RESEARCH HIGHLIGHT

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Housing Persons with an Intellectual Disability in Intentional Communities: Identifying Relevant Physical and Governance Structures

Although there is a large body of research on the housing needs of individuals with physical disabilities, there is very little on the housing needs of people with intellectual disabilities.[1] This project, undertaken by the Saskatoon Housing Initiatives Partnership (SHIP) and the Saskatchewan Association for Community Living (SACL), was designed to help address this gap.

BACKGROUND AND OBJECTIVES

Researchers at SHIP and SACL wanted to identify the housing needs of individuals with intellectual disabilities and explore the possibility of meeting those needs in an "intentional community [2]" setting. As intentional communities are typically committed to social inclusion, the researchers were curious to see if intentional communities could offer a suitable environment for people with disabilities.

The research had three objectives:

1. To understand how people with an intellectual disability use living spaces in the home and to identify appropriate design features.
2. To identify the features needed in the surrounding community or neighbourhood setting to ensure accessibility.
3. To identify the supports needed so that individuals with an intellectual disability could be meaningfully engaged in the decision-making process of an intentional community.

METHODOLOGY

The researchers focused on three elements they believed were important in meeting the housing needs of individuals with an intellectual disability:

1. The *accessibility* of the home, both in terms of specific design features of the building and equipment and in terms of the community or neighbourhood setting.

   The accessibility of housing for individuals with intellectual disabilities depends on several features, including the design of the home, the design of the neighbourhood or community setting and the level of supports provided in the living environment.

2. The level of *acceptance* of persons with intellectual disabilities by members of an intentional community.

   The way community members perceive disability has an influence on how well individuals with a disability are accepted.

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[1] An intellectual disability is a limited ability to learn that can sometimes cause difficulty in coping with the demands of daily life. It is a condition usually present from birth or before the age of 18. For more information, see the Saskatchewan Association for Community Living website at http://www.sacl.org/. English, retrieved October, 2008.

[2] "Intentional community" is a general term covering many housing types, including ecovillages, co-housing, residential land trusts, communes, co-ops and other housing projects in which people "strive together with a common vision." For more information, see the Intentional Communities website at http://www.ic.org/. English, retrieved October, 2008.

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Four models of viewing disability were reviewed:

- The *medical model* views a disabled person as having a medical condition that needs to be treated and managed by a doctor. In other words, the disabled person is seen as the problem.
- The *social model of disability* sees disability as a failure of society to ensure accessibility and acceptance, rather than as a personal limitation of the individual.
- The *affirmation model*, based on a "positive non-tragic view of disability," also sees disability as impairment between the individual and society rather than an impairment of the individual.
- The *social role valorisation (SRV) model* is based on the belief that everyone has inherent "gifts" or social value. Acceptance of individuals with a disability is best developed by identifying and promoting their inherent gifts.

3. The impacts on governance or management *authority* arising from including persons with intellectual disabilities in an intentional community.

These elements were explored through a literature review and through primary research with a sample of individuals with intellectual disabilities or their family members—or both—living in Saskatchewan.

Focus groups and surveys

In order to deepen their understanding of the housing needs of individuals with an intellectual disability, researchers gathered data from a sample of SACL clients and family members. Data was collected through a series of focus groups and also from a survey mailed out to selected participants. The sampling method chosen was a convenience sample, as random sampling did not seem practical or realistic under the circumstances. Twenty-seven people participated in the focus groups: 12 individuals with intellectual disabilities and 15 family members.

Surveys were distributed to people who were unable to attend focus group sessions and to focus group participants who wanted to provide additional detail in their responses. Thirteen surveys were returned.

While the conclusions drawn are, therefore, not necessarily representative of the total population of individuals with an intellectual disability, they do represent an important contribution to the field of knowledge about a subject that has very limited previous research at this point.

FINDINGS

Literature review

The researchers examined the literature about a variety of community-based housing models, including institutions, congregate living and intentional communities. They identified five intentional communities that included individuals with an intellectual disability (see Table 1).

The successful inclusion of individuals with an intellectual disability into intentional communities was dependent, to some degree, on the following:

- a sense of ownership of the housing unit and of the community;
- a significant percentage of residents having an intellectual disability to focus governance and planning around the needs of these individuals; and
- supported living arrangements that were well-established.

