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

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

A joint project of
Saskatoon Housing Initiatives Partnership (SHIP)
and
Saskatchewan Association for Community Living (SACL)

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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.

   Four models of viewing disability were reviewed:

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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/webapp/DesktopDefault.aspx?tabindex=0&tabid=1. 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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- 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).

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:

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	■ 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

- 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.

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.

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

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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LE POINT EN RECHERCHE

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Habitations pour les personnes ayant une déficience intellectuelle dans les communautés intentionnelles : détermination de structures pertinentes sur le plan de l'aménagement matériel et de l'administration

Bien que beaucoup de recherches aient été menées sur les besoins de logement des personnes souffrant d'incapacité physique, il en existe très peu sur les besoins de celles ayant une déficience intellectuelle[1]. Ce projet, réalisé par le Saskatoon Housing Initiatives Partnership (SHIP) et la Saskatchewan Association for Community Living (SACL), vise à combler cette lacune.

CONTEXTE ET OBJECTIFS

Les chercheurs du SHIP et de la SACL désiraient cerner les besoins en habitation des personnes atteintes de déficience intellectuelle et analyser la possibilité d'y répondre dans une « communauté intentionnelle »[2]. Étant donné que les communautés intentionnelles favorisent habituellement l'inclusion sociale, les chercheurs désiraient savoir si elles pouvaient aussi offrir un environnement convenant à ces personnes.

La recherche comportait trois objectifs :

1. Comprendre comment les personnes atteintes de déficience intellectuelle utilisent les surfaces habitables d'une maison et déterminer les bonnes caractéristiques de conception.
2. Définir les aménagements devant se trouver dans la collectivité ou le quartier pour assurer l'accessibilité.
3. Déterminer le soutien dont ont besoin les personnes souffrant de déficience intellectuelle pour participer concrètement au processus de prise de décision au sein d'une communauté intentionnelle.

MÉTHODE

Les chercheurs ont concentré leurs efforts sur les trois points qui leur semblaient importants pour répondre aux besoins en habitation des personnes ayant une déficience intellectuelle, à savoir :

1. l'*accessibilité* de l'habitation, à la fois sur le plan des caractéristiques particulières de la conception du bâtiment et des aménagements et sur celui de la collectivité ou du quartier.

   L'accessibilité de l'habitation pour les personnes ayant une déficience intellectuelle dépend de plusieurs facteurs, dont la conception de la maison, l'aménagement du quartier ou le milieu communautaire et le degré de soutien offert dans le milieu de vie.

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[1] Par déficience intellectuelle, on entend une capacité limitée d'apprentissage qui peut parfois se traduire par de la difficulté à faire face aux exigences de la vie quotidienne. Cet état se manifeste habituellement dès la naissance ou avant l'âge de 18 ans. Pour obtenir plus de renseignements, consultez le site Web de la Saskatchewan Association for Community Living à l'adresse http://www.sacl.org/webapp/DesktopDefault.aspx?tabindex=0&tabid=1. Ce site est en anglais et a été consulté en octobre 2008.

[2] L'expression « communauté intentionnelle » est une désignation générale qui englobe un grand nombre de types d'habitations, dont des écovillages, des habitations communautaires, des fiducies foncières résidentielles, des coopératives d'habitation et d'autres projets d'habitation au sein desquels les gens « luttent ensemble en partageant une vision commune ». Pour obtenir plus de renseignements, consultez le site Web sur les communautés intentionnelles à l'adresse http://www.ic.org/. Ce site est en anglais et a été consulté en octobre 2008.

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2. le degré d'*acceptation* des personnes ayant une déficience intellectuelle par les membres d'une communauté intentionnelle.

   La façon dont les membres de la collectivité perçoivent l'invalidité influe sur l'acceptation des personnes atteintes.

   Quatre modèles de perception de la déficience ont été étudiés :

   - selon le *modèle médical*, la personne handicapée souffre d'un état pathologique nécessitant les soins d'un médecin. En d'autres termes, elle est considérée comme le problème.
   - selon le *modèle social*, la déficience est le défaut de la société à assurer l'accessibilité et à faire preuve d'acceptation plutôt qu'une limite personnelle.
   - selon le *modèle de l'affirmation*, qui se fonde sur une vision positive non tragique de la déficience, celle-ci correspond à une déficience entre la personne et la société plutôt qu'à une déficience chez la personne.
   - selon le *modèle de la valorisation du rôle social (VRS)*, tous possèdent des dons naturels ou une valeur sociale. L'acceptation des personnes ayant une déficience s'établit mieux en définissant et en faisant connaître ces talents.

3. les effets sur l'administration ou l'*autorité* des gestionnaires engendrés par l'intégration de personnes ayant une déficience intellectuelle à une communauté intentionnelle.

Ces facteurs ont été étudiés en consultant de la documentation et en menant une recherche principale auprès d'un échantillon de personnes ayant une déficience intellectuelle ou des membres de leur famille, ou des deux, vivant en Saskatchewan.

Groupes échantillons et enquêtes

Pour approfondir leurs connaissances des besoins en habitation des personnes atteintes de déficience intellectuelle, les chercheurs ont réuni des données provenant d'un échantillon composé de clients de la SACL et de membres de leur famille. Les données ont été recueillies auprès de groupes échantillons ainsi que dans une enquête postée aux participants choisis. La méthode d'échantillonnage retenue consistait en un échantillon de commodité, car l'échantillonnage au hasard ne semblait pas pratique ni réaliste dans les circonstances. Vingt-sept personnes ont participé aux groupes échantillons, à savoir 12 ayant une déficience intellectuelle et 15 étant des membres de la famille.

Les enquêtes ont été distribuées aux personnes incapables d'assister aux séances des groupes témoins et aux participants à ces groupes qui désiraient fournir des détails supplémentaires dans leurs réponses. Treize enquêtes ont été retournées.

Les conclusions qui ont été tirées de l'enquête ne sont donc pas nécessairement représentatives de la population totale de personnes atteintes de déficience intellectuelle, mais elles constituent une importante contribution relativement à ce domaine, sur un sujet qui a fait l'objet de recherches antérieures très limitées jusqu'à présent.

RÉSULTATS

Consultation de la documentation

Les chercheurs ont consulté la documentation sur divers modèles d'habitations communautaires, dont des établissements, des habitations collectives et des communautés intentionnelles. Ils ont trouvé cinq communautés intentionnelles accueillant des personnes ayant une déficience intellectuelle (voir le tableau 1) :

Le succès de l'intégration de personnes ayant une déficience intellectuelle à des communautés intentionnelles dépend dans une certaine mesure des facteurs suivants :

- un sentiment d'appartenance à la communauté et de possession du logement;
- un pourcentage important de résidents ayant une déficience intellectuelle afin de concentrer l'administration et la planification sur leurs besoins;
- des conditions de logement bien établies.

Accessibilité : Les participants du groupe échantillon ont

Tableau 1 Communautés intentionnelles accueillant des personnes ayant une déficience intellectuelle

Communauté	Nombre de résidents ayant une déficience intellectuelle	Type d'habitation	Énoncé de mission
Innisfree Village Crozet, Virginie	39 sur 68	12 maisons de type unifamilial	Offrir aux personnes ayant des besoins particuliers un milieu de vie se caractérisant par le respect, le renforcement de l'autonomie et la créativité.
Rougemont Cooperative, Région de Durham, Ontario	6 sur 250	105 logements locatifs de coopérative de type appartement	Le réseau de soutien de Deohaeko travaille en collaboration avec la Rougemont Cooperative à favoriser un esprit de soutien mutuel dans le quartier.
Pinakarri Housing Cooperative, Fremantle (Perth), Australie	1 sur 12, avec un aide-résident	8 maisons en rangée louées et 4 maisons privées	Des personnes souscrivant pleinement à la responsabilité environnementale, à la justice sociale et aux valeurs communautaires.
Camphill Village 105 emplacements dans le monde	Pourcentage variable de résidents ayant une déficience intellectuelle.	Divers types, généralement des habitations spécialisées, en milieu rural ou agricole	Les communautés de Camphill se fondent sur l'anthroposophie, un aspect moderne de la spiritualité défini par Rudolf Steiner (1861–1925), qui était humaniste, éducateur, philosophe et scientiste. Camphill Village favorise le partage entre les personnes ayant une déficience intellectuelle et des bénévoles.
Fédération internationale des communautés de l'Arche 130 communautés dans le monde, dont 27 au Canada	Pourcentage variable de résidents ayant une déficience intellectuelle.	Habituellement une habitation spécialisée partagée	(a) Créer des maisons où des relations loyales fondées sur la compassion et les éloges sont nourries; (b) changer la société en choisissant de vivre dans une communauté en signe d'espoir et d'amour. Les personnes ayant une déficience et celles qui leur viennent en aide vivent ensemble et sont responsables à parts égales de la vie dans l'habitation et la communauté.

souligné qu'il n'y avait pas de méthode unique de conception des habitations destinées aux personnes ayant une déficience intellectuelle, qui ont toutes leurs préférences personnelles. Toutefois, la recherche a révélé que, sur le plan de l'accessibilité, ces personnes éprouvent des besoins similaires à ceux des familles composées de jeunes enfants.

L'accès aux moyens de transport publics représente un facteur important dans le choix de l'emplacement de l'habitation. Un grand nombre de participants a déclaré ne pas conduire et avoir besoin de moyens de transport pour se déplacer dans la collectivité, accéder aux services et créer des liens. Les participants ont indiqué leur préférence pour des habitations se trouvant à distance de marche d'un dépanneur ou d'un centre commercial. Ils désirent aussi être près de services médicaux pour avoir l'esprit tranquille.

Acceptation et intégration : Dans la recherche, on a mis l'importance sur la participation des personnes atteintes de déficience intellectuelle à l'étape de conception de leur habitation. Au cours des discussions dans les groupes échantillons, tous les participants ont souligné l'importance d'un soutien officialisé en ce qui a trait à l'autonomie possible et au degré d'acceptation susceptible d'être atteint au sein d'une collectivité.

Autorité et prise de décision : Actuellement, les personnes ayant une déficience intellectuelle n'ont aucunement voix au chapitre en ce qui concerne les pièces qu'elles occupent. En mettant à leur disposition des pièces semi-privées (par exemple, des cuisines et des salles de séjour) qu'elles pourront aménager, elles demanderont moins de grandes pièces privées, comme de vastes chambres à coucher.

Les personnes ayant une déficience intellectuelle peuvent être soutenues dans la prise de décision par des gens qui comprennent leurs valeurs, leurs intérêts, leurs talents et leurs aptitudes. Le processus de prise de décision appuyée tire parti de la force ainsi créée et se fonde sur la conviction que toute personne a droit à l'autodétermination.

Bien que l'on n'ait trouvé aucune documentation portant sur le rôle concret que joue la prise de décision appuyée dans les communautés intentionnelles, les documents traitant de la prise de décision appuyée indiquent que ce pourrait être un moyen de faire participer efficacement à l'administration les personnes ayant une déficience et d'exercer de l'autorité en ce qui a trait aux habitations. Signalons toutefois que cette démarche comporte des défis. En effet, la plupart des communautés intentionnelles prennent leurs décisions par consensus, ce qui, souvent, demande beaucoup de temps. En

Tableau 2 Définition d'une maison

Réponses des personnes ayant une déficience intellectuelle	
■ Abordable ■ Confortable ■ Environnement sécuritaire[3] ■ Un lieu où se retirer ■ Intimité ■ Bruit atténué ■ Spacieuse ■ Liberté de faire ce que l'on veut quand on le veut	■ Chaleur ■ Amour ■ Famille ■ Ambiance décontractée ■ Un lieu où se réfugier ■ Un lieu où penser ■ Un lieu où s'adonner à ses passe-temps ■ Un lieu où vivent nos animaux.
Réponses par les membres de la famille	
■ Abordable ■ Confortable ■ Pas de règles ni d'horaires officiels ■ Environnement sécuritaire ■ Un lieu où se retirer ■ Intimité ■ Un lieu où se divertir et recevoir des amis ■ Spacieuse ■ Liberté de faire ce que l'on veut quand on le veut	■ Nourriture ■ Invitant ■ Lieu social ■ Ambiance décontractée ■ Attraits ■ Pas de lieux interdits ■ Très important d'avoir un jardin ■ Un lieu où vivent nos animaux ■ Familier ■ Un milieu favorable ■ Propriété/responsabilité ■ Fonctionnel

englobant la prise de décision appuyée à la structure d'administration, on risque de prolonger la démarche.

On a aussi demandé aux participants de définir une maison, l'utilisation des pièces, la cuisine, la salle de séjour, les aires communes, les pièces privées, les caractéristiques de conception spécialisée ou importante et le type d'habitation.

Définition d'une maison : les participants ont décrit ce qu'est une maison en employant un vaste éventail de mots (voir le tableau 2).

Utilisation des pièces : Les besoins des personnes ayant une déficience intellectuelle semblaient similaires à ceux d'une famille comptant des enfants, à savoir :

- le plus possible d'aires ouvertes pour faciliter les déplacements en profitant d'une vue dégagée et d'un accès;
- de la souplesse afin de pouvoir aménager l'espace pour plusieurs fonctions;
- des pièces privées pour que les personnes puissent s'isoler dans le calme.

Cuisine : La cuisine est considérée comme un espace commun ou semi-privé ayant de nombreuses fonctions, dont la préparation des repas et la socialisation. Les participants préfèrent les aires ouvertes aux îlots, qui sont embêtants et gênent la circulation. Même si les participants ne cuisinent pas (ou qu'ils ne peuvent pas cuisiner), ils accordent de l'importance au caractère fonctionnel de la cuisine.

Salle de séjour : Les participants voient la salle de séjour comme un lieu servant au divertissement (par exemple, regarder la télévision), aux loisirs (par exemple, l'artisanat, la navigation dans Internet), à la prise des repas (par exemple, devant la télévision) et à la socialisation.

Aires communes : Les pièces servant aux réunions sociales sont importantes. Les participants ont déclaré qu'ils utiliseraient une aire commune dotée d'une cuisine et d'un salon réservé aux divertissements (par exemple, une pièce possédant un grand écran de télévision), même si elle servirait plutôt pour socialiser que pour ses appareils.

Pièces privées : Pour les participants, l'utilité des chambres à coucher est bien plus grande que le sommeil ou le retrait dans le calme. Ils désirent de grandes chambres possédant beaucoup de rangement pour leurs effets personnels, des

[3] Les mots employés pour décrire l'environnement sécuritaire sont serrures, systèmes de sécurité, se sentir en sécurité et savoir que nos biens personnels sont protégés.

dispositifs de sécurité supplémentaires et divers meubles permettant de s'adonner à plusieurs activités. Les chercheurs soupçonnent que les participants ont mis trop d'accent sur l'importance des chambres en raison de leurs conditions de vie actuelles, à savoir l'hébergement dans la maison familiale ou dans un logement collectif où leur seule pièce privée est leur chambre.

La sécurité dans les salles de bain représente une grande préoccupation en raison des problèmes de mobilité et du risque de se blesser pendant des crises. Les participants ont indiqué une préférence pour les douches téléphones, les barres d'appui dans une baignoire-douche ou une cabine de douche dont le fond est au niveau du sol et les rideaux de douche pour des raisons de sécurité et d'hygiène.

Les pièces privées servent à regarder la télévision, à utiliser l'ordinateur, à ranger les effets personnels, etc. Regarder la télévision et des films représente un volet important des habitudes sociales mais pour de nombreuses personnes, c'est un passe-temps auquel elles s'adonnent en solitaire.

Les buanderies sont importantes pour assurer la dignité des personnes atteintes d'incontinence.

Caractéristiques de conception spécialisées ou importantes : Les participants ont souligné le besoin de caractéristiques de conception qui tiennent compte des problèmes de mobilité. Parmi les autres caractéristiques de conception spécialisées, signalons :

- Un mobilier durable dont la conception maximise l'accessibilité à la surface utile.
- Une souplesse de l'éclairage — on préfère l'éclairage vertical et l'éclairage mural même si les lampes de table sont acceptables. On considère que les lampes de plancher ne sont pas sécuritaires.
- De grandes fenêtres habillées de toiles opaques sont importantes pour les habitudes de sommeil et d'éveil. On préfère les stores aux rideaux.
- Les espaces de rangement doivent être accessibles aux fauteuils roulants et aux déambulateurs.
- Les cuisines doivent comporter les appareils se trouvant généralement dans une maison moderne. Il est essentiel d'avoir des fours à micro-ondes. On préfère un plan de cuisson à serpentins aux plans de cuisson en céramique ou à gaz. On préfère un four encastré avec porte à ouverture latérale par rapport à la cuisinière traditionnelle.
- On préfère les surfaces dures aux tapis sur les planchers.
- On préfère les manettes et les poignées aux boutons.
- On préfère les robinets à une manette plutôt que la robinetterie à deux poignées pour des raisons de sécurité. Il est important de pouvoir régler la température de l'eau pour ne pas s'ébouillanter.
- Le fait de choisir la couleur de la peinture revêt de l'importance, car il donne l'impression d'être propriétaire de la maison (qu'elle appartienne aux occupants ou qu'elle soit louée).
- L'accès à l'extérieur est important. On préfère les jardins et les terasses aux balcons. Les participants étaient préoccupés par la sécurité en ce qui concerne les balcons.

Type d'habitation : Les participants semblaient préférer le type d'habitation qu'ils connaissent le mieux, c'est-à-dire les bâtiments de type appartement (avec ascenseurs) ou les maisons dans lesquelles ils ont une chambre.

Différence entre les réponses des membres de la famille et celles des personnes atteintes de déficience

- Selon les membres des familles, la personne mangera et socialisera dans l'aire commune plutôt que dans sa chambre. Par conséquent, seul un petit nombre d'appareils est nécessaire dans la cuisine (par exemple, un four à micro-ondes et un mini-réfrigérateur).
- Les membres des familles se disaient préoccupés par la sécurité et ont mentionné que la personne désirerait un système de sécurité doté d'un bouton de panique, à actionner en cas d'urgence dans la cuisine ou la salle de bains.
- Les membres des familles ont suggéré de munir les robinets d'une minuterie pour éviter une utilisation excessive d'eau et de régulateurs d'eau chaude pour éviter que la personne s'ébouillante.
- Les membres des familles ont accordé une plus grande importance aux appareils pour la cuisine, à l'aménagement et à l'espace que les personnes ayant une déficience.
- Selon les membres des familles, les ordinateurs devraient se trouver dans l'aire commune pour pouvoir en surveiller l'utilisation.

- Un grand nombre de membres des familles désiraient que la personne dispose d'un logement à deux chambres pour pouvoir accueillir un accompagnateur.
- Les membres des familles ont manifesté un intérêt beaucoup plus grand envers l'habitation collective[4] que les personnes ayant une déficience.

