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# RESEARCH REPORT

## HOUSING FOR ADULTS WITH INTELLECTUAL DISABILITIES



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# HOUSING FOR ADULTS WITH INTELLECTUAL DISABILITIES

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Final Report

January 2006

Submitted by:  
Beals, Lalonde & Associates  
Citizen Advocacy of Ottawa  
18 January 2006



## HOUSING FOR ADULTS WITH INTELLECTUAL DISABILITIES

### INTRODUCTION

This study examined the housing issues that adults with intellectual disabilities and their families are facing. Conducted between December 2004 and February 2006, it addressed:

1. the availability of housing and associated support services;
2. best practices;
3. transitions between housing situations;
4. the role of parents of adults;
5. risks that face persons with intellectual disabilities as they transition out of the family home or the juvenile system; and
6. gaps in the availability of housing, both existing and anticipated.

The research focused on three cities: Victoria, Ottawa and Halifax, with some input from stakeholders in other provinces. While not national in scope, nor exhaustive in its methods, it provides an overview of the housing and support issues facing adults with intellectual disabilities.

In 2001, there were 120,140 Canadians over the age of 15 with developmental disabilities<sup>1</sup>. Family members are the only, or the main source of support for almost 80 per cent of adults with intellectual disabilities. Fifty per cent of family members providing support indicate they are not getting the back-up assistance and in-home support they need from their communities.

Approximately 12 per cent of individuals with developmental disabilities are aged 65 and over, and population projections indicate that, because these people are living longer than they used to, the population of developmentally disabled people who are 55 years of age or older will double within the next 25 years. These individuals and the families who support them are likely to encounter a number of life transition issues, as both the parents and their adult children age. Many individuals and families continue to be presented with options that do not support lifestyles of choice but instead demand that people with developmental disabilities stay indefinitely in the family home, or move into group home programs or other considerably more institutional environments.

### METHODOLOGY

The study pursued three lines of enquiry

- A literature review: The literature review focused on North American sources, primarily those available on the web. An Internet search using key words related to housing for people with intellectual disabilities generated many publications, the majority of which were American. Other materials were generated through discussions with individuals working in the field of developmental disability with responsibility for supporting people with their residential needs, and engaged in creative developments in this field.
- Interviews: Thirty-nine telephone interviews were conducted with a range of government respondents, service providers, academics, and with representatives of relevant associations. Interviewers worked from a 17-question interview guide that included both open and closed questions.
- Focus groups: Nine focus groups comprising 83 participants were conducted—three each with people with intellectual disabilities (consumers), the families of consumers, and service providers in Victoria, Ottawa, and Halifax.

<sup>1</sup> Cossette, L. and Duclos, E. (2002). *A Profile of Disability in Canada 2001* (No. 89-577-XIE). Ottawa, Statistics Canada: Housing, Family and Social Statistics Division.

## FINDINGS

### Availability of Appropriate Housing and Support Services

Overwhelmingly, the participants in the study reported a significant gap between the housing needed and the housing available. They also indicated that providing the physical facilities is not the most difficult problem to address—of more concern is the availability of adequate and appropriate support services, including well-trained staff. These two factors combine to produce a reactive rather than a pro-active system—a family in crisis can almost always find a bed when the need is urgent, but the bed may be inappropriate, and planning for a smooth transition from a family home to a more independent living environment is seldom addressed.

As a result, and too often, adults with intellectual disabilities are housed in facilities that are not necessarily best suited to their needs.

### A Desire to Live Independently

Adults, including those with intellectual disabilities, usually want to live independently. They want to make their own decisions on whom to live with, where to live, and what to do with their time. People with intellectual disabilities face extra challenges in working towards that goal, however, such as

- limited financial resources, usually in the form of government pensions which impose restrictions on their other earnings or on living conditions
- limited support services that could assist them in planning for and effecting the transition to independent living and subsequently provide the specific support services they would need to live independently
- a system that is geared to accommodating them within existing housing, rather than creating housing situations geared to their needs
- families and support organizations that fear for their safety or question their ability to live on their own

### Financial Issues

A repeated theme in interviews and focus groups was the lack of funding from governments, coupled with limited family financial resources. The preferred housing option—private accommodations with support services as required—is primarily available to those families with the resources to purchase a home or apartment.

A range of financial considerations and funding policies are considered to have a negative impact on a family's ability to provide for their adult children with intellectual disabilities, such as

- restrictive or claw-back provisions in pension programs that keep an individual in poverty
- estate planning regulations that make it difficult to provide for children without losses from taxation
- mortgage rates that do not differentiate between regular mortgages, and those required to assist families in adapting their homes to keep their adult children in the family home
- financial institutions whose lending criteria do not recognize disability pensions as assurance for mortgage payments

### Impact of Municipal By-Laws

A range of municipal policies, or the interpretation and application of municipal policies, can have an impact on the availability of housing for adults with intellectual disabilities. For example, application of the building and safety requirements intended for institutional facilities to group homes can render them prohibitively expensive.

### Best Practices

Flexibility and choice: Many housing models emerged as desirable in different circumstances. The underlying principle that unifies them is consistent, however: the need for flexibility and choice. There is such variation in the abilities, needs and desires of people with intellectual disabilities and their families, that there must be a corresponding range of housing and support options.

De-linked funding: There was also a desire to separate physical housing from service supports, so that funding for services for an individual would not be tied to his or her residence. Currently, if a resident is unhappy with the quality or level of services provided, she or he often must change residences in order to change services.

The person-centred approach: This approach is one in which the person with an intellectual disability or his or her advocate is directly involved in planning and choosing the housing and support services that will best meet his or her needs. Typically, in a person-centred approach, funding is portable, tied to the individual rather than to an agency or a facility.

## Favoured Housing Models

A number of options or models were cited as best practices that embody the over-arching principle of flexibility and choice.

Independent living model: An independent living model is one in which the person with an intellectual disability lives independently, often sharing a house or apartment with other consumers and/or with service providers. Service providers may also be close by (for example in a neighbouring apartment) instead of sharing living quarters.

Co-ops and co-op-like arrangements: In co-op housing, a group gets together, builds their own multi-unit building, and gives up some private space for community space. Residents are people who want not just housing, but also community support.

Home ownership/adaptation of family homes: This option, while cited by many study participants as a best practice, is one that is rarely available to most people with intellectual disabilities.

L'Arche model: L'Arche was the only group home that was identified as a best practice. L'Arche homes exist in a number of provinces. All are faith-based, geared to aging-in-place, and feature employees who function more like family members than staff.

As part of a seniors' complex: A number of study participants felt that adults with intellectual disabilities need the same types of supports typically provided in seniors' residences, and saw merit in combining facilities for seniors and adults with intellectual disabilities.

## CONCLUSION

The research found that there is a significant unmet need for suitable housing for adults with intellectual disabilities, resulting from a lack of funding for physical facilities and supports. As well, the current system which provides housing for adults outside their family home is geared to meeting the needs of the system rather than those of the individuals it is meant to serve. Too often, individuals are housed where space is available, rather than in residences suited to their specific needs.

Making the transition from a family home to independent living can be difficult for any adult, but more so for adults with intellectual disabilities, because of their more limited ability to cope with the challenges of adapting to new situations and taking on new responsibilities. The shortage of support services can therefore be an impediment to a successful transition.

Family members, especially aging parents, want to participate in planning for the transition to other forms of housing and to have input to the decisions that affect their family members. While most service providers share that concern, their resources are often such that a desire for a pro-active and responsive approach is not translated into reality.

While many housing models emerged as desirable in different circumstances, they have a common focus on flexibility and choice, reflecting the variation in the abilities, needs and desires of people with intellectual disabilities and their families. Finally, study participants advocate a person-centred approach, in which people with intellectual disabilities or their advocates are directly involved in planning and choosing housing and support services, and in which funding is tied to the individual rather than to an agency or facility.

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## LOGEMENTS POUR ADULTES AYANT UNE DÉFICIENCE INTELLECTUELLE

### INTRODUCTION

Cette étude examine les difficultés à se loger auxquelles sont confrontés les adultes ayant une déficience intellectuelle et les membres de leur famille. Effectuée entre décembre 2004 et février 2006, l'étude traite :

1. de la disponibilité des logements et des services de soutien connexes;
2. des pratiques exemplaires;
3. des transitions d'une situation de logement à une autre;
4. du rôle des parents des adultes;
5. des risques auxquels sont soumises les personnes ayant une déficience intellectuelle quand elles quittent le foyer familial ou l'établissement spécialisé pour les jeunes;
6. des pénuries de logements, tant existantes que prévues.

La recherche s'articulait autour de trois villes, soit Victoria, Ottawa et Halifax, et a recueilli l'opinion d'intervenants d'autres provinces. Bien que la portée n'était pas nationale, pas plus d'ailleurs que sa démarche n'était exhaustive, elle offre une vue d'ensemble du logement et des difficultés qu'ont les adultes ayant une déficience intellectuelle à obtenir de l'aide.

En 2001, il y avait 120 140 Canadiens de plus de 15 ans qui souffraient de troubles du développement<sup>1</sup>. Les membres de la famille sont la seule ou la principale source de soutien pour presque 80 % des adultes ayant une déficience intellectuelle. Cinquante pour cent des membres d'une famille qui offrent un soutien indiquent qu'ils n'obtiennent pas, de la collectivité, l'aide supplémentaire et le soutien à la maison dont ils ont besoin.

Environ 12 % des personnes ayant des troubles du développement sont âgées de 65 ans ou plus, et les prévisions démographiques

plus vieilles que par le passé, le nombre de personnes de 55 ans ou plus ayant des troubles du développement doublera au cours des 25 prochaines années. Ces personnes et les membres de leur famille qui les soutiennent feront face à un certain nombre de problèmes liés à la transition au fur et à mesure que les parents et leurs enfants adultes vieilliront. On continue d'offrir à de nombreuses personnes, ainsi qu'aux membres de leur famille, des options qui ne leur permettent pas de choisir le style de vie qu'ils souhaitent, mais qui exigent plutôt que les personnes ayant des troubles du développement demeurent en permanence à la maison familiale ou déménagent dans un foyer de groupe ou dans un milieu plus institutionnalisé.

### MÉTHODE

L'étude comportait trois volets :

- Examen de la documentation : L'examen de la documentation ciblait les sources nord américaines, principalement celles disponibles sur le Web. Une recherche sur Internet à l'aide de mots clés liés au logement pour personnes ayant une déficience intellectuelle a généré de nombreuses publications dont la majorité était américaine. D'autres renseignements ont été tirés de discussions avec des personnes travaillant dans le domaine des troubles du développement et chargées d'aider les personnes à résoudre leurs problèmes de logement, notamment en faisant preuve de créativité dans ce domaine.

<sup>1</sup> Cossette, L. et Duclos, E. (2002). Un profil de l'incapacité au Canada en 2001 (n° 89-577-XIE). Ottawa, Statistique Canada : Division des statistiques sociales du logement et des familles.

visant la population indiquent que, parce que ces personnes vivent



- **Entrevues** : Trente-neuf entrevues téléphoniques ont été effectuées auprès de nombreux intervenants gouvernementaux, fournisseurs de services, universitaires et représentants d'associations concernées. Les entrevues se sont faites à partir d'un questionnaire comportant 17 questions, tant ouvertes que fermées.
- **Groupes de discussion** : Neuf groupes de discussion, composés de 83 participants, ont été formés : trois avec des personnes ayant des déficiences intellectuelles (consommateurs), trois avec les membres des familles des consommateurs et trois avec des fournisseurs de services de Victoria, d'Ottawa et de Halifax.

## CONSTATATIONS

### Disponibilité de logements et de services de soutien adéquats

La très grande majorité des participants à l'étude ont souligné l'écart important qui existe entre le nombre de logements nécessaires et le nombre de logements disponibles. Ils ont aussi indiqué que le problème des installations matérielles n'est pas le plus difficile à régler; l'accès à des services de soutien appropriés et opportuns est plus inquiétant, de même que la disponibilité de personnel compétent. Ces deux facteurs ont contribué à l'établissement d'un système réactif plutôt que proactif : une famille en pleine crise peut toujours trouver un lieu d'hébergement en cas d'urgence, mais ce lieu peut ne pas être adéquat, et la planification de la transition de la maison familiale à un milieu de vie plus autonome est rarement abordée.

