?

Interviews:

Participants' suggested that while programs and services are mostly adequate in meeting the basic physical health needs of disabled people, they have multiple negative effects on their psychosocial health and wellbeing.

Two elements were identified as important:

Home Space and Personal Care

Important elements of the home space:

- A space of 'one's own' is closely tied with personal identity and self expression
- Home is more than a container. It provides a sense of security, strength, and comfort
- Layout meets the physical needs of the disabled person and their caregivers
- Control over who can enter the home space
- Visitability: Provides access beyond the four walls of a dwelling. An accessible home is not adequate if the neighbourhood is largely inaccessible.
- Supports the ability to sustain personal relationships
- Integration with non-disabled people

Important elements of personal care:

- Access to self-directed care
- Respectful interpersonal relationships
- Attendant services beyond basic care → enable community participation
- Flexible services to accommodate spontaneity, unanticipated needs and individualized needs

Participants' Perspectives:

HOME: 'Home is like your own special place, it's your haven.'

INACCESSIBLE COMMUNITIES: 'I find the area is very unfriendly towards wheelchairs. You'll see a store and it'll have one little step. It would be so simple if people realized, to put in a little ramp.'

EXCLUSION: '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.'

FREEDOM: 'Home can be an institution if you feel a sense of freedom and belonging.'

CARE: 'If I had just been on my own in an accessible apartment, I wouldn't have been able to survive without services to go with it. And if you just have the services, but your place isn't accessible, you're either locked in or locked out, and in danger sometimes.'

FLEXIBILITY: 'Planning involves dealing with how your schedule is going to change... If it's going to be extraordinarily difficult for me to not come home at the time I said.'

Ethical Analysis:

Nora Jacobson's¹ notion of "Social Dignity" provides a conceptual lens for assessing the adequacy of home environments. Social Dignity relates to how respect and worth are conveyed in interactions, policies and social values.

Home environments have a significant impact on people's abilities to lead dignified lives. Policies and practices 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.

The findings indicate that an adequate home environment should foster the dignity of the individual by enabling their ability to sustain meaningful relationships, to access and engage in community life, enjoy flexibility in daily life, and participate in school, work or leisure activities.

Dignity Promoting Home Environments

**Adequate Home Environment =
Dignity-Enabling**

**The test of adequacy is promotion of social
dignity through access to:**



**Meaningful relationships
Community & civic life
Control, flexibility & spontaneity
Self-expression
Respectful care relationships
Participation in school, work or leisure
Security and safety**

Implications:

The findings can be utilized by decision makers, managers and service organizations to inform home and personal care related policy and practices to better meet the needs of disabled people.

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References: 1. Jacobson, N. (2009). A taxonomy of dignity: A grounded theory study. *BMC International Health and Human Rights*, 9(3), 1-33.