CONCLUSIONS

- On a constaté que les besoins en habitation d'une personne ayant une déficience intellectuelle sont similaires à ceux d'une famille avec des enfants.
- La façon dont les membres de la collectivité perçoivent la déficience influence le degré d'acceptation des personnes atteintes.
- Ce qui distingue la communauté intentionnelle des autres habitations, c'est la vision partagée de ses membres relativement aux valeurs de la collectivité. Généralement, les communautés intentionnelles soulignent la nécessité de faire participer tous les membres de la collectivité aux processus de gestion et de décision.
- On a constaté que la réussite de l'intégration des personnes ayant une déficience intellectuelle aux communautés intentionnelles dépendait dans une certaine mesure des facteurs suivants :
  - un sentiment d'appartenance à la communauté et l'impression d'être propriétaire du logement;
  - un pourcentage important de résidents ayant une déficience intellectuelle afin de concentrer l'administration et la planification sur leurs besoins;
  - des conditions de logement bien établies.
- Il est essentiel de reconnaître que les personnes aynat une déficience intellectuelle ont le droit d'exprimer leurs opinions et de participer à la gestion des affaires de la collectivité afin qu'elles soient acceptées comme des égaux au sein de la communauté intentionnelle. Une des façons d'y arriver consiste à voir le rôle que peut jouer la prise de décision appuyée dans le processus décisionnel. La prise de décision appuyée doit tirer parti des forces pour être axée sur les capacités de la personne plutôt que sur ses incapacités.
- Les membres de la communauté intentionnelle peuvent avoir l'impression que leurs investissements sont risqués quand la prise de décision appuyée est intégrée à l'administration. Il est donc important d'inclure aux règlements des mesures d'atténuation des risques.

Le tableau 3 résume les lignes directrices sur la conception universelle et les points dont il faut tenir compte qui ont été relevés à la lecture de la documentation et au cours de l'analyse des résultats tirés de la recherche principale.

[4] **Habitation collective :** L'habitation collective est une forme légèrement moins institutionnelle d'habitation. Elle comprend les maisons de repos, les résidences supervisées et les foyers collectifs. Généralement, on peut y demander des services de soutien et des soins, y prendre quotidiennement des repas préparés et servis dans une salle à manger communautaire, y bénéficier de services de transport, obtenir de l'aide pour la lessive et le ménage, participer à des activités récréatives et à des programmes de jour et y être protégé par des mesures de sécurité.

Tableau 3 Les sept principes de la conception universelle

Principe	Explications	Lignes directrices	Points dont il faut tenir compte/tendances
Utilisation équitable	La conception est utile et convient à des gens ayant des capacités diverses.	Fournir les mêmes moyens d'utilisation à tous les résidents, identiques chaque fois que c'est possible et équivalents dans le cas contraire. Concevoir les unités se trouvant au deuxième étage en songeant aux personnes n'éprouvant aucun problème de mobilité. Éviter de mettre à part ou de stigmatiser les utilisateurs. Les dispositions prises relativement à l'intimité et à la sécurité doivent viser également tous les utilisateurs. Rendre la conception attrayante pour tous les utilisateurs.	Veiller à ce que les logements soient dotés d'installations permettant d'accueillir divers types de résidents (peu importe les circonstances ou les capacités). Choisir l'emplacement du projet parmi des habitations dont le mode d'occupation est mixte, où les revenus sont mixtes et dans un parc résidentiel où vivent des personnes de divers âges. Offrir de l'intimité et plusieurs degrés de sécurité aux résidents. Faire participer les membres à la conception.
Souplesse d'utilisation	La conception tient compte d'un vaste éventail de préférences et de capacités personnelles.	Offrir un choix de méthodes d'utilisation.	Donner la liberté de personnaliser les unités. Tenir compte de l'accessibilité dans la conception des entrées et des couloirs.
Utilisation simple et intuitive	L'utilisation de l'aménagement est facile à comprendre, peu importe l'expérience de l'utilisateur, ses connaissances, ses aptitudes à s'exprimer ou son degré de concentration.	Éliminer la complexité non nécessaire. Respecter les attentes de l'utilisateur et son intuition. Tenir compte de tous les degrés de littératie et des aptitudes à s'exprimer. Organiser l'information en fonction de son importance. Fournir efficacement des instructions et des commentaires pendant et après la réalisation d'une tâche.	Le projet est conçu avec un degré de prévisibilité pour faciliter la circulation et conférer de la simplicité dans les angles. Les plans d'étage sont usuels. L'innovation se trouve dans les caractéristiques fonctionnelles ajoutées aux surfaces habitables. Les caractéristiques fonctionnelles ajoutées aux surfaces habitables fournissent des repères spatiaux ou visuels.
Information perceptible	La conception transmet efficacement l'information nécessaire à l'utilisateur, peu importe les conditions ambiantes ou les capacités sensorielles de l'utilisateur.	Employer divers modes de communication (pictural, verbal, tactile) pour présenter l'information essentielle de façon redondante. Prévoir un contraste adéquat entre l'information essentielle et ce qui l'entoure. Maximiser la lisibilité de l'information essentielle. Distinguer les éléments en les décrivant (c'est-à-dire faciliter la communication d'instructions ou de directives). Voilà qui permet de faire une différenciation et de faciliter l'orientation. Assurer la compatibilité de diverses techniques ou de divers dispositifs utilisés par des personnes ayant des restrictions sensorielles.	Les renseignements sur la préparation aux situations d'urgence et les dangers seront affichés bien en évidence à l'intention des locataires et des invités, sur des supports reconnus internationalement. Le projet est conçu avec un degré de prévisibilité. Les renseignements sur la préparation aux situations d'urgence seront mis en évidence par rapport aux autres caractéristiques du projet. Les caractéristiques fonctionnelles ajoutées aux surfaces habitables fournissent des repères spatiaux ou visuels. Les caractéristiques et les plans des pièces ne sont pas exactement les mêmes, mais les plans restent simples.
Tolérance à l'erreur	La conception réduit les dangers et les conséquences indésirables de gestes accidentels ou involontaires.	Organiser les éléments pour réduire les dangers et les erreurs : rendre les éléments les plus utilisés les plus accessibles, et éliminer, isoler ou couvrir ceux qui présentent des dangers. Avertir des dangers et des erreurs. Fournir des dispositifs à sécurité intégrée. Décourager les gestes posés inconsciemment dans les tâches qui exigent de la vigilance.	La conception et la décoration comprennent des éléments qui « pardonnent » une utilisation inappropriée. La participation du membre à l'étape de la conception a assuré que les normes les plus élevées en matière d'accessibilité sont équilibrées par rapport aux désirs d'habitabilité. Les renseignements sur la préparation aux situations d'urgence et les dangers seront affichés bien en évidence à l'intention des locataires et des invités, sur des supports reconnus internationalement. Le modèle d'habitation prévoit un mécanisme de type « surveillance de quartier » pour assurer la protection des locataires.
Faible effort physique	La conception permet une utilisation efficace et confortable et entraîne une fatigue minimale.	Permettre à l'utilisateur de garder le corps en position neutre. Utiliser une force raisonnable pour le fonctionnement. Réduire les gestes répétés. Réduire l'effort physique soutenu.	La participation du membre à l'étape de la conception a permis d'équilibrer accessibilité et habitabilité. Les caractéristiques d'accessibilité conférées au projet se fondent sur les normes de l'industrie pour les personnes atteintes de problèmes de mobilité.
Espace pour s'approcher des installations et les utiliser	Un espace suffisant est prévu pour s'approcher des éléments, les atteindre et les manipuler, peu importe l'utilisateur.	Dégager la vue pour qu'un utilisateur assis ou debout puisse repérer les éléments importants. Faciliter l'accès à tous les éléments pour un utilisateur assis ou debout. Prévoir assez d'espace pour l'utilisation d'appareils fonctionnels ou de l'aide personnelle.	La participation du membre à l'étape de la conception et la personnalisation des unités a accru l'habitabilité. L'accès des fauteuils roulants a été prévu dans les plans de toutes les pièces de l'ensemble.

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1. Introduction

Although there is now a large and growing body of literature on the housing needs of individuals with *physical* disabilities, there is very little research or published information on the housing needs of those with *intellectual* disabilities. This project, undertaken by the Saskatoon Housing Initiatives Partnership (SHIP) and Saskatchewan Association for Community Living (SACL), was designed to help address this gap in knowledge.

The project proponents were especially interested in the potential of intentional communities[1] to meet the housing needs of individuals with intellectual disabilities. They anticipated that, because intentional communities tend to place a high value on inclusion, they would likely offer a supportive and accessible environment for all people, including those with disabilities. The researchers wanted to understand the implications of including individuals with an intellectual disability in an intentional community setting and identify the supports needed to ensure their meaningful involvement in governance and decision-making.

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 also in terms of the community or neighbourhood setting;
2) the level of *acceptance* of persons with intellectual disabilities by other members of an intentional community; and
3) the impacts on governance or management *authority* arising from including persons with intellectual disabilities in an intentional community.

[1] See Section 3.1, Definitions, page 6

The researchers conducted a literature review and also collected primary data through focus groups and surveys of a sample of individuals with intellectual disabilities and/or their family members living in the province of Saskatchewan.

In undertaking this research, SHIP and SACL intended to expand the existing knowledge base of housing needs of individuals with an intellectual disability. They anticipated the knowledge gained from this project would apply to other population groups with common support needs for daily living tasks and would be transferable to other locations in the country.

This report summarizes the research. It is organized in eight sections, beginning with this introduction. Section 2 provides background information on the proponents, the topic in general and a description of the independent living model. Section 3 outlines the scope of the research including definitions, objectives and assumptions. Section 4 contains the literature review, followed by a description of the research methodology in Section 5. Section 6 reports on the research findings and Section 7 presents the conclusions based on the research. References consulted for the project are listed in Section 8.

As part of the project, the researchers produced a “concept map” or set of guidelines for providing housing for people with intellectual disabilities. The document, *Housing People With Intellectual Disabilities: identifying Relevant and Appropriate Uses of Physical Spaces,* contains a wealth of information including images and photographs designed to assist organizations, family members and others in designing homes for individuals with an intellectual disability. A copy of the concept map is included as Appendix 1. Other supplementary materials including research ethics, letter of introduction, consent forms, the Powerpoint presentation made to the focus groups and a copy of the survey are also provided as appendices to this report.

2. Background

2.1 Proponents

The research project was a joint initiative of the Saskatchewan Association for Community Living (SACL) and the Saskatoon Housing Initiatives Partnership (SHIP).

SACL is a provincial non-profit, charitable organization dedicated to promoting the active participation of people with intellectual disabilities in all aspects of community life. The mission of the organization is:

> *To ensure that those citizens of Saskatchewan who have intellectual disabilities are full, active and valued members of society and that they have worthwhile opportunities and choices in all aspects of daily life.*[2]

In fulfilling its mission, SACL is guided by the following principles:[3]

- People of all ages with an intellectual disability are citizens of their country, no less entitled than their fellow citizens to consideration, respect and protection under the law.
- People with an intellectual disability shall live, learn, work and enjoy life in the community and should be accepted and valued as any other citizen is accepted or valued.
- People with an intellectual disability should be provided with all assistance necessary to enable them to make the fullest use of their abilities.
- Intellectual disability shall not justify any form of discrimination.
- The ultimate basis for all decisions about a person with a disability must be about what is right for the individual and should always be culturally appropriate for that person.
- Should any restrictions or special provisions be deemed essential for the welfare of a person with an intellectual disability, these must be the least

[2] For more information see the SACL website - http://www.sacl.org/webapp/DesktopDefault.aspx
[3] ibid

> restrictive possible and must be associated with a program designed to remove such restrictions as quickly as possible.

The second proponent, the Saskatoon Housing Initiatives Partnership (SHIP) was formed in 1999 by a coalition of citizens and organizations concerned with the impact of poor quality housing on the well being of community members. SHIP believes that "investing in housing is a way of investing in the quality of life of Saskatoon"[4]. Its mission is:

> *. . . to support initiatives that invest in community stability through providing affordable housing and provide a sense of individual or community ownership*.[5]

These two groups, with their overlapping interests and commitment to meeting the housing needs of individuals with an intellectual disability, were well positioned to take on this research.

2.2 Historical overview

There has been a major shift, over the past hundred years, in the way people with intellectual disabilities have been viewed by Western Society. At the turn of the twentieth century, individuals with an intellectual disability were assumed to have a medical condition that needed to be treated and managed by a doctor. During this time, as Bodnar and Coflin (2004) observed: "(m)ost people who had a disability were seen as incurable and thus the only thing we could do was provide basic substance for (them)".[6] Typically, they were housed in asylums or institutions where they were considered to be under the protection of their doctor and, therefore, had no right to make decisions for themselves.

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[4] For more information, see: http://www.city.saskatoon.sk.ca/org/city_planning/affordable_housing/saskatoon_housing_initiatives.asp

[5] ibid

[6] Bodnar, F., Coflin, J. (2004). Supported Decision Making Handbook. Regina, SK.: Regina and District Association for Community Living, p. 10.

By the middle of the twentieth century, the awareness grew that people with disabilities were not ill and did not need constant supervision by medical staff. It was recognized that people with disabilities could live in community settings as long as they had financial support. The *welfare model* that developed in this era assumed people with disabilities were unable to earn a living and were dependent upon government for financial support. Consequently, although they could live in community settings, they were still not treated as independent individuals able to make their own decisions. Government bodies determined what was best for people with disabilities.

Over time, a new model, the *advocacy model* developed as a result of parents of children with disabilities pressing for change in the way their relatives were treated by society. Instead of doctors or government determining what was best for individuals with a disability, the advocacy model allowed relatives or others who were close to the disabled person to speak or advocate on their behalf.

By the end of the twentieth century, a new model, the *independent living model*, largely replaced the advocacy model. The independent living model differs from all previous models in that it recognizes people with disabilities have the right to freely live the way they choose. Principles of this model include the recognition that:

1) the person making the decision is in control
2) people have the right to take risk
3) individuals with a disability are not “sick” and should not be treated as though they are
4) people have the right to self-determination – individuals can follow their own goals and dreams and make their own decisions
5) individuals with a disability are able to make choices
6) all people are equal
7) all people have dignity
8) all people have the right to service and support.[7]

[7] Bodnar and Coflin (2004), op.cit, p. 15.

2.3 The independent living model

Although the independent living model has emerged as the preferred way to support individuals with an intellectual disability, there has been little research to identify the specific supportive elements or design features needed to meet their housing needs and integrate them into a mixed-demographic housing development or community. This project focused on three key components considered essential in meeting the housing needs of individuals with an intellectual disability:

1) the *accessibility* of the home, both in terms of the specific design features of the home itself and also in terms of the community or neighbourhood setting. What design features need to be included in the home and in the surrounding community to ensure housing is accessible to individuals with an intellectual disability?
2) the level of *acceptance* of persons with intellectual disabilities in an intentional community. What is needed to promote acceptance and inclusion within the community?
3) the impacts on governance or management *authority* arising from including persons with intellectual disabilities in an intentional community. What decision-making supports are needed to ensure individuals with a disability are as empowered as possible and have the authority to exercise choice over their living environment?

These three elements of *accessibility*, *acceptance* and *authority* were explored in the research with a particular focus on the potential of intentional communities to respond to these needs.

3. Scope of Work

3.1 Definitions

Intellectual disability: According to the Saskatchewan Association for Community Living (SACL):

> *An intellectual disability is a limited ability to learn. It sometimes causes difficulty in coping with the demands of daily life. It is a condition which is usually present from birth or before the age of 18. There are many causes and it is not the same as mental or psychiatric illness.*
>
> *Historically, society referred to people with intellectual disabilities or mental handicap (formerly known as mental retardation) with stigmatizing names. For this reason, we always refer to people first, and then their disability. Preferred terms are "people who have an intellectual disability" or "people who have a developmental disability" when it is necessary to label people at all. We were once known as the Saskatchewan Association for the Mentally Retarded; people with intellectual disabilities told us that was hurtful and demeaning. So we changed. Our name reflects the fact we are dedicated to the idea that people deserve a good life in the community.*[8]

Intentional communities: According to the Intentional Communities website, intentional communities is "an inclusive term for ecovillages, cohousing projects, residential land trusts, communes, student co-ops, urban housing cooperatives and other housing projects where people strive together with a common vision".[9] What sets the intentional community apart from other housing options is the shared vision among members in regard to community values. Typically, intentional communities stress the need for inclusion of all community members in governance and decision-making processes.

Supported decision-making: "a process of acting with an individual to discover their values, interests, talents and gifts in order to support them to choose the way they want to live their life".[10]

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[8] See: http://www.sacl.org/webapp/DesktopDefault.aspx?tabindex=0&tabid=207
[9] See: http://www.ic.org/
[10] Bodnar and Coflin (2004), op. cit.

3.2 Objectives

The research was designed in response to a gap in knowledge about the housing needs of individuals with intellectual disabilities. Specifically, the project had three objectives:

1) To identify how people with an intellectual disability use and understand living spaces (i.e., typical components of housing such as kitchen spaces and bedrooms) and the design features needed in the home to accommodate their needs;
2) To identify the design features needed in the community setting in which the housing is located to ensure accessibility; and
3) To gain an understanding of the supports required to meaningfully engage individuals with an intellectual disability in decision-making processes related to the operations and management of housing in intentional communities.

3.3 Assumptions

The project was based on the expectation that intentional communities may be in a good position to meet the housing needs of individuals with an intellectual disability as they typically place a high value on the principle of inclusion. The research was based on the following beliefs:

- Accessible housing for all people is a critical component of quality of life, both at the individual and societal level. Accessible housing is not a concept exclusively for those with a physical disability but for all segments of the population with accessibility challenges (e.g. the aged, those with mental health challenges, those with an intellectual disability, among others).
- Persons with intellectual disabilities have the right to voice their opinions and have the right to participate as equals in community decision-making structures. One way to facilitate inclusive decision-making may be to

incorporate “supported decision-making” processes into the governance structure of housing communities.

Recognizing that individuals with an intellectual disability may or may not have physical challenges, it was anticipated that some of the following features might contribute to independence:

- built-in simplicity of floor-layout and ease of maintenance
- enhanced ventilation, air conditioning, enhanced lighting, sunlight, window space, soundproofing, enhanced security, additional cupboard space to minimize visual clutter
- common areas to promote communications and relationships
- proximity to bus routes, shopping, and services (perhaps even within eyesight of front door) . For persons with an intellectual disability, it may be that accessibility of services needs to be more closely linked, or even part of, a housing development in order to foster accessibility
- reduced neighbourhood distractions, quiet neighbourhood, enhanced neighbourhood safety
- space for live-in support workers if necessary or helpful
- supportive neighbours, friends and family.

The literature review and the primary research were expected to yield some information to support or challenge these assumptions and expectations.

4. Literature Review

In conducting the literature review, the researchers accessed publications and web sites from academic, governmental and non-governmental organizations, both within Canada and internationally. As expected, they found very little literature dealing directly with the housing needs of persons with an intellectual disability.

The results of the literature review are summarized below according to the following topics: (1) Housing models, including intentional communities; (2) Accessibility: design features of the home and community that promote accessibility; (3) Acceptance and inclusion: social acceptance of persons with a disability; and (4) Authority and decision-making: models that support inclusion in decision-making.

4.1 Housing models

The literature reviewed on housing models covered institutions, congregate living, supported living and intentional communities. It also included articles on homeownership and housing type. Based on the case studies in the literature, housing type appeared to have little bearing on the success or failure of inclusion of persons with an intellectual disability. What was of greater significance was the scale and size of the residence. According to Hatton and Emerson (1996), smaller community-based homes were shown to provide more positive outcomes and greater autonomy for persons with an intellectual disability.