En conséquence, et trop souvent, les adultes ayant une déficience intellectuelle sont logés dans des endroits qui ne sont pas nécessairement les mieux adaptés à leurs besoins.

### Un désir de vivre de façon autonome

Les adultes, y compris ceux ayant une déficience intellectuelle, veulent d'habitude vivre de façon autonome. Ils veulent prendre leurs propres décisions quant aux personnes avec qui ils désirent vivre à leur lieu de résidence et à ce qu'ils veulent faire de leur temps. Les personnes ayant une déficience intellectuelle font cependant face à des difficultés supplémentaires quand elles essaient d'atteindre ce but, notamment :

- des ressources financières restreintes, généralement sous la forme de pensions de l'État qui imposent des restrictions quant aux autres sources de revenu ou aux conditions de vie;
- des services de soutien limités qui pourraient aider ces personnes à planifier et à effectuer la transition vers un milieu de vie autonome et qui, par la suite, leur offriraient les services de soutien particuliers dont elles ont besoin pour vivre de façon autonome;
- un système qui vise à adapter le logement existant plutôt que de créer des situations de logement axées sur leurs besoins;

- les familles et les organismes de soutien qui craignent pour la sécurité de ces personnes ou qui mettent en doute leur capacité à vivre seules.

### Problèmes financiers

Le manque de financement de la part des gouvernements, associé aux ressources financières familiales restreintes, est un thème qui a été soulevé à maintes reprises au cours des entrevues et pendant les discussions de groupes. L'option de logement préférée, soit un logement privé offrant au besoin des services de soutien, est surtout accessible aux familles ayant les ressources pour acheter une maison ou un appartement.

On juge que de nombreuses questions financières et politiques de financement ont des répercussions défavorables sur la capacité d'une famille à subvenir aux besoins de leurs enfants adultes ayant une déficience intellectuelle, notamment :

- les dispositions restrictives ou de récupération des programmes de pension qui maintiennent les personnes dans la pauvreté;
- les règlements sur la planification successorale qui font en sorte qu'il soit difficile d'aider les enfants financièrement sans subir des pertes au niveau de l'impôt;
- les taux des prêts hypothécaires qui ne font pas de distinction entre les prêts ordinaires et ceux requis pour adapter la maison familiale afin que les enfants adultes puissent y demeurer;
- les établissements financiers dont les critères de crédit ne reconnaissent pas les rentes d'invalidité comme garantie aux fins des paiements hypothécaires.

### Répercussions des règlements municipaux

De nombreux règlements municipaux, ou l'interprétation et l'application des ces derniers, peuvent avoir une incidence sur la disponibilité de logements pour les adultes ayant une déficience intellectuelle. Par exemple, lorsque les dispositions relatives au bâtiment et à la sécurité pour les établissements institutionnels sont appliquées aux foyers de groupe, elles peuvent entraîner des coûts exorbitants.

### Pratiques exemplaires

**Souplesse et choix** : De nombreux modèles de maisons semblent souhaitables dans différentes circonstances. Le principe sous-jacent qui les unit est toutefois le même : le besoin de souplesse et de choix. Les écarts dans les capacités, les besoins et les désirs des personnes ayant une déficience intellectuelle et des membres de leur famille sont tels qu'il doit y avoir une gamme correspondante de logements et d'options en matière de soutien.

Financement distinct : On souhaite également qu'une distinction soit faite entre le logement comme tel et les services de soutien, de sorte que le financement pour les services utilisés par une personne ne serait pas lié à son lieu de résidence. Actuellement, si un résident n'est pas satisfait de la qualité ou du niveau des services fournis, il doit souvent changer de résidence afin d'être en mesure de changer de services.

La méthode axée sur la personne : Il s'agit de permettre à une personne ayant une déficience intellectuelle ou à son mandataire de participer directement à la planification et au choix du logement et des services de soutien qui répondront le mieux à ses besoins. Généralement, dans une démarche axée sur la personne, le financement est transférable, c'est-à-dire qu'il est rattaché à la personne plutôt qu'à un organisme ou un établissement.

### **Modèles de logement privilégiés**

Un certain nombre d'options ou de modèles, dans lesquels le principe très important de souplesse et de choix trouve son application, ont été mentionnés à titre de pratiques exemplaires.

Modèle favorisant l'autonomie : Dans ce genre de modèle, la personne ayant une déficience intellectuelle vit de façon autonome, en partageant souvent une maison ou un appartement avec d'autres consommateurs et/ou avec les fournisseurs de services. Les fournisseurs de services peuvent aussi demeurer à proximité (dans un appartement voisin par exemple) au lieu de partager le même logement.

Coopérative ou établissement semblable : Dans une coopérative d'habitation, un groupe de personnes s'unissent, construisent leur propre collectif d'habitation et renoncent à un certain espace privé pour aménager un lieu communautaire. Les résidents sont des personnes qui ne désirent pas uniquement un logement, mais aussi un soutien communautaire.

Propriétaire-occupant/adaptation d'une maison familiale : Cette option, mentionnée par de nombreux participants à l'étude comme étant une pratique exemplaire, est rarement accessible à la plupart des personnes ayant une déficience intellectuelle.

Modèle L'Arche : L'Arche est le seul foyer de groupe qui a été mentionné comme étant une pratique exemplaire. Les maisons L'Arche existent dans plusieurs provinces. Toutes reposent sur la foi, visent à ce que les personnes puissent vieillir chez elles et se distinguent par des employés qui agissent davantage comme des membres de la famille plutôt que des membres du personnel.

Intégration à un établissement pour personnes âgées : Certains participants à l'étude avaient le sentiment que les adultes ayant une déficience intellectuelle doivent recevoir les mêmes services de soutien que ceux offerts dans une résidence pour personnes âgées, et voyaient un avantage de jumeler les établissements pour personnes âgées et ceux pour adultes ayant une déficience intellectuelle.

## **CONCLUSION**

La recherche a permis de découvrir qu'il existe un important besoin de logements convenables pour adultes ayant une déficience intellectuelle, en raison du sous-financement des installations matérielles et des services de soutien. Il faut ajouter que le système actuel qui offre des logements pour les adultes vivant à l'extérieur du foyer familial vise davantage à répondre aux besoins du système plutôt qu'à ceux des personnes qu'il est sensé servir. Trop souvent, les personnes sont logées là où l'espace le permet, plutôt que dans une résidence adaptée à leurs besoins particuliers.

Il peut s'avérer difficile, pour n'importe quel adulte, de faire la transition entre la vie au foyer familial et l'autonomie, mais c'est encore pire pour les adultes qui ont une déficience intellectuelle, en raison de leur capacité restreinte à s'adapter aux situations nouvelles et à assumer de nouvelles responsabilités. La pénurie de services de soutien peut donc entraver la réussite de la transition.

Les membres de la famille, particulièrement les parents qui prennent de l'âge, veulent participer à la planification de la transition vers d'autres formes de logements et à la prise des décisions qui touchent les membres de leur famille. Bien que la plupart des fournisseurs de services partagent cette préoccupation, leurs ressources sont telles que le désir d'adopter une démarche proactive et adaptée ne se concrétise pas.

Même si de nombreux modèles de maisons semblent souhaitables dans différentes circonstances, ils ont un objectif commun : offrir la souplesse et le choix, en tenant compte de la diversité des capacités, des besoins et des désirs des personnes ayant une déficience intellectuelle et des membres de leur famille. Enfin, les participants à l'étude préconisent une démarche axée sur la personne, c'est-à-dire que les personnes ayant une déficience intellectuelle ou leurs mandataires puissent participer directement à la planification et au choix du logement et des services de soutien, une démarche qui fait en sorte que le financement soit lié à la personne plutôt qu'à l'organisme ou à l'établissement.

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**Consultants : Beals, Lalonde & Associates**

Parrainage civique d'Ottawa

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# HOUSING FOR ADULTS WITH INTELLECTUAL DISABILITIES

Final Report – January 2006

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# HOUSING FOR ADULTS WITH INTELLECTUAL DISABILITIES

## 1. INTRODUCTION

The objective of this study was to identify housing needs and to explore housing options (primarily supportive housing) for adults with intellectual disabilities. The study, conducted between December of 2004 and February 2006, addresses the following issues:

1. The availability of housing and associated support services
2. Best practices (as identified in the literature and through interviews and focus groups)
3. Transitions between housing situations
4. The role of parents of adults (the role they wish to play, and the role that may be imposed on them by their available options)
5. Risks that face persons with intellectual disabilities as they transition out of the family home or the juvenile system
6. Housing requirements of people with multiple disabilities
7. Gaps in the availability of housing, both existing and anticipated

This study focussed on three municipalities: Victoria, Ottawa and Halifax, with additional input, on a very limited basis, from stakeholders in other provinces. While not national in scope, nor exhaustive in its methods, it provides an overview of the housing and support issues facing adults with intellectual disabilities.

### 1.1 Background

In 2001 there were 120,140 Canadians over the age of 15 with developmental disabilities<sup>1</sup>. Their support needs are high. According to the Canadian Association for Community Living (CACL), almost 2/3 of young people with intellectual disabilities<sup>2</sup> need assistance with everyday activities (compared with just over 15% of other young people with disabilities). Family members are the only, or the main source of support for almost 70% of people with intellectual disabilities. The figure is almost 80% once children become of adult age, indicating that there is less support for intellectually disabled adults than for intellectually disabled children. Fifty percent of family members providing support indicate they are not getting the back-up assistance and in-home support they need from their communities. CACL's website also indicates that the bulk of disability supports is currently provided on a voluntary, unpaid, basis by family members, including persons with disabilities themselves.

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<sup>1</sup> Cossette, L. & Duclos, E. (2002). A Profile of Disability in Canada 2001 (No. 89-577-XIE). Ottawa, Statistics Canada: Housing, Family and Social Statistics Division.

<sup>2</sup> Throughout this paper, the terms "developmental disability" and "intellectual disability" are used interchangeably.

The uneven distribution of support delivery is taxing on family members and persons with intellectual disabilities. Although there has been a general policy trend to move away from institutionalization and towards the kind of community integration which might be implied in this reliance on family, many individuals and families continue to be presented with options that do not support lifestyles of choice but instead demand that the consumer stay indefinitely in the family home, or move into group home programs and/or other considerably more institutional environments.

The lack of in-home support for families contributes to the enormous pressures families are experiencing as they attempt to provide the care and support for their family member - as children and then as adults. Approximately 12% of individuals with developmental disabilities are aged 65 and over, and population projections indicate that because these people are living longer than they used to, the population of developmentally disabled people who are 55 years of age or older will double within the next 25 years. These individuals and the families who support them are likely to encounter a number of life transition issues, as both the parents and their adult children age. In Canada, researchers have not yet assembled a comprehensive analysis of the situation, problems, and risks likely to be encountered by these (often inadvertent) pioneers in dealing with the on-going housing needs of adults with intellectual disabilities.

## **1.2 Structure of this Report**

The remainder of this report is structured as follows:

- Section 2, Methodology: describes how this study was conducted.
- Section 3, Findings: presents the findings that emerged from this study.
  - 3.1 Literature Review: presents a summary of the findings of the literature review, the full text of which is in Appendix C
  - 3.2 Availability and Gaps: addresses the availability of housing and associated support services; housing requirements of people with multiple disabilities; and gaps in the availability of housing, both existing and anticipated
  - 3.3 Transitions and Risks: addresses transitions between housing situations; and risks that face persons with intellectual disabilities as they transition out of the family home or the juvenile system

3.4 The Role of Parents: addresses the roles parents of adults with intellectual disabilities wish to play and the roles they may have imposed upon them by available options

3.5 Best practices identified throughout the course of the study.

- Section 4, Emergent Themes: presents the broad, significant themes that emerged during and weave their way throughout all of the findings.
- Section 5, Conclusion: summarizes the principal findings of the study.

## **2. METHODOLOGY**

### **2.1 Research Methods Used**

The research team for this study used a variety of research methods, as described below.