Table 1 Intentional communities that include individuals with an intellectual disability

Community	Number of residents with an intellectual disability	Type of housing	Mission statement
Innisfree Village Crozet, Virginia	39 of 68	10 village houses and 2 houses	To create and support a life of respect, empowerment, and creativity for persons with special needs.
Rougemont Cooperative, Durham Region, Ontario	6 of 250	105 apartment-style co-operative rental units	The Deohaeko Support Network works with the Rougemont Cooperative to foster a spirit of mutual neighbourhood support.
Pinakarri Housing Cooperative, Fremantle (Perth), Australia	1 in 12, who also have live-in supporter	8 rental townhouses and 4 private homes	Individuals committed to environmental responsibility, social justice, and community values.
Camphill Village 105 locations around the world	A varying percentage of residents have an intellectual disability	Varies, typically shared purpose-built home in a rural, agricultural setting	Camphill Communities is based on Anthroposophy, a modern path of spirituality defined by Rudolf Steiner (1861–1925) humanitarian, educator, philosopher and scientist. Camphill Village is about life-sharing between persons with an intellectual disability and volunteers.
International Federation of L'Arche Communities: 130 communities worldwide, 27 in Canada	A varying percentage of residents have an intellectual disability.	Typically shared purpose-built home	(a) To create homes where faithful relationships based on forgiveness and celebration are nurtured. (b) To change society by choosing to live in a community as a sign of hope and love. People with disabilities, and those who assist them, live together and are equally responsible for the life of their home and community.

Accessibility: Focus group participants emphasized that there is no "one size fits all" approach to house design for intellectually disabled individuals. They are all individuals and have individual preferences. However, the research did suggest individuals with an intellectual disability have similar housing needs, in terms of accessibility, to those of families with young children.

Accessibility to public transportation routes was also an important consideration in the location of housing. Many participants said they did not drive and required transportation to get around the community, access services and build connections. Participants stated a preference for housing located within walking distance of a convenience store or a shopping centre. They also wanted to be close to medical services for their peace of mind.

Acceptance and inclusion: The research emphasized the importance of including people with an intellectual disability in the design stage of their housing. In focus group discussions, all participants noted the importance of formalized support to both the level of independence possible and the level of acceptance likely to be achieved within a community.

Authority and decision-making: Persons with an intellectual disability currently experience a significant lack of control over the spaces in which they live. The introduction of semi-private spaces (for example, kitchens, living rooms) under the control and influence of the individual, should reduce the desire for large private spaces, such as large bedrooms.

Individuals with intellectual disabilities can be supported in making decisions by people who understand their values, interests, talents and gifts. The supported-decision-making process is strength-based and built on the belief that every person has the right to self-determination.

Although no literature was found that examined the role that supported-decision-making plays in intentional communities, the literature on supported-decision-making suggests it could be a way to ensure individuals with disabilities have meaningful input into governance issues and are able to exercise authority over their housing conditions. However, this process is not without challenges. Most intentional communities make decisions by consensus which often can be a time-consuming process. Including supported-decision-making into the governance structure could add to the length of time to reach decisions.

Participants were also asked about the meaning of home; use of spaces; kitchen; living room; common areas-shared spaces; private spaces; specialized or notable design features; and housing type.

How participants define home: Participants used a wide range of words to describe "home." (See Table 2.)

Table 2 The meaning of home

Responses by individuals with an intellectual disability	
■ Affordable ■ Comfortable ■ Secure/Safe environment[3] ■ A space to get away from others ■ Privacy ■ Less noise ■ Spacious ■ Freedom to do what you want when you want supportive environment ■ Ownership/responsibility ■ Functional	■ Warmth ■ Love ■ Family ■ Relaxing atmosphere ■ Knowing that you have a place to go to ■ A place to think ■ A place where you can do your hobbies ■ A place where your pet(s) live
Responses by family members	
■ Affordable ■ Comfortable ■ No official rules/schedules ■ Secure/safe environment ■ A space to get away from others ■ Privacy ■ A place to entertain/hang-out with friends ■ Spacious ■ Freedom to do what you want when you want	■ Food ■ Inviting ■ Social place ■ Relaxing atmosphere ■ Attractive features ■ No "off-limit" places ■ A yard is very important ■ A place where your pet(s) live ■ Familiar ■ A supportive environment ■ Ownership/responsibility ■ Functional

Use of spaces: The space needs of individuals with an intellectual disability appeared to be similar to those of a family with children, that is:

- Open layouts wherever possible to allow for ease of navigation through good sight lines and physical accessibility;
- Flexibility that allows space to be used for multiple functions; and
- Private spaces that allow an individual to find quiet solitude.