Institutions: Institutions have a significantly reduced role in the continuum of housing options for persons with an intellectual disability, both in Canada and around the world. The trend to deinstitutionalize is documented by Simmons and Watson (1999): they found the number of persons in institutions declined between 1970 and 1995 as follows (expressed as a rate per 10,000 population):

- 150 reduced to under 50 in Sweden

- 120 reduced to 25 in England
- 90 reduced to 40 in Wales
- 90 reduced to 25 in the United States
- 140 reduced to 10 in Norway[11]

Institutions are no longer considered an appropriate housing option for persons with an intellectual disability. The Canadian Association For Community Living and People First of Canada jointly established *Institution Watch* to build support for deinstitutionalization. This philosophy is described by *Institution Watch* as follows:

> *In Canada today, many thousands of Canadians with intellectual disabilities remain trapped in large segregated institutions - inappropriately and unjustifiably segregated from society. They remain, for the most part, hidden and removed from the mainstream of society despite a collective knowledge, based on research and practice over the past 30 years, that with proper community based supports all persons with intellectual disabilities thrive in the community. They remain in these institutions as a result of inaction by governments and communities.*[12]

In Canada, institutions typically provide a congregated living environment with a high level of support service provision including meals, day programming, qualified nursing care and, often, other medical services.

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 including 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.

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[11] Simmons, Ken and Watson, Debby (1999). The View From Arthurs Seat: A Literature Review of Housing and Support Options 'Beyond Scotland'. Bristol: Norah Fry Research Centre, Scottish Executive Central Research Unit.

[12] See http://www.institutionwatch.ca/petition-app

Supported Living: Supported living is "independent housing in the community that is coupled with the provision of support" either from service providers or from informal personal support networks (e.g. families and friends).[13] Supported living environments focus on the individuals rather than organizations, on inclusion rather than social homogeneity or isolation, and on autonomy rather than control. According to Rog (2004), this form of housing and support gained popularity in the 1990's, largely due to reports of the positive outcomes from early experiences with this model. However, she cautions that the evidence in these studies may be largely anecdotal and emphasizes the need for a rigorous research methodology to inform the literature and develop best practices for service providers.

Stancliffe et al. (2004) report that individuals with an intellectual disability living in a community setting "experienced a greater variety and frequency of community-based and social activities than participants who lived in "traditional" (congregated) setting".[14] However, they caution, much like Rog, that there is a lack of standardized approaches to assessing the outcomes associated with supported living options.

Racino (2002) documents the changes in the provision of supported housing over the past 15 years. Using examples from various projects in the State of New Hampshire, Racino builds a case for the state to play a key role in developing policy and programs for supported living and housing options. Supported housing in New Hampshire originated in the mid 1990's. State-owned or sponsored institutions were being shut down and local area agencies were created and charged with the responsibility of providing services to support individuals to live within a community setting. Part of the new mandate was to

[13] Rog, J. (2004). "The Evidence on Supported Housing." Psychiatric Rehabilitation Journal 27(3): 334-344, p. 334

[14] Stancliffe, R., Emerson, E. Lakin, C. (2004). "Residential Supports" in The International Handbook of Applied Research in Intellectual Disabilities E. Emerson, C. Hatton, T. Thompson, T. Parmenter (eds) London: John Wiley and Sons. Pgs 459-478, p. 461.

allow individuals to choose where and how they wanted to live. Racino found that individuals with intellectual disabilities could successfully live in the community on their own if they had the proper supports available to them.

Intentional communities: Intentional communities do not conform to a single model or definition - there are many different types of intentional communities including "ecovillages, cohousing projects, residential land trusts, communes, student co-ops, urban housing cooperatives and other housing projects where people strive together with a common vision".[15] What sets the intentional community apart from other housing options is the shared vision among community members in terms of community values. Typically, intentional communities share the following characteristics:

- Shared vision of the community's identity, principles, and purpose
- A common meeting place
- Governance structures that are equitable
- Active member engagement in the community[16]

Table 1 describes five intentional communities that include individuals with an intellectual disability.

Table 1
Intentional Communities Including Individuals with an Intellectual Disability

Community	Number of Residents	Type of housing	Mission Statement
Innisfree Village Crozet, Virginia, United States	39 of 68 (approximately 50%) residents have intellectual disabilities	10 village houses and 2 houses	Innisfree mission is to create and support a life of respect, empowerment, and creativity for persons with special needs.
Rougemont Cooperative Durham Region, Ontario, Canada	6 of 250 residents have an intellectual disability	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),	1 in 12 residents has an intellectual disability and live-	8 rental townhouses and 4 private homes	Individuals committed to environmental responsibility, social justice, and community

[15] See http://www.ic.org/
[16] ibid

Australia	in supporter		values.
Camphill Village 105 locations around the world	Varies by community with a mix of ages and abilities. Camphill Village is about life-sharing between persons with an intellectual disability and volunteers. A varying percentage of residents have an intellectual disability.	Varies, communities typically shared purpose-built home within a rural, agricultural setting	The underlying principles and striving of the Camphill Communities is based on Anthroposophy, a modern path of spirituality brought through Rudolf Steiner (1861-1925) humanitarian, educator, philosopher and scientist
International Federation of L'Arche Communities 130 Communities worldwide; 27 communities in Canada	At L'Arche, people with disabilities, and those who assist them, live together and are equally responsible for the life of their home and community. A varying percentage of residents have an intellectual disability.	Typically shared purpose-built home	The L'Arche mission is: (a) to create homes where faithful relationships based on forgiveness and celebration are nurtured; (b) to change society by choosing to live in community as a sign of hope and love

The successful inclusion of individuals with an intellectual disability in these communities is reliant to some degree upon the following factors:

- 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
- Well-established supported living arrangements
- Volunteer support.

The literature review also included two articles on the meaning of homeownership to individuals with an intellectual disability. Hagner et al. (2006) examined six homeownership programs in the United States and interviewed seven homeowners with an intellectual disability. Four interviewees owned single-family dwellings, one couple owned a condominium, and one person was

a member of a housing co-operative. Themes emerging from the study included choices involved in selecting a house, the advantages and disadvantages of homeownership, financial barriers, and community relationships.

Hagner et al. noted that homeownership has three relevant dimensions:

- Individuals experience a sense of place, inhabiting the residence in a comfortable and personalized way
- Individuals control the home and the support they need to live there
- Individuals feel secure and stable in their residence.[17]

The single-most important reason individuals wanted to own their own homes was to gain "more choice and control in their lives".[18] The selection criteria for individual housing choices included:

- Close proximity to work or to volunteering opportunities
- More space
- Safer neighbourhood
- Opportunity to own a pet[19]

Although homeownership was preferred over being a renter or living in a congregate facility, several disadvantages of homeownership were identified. These included the stress of mortgage payments or the need to do their own repairs. Hagner et al. (2006) suggest what is needed to aid people in achieving homeownership is the inclusion of long-term flexible supports (support networks and/or service plans) that enable individuals with an intellectual disability to obtain and retain homeownership.

Harrison and Davis (2001) identified two keys for finding appropriate housing options for individuals with an intellectual disability: (1) the physical

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[17] Hagner etal, (2006), Meaning of Homeownership for Individuals With Developmental Disabilities: A Qualitative Study, p. 296 See: http://lib.bioinfo.pl/auth:Hagner,D

[18] Ibid, p. 297
[19] ibid, p. 298

characteristics of the living space and (2) administration processes and financial aspects. They point out that individuals with an intellectual disability often have limited financial means, which further limits their housing choices.

4.2 Accessibility

The United Nations Program on Disability, "UN *enable*", emphasizes the importance of accessibility:

> *Accessibility is about giving equal access to everyone. Without being able to access the facilities and services found in the community, persons with disabilities will never be fully included. In most societies, however, there are innumerable obstacles and barriers that hinder persons with disabilities. These include such things as stairs, lack of information in accessible formats such as Braille and sign language, and community services provided in a form which persons with disabilities are not able to understand.*[20]

The 1999 *International Seminar on Environmental Accessibility,* sponsored by UN *enable*, advocated, among other things, for programs aimed at making the physical environment accessible.[21]

Housing accessibility for persons with intellectual disabilities can be related to several areas: the specific physical design features of the building; the neighbourhood or community setting where the house is located; and the level of supports provided in the living environment. The literature review included literature on these three aspects of accessibility:

1) Accessible homes - Design features of the home that facilitate maximum independence and quality of life. This includes the actual physical design and layout of the home as well as the design of products and features used in the home, such as appliances, door handles, faucets etc.

[20] From: http://www.un.org/esa/socdev/enable/disacc.htm
[21] From: http://www.un.org/esa/socdev/enable/disisea0.htm

2) Accessible community - Design features of the community or neighbourhood where the home is located. This includes proximity of services, transportation networks etc.
3) "Supported Living" Environments – The role supported living environments can play in increasing accessibility.

4.2.1 Design features of the home

Emphasizing the importance of accessibility in the home environment, Harrison and Davis (2001) suggest that a poorly designed space "inhibits effective self-management" of conditions and "may further exacerbate a condition".

The importance of accessibility for all people is emphasized in the large and growing body of literature on the concept of universal design. Ron Mace, one of the leaders of the universal design movement, defines universal design as:

> . . . *the design of products and environments to be useable by all people, to the greatest extent possible, without the need for adaptation or specialized design*.[22]

Mace et al (2000) point out a key distinction between the concept of "accessible" design or "barrier-free" design and the more inclusive concept of universal design: universal design targets all people and all buildings, while accessible design requirements specified by building codes or standards are aimed at benefiting only some people (typically, individuals with mobility limitations).[23]

Universal design embodies the following seven principles:

1) Equitable Use: The design is useful and marketable to people with diverse abilities and does not disadvantage or stigmatize any group of users.

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[22] See: http://www.universaldesign.com/

[23] The Centre for Universal Design. (2000). *Universal design: housing for the lifespan of all people*. Raleigh, NC: NC State University, p. 3. Available online at: http://www.design.ncsu.edu/cud/pubs_p/docs/housing%20for%20lifespan.pdf Accessed September 2007.

2) Flexibility in Use: The design accommodates a wide range of individual preferences and abilities.
3) 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.
4) Perceptible Information: The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
5) Tolerance for Error: The design minimizes hazards and the adverse consequences of accidental or unintended actions.
6) Low Physical Effort: The design can be used efficiently and comfortably and with a minimum of fatigue.
7) Appropriate Size and Space for Approach and Use: Appropriate size and space is provided for approach, reach, manipulation and use, regardless of the user's body size, posture, or mobility.[24]

Mace et al (2000) are strong advocates of universal design, suggesting it is:

> *. . . a sensible and economical way to reconcile the artistic integrity of a design with human needs in the environment. Solutions which result in no additional cost and no noticeable change in appearance can come about from knowledge about people, simple planning and careful selection of conventional products*[25]

Vanderheiden and Tobias (2000) note that universal design principles increase the accessibility of products in two ways: (1) by designing products that are flexible enough they can be used by people with a wide range of abilities and (2) by designing products that are compatible with available assistive technologies so they are accessible by people using these technologies.

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[24] www.design.ncsu

[25] Mace, R.L., Hardie, G.J., Place, J.P. (1991). "Accessible Environments: Toward Universal Design." In Design Intervention: toward a more humane architecture. W.E. Preiser, J.C. Vischer, E.T. White (Eds.). New York: Van Nostrand Reinhold.

4.2.2 Design features of the community/neighbourhood setting

Accessibility of housing refers not only to the physical design of the home and its appliances, products etc., but also to the surrounding landscape and community setting. Cummins and Lau (2003), suggest the immediate surroundings should foster a sense of community connectedness, personal interdependency and sense of belonging - "the feeling that one is part of a readily available, supportive and dependable structure".[26] The community setting should provide residents with opportunities to access a variety of shops and services without having to travel great distances and should be connected to transportation routes.

4.2.3 "Supported living" environments

"Supported living" refers to adaptations and supports that enable individuals with an intellectual disability to participate more fully in society. The concept is based on the recognition that some people require assistance to exercise their right to choose how, where, and with whom they live. A supported living environment respects independence by accommodating specialized needs through physical and social adaptations. According to Simmons and Watson (1999), supported living is premised on the idea that "nobody should be seen as 'too disabled' to live in their own home".

Research by Racino (2002) confirms the expectation that individuals with an intellectual disability can successfully live on their own if they are provided with the necessary supports. Supports include the hiring of personal aides, close working relationships with caseworkers and the opportunity to develop relationships with neighbours and other community members.

The Southampton City Council in the United Kingdom identifies nine principles of a supported living environment:

1. I choose who I live with

[26] Cummins, R.A., Lau, A.L.D. (2003). "Community Integration or Community Exposure? A review and discussion in relation to People with an Intellectual Disability." Journal of Applied Research in Intellectual Disabilities 16(2): 145-157, p. 151.

2. I choose where I live
3. I choose who supports me
4. I choose how I am supported
5. I choose what happens in my own home
6. I have my own home
7. I make friendships and relationships with people on my terms
8. I am supported to be healthy and safe on my terms
9. I have the same rights and responsibilities as other citizens.[27]

Harrison and Davis (2001) advocate a “person-centred" approach to meeting housing needs that provides the individual with “choice and support” in their homes.

> *Integral with the ideal of people-centred services is the theme of independence. This does not imply performing every task directly for oneself, but involves having control over one’s life, having assistance as and when required and exercising control over the way help is planned and delivered*.[28]

4.3 Acceptance and inclusion

In addition to accessibility, a second element essential for meeting the housing needs of individuals with an intellectual disability, or the housing needs of anyone, for that matter, is *acceptance and inclusion* within the community. The literature on inclusion identifies the following key beliefs:

- Inclusion is about all of us
- Inclusion is about living full lives and about learning to live together
- Inclusion treasures diversity and builds community
- Inclusion is about our 'abilities' - our gifts and how to share them.[29]

SHIP and SACL believe that the extent to which community-based housing can meet the needs of individuals with an intellectual disability depends upon mutual acceptance and the willingness of both the individuals with the disability and the

[27] See: http://www.southampton.gov.uk/housing
[28] Harrison and Davis (2001). Housing, social policy and difference. Bristol, UK: The Policy Press, p. 126.
[29] From: http://www.inclusion.com/inclusion.html

members of the broader society to enter into relationships with each other. This belief is also found in the literature. Schwartz and Rabinovitz (2001) stressed the importance of relationships with neighbours:

> *The neighbourhood is an important social context in the lives of people with ID's [intellectual disabilities] living in the community. It is where they spend most of their time. Ideally, neighbours can become acquaintances and friends and community activities can provide important social experiences*.[30]

Schwartz and Rabinovitz (2001) found that neighbours who took an active interest in visiting or forming friendships with individuals with an intellectual disability were more accepting of them. The most accepting neighbours were those who had family members also affected by some form of disability. Neighbours who had small children in their household were the most hesitant to have individuals with an intellectual disability as neighbours. This fear was heightened if the housing complex was perceived as being large.

The literature suggests that the way the community members perceive disability has an influence on how well individuals with a disability are accepted within the community. To explore this concept more fully, four models of viewing disability were reviewed: the medical model, the social model, social role valorization and the affirmation model.

The *medical model* of disability views the disabled person as the problem:

> *The 'medical model' of disability sees the disabled person as the problem. We are to be adapted to fit into the world as it is. If this is not possible, then we are shut away in some specialised institution or isolated at home, where only our most basic needs are met. The emphasis is on dependence, backed up by the stereotypes of disability that call forth pity, fear and patronising attitudes. Usually the focus is on the impairment rather than the needs of the person.* [31]

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[30] Schwartz, C. Rabibovitz, S. (2001). "Residential Facilities in the Community for People with Intellectual Disabilities: how neighbours' perceptions are affected by the interaction of facility and neighbour variables. *Journal of Applied Research in Intellectual Disabilities* **14**, p. 100.
[31] See: http://inclusion.uwe.ac.uk/inclusionweek/articles/socmod.htm

In contrast to the medical model, the *social model of disability* views the barriers to participation as the problem, rather than the individual with the impairment. Instead of viewing disability as a personal limitation of the individual, it is seen as a failure of society to ensure accessibility and acceptance. Swain and French (2000) offer the following graphic illustration of the social model of disability (see Figure 1).

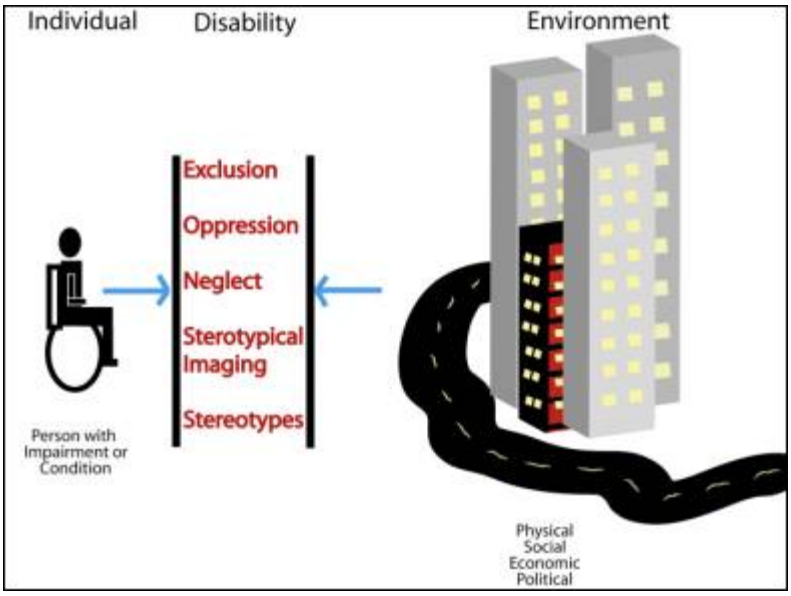

Figure 1: The Social Model of Disability

The *Social Role Valorisation (SRV)* model of disability is based on the view that every member of society has inherent "gifts" or social value. Adherents of this model focus on building acceptance of individuals with an intellectual disability by identifying and promoting their inherent "gifts". While positive in intent, Inglis, Cooper, Oxby and Robinson (2004) suggest that the model may not always lead to positive outcomes as it can place overwhelming pressure on individuals with a disability:

> *. . . we may create pressures on them [those with learning disabilities] that are immense. Although choice is included in all policies and documents underpinning [the practice of support workers and nurses], it is often difficult to offer real choice to*

> *clients because we have to spend so much time teaching new valued roles, encouraging inclusion and encouraging a change in behaviour. And although these are not always mutually exclusive, with choice, they often can be.*[32]

A fourth model of viewing disability, the *Affirmation* model, is based on a "positive non-tragic view of disability and a proud group identity." Swain & French (2000) describe the Affirmation model as a rejection of the notion of personal tragedy, dependency, and abnormality. Similar to the social model of disability, the Affirmation model views disability as an impairment between the individual and society rather than within the individual him or herself.

> *It challenges the value-laden views of society that see the disabled experience as one of tragedy; it asserts the value and validity of the life experiences of those with a disability. Therefore, the Affirmation model sees disability as liberating, positive, part of a persons identity.*[33]

4.4 Authority and decision-making

The researchers found little literature directly related to the supportive elements needed to include individuals with an intellectual disability into the decision-making processes of the community. Although some literature was found on supported decision-making, there was no literature available on the role this decision-making model played in intentional communities.

Based on the literature, the researchers made some speculations on the governance structures and by-laws which might be needed to ensure the meaningful involvement of individuals with an intellectual disability in decision-making. They are included in this section to help put the primary research into context.

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[32] Inglis, Cooper, Oxby and Robinson (2004). Social Role Valorisation and Forensic Learning Disability Services. Presentation to Learning Disability Offenders Conference. Available online at: http://www.ldoffenders.co.uk/conferences/3rdCon2004/3rdConDocuments/04partEIGHToi.doc Accessed May 2007.