- Literature Review: The literature review focused on North American sources. An Internet search using key words related to housing for people with developmental disabilities generated many publications, though most were not Canadian. Key words included: developmental disability and housing; intellectual disability and housing; normalization theory; social role valorization theory; and developmental disability and aging. Other materials were generated through discussions with individual working in the field of developmental disability with responsibility for supporting people with their residential needs, and engaged in creative developments in this field. The findings from the literature review are provided in Appendix C, and a summary is provided in section 3.1 of this report.
- Original Research: The team conducted primarily original research, through a series of interviews and focus groups.
  - Interviews: Thirty-nine telephone interviews were conducted with a range of government respondents, service providers, academics, and with representatives of relevant associations. They are listed at Appendix E. Interviewers worked from a 17-question interview guide that included both open and closed questions. The interview guide is included as Appendix A to this report. All of the interviewers submitted detailed notes that were compiled in a Key Informant Interviews Report, which included a number of statistical arrays and cross-tabulations. These may be cited at times in the report, but because the sample was very small. those numbers are only indicative – they are not statistically valid.



- **Focus Groups:** Nine focus groups comprising 83 participants were conducted - three each with consumers, the families of consumers, and service providers in Victoria, B.C.; Ottawa, Ontario; and Halifax, N.S. Focus group facilitators worked from different guides for each target group. Those guides are included as Appendix B to this report.

Throughout this report, the term “study participant” is meant to include both interviewees and focus group participants.

## **2.2 Analysis and Reporting**

Once all of the interview and focus group findings had been compiled, the principal researchers analyzed them to yield a response to each of the study questions presented in this report. These responses were also analyzed in terms of their consistency with the information presented in literature review. There was a high degree of consistency between the literature review findings and those that emerged through the original research.

## **2.3 Terminology**

Researchers encountered a wide range of subject-specific terms, used both in the literature and by study participants. While they found no formal corresponding definitions, they found that involved practitioners seemed to share a general understanding of terms, though there were some variations in the fine details, from person-to-person, or place-to-place. A glossary of terms that may be helpful to the reader is included as Appendix D.

## **3. FINDINGS**

In this section, an overview of the literature review is presented first. It is followed by a presentation of the findings from the interviews and focus groups, topically organized by study objective. The findings that start in section 3.2 and in subsequent sections of this report are liberally interspersed with quotes from study participants, and thus the grammar and syntax of quotes and examples is often unpolished.

### **3.1 Findings from the Literature Review**

A consensus has emerged in Canadian society that recognizes the right of people with disabilities to participate fully in society. Moving from rhetoric to actual practice is a slow process. Moving from isolation to integration, from paternalism to independence requires continued shifting at the public policy level if this change is to be realized. The place where one lives will have a critical influence on how we achieve full participation of people with intellectual disabilities in our

society. The literature suggests the general prevalence of developmental delays range from 1% to 3% of the population, however epidemiological studies tend to lend support for the lower estimates.

The literature review considered the definition of intellectual disability. The terminology has evolved over the past number of decades from reference to persons with “mental retardation” to “developmental disability” and the more recent terminology “intellectual disability”. There are several approaches to classifying persons with an intellectual disability identified in the literature including the categorical approach, the social systems approach and the functional approach.

The review considered the housing challenges for persons with intellectual disabilities. Housing Issues of Albertans with Developmental Disabilities (2001) summarizes these challenges very well. They include a lack of affordable, suitable and adequate housing due to low vacancy rates and disincentives to build low-cost housing; the limited availability of accessible housing for those who have physical disabilities; competition for affordable housing favouring other groups (such as single parents); and landlord reluctance to rent to individuals who have behavioural challenges or whose signatures on legal forms may not hold up in court. Housing challenges for the intellectually-challenged are also exacerbated when there are multiple disabilities that include an intellectual disability.

This paper also establishes that most people with developmental disabilities are poor with low and relatively fixed incomes, and have either no employment or minimum wage employment. The housing challenges they encounter are thus exacerbated by their poverty. Those who seek to own their homes find that little money can be saved from fixed incomes for down payments, few properties are available in the low-cost end of the market, they often lack a credit rating which makes getting a bank loan difficult and public trustee policies favour liquidity of assets over home ownership.

Shared accommodations might reduce the costs of housing for persons with intellectual disabilities but increases the need for support to deal with behavioural challenges thereby increasing support-related costs. Such accommodation might also limit the consumer’s freedom to make choices about how they live their lives.

The research indicates that there is a range of models and approaches to housing for persons with intellectual disabilities. Community living facilities for persons with intellectual disabilities are generally agency-owned, operated and/or licensed. Housing and services are generally linked; people with disabilities are expected to make the transition to less restrictive settings as they acquire additional skills or to move to more restrictive settings if problems occur. The perceived severity of a disability determines the type of facility in which an individual will be placed. A study undertaken by the state of Vermont (Burchard 1999) speaks to the requirement of social policy to reflect the real needs of individuals with intellectual disabilities for individualization, choice, as much personal control as possible, and more respect and faith in individuals’ abilities to make and exercise choices. Although it is an older study (undertaken in 1979), more recent

developments are consistent with the Vermont findings. In recent years there has been a shift in the field of developmental services, away from the notion of a continuum of residential facilities and towards more flexible and responsive approaches that are “non-facility based,” “person-centered,” or a “housing and support” approach for adults. The range of models presented in this literature review reflects this evolution.

The Group Home is examined and positioned as the most common and familiar housing model for people with intellectual disabilities. The literature suggests that the path to community living often leads families to the group home. While this model has responded to very real needs for decent housing for people with intellectual disabilities in many communities, the review critiques the model and its desirability, positioning it as an option that places priority on functionality and administrative ease, where decision-making is generally driven by economic considerations. It establishes that families and individuals are seeking alternatives to the traditional group home, seeking more flexibility and autonomy for the consumer.

One such approach is independent living in one’s own home or in an apartment. In the research, this was characterized as a dream available only to the very few who achieve a concordance of family support, funding structures, and service arrangements. For individuals requiring a higher level of support, a family home arrangement is another option for providing a home for the individual rather than a purely residential program. Shared accommodation with a live-in caregiver, cooperative ownership models and the cluster model (wherein a number of consumers live “clustered” together in a series of apartments in a single apartment building, for example) are additional examples of models of housing for individuals with intellectual disabilities that are explored in the literature review as more flexible alternatives to the traditional group home.

Older persons with developmental disabilities are a growing segment of North American society. The literature suggests there is a need to increase the number and variety of housing options for older adults with intellectual disabilities including options with access to community services and facilities. Aging-in-place is cited as an attractive concept, but one that has proved difficult to implement in Canada, given long waiting lists and the need to adapt accommodations to the needs of seniors with developmental disabilities. Permanency planning, collaboration between services providers in the disability and seniors sectors and an examination of how to support aging in place are all factors that require consideration in addressing housing requirements for seniors with an intellectual disability.

The literature review also explores the concept of microboards as an approach to supporting people in finding and sustaining housing and in developing personal support services for individuals with disabilities. The microboard model calls for a shift to individualized funding, governance structures that are directed by the individual being supported, supports that are adaptable to changes in a person’s needs, interest, relationships and environment, and lives that are defined less by services and increasingly by companionship, connection and community.

The literature review revealed a focus on the trend towards smaller scale housing for people with developmental disabilities that is widespread throughout North America and Canada. The benefits cited include flexibility, the option of staying in a familiar setting, family and social involvement, and the freedom to make choices. This is consistent with the general characteristics of successful housing models that emerged in the review: housing with supports that are flexible and individualized; housing that typifies North American living arrangements for people who do not have disabilities; housing that provides people with more control over where they live, who they live with and how they live; housing with supports that are more adaptable and able to innovate on an ongoing basis as situations change; and housing options that separate personal service needs and housing accommodations..

Successful housing policy starts with the person first. The implication for successful housing policy related to people with intellectual disabilities is that housing is about much more than bricks and mortar. Successful housing policy will involve both the public and private sectors and will require strong partnerships and collaboration.

## **3.2 Availability and Gaps**

### **3.2.1 Availability of Housing**

The vast majority of study group participants reported a severe and chronic shortage of appropriate housing for intellectually-challenged adults. Among the interviewees, for example, more than half assessed the availability of housing as poor or very poor, and only 14% assessed it as good.

Input from the focus groups brings these numbers to life. Service providers clearly established that long waiting lists for consumers looking for alternatives to the family home are the norm. In Ottawa, for example, service providers reported that all available spaces are used, and that there are 500 people on waiting lists. In Nova Scotia, all participants appeared to agree with the individual who said “If we’re talking older people....unless somebody dies there won’t be an opening. The region tells you that....It’s a dance that could take a few years.” The picture was similar in Victoria, where focus group participants agreed that routinely, family members have to recognize that there are almost no housing options for their adult children.

Parents were particularly emotive on the subject of waiting lists.

- “People come up to me and say, You have to apply now because it takes 7-8 years...You have to be desperate. You have to say I can’t live with [her] anymore.... You have to say bad things about your child to get her out of your house.”
- “Housing seems to be a real block because I am being told there is nothing available in terms of enough supervised group home settings. The doors have been closed”.

- “They told me two years. That is what they tell you to shut you up. They’re going to tell you whatever they need to tell you because they’re going to take people in a circumstance of abuse....”

There was a consensus throughout all the focus groups that this under-supply of housing leads to a reactive, crisis-driven management mode. In Ottawa, one participant at the service provider focus group said “We’re constantly in crisis mode, which means we can’t be proactive or get involved in planning with families”. This sentiment was expressed by both service providers and parents throughout the focus groups. In the Ottawa session, a service provider noted that of the 500 people on a waiting list, 77 are at risk of ending up in a crisis situation.

### **3.2.2 Availability of a Suitable Range of Housing Options**

A slightly less consistent picture emerged as study participants assessed the mix of housing models for consumers in their communities. 44% of interviewees assessed this as poor or very poor, but 34% assessed the mix of options as average, and 22% as good. This polarization was also evident in the comments of interviewees:

- Positive:
  - Victoria has a good mix of models, i.e. group homes, family care homes, supported independent living.
  - Manitoba has a lot of experimentation, a lot of models for people with intellectual disabilities.
- Negative:
  - Group home models are often pushed on people as the only option.
  - Options are limited for those who would like to live more independently.

The picture that emerged in the focus groups lacked the optimistic perspective that surfaced in some interviews. Consistently, families and service providers reported a lack of suitable options for adult consumers. For example:

- In Victoria, service providers agreed that there is a dearth of housing options available for developmentally disabled people. Right now, the person must fit the system instead of the system being responsive to them.
- In Nova Scotia, participants agreed with the individual who said “There’s nothing for people who are fairly independent and just need a little support. You take all or you take nothing.” “It often happens that persons with disabilities are placed in nursing homes and they are much too young. There’s just no other place to put them.”

Families frequently mentioned options they'd heard about, but their promise seemed elusive, and the day-to-day reality confined:

- They (the N.S. Department of Community Services) have this new renewal project. We haven't seen much come out of it yet. They're....looking for different options.
- They don't want to do small options any more. They want to do apartments and fostering.
- Some families expressed their interest in exploring the development of co-ops but found there was no assistance available to them to do this exploring.

Families were vocal when discussing the impact that better funding would have on the availability of a suitable range of options. Stories about desirable options tended to feature parents with the means to buy suitable housing for their children, or to renovate their homes to accommodate them. When asked what it would take to get their family member the kind of housing model they thought appropriate, the answer consistently was either "money" or "funding".

### **3.2.3. Availability and Appropriateness of Support Services**

The picture that emerged of the availability and appropriateness of support services was similar to that on the availability of housing, though it appeared to be most acute for consumers who didn't reside in special needs housing. Over half of the interviewees assessed service availability for consumers who didn't live in special needs housing as poor or very poor, 28 % as average, and 21% as good. For consumers in special needs housing, 41% of interviewees assessed service availability as poor or very poor, 31% as average, and 28% as good. Such service supports include day programs, job placement, and supported employment, social recreational and volunteer opportunities.

In the focus groups, the shortage of service support elicited significant comment from service providers. In Ottawa for example, all participants agreed with the individual who said "Staffing issues are the major limitation. They (consumers) need the supports, not just a house". At the same focus group it was said that "Even when families do get money to provide supports, they can't find qualified staff". Appropriate support also emerged as a major issue in Victoria, where the consensus appeared to be that even if money or availability were not at issue, appropriate support levels are a concern. Service providers there reflected parents' anxiety that their adult child may not receive enough and appropriate life-skill support.