Kitchen: Kitchens were seen as public or semi-private spaces accommodating many functions including food preparation and socializing. Open layouts were preferred to islands, which were seen as confusing and difficult to navigate. Even though participants did not (or could not) prepare their own meals, they still valued a functional kitchen.

Living room: Participants saw the living room as a place for entertainment (for example, watching television), leisure activities (for example, crafts, surfing the net), dining (for example, in front of a television) and socializing.

Common areas-shared spaces: Spaces for social gathering were important. Participants said they would use a common area with a kitchen and an entertainment lounge (for example, a room with a large-screen television), although the common area was desired more for socializing than for the kitchen facilities.

Private spaces: Participants viewed bedrooms as being much more than a place for sleeping or quiet solitude. They wanted large bedrooms that could accommodate significant storage for personal items, additional security features, and a variety of furnishings to support a variety of activities. Researchers suspected participants may have overemphasized the importance of bedrooms based on their current living experiences, that is, living in the family home or in a congregated living environment where their only private space was their bedroom.

Safety was a main concern in bathrooms due to mobility challenges and the potential for harm due to seizures. Participants preferred telephone showerheads, handrails within either a bathtub-shower or shower stall flush with the floor, and preferred shower curtains for reasons of safety and hygiene.

[3] Words that were included under "secure/safe environment" were: locks, security systems, feeling safe and knowing that private possessions would be secure.

Private spaces were used for watching television, using computers, storing personal possessions, etc. Television and watching movies was an important part of the social routine and also a private pastime for many individuals.

Private laundry facilities were important to the dignity of those who may struggle with incontinence.

Specialized or notable design features: Participants emphasized the need for design features that could accommodate mobility challenges. Other specific design features included:

- Durable furniture and furniture design that maximizes floor-space accessibility.
- Flexible lighting options—overhead and wall-mounted lighting were preferred, although tabletop lights were acceptable. Floor lamps were considered unsafe.
- Large windows with opaque coverings were important to accommodate sleep-wake patterns and blinds or shades were preferred to curtains.
- Storage should accommodate wheelchairs and walkers.
- Kitchens should include appliances typically found in a modern home. Microwave ovens were essential; stovetops with coil elements rather than ceramic tops or gas fixtures were preferred; and wall-mounted ovens with side-opening doors were preferred over the traditional free-standing stove.
- Hard-surface floorings were preferred over carpeting.
- Levers and handles were preferred over knobs.
- Single-lever faucets were preferred over two-handled tap-sets for safety reasons. Regulation of hot-water temperature was important to prevent scalding.
- The ability to choose paint colours was important, providing a sense of ownership over the space (whether owned or rented).
- Access to outdoor space was important; yards and patios were preferred to balconies. Participants were concerned about safety with balconies.

Housing type: Participants tended to prefer the housing type they were most familiar with, that is, apartment-style buildings (with an elevator) or a house with suites.

Differences in responses between family members and individuals with a disability

- Family members believed their relative would eat and socialize in a common room, rather than in their own suite and therefore the suite need only contain a minimum of kitchen features (e.g., a microwave and a bar fridge).
- Family members were concerned about safety and indicated their relative would want a security system to allow them to use a panic button if something was awry in the kitchen or bathroom.
- Family members suggested taps should have a timer to prevent excess uses of water and heat safety regulators to prevent scalding.
- Family members placed a higher value on kitchen features, layout and space than did individuals with a disability.
- Family members believed computers should be in a common room so that use could be monitored.
- Many family members wanted their relatives to have a two-bedroom unit to accommodate a personal attendant in the same unit.
- Family members showed a much stronger interest in congregate housing[4] than did individuals with disabilities.

CONCLUSIONS

- The physical housing needs of a person with an intellectual disability were found to be similar to those of a family with children.
- The way community members perceive disability has an influence on how well individuals with a disability are accepted.
- What sets the intentional community apart from other housing options is the shared vision between community members in regard to the community values. Typically, intentional communities stress the need for inclusion of all community members within governance and decision making processes.

[4] Congregate living: Congregate living is a slightly less institutional form of housing and includes nursing homes, assisted living residences and group homes. Congregate living typically includes the opportunity to hire support services and care, one or more meals per day prepared and served in a communal dining room, transportation services, laundry and housekeeping assistance, recreational and day-programming, and security.