[33] Swain, J., & French, S. (2000). "Towards an affirmation model of disability". Disability and Society, *15*(4): pp. 569-582.

4.4.1 Decision-making processes

The following excerpt from a recent newsletter produced by the European-based organization, *Inclusion International*, speaks to the way in which so-called "able-bodied" persons make decisions:

> *All people must have control over their own lives. We all make choices in our everyday life; what to eat, what to wear, where we live, who we have relationships with. We rarely make decisions alone, in isolation. We talk things over with people we love and trust. Those people are usually members of our family or our closest friends. These decisions do not have to be recognized in any legal way but they are choices we make that reflect our fundamental freedoms. For many people who have an intellectual disability these basic choices are denied or questioned simply because of their disability*.[34]

In order to respect the principles of the independent living model, people with disabilities must be allowed to make their own decisions. It is important to recognize that all human beings make decisions via various processes but typically, those processes include an element of consultation with others.

4.4.2 Supported decision-making

The recognition that persons with intellectual disabilities have the right to voice their opinions and the right to 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 incorporate supported decision-making into the process. Bodnar and Coflin (2004) define supported decision making as:

> *. . . a process of acting with an individual to discover their values, interests, talents and gifts in order to support them to choose the way they want to live their life.*[35]

[34] http://www.inclusion-international.org/site_uploads/File/Legalcap.%20bulletin.pdf
[35] Bodnar and Coflin (2004), op. cit.

Central to the supported decision-making process is the belief that every person has the right to self-determination. The process is centred on the person making the decision with others acting to support the decision process. The supported decision-making process should be strength-based and focus on an individual's abilities rather than disabilities.

According to Prince (2001), establishing an environment in which supported decision-making can be incorporated into community-based governance provides a number of benefits:

- Social learning – Neighbours as well as individuals supporting the person with a disability gain significant insight into needs, circumstances, and challenges influencing behaviours and outcomes. This insight can often increase tolerance and acceptance and further strengthen the community.
- Community participation and responsibility – An informed and involved group of residents are often more aware of community problems and the resources available to address them.
- Responsiveness and effectiveness – Services and supports are more likely to be tailored to the needs of the individual with a disability when the community takes ownership of the issues involved. This leads to a more authentic sense of control over one's circumstances.

However, including supported decision-making processes into community governance is not without challenges. Most intentional communities incorporate a consensus decision-making approach into their governance structure to ensure everyone's view is considered. Consensus can be a time-consuming process and, as Bigelow (2004) observes, there can be additional challenges in reaching decisions when supported decision-making is part of the process. These challenges include:

- Individuals with an intellectual disability may desire more time in providing their input due to the consultative process with their supporters.

- Everyone must be willing to value each other's views, speak freely and listen attentively. Each member should have an opportunity to provide a contribution to the decision-making process.
- Decision-making and decision taking require initiative and the ability to identify and acknowledge issues for which decisions are required.
- Expectations of members must be balanced against the capabilities of the supporters to interpret decision items within the required context.

4.4.3 Governance and by-laws

For supported decision-making to function in a meaningful way, the community by-laws must be designed to address a number of key components. These include defining membership, voting rights and the roles and responsibilities of supporters. Typically the by-laws of intentional communities establish membership based on the principle of one member one vote. Consideration would need to be given to the role and responsibility of the supporters and what constitutes a vote. One way may be to allow joint membership that would include the supporters. However there are complications with this approach as the supporters may change over time and so cannot realistically be named in the by-laws. Also, it could be that supporters may have differing degrees of authority or influence, depending on the extent of the disability of the individual they are supporting.

Once a decision has been made, Prince (2001) recommends good governance requires the following provisions to avoid abuses against the intent of the decision:

- Defined accountability structures that identify who enacts a decision and how and when the results will be reported back to the group.
- Specific indicators defining success such that members know how to proceed in future decision-making.

- Dispute resolution mechanisms that allow decision-making to continue through conflicts, miscommunication, and misinterpretation. This is particularly important in decision-making processes that engage supporters as joint members.
- Appropriate monitoring systems that facilitate courtesy and respect and prevent victimization.

Members of the intentional community may perceive their investments to be at risk when supported decision-making is included in the governance process. It would be important to build in risk mitigation measures into the by-laws, such as:

- Developing a microboard to ensure accountability and transparency of the decision-making process and facilitate a meaningful dialogue between members of the community and those supporting the resident with an intellectual disability.
- Formalizing the role of supporters as jointly accountable in the decision-making process.
- Recognizing the value of informal care provided by families and community members as helpful to the decision-making process

Clearly, there are potential risks involved in supported decision-making. However, the value of risk-taking is that, even though outcomes may be seen as failure or a mistake, there is value in learning from mistakes.

5. Research Methodology

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

5.1 Research ethics

The researchers adopted a set of ethics based on the Guiding Ethical Principles contained in the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (see Appendix 2).

Participation in the research was voluntary and participants had the right to refuse to answer any question or to withdraw from the project at any time. The consent process included a letter of introduction and a consent form (see Appendices 3 and 4) as well as a verbal and/or written explanation of the meaning of “free and informed consent”. Consent forms were edited for plain language to ensure they were as accessible as possible for participants with an intellectual disability. Signed consent forms are stored in a sealed envelope in a locked cabinet at the SHIP office and kept separate from the original research documents.

Researchers recorded three of the four focus groups. Participants were informed that the recording device could be turned off at any time, at their request. The purpose of the recording was to create a record of what was said so the researchers could check the validity of their field notes. The recordings were

transcribed and, subsequently, analysed for content and scope. Transcripts of the recordings are stored in a sealed envelope, separate from the signed consent forms or any information identifying participants. The recordings will not be made available to anyone other than the researchers named on the consent forms.

5.2 Data collection

Data for the case study was collected from two target groups: the first group consisted of individuals with an intellectual disability and was drawn from the membership of SACL; the second group consisted of family members. Participating family members either had a relative with an intellectual disability living at home who wanted to move out in the near future, or a relative living away from home who wanted to live in a different setting (i.e. a non-congregated setting).

5.2.1 Focus groups

Employees of SACL contacted 45 potential participants, describing the purpose of the research and explaining that the focus group sessions would be recorded. Participants were given a choice of dates and times they could attend. The project was also publicised at the SACL conference, *Individualized Funding for People with Intellectual Disabilities,* where a sign-up sheet was provided. However, none of the conference participants signed up.

Four focus groups were held in April 2007: two with individuals with an intellectual disability and two with family members. In total, 27 people participated: 12 individuals with intellectual disabilities and 15 family members. All focus groups were held at SACL headquarters in Saskatoon. A special allowance for individuals or family members who had transportation or childcare concerns was provided by SHIP.

Focus Group Procedures: Focus groups were facilitated by Karen Lynch of SHIP. Staff of SHIP and SACL took field notes during the sessions and helped to

clarify the questions, as required. At the beginning of each focus group, participants and facilitators introduced themselves and reviewed the consent form. The form was read aloud and participants were given the opportunity to ask questions. All participants signed the consent form and were given a copy for their records. Participants were again informed that the focus groups would be recorded and were asked if they had any objections. One of the participants did object and, consequently, that session was not recorded.

The rules of conduct for the focus groups were reviewed with the participants:

- There are no right or wrong answers
- Everyone is entitled to state their opinions
- Only one person at a time can speak
- Everyone gets a chance to speak on each topic
- No talking with other participants when someone else is talking
- What is said in the room stays in the room

Focus Group Questions: The questions were designed to generate discussion about the participants' experiences related to housing, the meaning of home and the housing design features they considered important. The topics included:

- How participants define home
- How participants view specific spaces found in a home (i.e., kitchen, living room, and personal spaces such as bedrooms and bathrooms)
- How each type of space might be used
- What type of housing design features and structures were desired
- Other desirable features to include in a home.

The facilitators and aides used a power point presentation and flip charts to guide the discussion. Slides included pictures and keywords or phrases (see Appendix 5). Images were used to help focus the participants' attention on the topic and visually represent typical features found in a home. Family members were asked to respond to the questions with their relative in mind, identifying what they thought their relative would need to support their qualify of life in an intentional community.

All participants were given an opportunity to state their opinions about each topic. The facilitator informed them they did not have to answer any questions they preferred not to and also reiterated that they could leave the focus group session at any time. None did.

5.2.2 Surveys

The survey was developed to supplement the information collected in the focus groups. Surveys were distributed to individuals unable to attend focus group sessions and also to those focus group participants who wanted to provide additional detail in their responses.

The survey closely resembled the structure of the focus groups, focusing on the physical aspects of home that might best accommodate a person with an intellectual disability. The questions were original and were created through a process of trial and error (see Appendix 6 for survey form). The intent of the questions was to identify how persons with an intellectual disability used space and what they considered to be important features in a home. To ensure anonymity, the participants were provided with pre-paid stamped envelopes to return their completed surveys.

On the advice of SACL, surveys were distributed to a pre-screened list of participants rather than to a random sample of the target population. This sampling methodology was considered to be the most respectful of the participants who, as a group, tend to be subject to a great number of research initiatives. The participants were selected based on the terms of reference for the research and the likelihood of them responding. The criteria used to determine the likelihood of response was whether or not the individual or family member was known to have an interest or an issue regarding housing. This approach allowed the survey to target those with the greatest interest in the project while limiting time and expense on the part of the participants.

A total of 13 surveys were returned, all of which were completed by family members who had a child with an intellectual disability residing at home. The majority of respondents (86 per cent) lived in Saskatoon with the balance residing outside the city. The majority (71 per cent) had a child with an intellectual disability aged 19 to 25 years old; the remaining 29 per cent had a child under the age of 19.

6. Research Findings

6.1 Findings from focus groups and surveys

The results from the focus groups and surveys are presented below and cover the following topics: the meaning of home, use of spaces, kitchen, living room, common areas/shared spaces, private spaces, specialized or notable design features and housing type. The section concludes with a summary of the differences observed between responses from family members and from individuals with an intellectual disability.

The meaning of home: Participants described "home" with a wide range of words (see Table 2). Home was often described in terms of subjective words (e.g., warmth, comfortable) versus features (e.g., walk in closet, entertainment centre). Home was also synonymous with the presence of family and pets. Family members, especially, also described the concept of home in terms of commonalities with the family home.

Table 2 - Words that describe "home"

Responses by Individuals with an Intellectual Disability	
• Affordable • Comfortable • Secure/Safe environment[36] • A space to get away from others • Privacy • Less noise • Spacious • Freedom to do what you want when you want	• 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 • 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	• Food • Inviting • Social place • Relaxing atmosphere • Attractive features

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

• Privacy • Place to entertain/hang-out with friends • Spacious • Freedom to do what you want when you want	• No “off-limit” places • A yard is very important • Place where your pet(s) live • Familiar • A supportive environment • Ownership/responsibility • Functional

Use of Spaces: Identifying specific floor plans proved challenging for participants. However, it became apparent from the conversations that the space needs of individuals with an intellectual disability were similar, in many ways, to those of a family with children. These included:

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

Kitchen: Kitchens were seen as public or semi-private spaces that should accommodate many functions. Open layouts were preferred (see Figure 2); islands were less desirable as they were seen to be confusing and difficult to navigate.[37] Physical accessibility and mobility were considered important and some participants indicated that, even though they did not currently use a wheelchair, they felt they may need to in the future and wanted to ensure there would be enough space to accommodate one. The majority of participants indicated they did not currently have mobility issues (see Figure 3).

[37] Note: It is ideal to create kitchen space that is open and welcoming – with enough room to allow movement regardless of mobility issues. Countertop heights should vary so that the kitchen accommodates a person who has to sit down while preparing food (a 36 inch work surface) and a countertop between 42 and 45 inches to accommodate taller individuals.

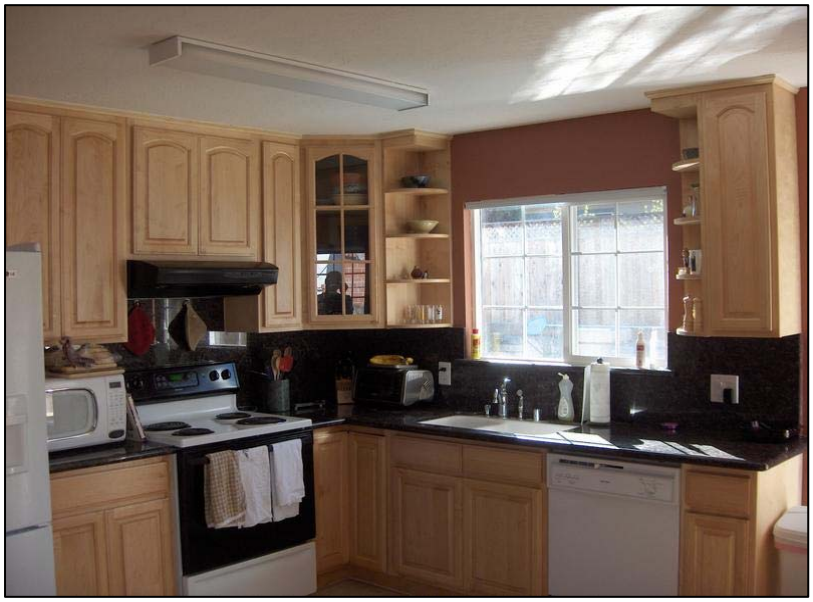

Figure 2: Preferred kitchen layout – the open concept

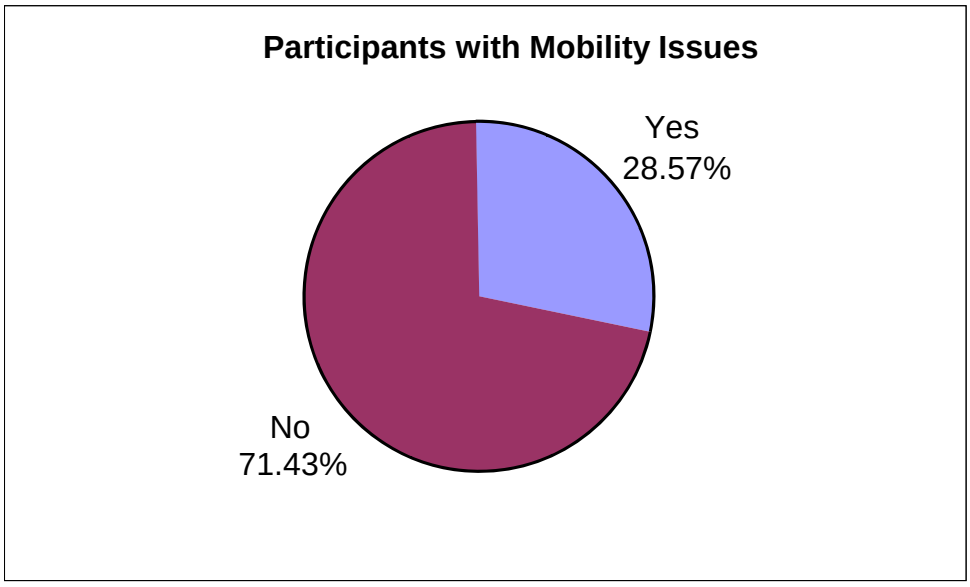

Figure 3

Specific uses, activities, appliances, and designs were also discussed. Kitchen uses included food preparation[38] and social activities. The kitchen table was considered to be an important feature in the kitchen – participants used kitchen tables to eat their meals, as a surface for crafts and to socialize around. All participants indicated that their support workers prepared their food (see Figure 4).

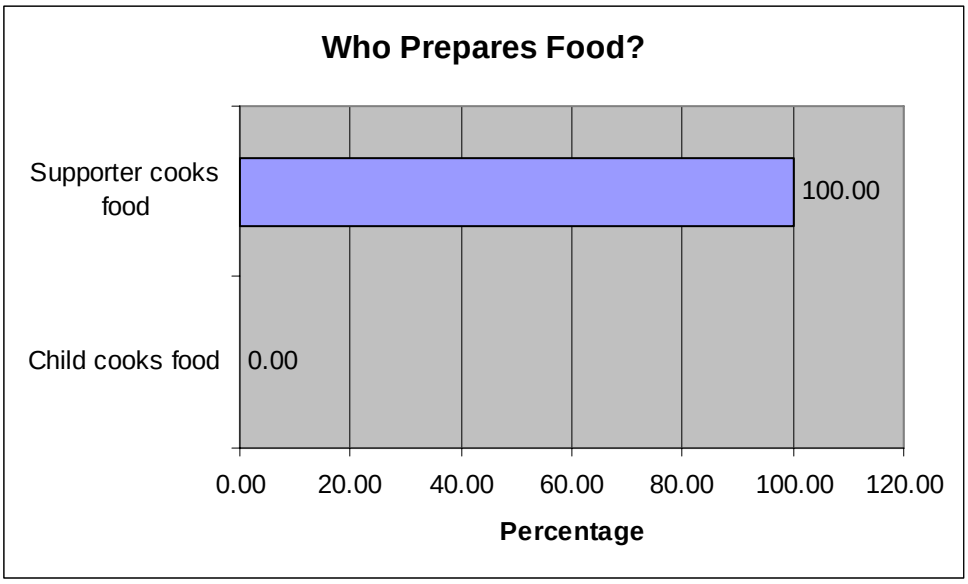

Figure 4 – Food preparation

Even though the participants did not (or could not) prepare their own meals, they still valued having a functional kitchen. All participants stated they used a microwave on a regular basis. The combination of touch control features and visual clues (e.g. a slice of pizza) were considered important in selecting the appropriate controls on the microwave. Other appliances used in the kitchen included toaster, coffee-maker and electric kettle (see Figure 5).

[38] The focus of the kitchen is the preparation of food. The type of food typically consumed will affect the time spent in the kitchen, the appliances used and the amount of cupboards needed. Design recommendations contained in the GE Universal Design Website (General Electric (2007). GE Universal Design: FAQ. Available on line at: http://www.geappliances.com/design_center/universal_design/faq.htm#faq4) suggest a minimum of 30 to 48 inches in front of each appliance and work surface and 42 – 48 inch wide aisles.

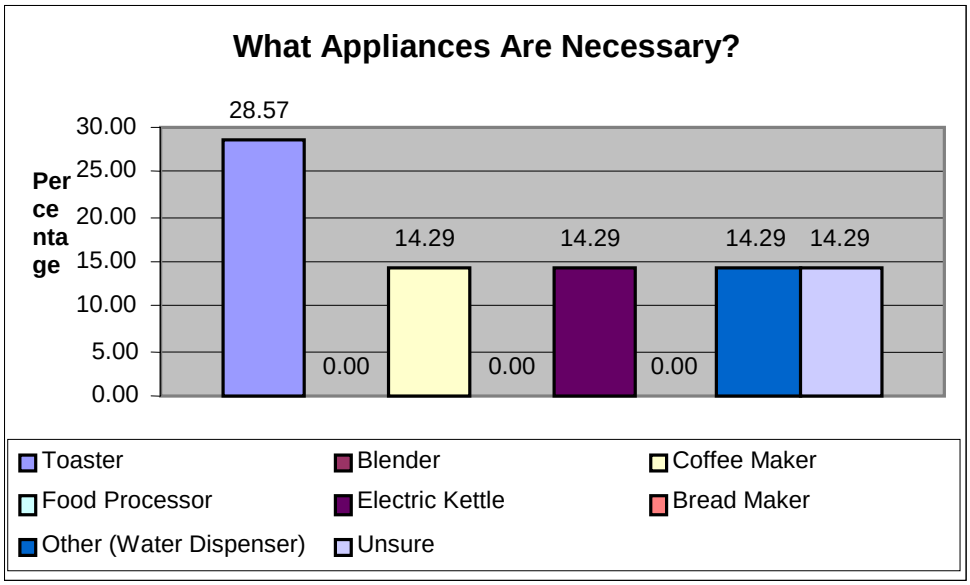

Figure 5

The types of food preferred by participants included homemade meals, ready-made foods and fast foods (see Figure 6).