The concern about staff was not limited to service providers. It was mirrored by family members, who discussed the extent to which they rely on staff. One said "That's very scary, because funding is not there to provide adequately trained individuals". In the Ottawa focus group,

families appeared to agree that compared to “bricks and mortar...providing on-going supports that are tailored for the person is more difficult to secure, primarily due to funding constraints”.

A very sharp focus on the absence of service supports in rural communities emerged in the family focus group in Nova Scotia, where parents reported having to move, or that they were considering moving, in order to have better access to the kinds of supports their children needed.

### **3.2.4 Housing Requirements of People with Multiple Disabilities**

Though there was an interview question targeted specifically at identifying housing issues facing adults with multiple disabilities, it did not elicit much response. For the most part, respondents identified the same concerns that would emerge in dealing with people who are only physically challenged: physical accessibility and community acceptance. The same sorts of concerns were voiced by consumers in their focus groups. They were concerned that washrooms, ramps and hallways be accessible, and that fire escapes should be improved for people with disabilities.

A number of study participants mentioned the plight of consumers with a dual diagnosis (intellectually challenged and mentally ill). Their concerns were highlighted by the interviewee who said that these consumers “...tend to fall between the cracks and so there must be a greater focus on this disability group as far as housing that is adapted to their needs is concerned.” This concern surfaced at all of the service-provider focus groups. Previous comments about the absence of a range of suitable options appear to be as, or more relevant, to this small sub-set of consumers.

- In Victoria for example, focus group participants believed that though the numbers are not known, many people who have a developmental disability and a concurrent disorder are homeless.
- In Ottawa, focus group participants noted that the needs of these consumers are not being met. They said there are no secure treatment facilities and no budget or legislation to provide them, and that as a result consumers who are both intellectually challenged and mentally ill drain the system’s resources, since they often are placed in hospital beds (at \$2000/day) or in jail.
- A number of interviewees and focus group participants felt that homelessness was a risk for consumers with dual disorders, but not for other consumers.

## **3.3 Transitions and Risks**

A wealth of information about the challenge for consumers “in transition” and the risks attendant upon the process, emerged from both focus groups and interviews. “Transition” encompassed:

- a physical move from one housing arrangement to another; and
- a more conceptual move from one stage of life, to another – for example, from attending school to graduation, or from working to retirement.

### **3.3.1 A Physical Move From the Family Home**

The consumer focus groups revealed that some consumers who currently reside in family homes were very satisfied with their arrangements. Others, who used to reside in family homes, shared their enthusiasm for “the comforts of home”:

- “the money: If you want something, you can get it.”
- having someone cook, clean and do the housework for them
- having company, advice and support.

Consumers also identified many negative aspects of staying in the family home, which all summed to a lack of freedom and an inability to “have my own life”:

- lack of privacy
- too many rules
- too many questions
- can’t have friends over
- nagging
- fights.

Finally, consumers identified all of the following as concerns, when discussing either how they had felt or how they would feel if they were leaving the family home:

- poverty
- the challenge of financial management
- getting used to the unfamiliar - using new appliances, getting to know a new neighbourhood
- feeling lonely and missing family
- being afraid and worried about personal safety.

The focus group consumers were not alone in their concerns. The majority of interviewees and other focus group participants thought it likely or very likely that consumers would encounter all of these risks when making the transition from the family home:

- feelings of abandonment, fear, loneliness
- poverty and difficulties managing finances
- learning living skills they may not have needed before
- personal safety and security.



Personal safety and security emerged as a consistent and compelling concern. It was perhaps the most consistent concern at consumers' focus groups, and almost all interviewees also identified it as a concern and felt that the concern was valid.

Noteworthy findings also emerged in terms of transition risks NOT deemed to be likely by most respondents. Specifically, the vast majority of respondents did NOT think that:

- lack of acceptance by existing residents would be an issue for consumers moving from the family home into special needs arrangements
- homelessness was a significant risk, except for those with dual disorders

Perhaps the most striking element of these findings about transition issues is how similar they are to the concerns one would anticipate when any young adult considers leaving the family home. This point was made strongly by a number of interviewees:

- “Of course there is fear and loneliness. This is a foolish question. We all experience fear and loneliness when making a major change in our lives.”
- “Accepting change is the issue. Everyone who moves has this issue”.

This perspective emerged, even when addressing the persistent concern with personal safety:

- “Security and safety in the community are something that everybody is looking for. I do not think it is an exclusive issue for only people with disabilities”.
- “If you’re poor, you have to live in unsafe areas.”
- Not all of them [fears] are valid. Many fears reflect the discomfort that society feels with intellectually disabled people living in the community.”

While the research team agrees with these statements, this should not be interpreted as belittling the many concerns about personal safety and security expressed by other study participants. While their concerns may exactly parallel those of the mainstream, the consumer's ability to respond to the challenges is likely to compare much less favourably. Thus, the shortage of support services previously discussed is likely to comprise a significant impediment for those going through these types of transitions.

### **3.3.2. Transition from One Stage of Life to Another**

At the focus groups, numerous concerns about issues confronting consumers and their families as the consumers make the transition from one stage of life to another, were raised.

- “Some families cannot provide appropriate supports as their child ages and their needs change. For example, children who were occupied in school, upon graduation may not have access to day programs or work programs, and may well be left idle for much of the time, especially if all other family members work”.
- Focus group participants indicated that the consumer’s graduation from school can often be the catalyst for increased family dysfunction.
- “Some families break down when their child becomes an adult. Their routine is disrupted. Behavioural problems may escalate, which puts tremendous strain on family care givers. Families, especially those of adult children, make extensive use of emergency services. In some cases, care givers with full-time employment must consider quitting their jobs”.
- “When consumers leave highschool, they not only lose the structure it gave them, it also limits their access to other parts of the system, e.g. their peer group, psychiatrists, therapists.”
- Service providers in Ottawa discussed the decreased functioning of consumers who are under-challenged by their families. “Parents sometimes control their child’s life, leaving the adult with no voice in decisions that concern them. The lack of challenge and autonomy often means that consumers become less able than they would be in a different environment. The isolation of the adult can and does facilitate abuse of all kinds.” Their concern was shared by both family members and service providers at other sessions, who felt that the longer consumers live at home, the more difficult their transition to another form of housing is likely to be.

Focus group participants also discussed the often inter-related impacts of aging consumers and aging care givers.

- In Halifax, service providers agreed that the aging population is “such a wedge here”... If you don’t address the support side, you’re going to get huge shifts in population because in rural areas there may not be apartments or supported living arrangements... People in rural areas have fewer resources. They go from Home Care in their own home to a nursing home which they may not necessarily need.”
- In Victoria, service providers agreed that because they don’t see a reasonable alternative, parents often continue to act as primary care givers well into their older years. This can lead to increased stress and limited resources in the family. The parent and adult child can become increasingly isolated. In the worst-case scenario, the parent dies unexpectedly and the consumer is left unconnected to the service system and without support or resources.

Some of the most compelling transition concerns that emerged during focus groups were those related to the impact that the death of a caregiver has on the consumer.

- A Halifax service provider described how three times in an 18 month period, the death of an elderly parent precipitated a consumer into an inappropriate housing arrangement.
- Also in Halifax, a participant described a consumer with Down's Syndrome whose mother died. The end result was that the consumer, who was well-suited to a small options approach, ended up in a nursing home.
- In Ottawa, a service provider reported that parents would prefer that their children not survive them. And, should they need to move to retirement homes, that they could take their children with them. "They don't want their children to end up in the types of homes now available".
- Also in Ottawa, several families indicated that their biggest fear is that their children will still be at home when the parents die, and that they will be placed in inappropriate housing in response to a crisis.

Clearly, the roles that parents play, and the roles they'd like to play, are key elements in understanding the housing situation of adults with intellectual disabilities.

### **3.4 The Role of Parents**

Interviewees were presented with a list of possible roles that parents of consumers might assume, and were asked which ones they thought families could or should play. The only potential role that was roundly rejected was that of sole decision-maker: 83% of interviewees felt that was not a role parents could or should assume. However, this in no way indicated a lack of desire for parental involvement. Interviewee responses showed a consistent preference for parental pro-activity. For example:

- Almost all interviewees felt the parental role should include:
  - acting as part of a circle of support that would help the consumer make decisions
  - providing emotional support
  - organizing a support network outside the regular support services provided by agencies.
- A significant majority of respondents felt that the parental role should also include:
  - exploring options for the consumer independently, before engaging in discussions with service providers
  - providing financial support.

This was consistent with the family focus groups, where parents cited all of the following as roles they'd played or would play, and were generally comfortable in playing, in finding a new home for their children with intellectual disabilities:

- Advocate
- Educator
- Case Manager
- Help with transition
- Help with the “falls” – the problems and failures experienced by consumers
- Activist (for example for tax reform).

Significant benefits of parental involvement were cited to support this preference for pro-activity:

- Families usually have the best understanding of consumers, are most interested in their welfare, and are better able to communicate with them. Having them involved in planning and living arrangements maintains their important place in the consumer's life.
- A plan developed by families can be more personalized, and thus allow consumers to be more in charge of their own lives.

Interviewees also noted the potential for some problems associated with parental or family involvement:

- unrealistic plans and expectations
- over-involved and over-protective parents who interfere with consumers' abilities to make decisions for themselves.

Both the advantages and drawbacks cited above are consistent with the consumers' perspectives on the advantages and disadvantages of living in the family home, described earlier.

Participants in family focus groups appeared sanguine when discussing the roles parents could and should play in moving their children out of the family home. The tone was considerably darker when they discussed the impact of the roles they are forced to assume as they keep their adult children in the family home because of a lack of viable alternatives. These perspectives are consistent with the earlier treatment of transition issues facing aging consumers and care givers.

- In Ottawa, one family member indicated that her son needs a high level of support and as a parent she was burned out, fearing hospitalization and a resulting crisis in the home. Another family member indicated that supporting their daughter was creating a significant strain on their marriage.

- In Halifax, one family member said “We just don’t go away alone together as a couple. Last year was the first time we went away for a weekend. We don’t get a break, really. We’d have a break if she wasn’t there”. Another talked about the pressures they felt trying to make sure their child acquired and mastered the skills required for independent living.

The importance of parents who share their homes with adult consumers getting “a break” arose numerous times in the focus groups:

- “We have a cousin [in Boston] with Down’s syndrome. She goes to a group home for weekends. She loves it. I like that pattern. My daughter could go for weekends, like going to camp, so that when it’s time for her to move, she’d be enthusiastic about going....Wouldn’t it be great to have that transition? We don’t provide respite as they do in Boston.”
- “There is a lack of respite care, i.e. a place for consumers to go to give their families a break. Currently, such respite spaces are used to receive consumers in a crisis, where they should be used to prevent crises. It sometimes happens that, after such a crisis, the family refuses to take them back into their homes.”
- “It would be best to be able to support natural family connections, by providing for example, respite care, in-home supports, day programs.”

### **3.5 Best Practices**

#### **3.5.1 Conceptual Best Practice**

When this study started, the research team believed that when addressing best practices, the final output would likely be a report section in which a discrete number of “best practice” housing and support models would be described. What emerged instead was a tremendous range of models and options. These might have defied meaningful categorization, had study participants not been so consistent in discussing the underlying principle that unifies them all: that there is so much variation in the abilities, needs and desires of consumers and their families, that there must be a corresponding range of housing and support options. Thus, through this study, a single conceptual Best Practice emerged: **an approach that allows and promotes flexibility and choice**. This approach then drives how one considers a range of more specific “models” deemed to have promise. Here is a sample of the comments received from study participants that point in this direction:

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- Use planning tools that facilitate choice.
- You should be able to choose where and with whom you want to live, within reason.
- “Goodness of fit” - ensuring a close match between individual preferences and needs, and the particular housing option.
- Respecting individual choice.
- Consumer driven/person-centered approach to housing.
- Maximize independence. Normalization. Match independence to the right level of support.
- Flexibility is important. We need to respond to the needs of the consumer, not assume everyone needs or can handle the same thing.
- Range of models that provide a level of support tailored to his needs.
- Choices that are reflective of a range of needs.
- Flexible range of opportunities, preceded by a range of planning activities.
- Person-centered staff are there to assist with what the person needs or wants, and connect that person to the community.
- Most important is that the person has choice.
- Families/individuals would have choices. There has to be respect among service providers and families, recognition that one size does not fit all.
- Having a range of mixed housing options available.
- Have a continuum of housing types, different levels/types of support.