- The successful inclusion of individuals with an intellectual disability into intentional communities was found to be dependent, to some degree, on the following factors:
  - a sense of ownership of the housing unit and of the community;
  - a significant percentage of residents having an intellectual disability to focus governance and planning around the needs of these individuals; and
  - supported living arrangements that are well established.
- The recognition that persons with intellectual disabilities have the right to voice their opinions and participate in community governance structures is crucial if they are to be accepted as peers within an intentional community. One way to allow individuals with an intellectual disability to voice their opinions is to acknowledge the role that supported decision-making processes can play in decision-making. The supported decision-making process should be strength-based so as to focus on an individual's abilities rather than disabilities.
- Members of the intentional community may perceive their investments to be at risk when supported-decision-making is included in the governance process. Therefore, it would be important to build risk-mitigation measures into the bylaws.

Table 3 summarizes the universal design guidelines and considerations obtained from the literature review and through an analysis of the results from the primary research.

Table 3 The seven principles of universal design

Principle	Explanation	Guidelines	Considerations/Trends
Equitable use	The design is useful and marketable to people with diverse abilities.	■ Provide the same means of use for all users: identical whenever possible; equivalent when not. ■ Second storey units are designed with non-mobility challenged persons in mind. ■ Avoid segregating or stigmatizing any users. ■ Provisions for privacy, security, and safety should be equally available to all users. ■ Make the design appealing to all users.	■ Ensuring housing units include features for accommodating a variety of types of users (regardless of circumstance or ability). ■ Locating project among housing of mixed tenure, mixed income, and mixed housing stock age. ■ Affording privacy and several levels of security to the individual resident. ■ Member participation in design.
Flexibility in use	The design accommodates a wide range of individual preferences and abilities.	■ Provide choice in methods of use.	■ Freedom to customize units. ■ Physical accessibility considered in the design of all entrances, and hallways.
Simple and intuitive use	Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills or current concentration level.	■ Eliminate unnecessary complexity. ■ Be consistent with user expectations and intuition. ■ Accommodate a wide range of literacy and language skills. ■ Arrange information consistent with its importance. ■ Provide effective prompting and feedback during and after task completion.	■ The project is designed with a level of predictability to ease navigation as well as simplicity of angles. ■ The floor-plan lay-outs are common, innovation comes in the utility features added to the living spaces. ■ Utility features added to the living spaces provide spatial and/or visual clues to use.
Perceptible information	The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.	■ Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information. ■ Provide adequate contrast between essential information and its surroundings. ■ Maximize "legibility" of essential information. ■ Differentiate elements in ways that can be described (i.e. make it easy to give instructions or directions). This provides differentiation and ease of direction. ■ Provide compatibility with a variety of techniques or devices used by people with sensory limitations.	■ Emergency preparedness and hazard information will be prominently displayed to tenants and guests using internationally recognized mediums. ■ The project is designed with a level of predictability. Emergency preparedness information will stand out in contrast to other residential features of the project. ■ Utility features added to the living spaces provide spatial and/or visual clues to use. ■ The features and lay-out of no two rooms in a suite are exactly the same, yet spaces are simple in lay-out.
Tolerance for error	The design minimizes hazards and the adverse consequences of accidental or unintended actions.	■ Arrange elements to minimize hazards and errors: most used elements, most accessible; hazardous elements eliminated, isolated, or shielded. ■ Provide warnings of hazards and errors. ■ Provide fail-safe features. ■ Discourage unconscious action in tasks that require vigilance.	■ The design and decorating includes features that "forgive" inaccurate use. Member input on design has ensured highest accessibility standards are balanced with livability desires. ■ Emergency preparedness and hazard information will be prominently displayed to tenants and guests using internationally recognized mediums. ■ The housing model provides a "neighbourhood watch" type mechanism of support among tenants.
Low physical effort	The design can be used efficiently and comfortably and with a minimum of fatigue.	■ Allow user to maintain a neutral body position. ■ Use reasonable operating forces. ■ Minimize repetitive actions. ■ Minimize sustained physical effort.	■ Member input on design helps balance accessibility with livability. ■ Accessibility features built into the project are based on industry standards for the mobility challenged.
Size and space for approach and use	Appropriate size and space is provided for approach, reach, manipulation and use regardless of user's body.	■ Provide a clear line of sight to important elements for any seated or standing user. ■ Make reach to all components comfortable for any seated or standing user. ■ Provide adequate space for the use of assistive devices or personal assistance.	■ Member input on design (and individual unit customizations) has provided increased livability. ■ Physical accessibility for wheelchairs has been designed into the layout of all spaces in the project.

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