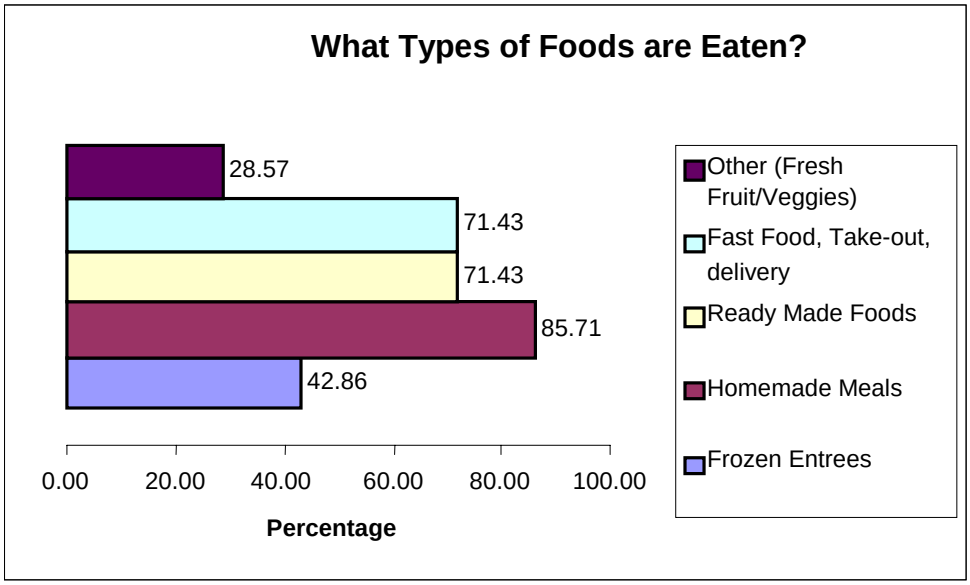

Figure 6

Other important kitchen features identified included:

- Heat proof surfaces
- Rounded edges on corners to prevent injuries
- Countertops with raised edges to prevent liquid from spilling onto the floor
- Wall-mounted oven with a door that swings open (like a microwave) rather than the traditional top down door.
- Sinks with lever handles and anti-scald protection.

Accommodations for specialized fixtures, mobility aides, automatic shut-offs or alarms, and other protective features were considered important to ensure safety in the kitchen.[39]

Living Room: Furnishings, lighting, window coverings, activities, uses, and storage were all discussed in relation to living rooms. What became apparent was that a living room should be designed to accommodate multiple functions and allow plenty of space for socializing. Words that participants used to describe the purpose of a living room included: entertainment (e.g., watching television), leisure activities (e.g., crafts, surfing the net) and having friends and family members over to visit.

A variety of furniture should be provided in the living room, including couches and chairs to provide alternative seating choices, entertainment stands and related equipment, television etc. (See Figures 7 and 8).

[39] Note: While many people with intellectual disabilities have their meals prepared for them by their families or support workers, many kitchen appliances are used regularly. The appliances that are chosen to furnish the home should adhere to the principles of Universal Design: they should require low physical effort; they should be simple and intuitive; and they should have perceptible instructions (i.e. the use of meaningful icons as well as text labels). Design recommendatsions from the GE Universal Design Website (http://www.geappliances.com/design_center/universal_design/faq.htm#faq4) suggest a minimum of 30–48 inches in front of each appliance and work surface and 42-48 inch wide aisles.

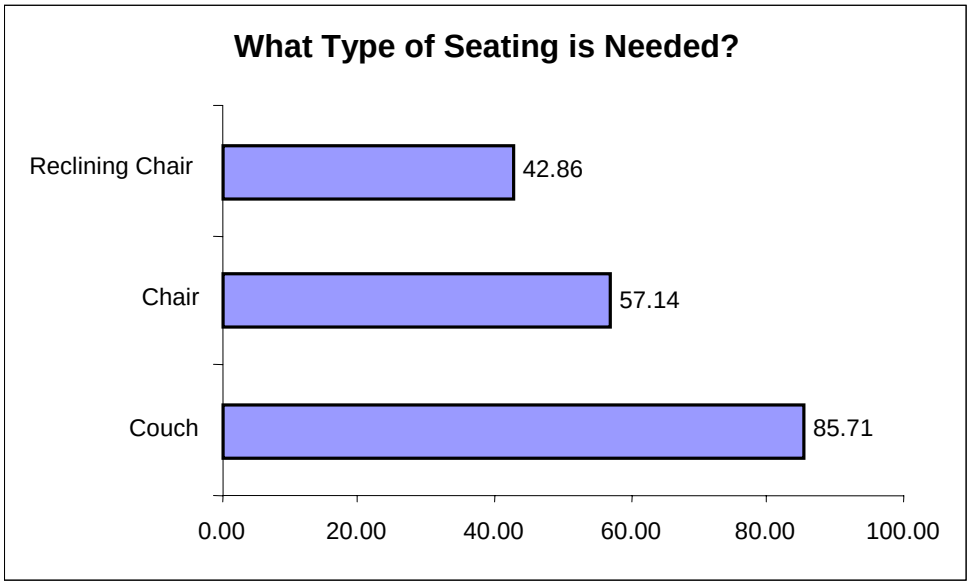

Figure 7

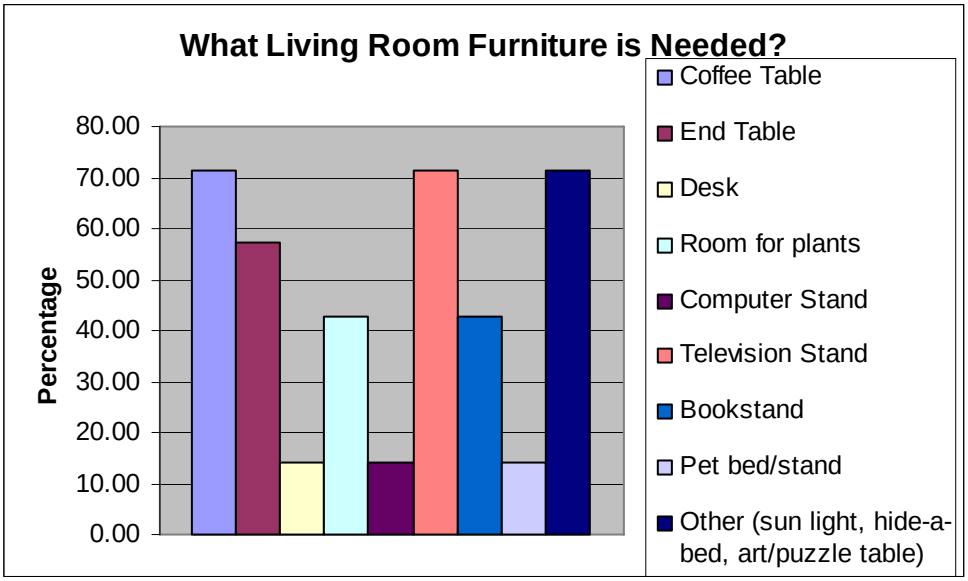

Figure 8

Other recommendations related to furnishings included:

- Tables, desks, shelves and entertainment units should have rounded corners
- Allow for a minimum of 3 feet clear space in front of furniture

- Allow for natural light and place artificial lighting close to seating and working areas.

Open layouts were preferred to provide flexibility for a variety of furnishings and a variety of activities. Participants were clear they did not want a small living room as small spaces often limit the opportunity to socialize. Some participants perceived small living rooms as a form of discrimination against persons with an intellectual disability and stated that their homes should have enough space to accommodate visitors, including family and friends.

As living rooms were often used for dining (e.g. in front of a television), participants suggested flooring and furnishings should be selected that would accommodate dining and easy cleaning. (See Figure 9 for common activities in the living room.)

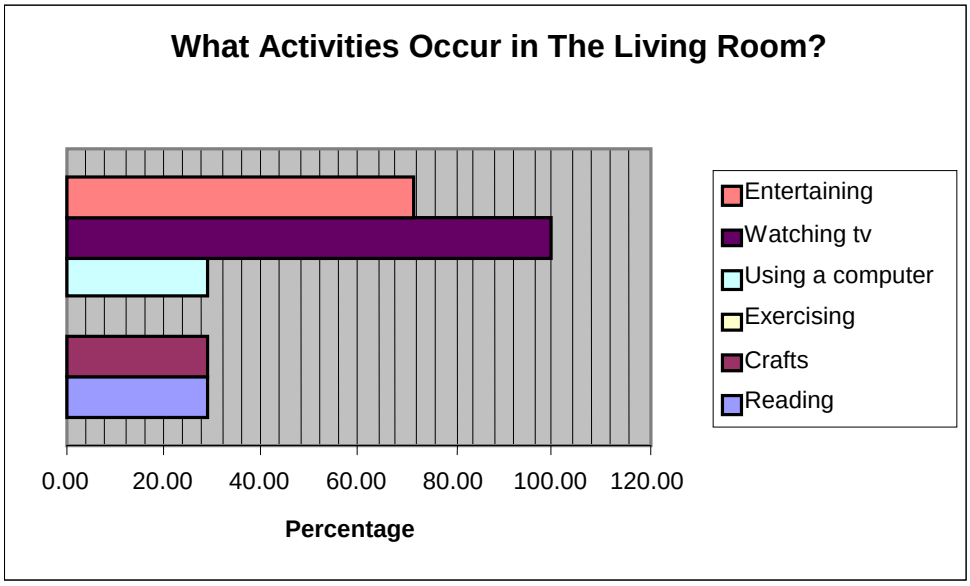

Figure 9

Common Areas/Shared Spaces: Participants indicated a preference for gathering in common areas for entertainment and socializing (see Figure 10).

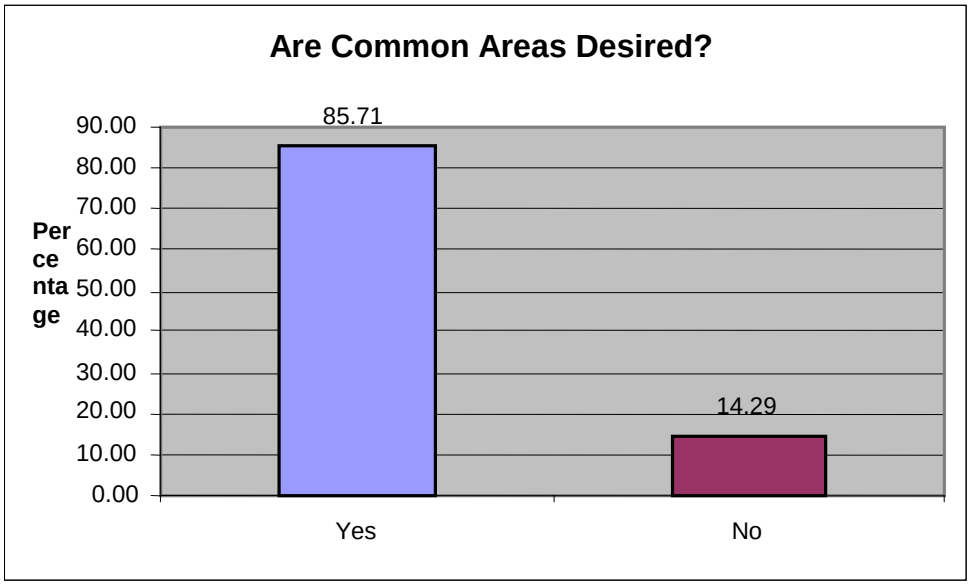

Figure 10

Spaces for social gathering were considered very important. Participants indicated they would use a common area with a kitchen and an entertainment lounge (e.g. a room with a large screen television), although the common area was desired more for the social aspect of visiting rather than for the kitchen itself. The option to eat when and with whom one chooses was important.

Private spaces: Private spaces included bedrooms, bathrooms[40], and closet/storage spaces. Participants viewed bedrooms as being much more than a place for sleeping or quiet solitude. They wanted their homes to have large bedrooms that could accommodate significant storage for personal items, additional security features, and a variety of furnishings to accommodate a variety of activities within the space. The researchers suspected that participants may have overemphasized the importance of bedrooms based on their current

[40] Note: Employing the principles of Universal Design in the bathroom requires bathrooms be flexible spaces with simple-to-use facilities that limit physical effort and offer a tolerance for error to limit potential dangers. The researchers suggest that a bathroom should have the following features:

- 60” diameter clear turnaround area
- level type faucets with anti-scald features
- non-slip flooring
- safety bars
- personal alarm system

living experiences, ie. living in the family home or in a congregated living environment (group home) where their only private space was their bedroom.

Participants wanted their bedrooms to have space for a double or queen size bed, television stand and/or bookstand, dresser and mirror. They preferred overhead lighting to other lighting choices such as table-lamp or floor lamp. The majority of participants indicated that the installation of a pole by the bed would be helpful if mobility became an issue.

In regards to bathrooms, safety was a significant consideration, primarily because of mobility challenges and the potential for harm due to seizures. The majority of participants preferred a bath/shower combination over a bathtub. No one preferred a shower stall (see Figure 11). Participants revealed a preference for telephone showerheads and handrails within either a bathtub/shower or shower stall flush with the floor. Participants also recommended avoiding shower doors and installing shower curtains for reasons of safety (i.e. falling through shower doors) and hygiene (i.e. ease of cleaning).

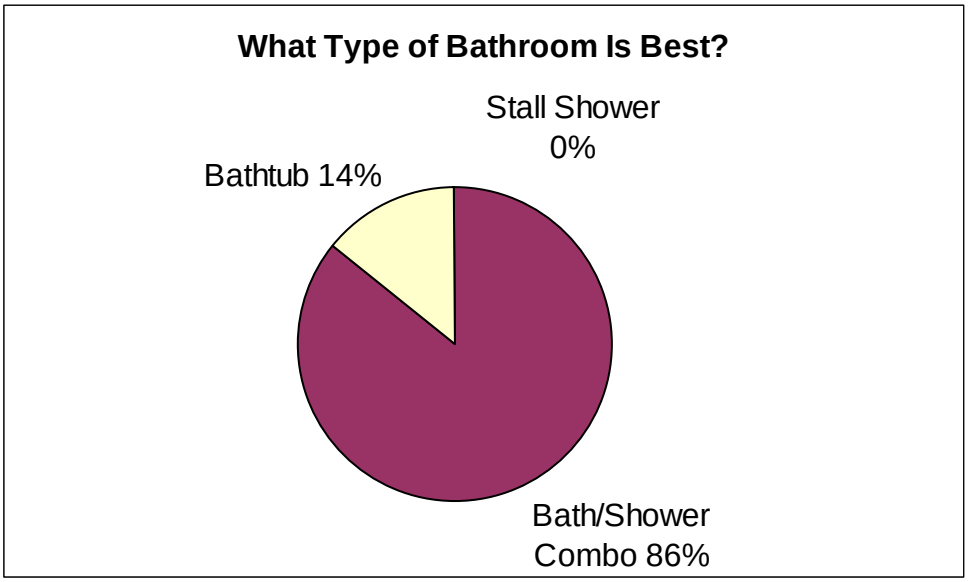

Figure 11

Other important features identified for a bathroom include:

- A bathroom door that is at least 32 inches wide
- A door lock that can be opened from the outside
- A flat ledge on the tub where a person can sit
- A non-slip surface in the bathtub/shower stall
- Grab bars with a textured finish
- Accessible storage for towels and supplies.

Many participants identified strong preferences for the highest level of control over the use of private spaces. Such uses included watching television, using computers, storing personal possessions, etc. The importance of television (with DVD player) to individuals with an intellectual disability was raised. Television and movie-watching is both an important component of the social routine, and also a private pastime for many individuals. Therefore, space for televisions in private spaces and shared spaces is important.

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

Specialized or notable design features: This topic included discussions around flooring, furniture, lighting options, window coverings, storage[41], kitchen appliances, faucets etc. (see Figure 12 for the preferred features).

[41] Note: Closet spaces are more accessible if the closet rods are adjustable. An adjustable rod which fits into notched mounting blocks can accommodate people of different heights as well as individuals confined to a wheel chair. (see Centre for Universal Design, 2000)

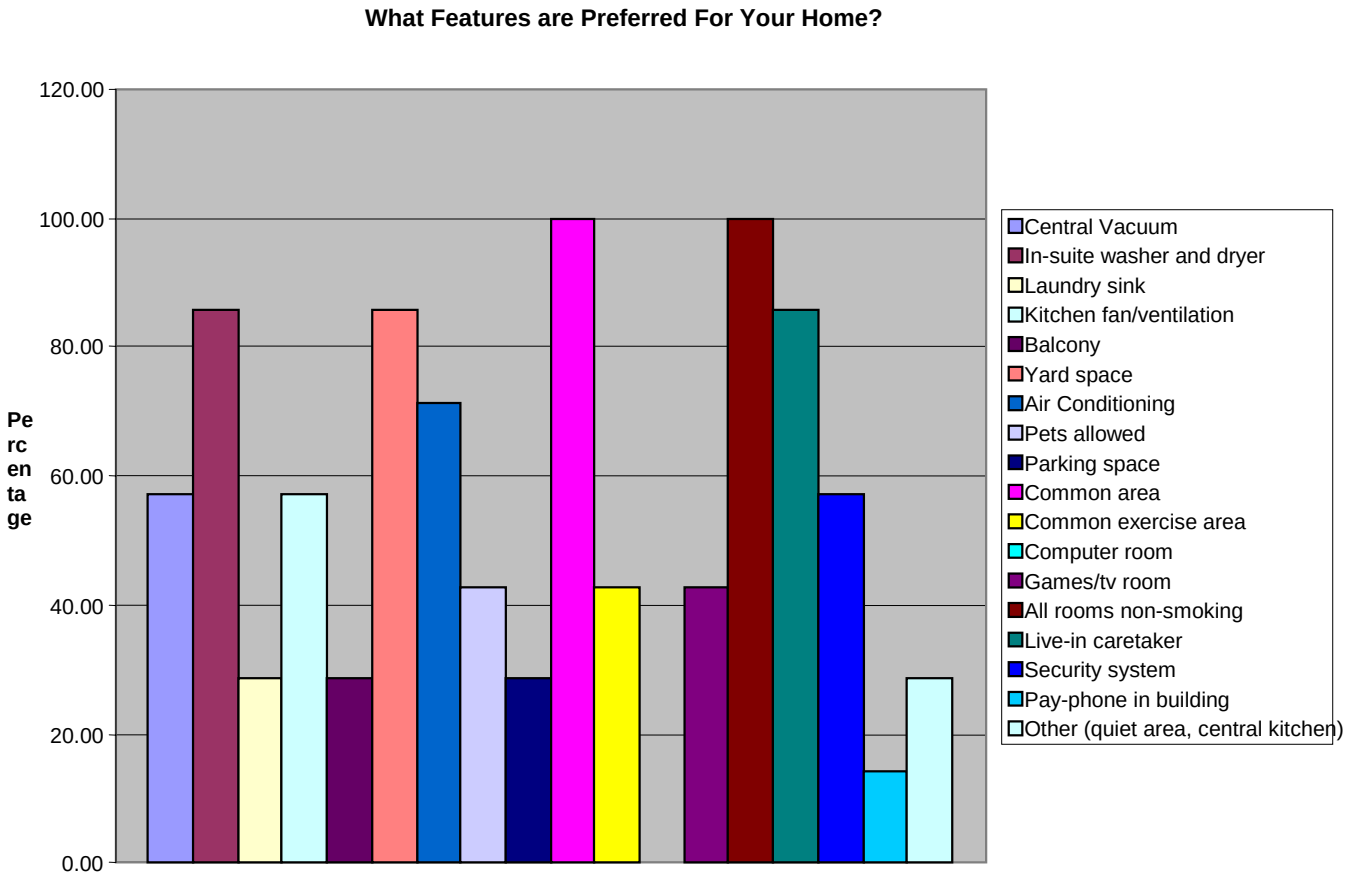

Figure 12

Participants emphasized the importance of design features that accommodated physical mobility challenges (i.e. grab-bars). Whether or not they currently had physical disabilities, participants had a high level of awareness of the potential challenges such disabilities presented for their friends, relatives, or themselves in the future.