A number of study participants further focused this call for flexibility and choice by discussing their desire to separate housing and service supports, for both operations and funding:

- Be sure that the home is not tied to the support provider so that people have the choice of going elsewhere for their supports without having to give up their homes. Choice is important if one is to live with dignity.

- Make support portable. Not locked in by where they live. Can't make funding attached to a particular agency or group home.
- Individualized, portable funding
- Individualized funding, so they can choose how they want to live.
- Provide subsidies that are attached to the person not the building.

Two general approaches that were often cited as examples of this conceptual best practice are described below.

#### **The Person-Centred Approach**

This approach was recommended often, either specifically as a “person-centred” approach, or in a description that closely conformed to the general understanding of a person-centred approach: one in which the consumer or advocates for the consumer are directly involved in planning and choosing the housing and support services that will best meet the consumer’s needs. Typically, in a person-centered approach, funding is portable, tied to the individual rather than to an agency or a facility.

#### **Small Options Model**

The Small Options model was mentioned frequently and praised highly by study participants in Nova Scotia. “I like the small options idea...where there are usually three of the same gender, at similar physical and intellectual levels. They can form friendships, a family away from home. It's a friendship, not a family.”

### **3.5.2 Favoured Models**

As indicated above, the over-arching best practice doesn't reside in specific models, but lives in an approach. Nevertheless, there were a number of specific options or models that were often identified as best practices. The advantages cited for options recommended as best practices were strikingly consistent with input elicited from interviewees in response to a question in which they were asked to identify the advantages and disadvantages of nine types of housing. The compiled responses of interviewees are presented below. These responses not only affirm the best practices discussed next, but also provide context for why many of the other options that interviewees were asked to consider were not so highly regarded.

Type of housing	Advantages	Disadvantages
<b>Family home</b>	<ul style="list-style-type: none"><li>• History, family bond</li><li>• Families best know the needs of the individual and may be the most caring people in his life.</li><li>• Can be with loved ones, can offer a lot of stability and security, i.e. financial, emotional.</li><li>• Emotional support and personal supports of being in family.</li><li>• Having one's own space and security of one's family</li><li>• Personal, consistent care</li><li>• Parents may cede home to individuals – natural kind of continuum.</li></ul>	<ul style="list-style-type: none"><li>• Can break down over time</li><li>• Siblings move out and leave the individual with aging parents. Families may tend to over protect the one with an intellectual disability</li><li>• Maybe the individual would prefer more independence. Does not offer the opportunity to learn to live independently. What happens when the parents pass away?</li><li>• Not living independently. Can be treated as a child.</li><li>• Not good long term plan</li><li>• Lack of possibility to develop learning skills</li><li>• Staying too long at home tends to erode one's independence</li><li>• Lack of choice, unnatural for age</li><li>• Depends on the relationships. Can be inappropriate because of costs and aging parents.</li><li>• Financial issue; money can create problems. If family is dysfunctional, not much help for the individual; really depends on the family</li><li>• Risk of isolation</li><li>• Living with your family perpetuates the myth of people with disabilities as children.</li></ul>



Type of housing	Advantages	Disadvantages
<b>Foster family</b>	<ul style="list-style-type: none"><li>• Foster parents are trained to work with individuals with Intellectual disabilities (maybe?)</li><li>• Can live in a "family" type setting. May offer more opportunities for independence than living with the family. The foster home may be in a neighbourhood the person is familiar with.</li><li>• Semi-independence. Group support from house-mates and staff. Assisted decision-making.</li><li>• Caring family environment</li><li>• Stability</li><li>• Good alternative to the family setting</li><li>• If the foster family isn't well chosen, that can put a rift between individual and his/her natural family.</li></ul>	<ul style="list-style-type: none"><li>• High cost</li><li>• The foster home is a temporary arrangement. This setting may create dependencies. If there is more than one foster person the individual may compete to get his needs met. This setting is usually seen as one for children.</li><li>• Perhaps the foster family is only in it for the money? Less stable, might be forced to move more often.</li><li>• Ghettoized. Not fully independent.</li><li>• Not life long plan</li><li>• This service is one designed for children</li><li>• Resistance from blood family. Hard to find good ones.</li><li>• Parents who know their children best are kept at arm's length.</li><li>• Comfortable for governments and agencies. Individuals' needs are suppressed, they do not have a say.</li></ul>

Type of housing	Advantages	Disadvantages
<b>Group home</b>	<ul style="list-style-type: none"> <li>• Social contact, community</li> <li>• People would learn social skills with more interactions with different people.</li> <li>• Long term care</li> <li>• Trained staff</li> <li>• Better setting than an institution</li> <li>• Social environment, high energy</li> <li>• Traditional, well-understood.</li> <li>• Potential to build relationship.</li> </ul>	<ul style="list-style-type: none"> <li>• Not enough of them available, can decrease independence</li> <li>• The number of residents may be problematic for the individual. Life tends to become too routine and regulated. Staff changes regularly during a 24-hour period. The resident is not separated from the service he is receiving, i.e., if he doesn't like it there is not much he can do about it.</li> <li>• Potential for conflicts with other residents. Lowest common denominator...may have to lock the doors because of one person. Privacy.</li> <li>• Lack of stability</li> <li>• Rules and over protectiveness</li> <li>• High staff turn-over, impersonal</li> <li>• Doesn't work for autistic people because too many people.</li> <li>• The more people you get the fewer choices you have about everything; for example, what you have for breakfast. Also you have a lot of staff, on shift. Not homey, not personal</li> <li>• Segregated living</li> <li>• They can become place of warehousing people.</li> <li>• You have to follow the system, abide by the rules, consider others. More about the staff than the residents.</li> </ul>

<b>Type of housing</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>Supportive independent living</b>	<ul style="list-style-type: none"><li>• Normalizes lifestyle</li><li>• Specific services are given to fulfill specific needs while allowing for maximum autonomy. Less intrusive</li><li>• More personalized assistance. Can have more choice in day-to-day living decisions.</li><li>• To me, it means living alone or with room-mate with some support. Probably best option for most people. Living independently. Most nurturing of independence among these options. Gives one self-confidence to reach potential.</li><li>• Independence "home of your own"</li><li>• Person centered, empowering</li><li>• Gives the person some dignity and the chance to exercise their rights and their choices. It's a measure of freedom.</li></ul>	<ul style="list-style-type: none"><li>• Cost, not always inexpensive</li><li>• Danger of isolation taking place.</li><li>• If the planning was done right and the proper supports are in place, there should be few disadvantages. Perhaps the person may miss being with their family.</li><li>• Might not be best for everyone.</li><li>• Can promote isolation of the individual</li><li>• Potential high risk, isolation, loneliness</li><li>• Good only for people who can look after themselves.</li></ul>

Type of housing	Advantages	Disadvantages
<b>Boarding house with supervision</b>	<ul style="list-style-type: none"><li>• Independence, empowerment</li><li>• The availability of privacy and social involvement possible here. This setting allows for freedom of movement. Meals are provided and the environment may be friendly and caring.</li><li>• Supports may be readily available in this arrangement. Could be more economical?</li><li>• Could work. Depends on what support they need.</li><li>• For higher functioning people.</li><li>• Low cost but convenient for the system</li></ul>	<ul style="list-style-type: none"><li>• Need the right support mix to succeed</li><li>• Danger of isolation taking place.</li><li>• Lowest common denominator problem again. Perhaps resident is grouped with others on the basis of disability. Assigned roommates. Potential of abuse from either supervisors or other residents. Privacy. Can't control who visits or stays.</li><li>• Could be problems if boarding house is not in good condition.</li><li>• Individual might be vulnerable to exploitation</li><li>• Impersonal</li><li>• Lack of autonomy</li><li>• Someone is financially benefiting from keeping people there and without any obligation other than providing a house, a roof over their heads. About supervision, I don't know if people are powerful enough in that role to make the changes that are necessary.</li><li>• Isolated and lonely</li><li>• Smacks of poverty model</li></ul>

<b>Type of housing</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>Nursing home</b>	<ul style="list-style-type: none"><li>• Skilled staff, security</li><li>• There is trained and skilled staff. Care is available 24/7 for the residents.</li><li>• Can offer a very high level of support and care, usually 24 hour.</li><li>• Institutional setting.</li><li>• For those 85+-year-old individuals they can receive the care they need.</li><li>• Accessible and it can create a community for someone to live, and we have had some young adults that have opted for that.</li><li>• There is pride and independence</li><li>• If the person is growing old</li></ul>	<ul style="list-style-type: none"><li>• Less specialized support</li><li>• Often there are many rules that are not suitable to all residents (i.e., the rules reflect the needs of the home and not necessarily the resident). The nursing home is more institutionalized and follows the medical model.</li><li>• Often not with similar aged peers. Few choices for daily living. Very regimented. Resident usually is left with about \$100 of his money to spend. Little privacy.</li><li>• More than what most people would need. Treating people as children even if they can make own decisions with some support.</li><li>• Younger individuals in this setting are out of place.</li><li>• Unfriendly, isolation, loneliness</li><li>• Run by corporations whose main goal is economic, so supports are secondary.</li><li>• There needs to be formal and informal safety measures in place It is convenient for governments but what are the ages in the home.</li><li>• Perpetuates all stereotypes and myths. Doesn't allow for personhood.</li></ul>

<b>Type of housing</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>House owned by consumer(s)</b>	<ul style="list-style-type: none"><li>• This setting is more stable for the individual with an intellectual disability. It separates the support services from the home and allows more autonomy for the individual. As a homeowner the individual may be seen as being a contributor to the community. Home ownership is a good way to help the individual build his financial security for later years (equity).</li><li>• Residents can have access to personalized assistance and support from others who care about him/her. Can have lots of privacy. Can control who visits or stays. An investment.</li><li>• Great if they win the lottery, and then they can purchase the supports they need.</li><li>• Ideal situation for maximum independence and social needs</li><li>• Tangible resource they can leverage if they have to leave. Has all the advantages of controlling their situation.</li></ul>	<ul style="list-style-type: none"><li>• Cost and maintenance.</li><li>• May be difficult to manage financially.</li><li>• Need supports if they own the home. Not realistic.</li><li>• This situation might be viewed as the end of the road by support agencies and services might be minimized</li><li>• Need good trustee relationship. Trust should own, not the consumer, to not jeopardize Ontario Disability Support Program (ODSP).</li><li>• Need safeguards in place</li></ul>

<b>Type of housing</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>Private apartment</b>	<ul style="list-style-type: none"><li>• Independence with right support</li><li>• May be affordable and allows for autonomy. May allow for greater contact with people (getting to know neighbours in the apartment building) without needing to travel distances when transportation services are not good.</li><li>• Can have a rent subsidy. Offers privacy and choice.</li><li>• Some people could manage this perfectly well with supports in community.</li></ul>	<ul style="list-style-type: none"><li>• Loneliness, cost</li><li>• Living conditions and vacancy rates might not be good. Could lead to isolation. Might not be adapted to the needs of the individual. No choice as to who one will have as neighbours.</li><li>• May need to sign a restrictive lease. Perhaps they are grouped on the basis of disability with others living in the same complex. Can be expensive.</li><li>• Have to make sure persons have necessary life skills; if person doesn't have the skills, they need to have supports.</li><li>• As a renter, not in control of apartment. i.e. rent increases</li><li>• Can lead to isolation</li><li>• Health &amp; safety risk</li><li>• Have supports and know their rights and the rights of tenants. Know the ways to cooperate with other apartment occupants</li></ul>

Type of housing	Advantages	Disadvantages
<b>Cooperative Housing</b>	<ul style="list-style-type: none"> <li>• This environment can create a sense of community for the individual and create a sense of belonging.</li> <li>• Can be more affordable, offers more privacy, offers choice in day to day living options.</li> <li>• Individuals have advantage of living independently and taking on rights and responsibilities and duties as volunteers. Not much different from other co-op residents: some are excellent volunteers, and others not. "I have experience seeing this as a consultant and co-op co-ordinator. One co-op I was involved with had an agreement to reserve certain spaces for persons with mental health and intellectual disabilities."</li> <li>• Responsibility.</li> <li>• Less rent, companionship</li> <li>• I like that idea because the economic needs are sometimes met and they have a built in responsibility to contribute to the well being of the tenants of the co-op. I like that community feel.</li> </ul>	<ul style="list-style-type: none"> <li>• Inadequate support, needs to be the right mix</li> <li>• Rules are made by a board and may not be suitable to residents with an intellectual disability. The individual might have little influence in the decision making process.</li> <li>• Need special permission or meet special requirements. May congregate people based on income or disability.</li> <li>• Only depending on severity of disability. Have to be able to understand participation, rights and responsibilities. If the community supports are there for them, they should be able to make the decisions to carry out their duties.</li> <li>• Not a balanced form of housing</li> <li>• Loss of independence</li> <li>• May not be in best socio-economic areas, may not be well-maintained.</li> <li>• They may not able to met the needs of the co-op so the co-op has to be flexible in people's roles and what they can contribute.</li> </ul>

To embody the over-arching principle of flexibility and choice then, the system would encompass a range of the practices described below.