Specific design features identified included:

- The importance of durable furniture and furniture design that maximizes floor-space accessibility
- Flexibility in lighting options - overhead and wall-mounted lighting were most preferred, although tabletop lights were also acceptable. Floor lamps were considered unsafe.

- Large windows with opaque coverings were important to accommodate the sleep-wake patterns of individuals with an intellectual disability. Blinds and shades were preferred to curtains. Vertical blinds were the most popular, although no rationale was given.
- Storage should accommodate wheelchairs and walkers (and therefore would be of sufficient size to accommodate sporting equipment for able-bodied individuals).
- Kitchens should include all the 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 (easier to use and clean).
- Hard surface floorings were preferred over carpeting due to allergies, cleanliness, and ease of mobility (i.e. less "trippy").
- Levers and handles were preferred over knobs for ease of use.
- Single-lever faucets were preferred over two-handled tap-sets for safety reasons. Regulation of hot-water temperature was identified as important to prevent scalding.
- The ability to choose the paint colour was important, providing a sense of ownership over the space (whether owned or rented).
- Access to outdoor space was important; yards[42] and patios were preferred to balconies. Participants expressed concerns about safety with balconies.
- Many people would like to own pets (71 per cent of respondents, compared to 29 per cent who were unsure)

Housing type: Participants were shown a series of slides of different housing types: an apartment building, a family-friendly co-op, a townhouse, a rooming

[42] Yard spaces should have visually distinct pathways which are at least 36" wide leading to and from the house. "Entrances to the house should have at least 32" of space when the door is open. The door needs level handles that are easy to open. The threshold should not be any higher than ½ inch." (AARP, 2007)

house/small apartment building, a suite in a house or a granny flat (suite behind a house). The facilitator and the aides described each type of housing and participants were asked to discuss the pros and cons of each. This conversation proved to be the most difficult for each of the focus groups. Participants had limited experience with housing options and tended to prefer the housing type they were most familiar with, i.e. apartment-style buildings (with an elevator) or a house with suites.

Distinctions between responses of family members and individuals with a disability: The researchers discovered several differences between the responses given by family members and those given by individuals with a disability. Some examples were:

- 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 minimal amounts of kitchen features (i.e., a microwave and a bar fridge). Family members tended to prefer communal dining for their relative while the individuals themselves preferred to have choices of communal spaces and their own kitchen.
- Family members had significant concerns about safety and indicated their relative would want a security system to allow them to hit a panic button if something was awry in the kitchen or bathroom[43].
- Family members suggested all taps might need some sort of timer on them to prevent excess uses of water, and heat safety regulators to prevent scalding.
- Family members placed a much higher value on kitchen features, layout, and space than did individuals with a disability.

[43] Of note, security of the person and property are paramount concerns for persons with an intellectual disability. Implementing concepts such as those promoted by the Crime Prevention Through Environmental Design (CPTED) audit process are viewed as helpful. CPTED promotes safety and security through features that include peepholes in exterior doors, locking mechanisms for windows, appropriate landscaping to avoid blind-spots on a property and windows in all directions to maintain “eyes on the street”.

- Family members believed computers should be placed in a common room so that use could be monitored.
- Many family members wanted their relatives to have a two-bedroom unit so that a personal attendant could live in the same unit.
- Family members showed a much stronger interest in congregate housing models than by individuals with intellectual disabilities themselves.

6.2 Summary of research findings

Accessibility: 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 indicated 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 stated the desire 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: Researchers believe what underlies the feedback received within the study suggests persons with an intellectual disability currently experience a significant lack of control over the spaces in which they live. It is believed that with the introduction of semi-private spaces (e.g. kitchens, living rooms) under the control and influence of the individual, the desire for large private spaces (e.g. large bedrooms) will lessen.

7. Conclusions

In undertaking this project, SHIP and SACL intended to expand the existing knowledge base of the housing needs of individuals with an intellectual disability. The researchers were especially curious about the role that intentional communities could play in meeting these needs and, furthermore, the role that supported decision-making could play within that context.

In order to create an environment that includes individuals with an intellectual disability into the community, housing providers should consider the following:

- the *accessibility* of the physical structure and the surrounding community setting
- the level of *acceptance* for persons with intellectual disabilities in community-based housing
- the impacts on governance or management *authority* within community-based housing that arise as a result of including persons with intellectual disabilities.

Accessibility relates to building features, housing location, and participation in society. In terms of building features, the researchers explored the concepts of universal design to gain a better understanding of the physical components of house design that could help accommodate people with intellectual disabilities in an intentional community. Table 3 below summarizes the guidelines and considerations obtained from the literature review and 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	Provide the same means of use for all users: identical whenever possible; equivalent when not. Second storey units are designed	Ensuring housing units include features for accommodating a variety of types of users (regardless of circumstance or

	with diverse abilities	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.	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	Arrange elements to minimize hazards and errors: most used elements, most accessible; hazardous elements eliminated,	The design and decorating includes features that "forgive" inaccurate use. Member input on design has ensured highest

	consequences of accidental or unintended actions	isolated, or shielded. Provide warnings of hazards and errors. Provide fail-safe features. Discourage unconscious action in tasks that require vigilance.	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 has helped 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) provides increased liveability. Physical accessibility for wheelchairs has been designed into the layout of all spaces in the project.

The following physical characteristics of housing were identified from the literature review and the primary research:

- The physical housing needs of a person with an intellectual disability were found to be similar to those of a family with children. These included:
    - Open layouts wherever possible to accommodate ease of navigation through good sight lines and physical accessibility
    - Flexible space that accommodates multiple functions
    - Private spaces that allow an individual to find quiet solitude.
- In case studies reviewed in the literature, it appeared that housing type had little bearing on the inclusion of persons with an intellectual disability into the community. What was of greater significance was the scale and

size of the residence. Smaller community-based homes were found to yield more positive outcomes and greater autonomy for persons with an intellectual disability.

In addition to accessibility, a second element essential for meeting the housing needs of individuals with an intellectual disability, or the housing needs of anyone, for that matter is *acceptance and inclusion* within the community. The literature suggests that the way the community members perceive disability has an influence on how well individuals with a disability are accepted.

The Social Model of Disability views disability as a failure of society to ensure accessibility and acceptance, instead of viewing disability as a personal limitation of the individual (see Figure 14)[44].

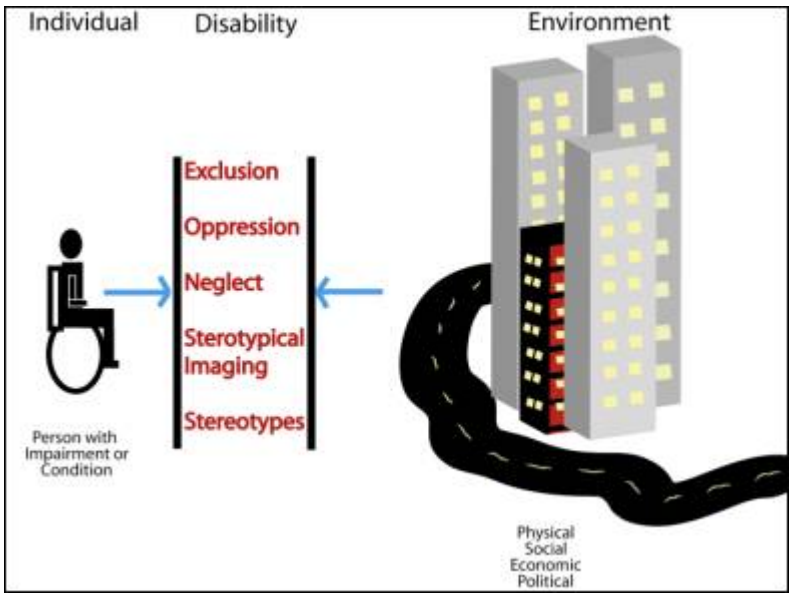

Figure 14 - The Social Model of Disability

The Affirmation Model also views disability as an impairment between the individual and society, rather than of the individuals themselves. The model suggests that disability is a normal consequence of life and that the presence of a

[44] Swain and French (2000), op. cit.

disability creates unique opportunities for self-expression in everything from advocacy to art. The Social Role Valorisation Model is based on the view that every member of society has inherent “gifts” or social value.

Acceptance and the concept of *authority* also relate directly to individual rights to participate in community decision-making through means that protect both the rights of the individual and the rest of the community. The Supported Living Model builds on the idea that individuals can exercise authority over their own lives. The Southampton City Council in the United Kingdom has identified nine goals of Supported Living:

1. I choose who I live with
2. I choose where I live
3. I choose who supports me
4. I choose how I am supported
5. I choose what happens in my own home
6. I have my own home
7. I make friendships and relationships with people on my terms
8. I am supported to be healthy and safe on my terms
9. I have the same rights and responsibilities as other citizens

The researchers explored a variety of community-based housing models and concluded that the intentional community model seemed to hold the most promise for delivering a Supported Living environment. What sets the intentional community apart from other housing options is the shared vision between community members in regards to the community values. Typically, intentional communities stress the need for inclusion of all community members within governance and decision making processes.

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
- Supported living arrangements that are well established.

The recognition that persons with intellectual disabilities have the right to voice their opinions and have the right to 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 by-laws, such as:

- Developing a microboard to ensure accountability and transparency of the decision-making process and facilitate a meaningful dialogue between members of the community and those supporting the resident with an intellectual disability.
- Formalizing the role of support service providers as jointly accountable in the decision-making process.
- Recognizing the value of informal care provision available from families and community members as helpful to the decision-making process

There are potential risks involved in supported decision-making. However, the value of risk-taking is that even though outcomes may be seen as failure or as a mistake, there is always value in learning from mistakes.

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Appendix 1 – Concept Map

HOUSING PEOPLE WITH INTELLECTUAL DISABILITIES:

Identifying Relevant & Appropriate Uses Of Physical Spaces

Table of Contents

Section 1: Universal Design Principles

1. What is Universal Design

Universal design applies to a broad range of products, such as the design of appliances and layouts of homes, which enable all individuals regardless of their capacities to use products with greater ease. Products that follow universal design principles are design to be functional given any life stage. The goal of universal design is to create products that make life easier for all individuals. The concept of universal design is important for this research project as the application of the design principles within housing complexes facilitate the range of all the residents needs. An important factor in universal design is that the products blend into the housing structure as opposed to institutional-like features, which may stigmatize residents and lead to isolate from other residents within the community.

Principles of Universal Design

- **Equitable Use**
  The design does not disadvantage or stigmatize any group of users.
- **Flexibility in Use**
  The design accommodates a wide range of individual preferences and abilities.
- **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.
- **Perceptible Information**
  The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
- **Tolerance for Error**
  The design minimizes hazards and the adverse consequences of accidental or unintended fatigue.
- **Low Physical Effort**
  The design can be used efficiently and comfortably and with a minimum of fatigue.
- **Size and Space for Approach and Use**
  Appropriate size and space is provided for approach, reach, manipulation, and use, regardless of the user's body size, posture, or mobility.

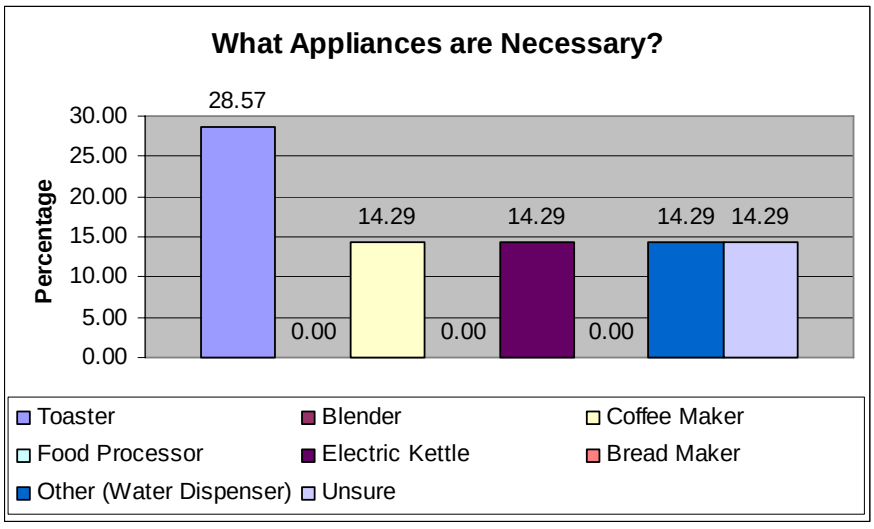
The selected findings presented in this booklet represent the opinions of individuals and their family members who participated in focus groups, face-to-face interviews, and well as in surveys. The findings are presented as generalized guidelines – individual needs have to be taken into account when planning and designing living spaces. For further details on the findings of the research project please contact SHIP or SACL.

Section 2: Kitchen and Dining Areas

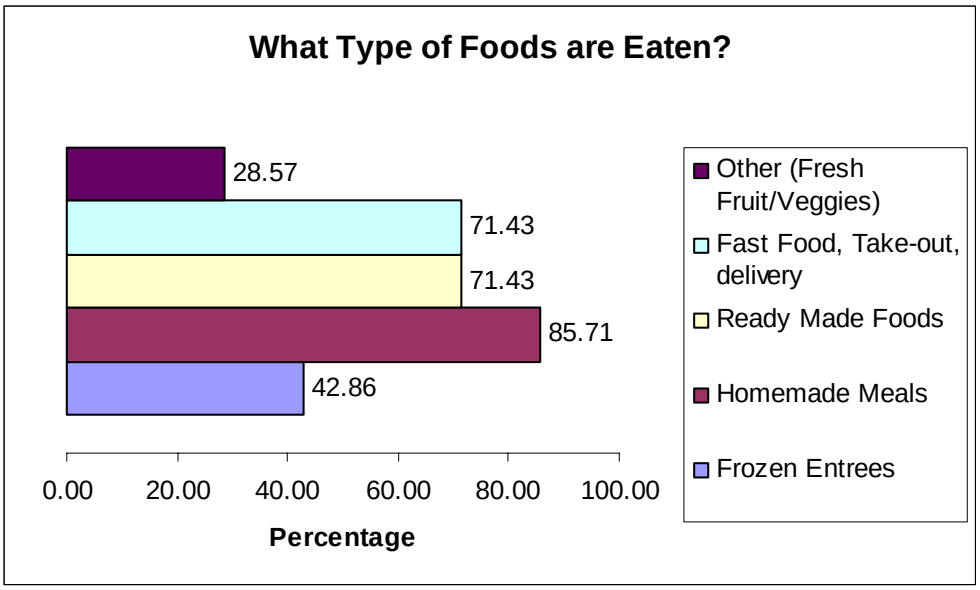
2. Food Preparation

Utilizing the principles of Universal Design, it is important to ensure that all aspects of the home are simple & intuitive with a tolerance for error. This principle is very true in the case of kitchen appliances. For example, coil-element stovetops are very common and easy to operate. Ceramic top stoves and gas grills, on the other hand, are more difficult to use and pose unnecessary risks.

All participants stated that they used a microwave on a regular basis - the combination of touch control features and visual clues (e.g. a slice of pizza) which prompt the users to select the appropriate buttons are important features



While many people with Intellectual Disabilities have their meals prepared for them by their families or support workers, many kitchen appliances are used regularly. The appliances that are chosen to furnish the home should adhere to the principles of Universal Design: they should require low physical effort; they should be simple and intuitive; and they should have perceptible instructions (i.e., the use of meaningful icons as well as text labels).



The focus of the kitchen is the preparation of food. The type of food typically consumed will affect the time spent in the kitchen, the amount of appliances used and the amount of cupboards needed. Design recommendations stipulate that one should allow for a "minimum of 30" to 48" in front of each appliance and work surface, and 42" to 48" wide aisles" (GE Universal Design Website, 2007).

3. Kitchen Layout

It is ideal to create kitchen space that is open and welcoming – with enough room that would facilitate movement regardless of mobility issues. Changes in personal mobility is one of the challenges a person can person can face in their lives, having ample space can help to accommodate such changes. Participants preferred the open concept kitchen outlay. According to universal design principles countertop heights should vary so that the kitchen accommodates a person who has to sit down while preparing food, the standard (36") work surface height and a countertop which is between 42" to 45" to accommodate taller individuals.

Another option for a kitchen layout would be one that included an island. The island can provide storage, work, and eating spaces. In order to conform to a universal design standard the island should not obstruct access to any part of the kitchen.

4. Other Important Kitchen Features

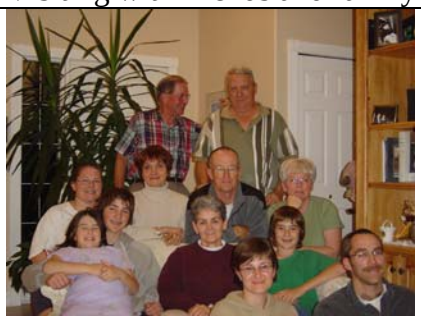
- Heat proof surfaces
- Round-edges on corners to prevent injuries
- Raised edges detail on edges of countertops to prevent liquid from spilling on to the floor; in addition the raised edges give visual clues
- Wall mounted oven with a door that swings open (like a microwave) as opposed to the traditional top down door
- Sinks with lever handles and anti-scald protection

Another important feature of the kitchen is a kitchen table – participants used kitchen tables to eat their meals at, used as a surface for crafts, and to socialize around.