### **Independent Living Model**

An independent living model is one in which the consumer lives independently, often sharing a house or apartment with other consumers and/or with service providers. Service providers may also be close by (for example in a neighbouring apartment) instead of sharing living quarters. Many of the best practices cited conformed to this model. For example:



- An agency bought three houses in a well-to-do neighbourhood. Consumers then rented the houses and received supports for independent living.
- Ottawa-Carleton Association for Persons with Development Disabilities' (OCAPDD) Crosswinds is a high-rise apartment building in Ottawa, in which approximately 20 apartments are leased by people with intellectual disabilities. OCAPDD assists consumers in leasing these apartments, but the consumer holds the lease and OCAPDD provides support services through 24-hour, on-site staffing.
- Subsidized apartments where people live independently but on-site support is provided from 9 am to 10 pm.
- In Ontario, a project was established for people with Asperger's Syndrome. Consumers lived in apartments that were part of a regular apartment complex and the residents had a small business doing the recycling and yard maintenance. Benefits: better integration, employment skills.
- A double bungalow (semi-detached) is a good approach. Staff and residents live on both sides, but staff can get involved in situations on both sides as necessary.

### **Co-ops and Co-op-Like Arrangements**

Numerous study participants cited co-ops and co-op-like arrangements as best practices. Comments/descriptions/recommendations they offered are shown below.

- In co-op housing, a group gets together, builds their own multi-unit building, and give up some private space for community space. They select people who want not just housing, but also community support. More community-oriented than a condo.
- Cooperative apartments and individualized support is innovative in Manitoba.
- NABORS in Toronto is a housing cooperative formed and governed by families, community members and consumers. Support circles are included and there is a mix of paid and unpaid supports.
- In Durham, Ontario, the Deohaeko Co-op can accommodate 50 people and includes 8-10 units for people with intellectual disabilities.
- In Ottawa, families were interested in exploring the development of co-ops but found there was no assistance available to them to do this exploring.
- Several consumers have separate apartments in a regular apartment building (for example in a co-op building) but share the services of support staff.

### **Home Ownership/Adaptation of Family Homes**

Many study participants cited home ownership or adaptation of family homes as a best practice, though one that was rarely available for most consumers. Relevant comments, descriptions, and recommendations from study participants are presented below.

- The HOME Program in Edmonton helps people with disabilities to buy their own homes.
- In Alberta, home ownership is being tried. Agencies have gone into partnership on a 50/50 basis with individuals with intellectual disabilities. This allows the individual to be a property owner and pay an affordable rent. The partner or co-owner may take care of maintenance, mortgage payments, etc, which the consumer might not be able to manage.
- Participants in the family focus group in Halifax reported that other parents they knew bought a condo and their daughter moved there. Once they got the initial funding it followed her to the condo. They indicated that a portion of condo costs will be paid by the government.
- In Ontario, parents are getting together, purchasing a home, splitting a mortgage and the government is coming in and saying “If you go that far, we’ll supply the supervision”.
- Parents renovated their home so that the consumer has her own wing of the house with a bathroom and tracks for lifting, and a care giver suite off of her room.
- Families finding a way for an adult child to live independently in own home e.g. attached apartment.

### **L’Arche Model**

L’Arche was the only group home that was identified as a best practice. L’Arche has homes in a number of provinces. All are faith-based, geared to aging-in-place, and feature employees who are called assistants and must function more like family members rather than staff. L’Arche was mentioned numerous times by study participants. A small sample of their comments and descriptions are shown below.

- In the L’Arche model, everyone helps everybody else. They get volunteers coming in. There’s a community spirit. They live on site. It sounds so beautiful. It has worked so successfully, they are launching another (L’Arche community in N.S.)
- Another parent described it as the kind of lifestyle he wants for his son – always a work component, with different kinds of crafts. ....It’s different kinds of people getting together. It’s networking.

### **As Part of Seniors' Complex**

A number of study participants felt that adults with intellectual disabilities need the same types of supports typically provided in seniors' residences, and saw merit in combining facilities for seniors and adults with intellectual disabilities:

- People with developmental disabilities could be incorporated into seniors' housing
- Mixed housing, preferably one-bedroom condominiums within a typical housing complex or seniors' complex would be ideal.
- It was also recommended that some housing integrate seniors with people who have developmental disabilities as these two groups interact well together.

### **Understanding The Options**

As previously noted, the range of best practice recommendations made by study participants created a significant categorization challenge. What may be helpful in understanding the "best practices" as arrayed above, other than that all fit well into a flexibility/choice/normalization approach, is what they are NOT. They are not isolated large scale institutions, or traditional group homes in which a single agency is responsible for facilities and support services for as many as 12 consumers. They represent far more of an opportunity for consumers to achieve what many of them said they want for the future:

- freedom
- to be independent, because independence leads to freedom
- to have care giver support and help with problems encountered
- to live in a private, no-frill home with access to supports when needed.

## **4. EMERGENT ISSUES**

Throughout this study, a number of major issues or themes emerged, which illuminate and weave their way through those responses, and will be helpful in fully appreciating them.

### **4.1 The Impact of Living in Crisis Management Mode**

This issue is described at the end of section 3.2.1 (Availability of Housing) where it was established that the under-supply of housing and services has led to a reactive, crisis-driven management mode. While this summarizes the issue, it doesn't convey how often this concern arose or how pervasive it was. In the focus group in Nova Scotia for example, a frustrated participant said: "If the policy is written to respond to crisis, it's wrong". In Ottawa, family focus group participants agreed that the only way you could secure a place to live was if there was a crisis. Their sentiments were mirrored by service providers, who raised the issue even more frequently. In Halifax, service providers agreed that "There is no way to plan for the future – planning for the time when they (consumers) will move out won't happen until there's a crisis."

It's not even planning for a crisis - it's reacting." This concern was most focused in Ottawa, where participants agreed that "we're constantly in crisis mode, we can't be proactive or get involved in planning with families".

Lack of service and supports mean that consumers stay at home even when it is no longer the best place for them to be. This generates huge stresses for the whole family, can lead to abuse, and is likely to precipitate crisis. Under-staffed agencies must respond to these crises, which take up so much of their resources that they preclude a more rational, planned approach. Crisis management is expensive both in terms of times and dollars. It perpetuates clients struggling to "make do" until their situation eventually deteriorates into a full-blown crisis.

## **4.2 Income and Funding Concerns**

As noted in section 3.5.1 (Conceptual Best Practice) a strong call to make funding portable, tied to the individual rather than to a facility or agency, was sounded by study participants. However, this is only one dimension of a concern about both income and funding that pervaded the findings.

### **4.2.1 The Evolution of a Two-Tiered System**

Consistently, some of the most attractive options described throughout the study were ones where parents either purchased homes for their adult children, or renovated their own family homes to accommodate their needs. For example:

- "One man we know bought a house, set it up for his daughter and friend's daughter. It didn't work out because of personalities. They bought a condo and the daughter moved there. "
- "My husband and I are more than willing to participate financially in any way we can. Let's say you even went three ways on a home....and the government kicked in the rest, then maybe you could do a partnership"
- "The risk of all of the housing options were too great. No satisfactory option was available so we had to make our own."
- "Family required funding to make desired changes to the family home so that the daughter could continue to live at home."
- "...in Ontario, parents are getting together, purchasing a home, splitting a mortgage, and the government is coming in and saying *If you go that far, we'll supply the supervision.* That opens a lot of doors.....(although) not everyone could afford that as an option...."

Clearly, these are options only for families with at least middle-class incomes, while the majority of people with disabilities receive public financial support that is below the poverty level. Thus, it may be accurate to characterize today's system as two-tiered, allowing families with higher incomes a range of options not available to others. Certainly, this was recognized by the many study participants who said resoundingly that what they'd need in order to procure suitable housing for their children, was money. "To get that [desired] type of house situation - win a lottery, build a house, hire staff."

The socio-economic divide appears to be at play in another related arena, as pointed out at a focus group by a service provider: "Families who get the support they need seem able to ask the right questions and put on pressure. They seem to be people who have a little power themselves. How many phone calls can they make? How loud can they yell? How many people can they get to support them. But there are other families in Nova Scotia who can't get access to the ear of the person they need to help them, who don't have an MLA who can put on pressure for them."

While understanding a system well enough to make it work to one's advantage is not necessarily tied to socio-economic status, it seems likely that there is a strong socio-economic dimension to this ability to wield power and work the system. So, not only do the middle class families have the option of stepping out of the system, they also are better equipped to get more out of the system than others of lesser means, who may need to depend to a greater extent on advocacy and support organizations.

#### **4.2.2 The Impact of Claw-Backs, Taxation, and Mortgage Policies**

Study participants were vocal on the negative impact of current funding policies, with a particular focus on the adverse effects of a range of claw-back provisions that keep an individual in poverty. For example:

- One participant described a positive practice in Alberta, contrasting it with more restrictive and less-desirable practices: "The Assured Income program in Alberta provides the individual with just over \$1000 per month, up from \$900. The provision of a liveable income is essential. In Alberta this amount is not reduced when two or more individuals decide to co-habit. The removal of penalties for those earning more than the imposed income ceiling would also help to alleviate the housing problems for those with intellectual disabilities by encouraging them to participate to a greater extent in the community work force, thereby increasing their incomes and ability to pay for their housing costs."
- "A major change will come when government revise the laws governing how much someone living on a disability pension such as the Ontario Disability Support Program (ODSP) can earn over and above his or her assigned revenue. Many people with intellectual disabilities could hold jobs that would increase their revenues and if this was

allowed without clawing back their disability earning their quality of life could change significantly giving them great independence.”

Study participants also identified relevant concerns about taxation and mortgage policies:

- “Ease the regulations with respect to estate planning so that family members with intellectual disabilities can be provided for through family initiatives without losses from taxation.”
- “Advocating for tax reform that would enable families to contribute more financially with tax savings....”
- “Revising tax laws to reduce the income tax payable by these people would be helpful.”
- “There is need for reform in government policies, specifically tax reform .”
- [We need] ...”lower mortgage rates to assist with caring for a family member at home.”
- [We need] “..policies in place that make it easier for people to borrow money as a down payment if it is for a house for a person with a developmental disability.”
- “If the person is receiving a pension, that [should].... be acceptable as assurance around mortgage payments.”

These perspectives emerged most strongly in interviews, where there was a specific question asking respondents to identify barriers facing consumers who want to live independently, or with one or two friends. Their input on these questions, when considered together with the previously described desire to separate funding for housing and support services, indicates that those most involved with the system feel that a range of funding reforms are required. A number of study participants referred the research team to Nova Scotia’s “Kendrick Report”(An Independent Evaluation of the Nova Scotia Community Based Options Community Residential Service System, January 29, 2001, Report Prepared by Michael J. Kendrick PhD, for the Nova Scotia Department of Community Services), in which Dr. Kendrick recommended flexible personal and family supports.