Section 3: Living Rooms and Entertaining Areas

5. Activities and Uses

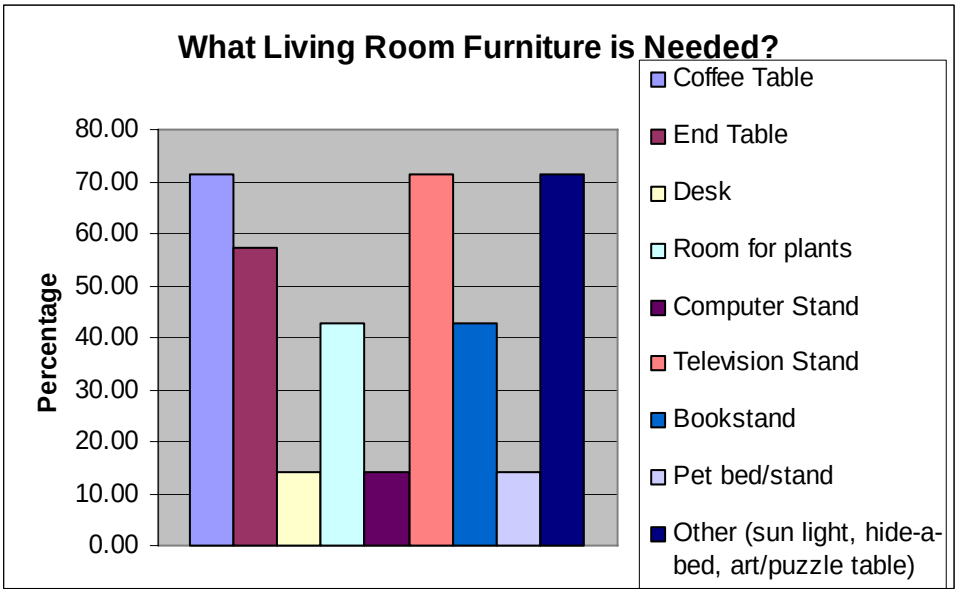
Living rooms and entertaining areas are rooms that must be designed for maximum flexibility. The tasks that are regularly performed in these rooms are often varied and may include:

Watching TV	Reading
	
Using a computer	Exercising
	
Eating a meal	Playing with a pet
	
Listening to music	Visiting with friends and family
	

6. Required Furniture

It is best to offer a varied selection of Living Room furnishings to ensure that the room is available for equitable use. For example, it is effective to furnish with different types of seating options, such as both couches and chairs:

Additional desired furniture includes entertainment stand and related equipment as well as space for entertaining friends/family. Other regularly utilized furnishings are indicated in the following chart:



In addition to the different types of furniture found in a living room the following recommendations were made by participants:

- Tables, desks, shelves, entertainment units should have rounded edges
- Allow for a minimum of 36" clear space in front of furniture
- Allow for natural light and place artificial lights close to seating and working areas

Section 4: Bathrooms

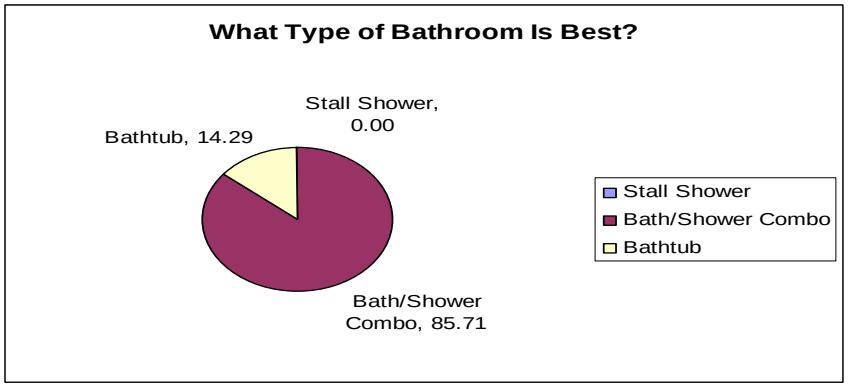
7. Safest and Most Effective Types

Employing the principles of Universal Design, it is crucial for bathrooms to flexible spaces with simple to use facilities that limit physical effort and offer a tolerance for error that limits potential dangers. It is suggested that a bathroom should have the following features:

- 60” diameter clear turnaround area
- Lever type facets with anti-scald features
- Non-slip flooring
- Safety bars
- Personal alarm system

In terms of flexibility, the bathtub/shower combination offers the most flexible and efficient use of space:

A bathtub/shower combination was preferred by participants as illustrated in the following graph:



Additionally, the use of shower curtains limits the potential danger created by shower doors (i.e. falling through them).

8. Other Important Features

In order to increase the universality of bathrooms, there are other features that can be added. The installation of a telephone-style shower head increases ease of use and overall accessibility. The installation of handles and seats also increases accessibility while also limiting physical effort and mitigating potential injuries.



Other important features in a bathroom include:

- A bathroom door is at least 32 inches wide
- Someone can unlock the door from the outside
- A flat ledge on the tub where a person can sit
- Bathtub/shower stall has a non-slip surface
- The bathtub/shower stall has a shelf to hold toiletries
- Grab bars have a textured finish
- Accessible storage for towels and supplies

Section 5: Bedroom

9. Furniture required in a bedroom

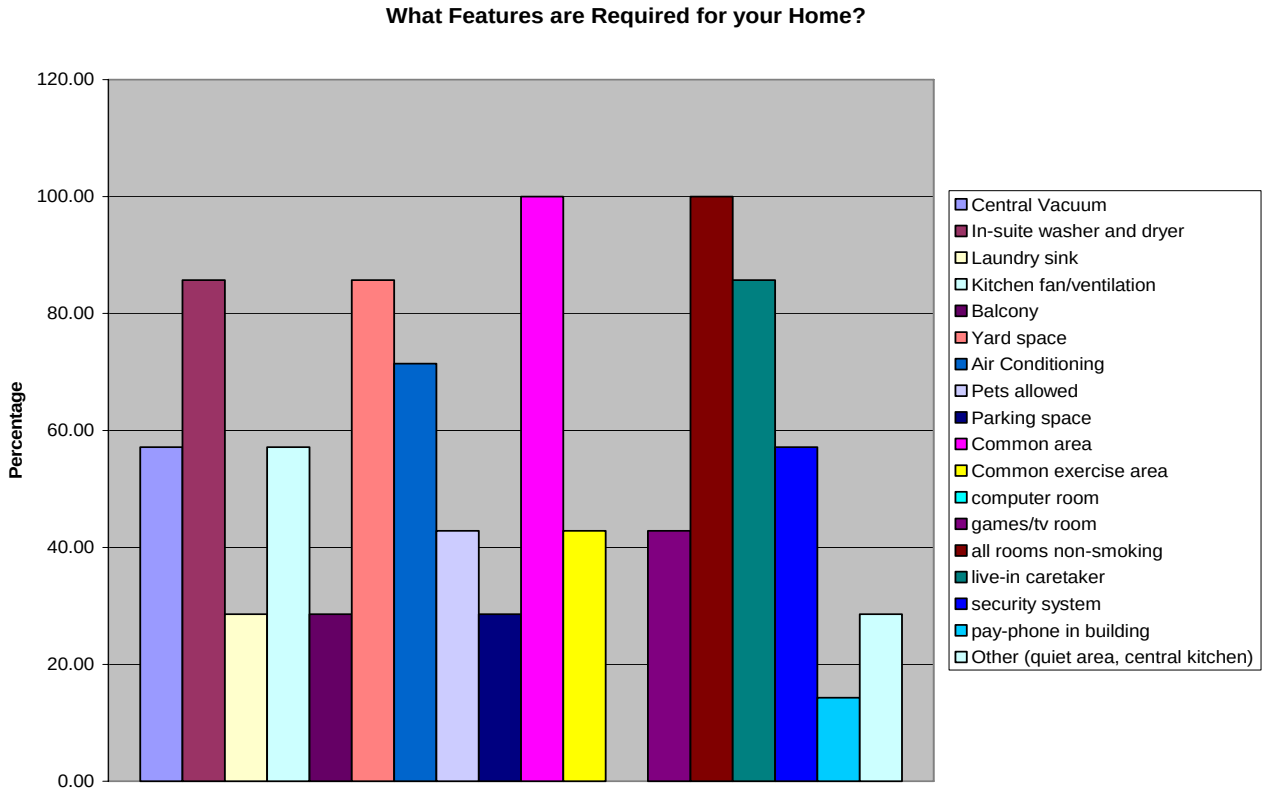
Participants required their bedroom have to have space for a double or queen size bed, a television stand and/or bookstand, a dresser and a mirror. The type of lighting that was preferred in the bedroom was overhead lighting. The majority of participants said that the installation of a pole by the bed was a feature that would come in handy if mobility becomes an issue. Typically, a two-bedroom unit was desire so that the living space could accommodate a personal attendant or offer lodgings to visitors.

One common feature found with a bedroom is a closet. Closet spaces become more accessible if the closet rods are adjustable. An adjustable rod which fits into notched mounting blocks can accommodate people who are different heights and can accommodate persons who find themselves restricted to a wheelchair (The Centre for Universal Design, 2000).

Section 6: Other Spaces and Features of Home

10. Commonly Requested Features in a home

Besides the already discussed rooms, people with intellectual disabilities also require other numerous other features in their home. The following chart indicates what features are commonly considered required:



Based on the above chart, a few items appear as very important:
1) Yard Space:

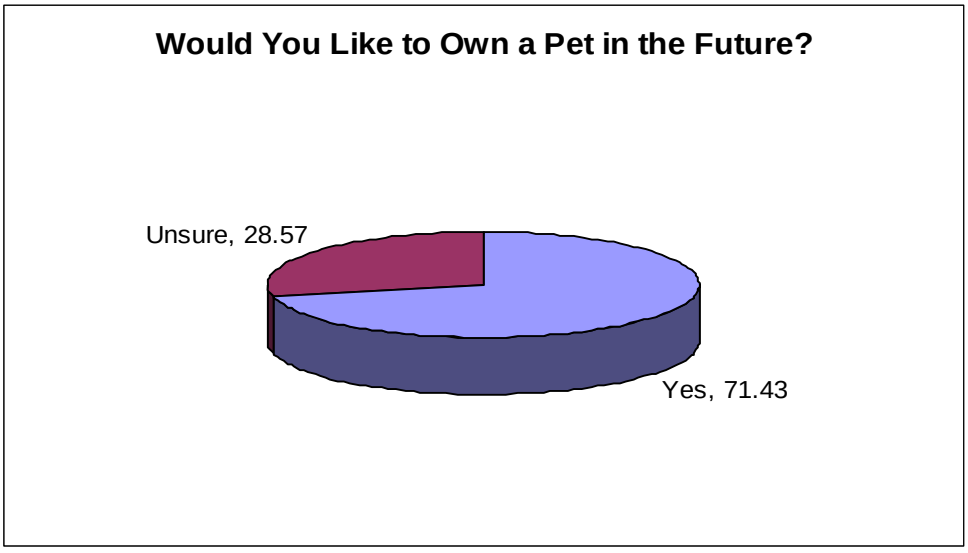
Yard spaces should have visually distinct pathways which are at least 36" wide leading to and from the house. "Entrances to the house should have at least 32 inches of space when the door is open. The door needs lever handles that are easy to open. The threshold should not be any higher than ½ inch" (AARP, 2007).

2) Common Area in which residents can gather to socialize and participant in activities and social events

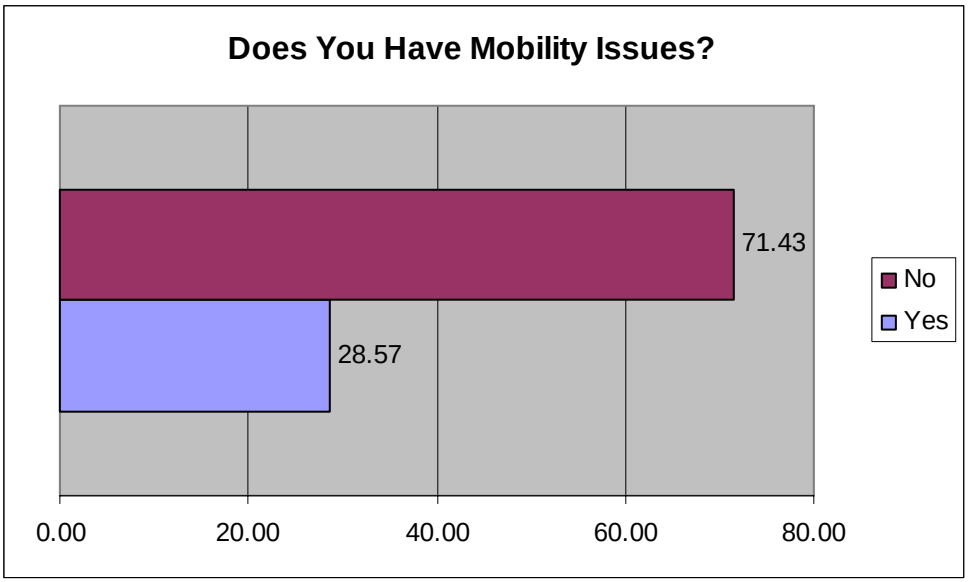
11. Other Issues

When designing homes for people with intellectual disabilities, it is important to also consider the following issues:

- Many people would like to own pets:



- Some people with intellectual disabilities also have mobility challenges:



Section 7: Conclusions

As stated in the previous sections, the concept of universal design facilitates the creation of an optimum living space for persons of all abilities. Participants in this research project did not require (nor request) any extraordinary modifications to the typical living space, rather they require a living space which is adaptable to changing personal circumstances (whether it be health or relationships) and offers an environment in which the residents can engage in their daily activities in a way they desire to. All units within a housing complex should use the aforementioned principles of universal design, this way all units are accessible to the majority of individuals.

References:

The Centre for Universal Design. (2000). Universal design: housing for the lifespan of all people. Raleigh, NC: NC State University. Available online at: http://www.design.ncsu.edu/cud/pubs_p/docs/housing%20for%20lifespan.pdf Accessed September 2007.

General Electric (2007). GE Universal Design: FAQ. Available on line at: http://www.geappliances.com/design_center/universal_design/faq.htm#faq4 Accessed September, 2007.

Appendix 2 – Guiding Ethical Principles

Guiding Ethical Principle	**Incorporation into Research Project**
Respect for Human Dignity	Collection of primary research information was incorporated, as much as possible, into regular gatherings held by the target population. Surveying was limited to an identified group of individuals interested in the research topics.
Respect for Free and Informed Consent	A consent process was built into the research methodology.
Respect for Vulnerable Persons	The consent process was built around special considerations for persons with an intellectual disability. Plain language, larger font, and graphical representations of concepts were incorporated as much as possible to avoid exploitation and discrimination in the research process.
Respect for Privacy and Confidentiality	Original materials from the primary research collection process are maintained in a sealed envelope and a locked cabinet within the offices of the Saskatoon Housing Initiatives Partnership. Reporting on research findings are aggregated to avoid the potential for identification of the source. In all cases, primary research information and names of participants have been separated from one another.
Respect for Justice and Inclusiveness	Information sharing protocols have been established to allow persons to participate in both the research information collection and distribution phases. Accommodations have been made to support participation.
Balancing Harms and Benefits	The research project does not describe nor make value-judgements on existing housing or services provided to persons with an intellectual disability. In this way, it is hoped the benefits of enhanced knowledge will outweigh any potential perceived harm to the reputations of existing providers.

Appendix 3 - Letter of Introduction

With this letter you are invited to participate in a research project on housing for people with intellectual disabilities.

We are collecting information to learn how people with intellectual disabilities use space in the home. There is a lot of information about housing for people with physical disabilities, but there is not very much about what is needed to include people with intellectual disabilities. Specifically, there is not much about what physical characteristics a house should have so that it can best accommodate the needs of people with intellectual disabilities. We are also interested in learning about how to use supported decision making within the context of housing.

This survey is one of three tools that are being used to gather information. We are also using focus groups and face-to-face interviews. In addition, we are reviewing work done by others in published documents and on the internet. Our hope is that the report based on our research will be a practical tool that helps improve housing options for people with intellectual disabilities.

Your participation is voluntary. You may answer as many questions as you want. There is no right or wrong answers. The point of this research is to collect information so that the housing needs of people with intellectual disabilities will be better understood.

Once you have finished the survey, please return it in the envelope that is provided. So that your information remains private, please do not put a return address on the envelope or write your name anywhere on the survey. **The last day that you can return the survey is May 4, 2007**. If you have any questions please call me at (306) 934-1711 or email research@shipweb.org.

Thank you for filling out this survey and participating in our research project!

Sincerely,

Brenda Wallace
Executive Director
Saskatoon Housing Initiatives Partnership

Appendix 4 – Research Consent Form

Research Consent Form

***Housing For Persons With An Intellectual Disability*:**

Identifying Relevant Physical and Governance Structures

You are being invited to participate in a research project. The research is being conducted by two organizations:

Saskatoon Housing Initiatives Partnership (SHIP)
represented by Brenda Wallace and Karen Lynch
and
Saskatchewan Association for Community Living (SACL)
represented by Judy Hannah, Dionne Miazdyck-Shield, and Faith Bodnar

The Research is being performed for Canada *Mortgage and Housing Corporation*

Why we are collecting information:

The reason we are collecting information is to learn how people with intellectual disabilities can be best included in a variety of forms of housing. We will focus our research on two areas:

1. What changes or accommodations must be made to the physical structures of a house so that people with intellectual disabilities can safely and easily access them; and
2. What support and communication tools are needed to help people with intellectual disabilities use supported-decision making in an inclusive housing environment.

How we will be collecting information:

We will be collecting information in two different ways:

1. Primary Research: this includes focus groups, individual interviews, and a mail-out survey; and
2. Secondary Research: this includes a literature review of books and articles that have been written about housing for people with intellectual disabilities.

Through the use of these methods, our research will try to discover what physical and governance structures are needed so that people with intellectual disabilities can be included in all the types of housing that may exist in a community.

Specifically, we will try to answer the following three (3) important questions:

1. How do people with intellectual disabilities use space?
2. How might the physical attributes of homes be changed to best accommodate people with intellectual disabilities?
3. What impact does the inclusion of people with intellectual disabilities have on the day-to-day operations and management of housing?

How we hope it will help:

The information that we collect will be used to write a report. The report will be used to give information to *Canada Mortgage and Housing Corporation* (CHMC) so that they will be aware of what changes are needed in order to include people with intellectual disabilities in community-based housing. We think that it will help make changes for all people with intellectual disabilities over time.

This is how you do it:

1. You will be asked fill out a survey.
2. Your participation is voluntary and you can quit at any time. You can still quit even if you have signed and agreed to the consent form.
3. Your participation is anonymous. This means that your answers will be kept private and no one will be able to know what answers you gave. Consent forms are stored separately from the surveys.
4. You do not have to answer all of the questions.

5. Once you have submitted your survey, you will be unable to change your answers or quit the research project.
6. If you submit your survey electronically (via email) your submission is a sign of your consent to participate in the research. In regards to the consent form please either submit the consent form with an "X" or an electronic signature on the participant signature line.

I understand the reasons for the research and I agree to participate.

_____
Participant Signature

I explained the research to the participant and, to the best of my knowledge, the participant understood the proposed research and freely consented to participate.

_____
Support Person's Signature (If applicable)

Date:_____

Appendix 5 – Focus Group Powerpoint Presentation

Housing For Persons With An Intellectual Disability

FOCUS GROUP AGENDA

7:00PM	Background
7:15PM	Words that Mean Home
7:20PM	Focus on Kitchen
7:40PM	Focus on Living Room
8:00PM	Snack
8:10PM	Focus on Private Spaces
8:30PM	Focus on House Design
8:45PM	Wrapping Up
9:00PM	Go Home!

Housing For Persons With An Intellectual Disability

The following slides show different types of houses and house features.

Please tell us which are best for you.

SLIDE SERIES 1: the kitchen

The next few slides examine types of kitchens, kitchen features, and appliances.

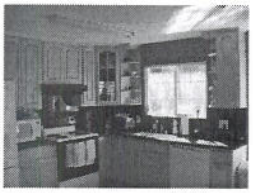
Kitchen Layout:

Would you prefer a Kitchen:

With an Island?

or

Open layout?