#### **4.3 Perceived Need to Harmonize Policies, By-Laws, and Regulations**

Another systemic reform that received considerable attention from study participants was the perceived need to amend and harmonize a range of provincial and municipal laws, regulations or practices, in order to remove or alleviate barriers to appropriate housing for adults with intellectual disabilities. This was sharply focused by interviewees responding to an interview question about whether relevant policies and/or regulations should be changed. One hundred

percent of those who responded to this question said “YES”, and the supporting comments they offered to related questions included these comments:

- “Family Income Security Act (New Brunswick) - The ‘Economic unit policy’ of social assistance can limit who the person lives with. Persons with disabilities should be able to live with whom ever they want without a reduction/elimination of benefits. Governments could do more through legislation to help promote the concept of housing trust funds.”
- “Remove regulation barriers and red tape. For example in the town of Rothesay, NB, the municipality is adding about \$80,000 to the cost of accessible housing units for persons with mobility disabilities because they are obliging the non-profit housing group to pay for sidewalks when the adjoining streets do not have them and they are also requesting that the units be attached to the municipal water/sewer whereas nearby homes are not attached.”

The negative impact of a range of municipal policies, or of the interpretation and application of municipal policies, elicited considerable input. In Victoria, focus group participants indicated that these barriers exist, but are being mediated to some extent:

- “Occasionally, building codes are relaxed so that an additional floor of subsidized housing can be added.”
- “Victoria is in the process of legalizing more secondary suites in houses.”

This did not appear to be the case elsewhere. One interviewee in Ontario said that the most significant barrier was the different way fire codes were interpreted in different municipalities. He implied that a very strict interpretation of code was related to the prevalence of NIMBY (Not In My Back Yard) thinking and proposed legislation, which encourages Fire Marshals to “play by the book” and make the establishment of appropriate housing for consumers very difficult. Service providers at the Ottawa focus group discussed the same issue, saying that definitions embedded in relevant legislation or by-laws result in a range of independent living arrangements (including homes owned by consumers) being deemed to be “group homes” and thus subject to the same stringent requirements for exit signs, etc. prevalent in larger facilities and institutions.

The Ottawa service provider focus group was replete with a range of related concerns:

- “In Ottawa, because of privacy concerns, the locations of group homes are not published. If we want to build or buy a house for a group home, all the city will tell us is that the location is too close to another group home. We could go through lots of potential sites before we find one the city has no objection to. There needs to be more information sharing and coordination.”

- “Multiple ministries are involved and work in silos.”
- [We] “need multi-jurisdictional approach to overcome artificial barriers.”

Interviewees also offered recommendations on how to address these problems:

- “Policies should foster inter-agency linkages and collaboration, communication .”
- “There needs to be more cooperation between Housing, Health and MCSS [in Ontario].”
- “Municipalities should change policies to allow group homes to be set up .”

## **5. CONCLUSION**

This study focused on just three communities and a relatively limited number of interviews. While the sample of study participants was small, their input was fairly consistent and thus provides good anecdotal evidence. Nevertheless, it should be recognized that individual provinces vary greatly in their approaches to supporting adults with intellectual disabilities, and the findings should therefore be read as applying primarily to the three communities studied, namely Halifax, Ottawa and Victoria.

The research found that there is a significant unmet need for suitable housing for adults with intellectual disabilities, resulting from a lack of funding for physical facilities and supports. As well, the current system which provides housing for adults outside their family home is geared to meeting the needs of the system rather those of the individuals it is meant to serve. Too often, individuals are housed where space is available, rather than in residences suited to their specific needs.

Making the transition from a family home to any form of independent living can be difficult for any adult, but more so for adults with intellectual disabilities, because of their more limited ability to cope with the challenges of adapting to new situations and taking on new responsibilities. The shortage of support services can therefore be an impediment to a successful transition.

Family members, especially aging parents, want to participate in planning for the transition to other forms of housing and to have input to the decisions that affect their family members. While most service providers share that concern, their resources are often such that a desire for a proactive and responsive approach is not translated into reality.

While many housing models emerged as desirable in different circumstances, they have a common focus on the need for flexibility and choice, reflecting the variation in the abilities, needs and desires of consumers and their families. There was also a desire to separate physical



housing from service supports, for both operations and funding. Thus, funding for an individual would not be tied to his/her residence. Finally, study participants advocate a person-centred approach, in which the consumer or advocates for the consumer are directly involved in planning and choosing the housing and support services that will best meet the consumer's needs, and in which, typically, funding is portable, that is, it is tied to the individual rather than to an agency or a facility.

**APPENDIX A**  
**INTERVIEW GUIDE**

## KEY INFORMANT INTERVIEW GUIDE

### HOUSING ISSUES FOR ADULTS WITH INTELLECTUAL DISABILITIES

Interview with: \_\_\_\_\_ Date: \_\_\_\_\_

Before we get into the specific questions, could you please give me a short description of your background and how it applies to the issue of housing for adults with intellectual disabilities.

Please note that the following questions are intended to deal **only** with the situation facing adults with intellectual disabilities.

1. On a scale of 1 to 5, (where 1= Very poor, and 5 = Very good):
  - a. How would you rate the availability of housing for persons with intellectual disabilities in your community/province? Please explain your rating.  
Rating: [   ]
  - b. How would you rate the availability of support services for people with intellectual disabilities who reside in their homes, in your community/province? Please explain your rating.  
Rating: [   ]
  - c. How would you rate the availability of support services for people with intellectual disabilities in special needs housing in your community/province? Please explain your rating.  
Rating: [   ]
  - d. How would you rate the mix of housing models for persons with intellectual disabilities in your community/province? Please explain your rating.  
Rating: [   ]
  - e. How would you rate the appropriateness of support services for people with intellectual disabilities in your community/province? That is, are the support services offered the right ones? Please explain your rating.  
Rating: [   ]
2. Are you aware of any plans or initiatives that will change the housing situation in the future (i.e. will it get better or worse)?
  - a. related to physical facilities
  - b. related to support services.

3. Individual living settings, or settings with one or two friends promote the taking of responsibility and exercising of independence and choice, and create greater personal satisfaction (than other housing options).
  - a. What are the barriers facing adults with intellectual disabilities who want to live in such settings?
  - b. What could be done to minimize or eliminate those barriers?
4. There may be some risks associated with making the transition from the family home to a new home.

On a scale of 1 to 5 (where 1= not likely, and 5 = very likely), how likely do you think it is that adults with intellectual disabilities will face these issues during such a transition:

- a. emotional (e.g. feelings of abandonment, fear, loneliness)  
Rating [   ]
  - b. financial  
Rating [   ]
  - c. homelessness  
Rating [   ]
  - d. lack of acceptance by existing residents  
Rating [   ]
  - e. difficulties conforming to new rules (which may be less flexible than the home setting)  
Rating [   ]
  - f. learning living skills they may not have needed before  
Rating [   ]
  - g. Are there other issues we haven't listed? If so – what are they and how likely are they?
5. Fear for the safety and security of the person with severe disabilities remains one of the biggest obstacles in achieving more independent living.
    - a. Do you agree with this statement?  
Yes [   ]      No [   ]

- b. Are these fears valid?  
Yes [ ]      No [ ]
  - c. What could be done to alleviate these fears?
6. Some supported living models encourage and support family responsibility for planning and creating living arrangements for their family member, including finding and paying for support staff.
- a. What are the advantages and disadvantages of such family involvement?
  - b. What barriers exist to involving family members?
7. Do you think families could or should play the following roles in finding housing for their child/sibling and in the transition from the family home to specialized housing?
- a. part of a circle of support that together with their family member (if possible) would make decisions  
Yes [ ]      No [ ]
  - b. sole decision-maker  
Yes [ ]      No [ ]
  - c. exploring options independently, prior to engaging in discussions with service providers  
Yes [ ]      No [ ]
  - d. providing emotional support  
Yes [ ]      No [ ]
  - e. providing financial support  
Yes [ ]      No [ ]
  - f. organizing a support network outside the regular support services provided by agencies  
Yes [ ]      No [ ]
  - g. Are there other roles families could play?
8. Are you aware of any innovative housing approaches that have been tried? How successful have they been? Please explain.
9. What are the advantages and disadvantages, for adults, of the following types of housing:

Type of housing	Advantages	Disadvantages
Family home		
Foster family		
Group home		
Supportive independent living		
Boarding house with supervision		
Nursing home		
House owned by consumer(s)		
Private apartment		
Cooperative Housing		
Others?		

10. The role of agencies that provide various types of housing to adults with intellectual disabilities is evolving. On a scale of 1 to 5 (where 1 = not at all, and 5 = very much):

- a. How well do you think such agencies in general are equipped to help families make appropriate decisions for their family member?

Rating [   ]

What would they need to increase capacity in this area?

- b. How well are such agencies in general equipped to help **seniors** with intellectual disabilities?

Rating [   ]

What would they need to increase capacity in this area?

- c. How would you describe agencies' ability to be flexible in adapting to an individual's particular and changing needs?

Rating [   ]

11. Staff and manager attitudes, values and practices are important factors in promoting "normalization" (i.e. assisting persons with disabilities to participate as fully as possible in their community) and the residents' level of satisfaction in his /her activities and living situation.

- a. Do you agree with this statement?

Yes [   ]      No [   ]

- b. Are prevailing attitudes among service providers supportive of normalization?

Yes [   ]      No [   ]

- c. If not, what needs to be done to change attitudes?

12. Governments (federal, provincial and municipal) also have a role to play relative to the issue of housing for adults with intellectual disabilities.
- a. Should policies and/or regulations be changed and in what way?  
Yes [ ☐ ]      No [ ☐ ]
  - b. Should relevant legislation in your province/territory be changed and in what way?  
Yes [ ☐ ]      No [ ☐ ]
  - c. What do you think are the most appropriate roles for governments (federal, provincial and municipal) to play?
13. Are there particular housing issues facing adults with other disabilities, over and above their intellectual disabilities? .
14. In your opinion, what are three (3) best practices with respect to housing for people with intellectual disabilities?
15. Are you aware of any documents, published or unpublished, that address the issue of housing for adults with intellectual disabilities? Would you share a copy with us, or tell us where we could obtain one?
16. Do you have any statistics on the availability of housing and support services in your community/province?
17. Is there anything else you think we should know about the situation facing adults with intellectual disabilities in regards to housing?

**THANK YOU**

**APPENDIX B**  
**FOCUS GROUP GUIDES**



# FOCUS GROUP GUIDE -- FAMILIES

## HOUSING ISSUES FOR ADULTS WITH INTELLECTUAL DISABILITIES

### Facilitator=s Script

#### Introductions (10 minutes)

- **Introduce yourself and your colleague, and explain the focus group objectives and the role of facilitator and reporter.**

**Names and Objectives:** \_\_\_\_\_ and I are consultants who have been contracted by Canada Mortgage and Housing Corporation to identify the housing needs and investigate housing options for adults with intellectual disabilities. In today's session, we're going to explore this with you. We're looking for your opinions, based on your experiences and your knowledge of the housing situation in your area. I will facilitate the session and \_\_\_\_\_ will take notes.