Stove Top:

What type of Burner would be best on your stove?

Coil Element?

Gas Burning?

Ceramic Glass Top?

Oven:

Traditional?

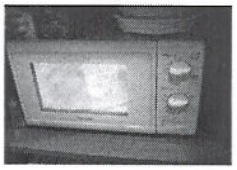
OR

Wall-Mounted?

Microwave Oven:

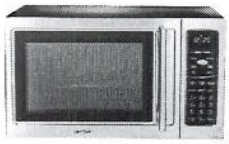
Would you like your microwave to be:

Dial-Operated?



OR

Digital Display?



Taps/Water Faucet:

What type of faucet would work best for you:

Single Handle?

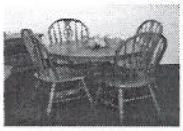
OR

Two Separate Handles?

Dining/Eating Area:

Where do you like to eat meals?

At a Dining Table?



On couch?

At an island/bar?

Kitchen:

Wrapping Up

What words describe the purpose of a kitchen?

Use the flip-chart.

SLIDE SERIES 2: living room

The next group of slides will be about the living (or entertainment) room.

Living Room

Do you like sitting on:

Couches?

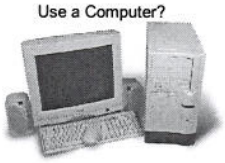
OR

Chairs?

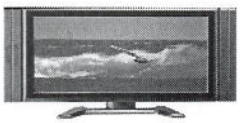
Living Room

Do you want to do these things in a living room?

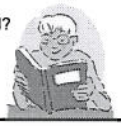
Use a Computer?



Watch Television?



Read?

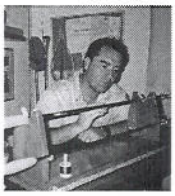


Living Room

Do you want to do these things in a living room?

Exercise?

Do a Craft?



Visit?

Living Room:

Wrapping Up

What words describe the purpose of a living room?

Use the flip-chart.

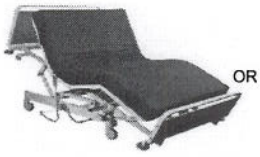
SLIDE SERIES 3: private spaces

Now we are going to show some options for bedrooms, bathrooms, and closets.

Bedroom

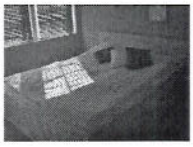
Is it important to have:

A Specialized Bed?



OR

A Simple Bed?



Bedroom

What type of lamps/lighting?

Bedside or Table Lamp?

Floor Lamp?

Wall-Mounted Lamp?

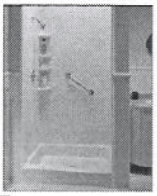
Bedroom
What about other furniture?

Bedside Table?

Dresser?

Bathroom
Shower and bath:

Upright Shower Stall?



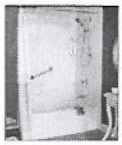
OR

Bathtub with Shower?

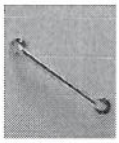
Bathroom
Do you need:

A Shower seat?

A telephone showerhead?

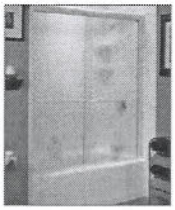


A Handle?



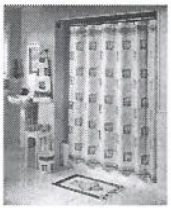
Bathroom
Would you prefer:

Shower Doors?



OR

A Shower Curtain?



Closet Areas

Describe the kinds of things you need to store in your home.

Private Spaces:
Wrapping Up

What words describe the how you use private spaces in your home?

Use the flip-chart.

SLIDE SERIES 4: house design

The next set of slides will look at different house design options that apply to more than just one room.

Flooring

Which type of flooring do you prefer?

Carpet?

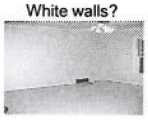
Hardwood/Laminate?

Linoleum/Tile?

Paint Colour

Do you prefer:

White walls?



Light Coloured Walls?

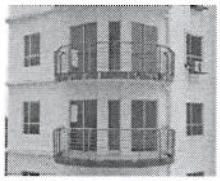
Dark Coloured walls?

Multi-Coloured Walls?

Outdoors

Are these necessary?

A Balcony?



OR

A Backyard?

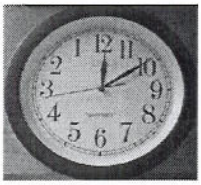
Clocks

Do you feel more comfortable with:

A Digital Clock?

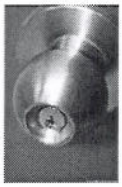
OR

Regular Clock?



Doors

Which works best for you?



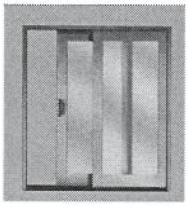
Windows:

Which type of window do you prefer?

Hand-Crank Windows?

OR

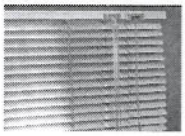
Sliding Windows?



Window Coverings:

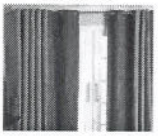
What type of blinds/window covers do you prefer?

Venetian/Horizontal?



Vertical?

Curtains?



Roller Blinds?

Plants:

Do you like houseplants?

House Type

Would you rather live in:

An Apartment?

A Family-Friendly Co-op?

House Type

Would you rather live in:

A Townhouse?

A Small Apartment/Rooming House?

House Type

Would you rather live in:

A suite in a house?

A Suite BEHIND a house?

House Design:
Wrapping Up

Is there anything about the home you would like to live in that we have not discussed?

Use the flip-chart.

Appendix 6 – Mail-Out Survey Form

Part One: Background Information

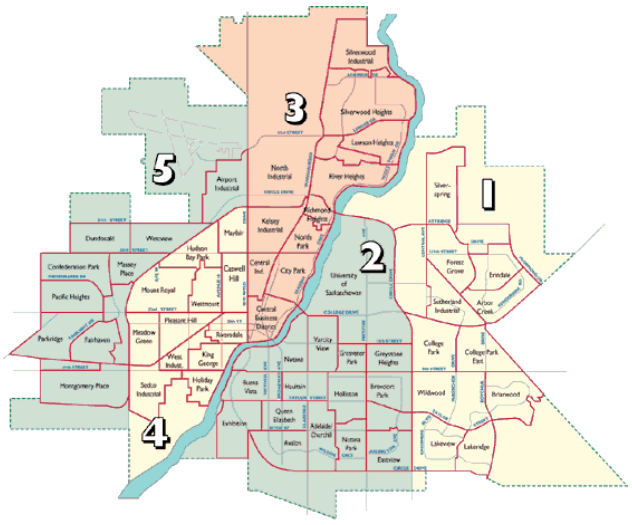
1.1) How old is your adult son/daughter?

- ☐ Younger than 19 years old
- ☐ 19-25 years old
- ☐ 26-35 years old
- ☐ 36-45 years old
- ☐ 46-55 years old
- ☐ 56 years old or older

1.2) Where does your adult son/daughter currently live?

- ☐ At home with the family
- ☐ At a group home
- ☐ In a suite in a house
- ☐ As a boarder in home (shared facilities with some meals provided)
- ☐ On their own; in an apartment (no roommates)
- ☐ On their own; in an apartment (with roommates)
- ☐ Other (please specify the type of residence) _____

1.3) Where in the city does your adult son/daughter live?



☐ Area 1

☐ Area 2

☐ Area 3

☐ Area 4

☐ Area 5

☐ Outside of Saskatoon

1.4) Why did your adult son/daughter chose the housing that they currently live in? Please choose all the reasons that apply from the list.

☐ Close to school

☐ Close to shopping

☐ Close to good bus route

☐ Affordability

☐ Close to work

☐ They chose the first available housing unit that they found

☐ They had no choice in their housing/Somebody else chose their housing

☐ Other (please specify) _____

1.5) How much does your adult son/daughter pay per month for their lodgings?

- ☐ Less than $300.00 per month
- ☐ Between $300.00 and $500.00 per month
- ☐ Between $500.00 and $700.00 per month
- ☐ Between $700.00 and $900.00 per month
- ☐ Over $900.00 per month
- ☐ Not sure what they pay
- ☐ They do not pay any monthly fees related to where they live
- ☐ Other (please specify)_____

1.6) Have you had to deal with issues related to housing your adult son/daughter?

☐ Yes ☐ No

1.6.1) If you checked "yes" please categorize the housing issue(s). Choose all that apply. (If not, please go to question 1.7)

- ☐ Rent too expensive
- ☐ Heat and/or electricity too expensive
- ☐ Landlord uncooperative
- ☐ Neighbourhood not desirable/ they do not feel safe
- ☐ Transportation difficult/ poor bus connections
- ☐ Housing too crowded
- ☐ Housing doesn't suit their needs (too small etc)
- ☐ We had no choice in the type of housing
- ☐ Other (please specify) _____

1.7) Is your adult son/daughter engaged in work?

☐ Yes ☐ No

1.7.1) If you answered "yes" could you please specify on average how many hours per week your adult son/daughter works?

☐ 0 to 10 hours

☐ 10 to 20 hours

☐ 20 to 30 hours

☐ 30 to 40 hours

☐ Other (please specify)
_____

1.7.2) Does your adult son/daughter get paid for their work?

☐ Yes ☐ No

1.7.3) How does your adult son/daughter get to work?

☐ They drive themselves

☐ A parent/family member drives them

☐ They take public transportation

☐ Their employer provides transportation

☐ Other (please specify)_____

1.8) How does your adult son/daughter financially support themselves? (Check as many that apply)

☐ Through employment

☐ Social Assistance/Income Support

☐ Via family arrangements (trusts, allowances etc.)

☐ Other (please specify)_____

1.9) What do you feel are the challenges that your adult son/daughter faces due to their intellectual disability? (Check as many that apply) (Please feel free to use the back of the page)

- ☐ Finding meaningful employment
- ☐ Finding a residence that suits their needs and desires
- ☐ Finding appropriate training programs
- ☐ Other (please specify): _____

_____

_____

_____

_____

_____

Part Two: Physical aspects of living space

2.0) The kitchen area

2.1) Does your adult son/daughter prepare their own food?

- ☐ Yes
- ☐ No
- ☐ Sometimes
- ☐ Unsure

2.1.2) Does their supporter cook for your adult son/daughter?

- ☐ Yes
- ☐ No
- ☐ Sometimes
- ☐ Unsure

2.2) How does your adult son/daughter (or their supporter) cook their food? (Check all that apply)

- ☐ Mircrowave
- ☐ Stove
- ☐ Oven
- ☐ Toaster oven
- ☐ Other (specify): _____
- ☐ Unsure

2.2.1) Please check off all the appliances that your adult son/daughter use on a regular basis?

- ☐ Toaster
- ☐ Blender
- ☐ Food Processor
- ☐ Bread Maker
- ☐ Coffee Maker
- ☐ Electric Kettle
- ☐ Other (Specify)
- ☐ Other (Specify)
- ☐ Unsure if you they use small appliances

2.3) What sort of foods does your adult son/daughter eat/cook? (Check all that apply)

- ☐ Frozen entrées (frozen pizza, TV Dinners)
- ☐ Homemade Meals (from dry and fresh foods)
- ☐ Ready made soups, foods (*for example: macaroni and cheese, cereal*)
- ☐ Fast-food, take-out, or home delivery
- ☐ Other (specify):
- ☐ Unsure

2.4) How does your adult son/daughter store your food? (Check all that apply)

- ☐ Cupboards
- ☐ Fridge
- ☐ Freezer
- ☐ Pantry located in the kitchen
- ☐ Other (specify): _____
- ☐ Unsure

2.5) How does your adult son/daughter clean up after food preparation?

- ☐ Dishwasher
- ☐ Wash the dishes by hand
- ☐ Have someone else come in to clean up
- ☐ Other (specify): _____
- ☐ Unsure

2.6) Where does your adult son/daughter like to eat?

- ☐ In the kitchen at a table
- ☐ In the kitchen at an island with stools/ or high back chairs
- ☐ In an other room (specifiy the room): _____
- ☐ They have no choice in where they eat
- ☐ Other (specify):_____
- ☐ Unsure

2.7) How many people does your adult son/daughter typically eat with?

- ☐ My child prefers to eat alone
- ☐ One other person
- ☐ Two or more
- ☐ They have no choice with who they eat
- ☐ Unsure

2.8) Are there any other comments you would like to make in regards to the kitchen space? (*Please use the back of this page if you need more room*)

3.0) Living Room

3.1) What type of furniture does your adult son/daughter prefer to sit on?

- ☐ Couch
- ☐ Chair
- ☐ Reclining Chair (like a lazy-boy)
- ☐ Other (please specify) _____
- ☐ Unsure

3.2) How many times per month does your adult son/daughter have people over at their place (socially)?

- ☐ 1-2 times per month
- ☐ 3-4 times per month
- ☐ They never have people over socially
- ☐ They are not allowed to have people over to where they currently live
- ☐ They would like to have people over once they get a place of their own
- ☐ I am not sure how often they have people over
- ☐ Other (please specify) _____

3.3) What sort of furniture or features would you require in a living room? (Check all that apply)

- ☐ Coffee table
- ☐ End table
- ☐ Desk
- ☐ Computer stand
- ☐ Television stand
- ☐ Room for plant(s)
- ☐ Bookstand(s)
- ☐ Pet bed/stand
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Unsure/Do not know what is required

3.4) Typically, what activities does your adult son/daughter engage in the living room (check all that apply)

- ☐ Reading
- ☐ Crafts
- ☐ Exercising
- ☐ Using a computer
- ☐ Watching television
- ☐ Entertaining
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Unsure/Do not know

3.5) Are there any other comments you would like to make in regards to the living room? (*Please use the back of this page if you need more room*)

4.0) Bathroom

4.1) What type of bathroom features does your adult son/daughter prefer to have:

- ☐ A Shower stall
- ☐ Bath/ Shower Combination
- ☐ A bathtub
- ☐ Unsure
- ☐ Other_____

4.2) Does your adult son/daughter require electrical outlets in the bathroom?

☐ Yes ☐ No

☐ Unsure

4.3) What type of ventilation would your adult son/daughter prefer in the bathroom?

- ☐ Fan
- ☐ Window
- ☐ Other (specify):
- ☐ Not important to them
- ☐ Unsure

4.3) Are there any other comments you would like to make in regards to the bathroom? (*please use the back of this page if you need more room*)

5.0) Bedroom

5.1) What features would be required in a bedroom?

- ☐ Specialized Bed (Please specify what size of bed):
- ☐ Simple Bed (Please specify what size of bed):
- ☐ Bedside Table
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Unsure/Do not know what is required

5.2) How many bedrooms does your adult son/daughter need to have in their residence?

- ☐ One bedroom
- ☐ Two bedrooms
- ☐ Three bedrooms
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Unsure

5.3) Are there any other comments you would like to make in regards to the bedroom? (*Please use the back of this page if you need more room*)

6.0) Closet Area

6.1) Would your adult son/daughter need an additional closet area?

- ☐ Yes
- ☐ No
- ☐ Unsure

6.2) If you answered "yes" what type of closet area would they want?

- ☐ A walk-in room located in the residence
- ☐ Walk-in unit located elsewhere in the building
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Unsure

6.3) Are there any other comments you would like to make in regards to the storage area? (*Please use the back of this page if you need more room*)

7.0) Other features required in a residence

7.1) What other type of features does your adult son/daughter prefer in a residence? (Please check all that apply)

- ☐ Central Vacuum System
- ☐ Washer/Dryer located in the residence
- ☐ Sink for laundry
- ☐ Ventilation fan/system in the kitchen
- ☐ Balcony
- ☐ Yard space
- ☐ Air conditioning
- ☐ Pets have to be allowed
- ☐ Parking space
- ☐ Common area
- ☐ Common exercise room
- ☐ Common computer room
- ☐ Common games room/television lounge
- ☐ All residences to be non-smoking
- ☐ Live-in caretaker
- ☐ Security system
- ☐ Pay phone in the building
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Unsure

7.2) Does your adult son/daughter do their own laundry?

☐ Yes ☐ No

☐ Unsure

7.3) In terms of temperature does your adult son/daughter prefer a living space that is: (circle the number that applies)

1……..2……..3……..4……..5……..6 7

☐ ☐ ☐ ☐ ☐ ☐ ☐

Hot Warm Cold Unsure

7.4.1) Which lighting style/feature(s) does your adult son/daughter prefer? (Please check all that apply)

- ☐ Overhead lighting features
- ☐ Floor and table lamps
- ☐ Other (specify):
- ☐ Unsure

7.4.2) What type of lighting levels does your adult son/daughter need in their residence?

1……..2……..3……..4……..5……..6 7

☐ ☐ ☐ ☐ ☐ ☐ ☐

Bright Neutral Low light Unsure

7.4.2.1)Does your adult son/daughter lighting levels vary depending on the rooms?

☐ Yes ☐ No ☐ Unsure

7.4.2.1.1)They need *more* lighting, or b*right* lighting in the: (check all that apply)

- ☐ Kitchen
- ☐ Dining area
- ☐ Living Room
- ☐ Bedroom
- ☐ Bathroom
- ☐ Storage area
- ☐ Other (specify):
- ☐ Unsure

7.4.2.1.2) They need *low* levels of lighting, or low lighting in the (check all that apply)

- ☐ Kitchen
- ☐ Dining area
- ☐ Living Room
- ☐ Bedroom
- ☐ Bathroom
- ☐ Storage area
- ☐ Other (specify):
- ☐ Unsure

7.4.3) What type of light does your adult son/daughter prefer?

- ☐ Natural light from Windows
- ☐ Combination of natural light and light bulbs
- ☐ Light from lighting features
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Unsure

7.4) What type of floor covering does your adult son/daughter prefer in their residence?

- ☐ Hardwood/Laminate
- ☐ Linoleum
- ☐ Carpet
- ☐ Other (specify):
- ☐ Other (specify):
- ☐ Unsure

7.6.1) If you lived in a multi-storey building which floor does your adult son/daughter want to live on?

☐	Basement
☐	Ground floor
☐	Second floor
☐	Top floor
☐	Other (specify):
☐	Unsure

7.6.2) Does your adult son/daughter have mobility challenges?

☐ Yes ☐ No

☐ Unsure

7.6.2.1) If you checked "yes" could you tell us how your adult son/daughter moves around in their current home?

_____

_____

7.6.3) Does your adult son/daughter have any other physical challenges that affect the ways in which they use their living space?

☐ Yes ☐ No

☐ Unsure

7.6.3.1)If you checked "yes" could you tell us how you more about their mobility issues?

_____

_____

_____

7.7) Does your adult son/daughter own a vehicle?

☐ Yes ☐ No

☐ Unsure

7.8) Does your adult son/daughter own a pet?

☐ Yes ☐ No

☐ Unsure

7.8.1) If you checked "yes" what type of pet do they own?

_____

7.8.2) Would they like to own a pet in the future?

☐ Yes ☐ No

☐ Unsure

7.9) If you there was a common room in the building do you think your adult son/daughter would use the common room?

☐ Yes ☐ No

☐ Unsure

7.10) Are there any other comments you would like to make in regards to the other features that would be needed in their living space? (*Please use the back of this page if you need more room*)

_____

_____

_____

_____

_____

_____

Part Three: Other comments

8.0) Are there any other comments or topics that you wish to make in regards to the physical requirements/features of a residence? (*Please use the back of this page if you need more room*).