**Focus:** *We're interested in hearing what you have to say about this subject for all adults with intellectual disabilities in your area. But we are particularly interested in two sorts of sub-sets of this group.*

- First and foremost - we are interested in adults with intellectual disabilities who live with their families. We want to hear about the housing challenges they face in key transition periods in their lives. We're talking here about the sort of challenges encountered as teenagers become young adults, and most of all, about issues confronting older adults with intellectual disabilities, as their parents or caregivers age and can no longer continue to provide on-going support.
- *The other sub-set in which we have a strong interest is intellectually challenged adults with multiple disabilities.*

**Terminology:** *Throughout this focus group, you'll probably hear me asking questions or making references to intellectually challenged adults living with their families. Recognize that this is not intended to limit discussion to only those who live with their parents, siblings, or other blood relations. We recognize that there are many variations on this theme, and we're using the word "family" as a short form to cover the full range of caregivers who give the kind of support most typically provided by parents or siblings.*

- **Explain how the session will be conducted, and the ground rules.**

**Participants' jobs, openness and attribution:** *Your job for the next two hours is to be open and forthcoming. I assure you that no names will be included in our report, which will be written so that important things that people say will be included, but no one reading the report will know which individuals were involved, or who said what.*

**Informality:** *We want you to be comfortable, and we want our session to be as much like a real conversation as possible. So please – be informal in how you express yourself and interact with others. If you want to talk - go ahead. I=ll referee if we have a couple of people talking at once. And if you want to ask a question – just ask. Don't wait for a formal Question and Answer period.*

**Time Constraints:** *We have two hours to spend together, and a lot to talk about in that time. So you may find that I sometimes need to intervene in discussions so that we can cover all the questions planned.*

- **Ask for and respond to any questions raised by participants. Stress again that they should ask questions when they wish to.**

- **Orchestrate introductions.**

*We=re going to be talking together for the next couple of hours. That=s generally easier to do when you know a little bit about the people you=re talking to. So let=s take a minute for each of you to introduce yourselves. Could each of you tell us:*

- *Your name*
- *Whether a person with an intellectual disability currently lives with you or whether they've already left to live somewhere else*

### **Question 1: Assessing Significance and Availability (10 minutes)**

- **Ask: “Is the issue of finding suitable housing for your family member an important one for you?”**

**Probe (if required) for:**

- WHY participants have accorded the issue the significance they have
- Details on both facilities and support services.
- **Ask: “How would you assess/describe the availability of housing in your region for adults with intellectual disabilities?”**

### **Question 2: Identify The Challenges (20 minutes)**

- **Ask: “What issues or problems have you encountered in dealing with housing for your family member?”**

**Probe (if required) for:**

- Input on transition situations (both for young adults, and for older adults living with aging caregivers)
- Input on intellectually challenged adults with other disabilities
- Details and real-life examples.
- If they have not looked for other housing, why not?

**Probe also for differences in responses between situations where consumers reside with or outside their families.**

### **Question 3: Housing Needs (30 minutes)**

- **Ask: “In the ideal situation, what would be the characteristics of the home you would like for your family member?”**

**Probe (if required) for:**

- type of physical facility, e.g. private home, apartment, group home
- types of support available, e.g. live-in, oversight, financial management
- the impact of multiple disabilities

- **Ask: “What would it take for your family member to get that type of home situation?”**

**Probe (if required) for:**

- agencies willing and able to provide the right kind of location and services
- changes to the way disability incomes are provided

#### **Question 4: Risks (20 minutes)**

- **Say: “*What concerns do you have about your family member making the transition to another home?*”**

**Probe (if required) for:**

- the risks the individual may face (e.g. lack of funds, getting lost in the system, becoming homeless)

#### **Question 4: The Role of Parents/Siblings (35 minutes)**

- **Ask: “What has been your role in finding a new home situation for your family member?”**
- **Ask: “How does that compare to the role you think you should play/have played/ would like to have played?”**

#### **Closing: (5 minutes)**

- **Note that it’s now time to wrap up the session.**
- **Explain the time lines for this project:**
  - Project due to be completed in February of 2006.
  - Final report should be available on CMHC website after project completion
  - For information on final report, contact: \_\_\_\_\_.
- **Note that the research phase will continue for quite a while longer, and that your team is interested in any relevant publications or articles. Supply coordinates so that attendees can forward any relevant information to you.**
- **Thank attendees for their participation and close the session.**

# FOCUS GROUP GUIDE - CONSUMERS HOUSING ISSUES FOR ADULTS WITH INTELLECTUAL DISABILITIES

## Facilitator=s Script

### Introductions (10 minutes)

- **Introduce yourself and your colleague, and explain the focus group objectives and the role of facilitator and reporter.**

**Names and Objectives:** \_\_\_\_\_ and I want to talk to you about creating a home for adults with disabilities like you have. We're looking for your opinions, based on your own experiences. I will lead the discussion and \_\_\_\_\_ will take notes.

- **Explain how the session will be conducted, and the ground rules.**

**Participants' jobs, openness and attribution:** *Your job for the next two hours is to be open and honest. We'll never tell anybody exactly what you said, so you don't need to worry about getting into any kind of trouble for saying anything.*

**Informality:** *Think of what we're doing here as having a conversation. You can talk and ask questions whenever you want to.*

**Time Constraints:** *We have two hours to spend together, and a lot to talk about in that time. Sometimes I may have to stop a discussion so we can move on to other questions.*

- **Ask for and respond to any questions raised by participants. Stress again that they should ask questions when they wish to.**

- **Orchestrate introductions.**

*We're going to be talking together for the next couple of hours. That=s generally easier to do when you know a little bit about the people you=re talking to. So let=s take a minute for each of you to introduce yourselves. Could each of you tell us:*

- *Your name*
- *Whether you live with your family or somewhere else*

**Question 1: Advantages/disadvantages of living with family (25 minutes)**

- Ask: *“Let’s talk about what’s good and bad about living with your family.”*
- First, what are some of the things you like, or liked, about living with your family?

**Probe (if required) for:**

- WHY they like particular aspects of living with their families
- the types of support they receive from their families, like emotional support, family advocates on their behalf, always someone there to do things with
- physical aspects, like having their own room, having access to easy transportation, having things like TVs, computers, etc. on hand

- Ask: *“Is there anything about living with your family that you don’t or didn’t like?”*

**Probe (if required) for:**

- WHY they don’t like particular aspects of living with their families
  - things their families might do, like making their decisions for them, controlling their comings and goings, lack of other friends

**Question 2: Transition to other types of housing (60 minutes)**

- Ask: *“If you’re living with your family now, do you think you’ll ever have to go live somewhere else?”*

- Assume some participants will say yes. If not, proceed to Question 3.

- Ask: *“When you think about living somewhere else, having your own place or living with someone else, what are the things that would make you happy?”*

**Probe (if required) for:**

- making new friends
- learning new skills
- doing what they want when they want
- having control over what they eat

- **Ask: What are some of the things that would make you worry, some of the things that you are afraid of?**

**Probe (if required) for:**

- loss of independence
- emotional concerns
- financial concerns
- finding the right place to live
- loneliness
- safety

- **Say: “Some of you don’t live with your families anymore. Try to remember what it was like after you moved.”**

- **Ask: “What was it like not to live with your family anymore?”**

**Probe (if required) for:**

**Negatives**

- loss of independence/control
- dislike of change
- financial problems
- loss of supports/advocate
- loneliness
- lack of privacy

**Positives**

- making new friends
- learning new skills
- doing what they want when they want
- having control over what they eat

**Question 3: The Ideal (20 minutes)**

- **Say: “Is there someplace else that you’d rather be living right now? Why?”**

**Probe (as required) to elicit details on:**

**If the answer is NO:**

- they get all the help they need
- they don’t like change

- it might be worse elsewhere
- they really like where they are now and wouldn't want to change

If the answer is YES:

- What kind of a home would you like to live in?
- Would you like to live by yourself or with other people?
- Who would you like to help you live in your own home?
- What would they help you with?
- Where would you like to live?

**Probe for differences (if any) between participants who are and are not living with their families.**

**Closing: (5 minutes)**

- **Note that it's now time to wrap up the session.**
- **Explain the time lines for this project:**
  - Project due to be completed in February of 2006.
- **Thank attendees for their participation and close the session.**



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## FOCUS GROUP GUIDE – SERVICE PROVIDERS HOUSING ISSUES FOR ADULTS WITH INTELLECTUAL DISABILITIES

### Facilitator=s Script

#### Introductions (10 minutes)

- **Introduce yourself and your colleague, and explain the focus group objectives and the role of facilitator and reporter.**

**Names and Objectives:** \_\_\_\_\_ and I are consultants who have been contracted by Canada Mortgage and Housing Corporation to identify the housing needs and investigate housing options for adults with intellectual disabilities. In today's session, we're going to explore this with you. We're looking for your opinions, based on the experiences you've had in this region. I will facilitate the session and \_\_\_\_\_ will take notes.

**Focus:** *We're interested in hearing what you have to say about this subject for all adults with intellectual disabilities in your region. But we are particularly interested in two sorts of sub-sets of this group.*

- First and foremost - we are interested in adults with intellectual disabilities who live with their families. We want to hear about the housing challenges they face in key transition periods in their lives. We're talking here about the sort of challenges encountered as teenagers become young adults, and most of all, about issues confronting older adults with intellectual disabilities, as their parents or caregivers age and can no longer continue to provide on-going support.
- *The other sub-set in which we have a strong interest is intellectually challenged adults with multiple disabilities.*

**Terminology:** *Throughout this focus group, you'll probably hear me asking questions or making references to intellectually challenged adults living with their families. Recognize that this is not intended to limit discussion to only those who live with their parents, siblings, or other blood relations. We recognize that there are many variations on this theme, and we're using the word "family" as a short form to cover the full range of caregivers who give the kind of support most typically provided by parents or siblings.*

- 
- **Explain how the session will be conducted, and the ground rules.**

**Participants' jobs, openness and attribution:** *Your job for the next two hours is to be open and forthcoming. I assure you that no names will be included in our report, which will be written so that important things that people say will be included, but no one reading the report will know which individuals were involved, or who said what.*

**Informality:** *We want you to be comfortable, and we want our session to be as much like a real conversation as possible. So please – be informal in how you express yourself and interact with others. If you want to talk - go ahead. I=ll referee if we have a couple of people talking at once. And if you want to ask a question – just ask. Don't wait for a formal Question and Answer period.*

**Time Constraints:** *We have two hours to spend together, and a lot to talk about in that time. So you may find that I sometimes need to intervene in discussions so that we can cover all the questions planned.*

- **Ask for and respond to any questions raised by participants. Stress again that they should ask questions when they wish to.**

- **Orchestrate introductions.**

*We=re going to be talking together for the next couple of hours. That=s generally easier to do when you know a little bit about the people you=re talking to. So let=s take a minute for each of you to introduce yourselves. Could each of you tell us:*

- *Your name*
- *The organization you represent and the position you hold.*

---

**Question 1: Assessing Significance and Availability (20 minutes)**

- Ask: *“When you consider the range of issues confronting adults with intellectual disabilities in your region, how significant is housing and issues related to housing?”*

**Probe (if required) for:**

- WHY participants have accorded the issue the significance they have
- Details on both facilities and support services.
- If this doesn't emerge through discussion, ask: *“How would you assess/describe the availability of housing in your region for adults with intellectual disabilities?”*

**Question 2: Identify The Challenges (20 minutes)**

- Ask: *“In this region, what do you think are the most consistent and challenging housing issues adults with intellectual disabilities who currently live with their families are encountering, or are likely to encounter?”*

**Probe (if required) for:**

- Input on transition situations (both for young adults, and for older adults living with aging caregivers)
- Input on intellectually challenged adults with other disabilities
- Details and real-life examples.

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**Question 3: Best Practices (20 minutes)**

- Say: *“We want to get a handle on best practices in your area. Can you describe for us any particularly successful or innovative approaches to housing for adults with intellectual abilities that you’ve encountered in your region?”*

**Probe (if required) for:**

- Input on transition situations (both for young adults, and for older adults living with aging caregivers)
- Input on intellectually challenged adults with other disabilities
- Details for follow-up: names, positions, phone numbers of contacts who may be able to provide more information.

**Question 4: The Ideal (30 minutes)**

- Say: *“You’ve just talked about the best arrangements you’ve encountered. But let’s take it a step further and talk about what would work even better. Imagine the ideal. Can you give us your ideas for the very best ways of handling the housing needs of adults with intellectual disabilities?”*

**Probe (as required) to elicit details on:**

- Facilities
- What role families/caregivers should play
- Favoured approaches for transition situations (both for young adults, and for older adults living with aging caregivers)
- Favoured approaches for intellectually challenged adults with other disabilities
- Systemic dimensions: the role to be played by governments, and legislative or policy changes that should be considered.

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**Closing: (5 minutes)**

- **Note that it's now time to wrap up the session.**
  
- **Explain the time lines for this project:**
  - Project due to be completed in February of 2006.
  - Final report should be available on CMHC website after project completion
  - For information on final report, contact: \_\_\_\_\_.
  
- **Note that the research phase will continue for quite a while longer, and that your team is interested in any relevant publications or articles. Supply coordinates so that attendees can forward any relevant information to you.**
  
- **Thank attendees for their participation and close the session.**

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## **APPENDIX C**

### **LITERATURE REVIEW**

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## LITERATURE REVIEW

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## 1. Introduction

A consensus has emerged in Canadian society that recognizes the right of people with disabilities to participate fully in society. Moving from rhetoric to actual practice is a slow process. Moving from isolation to integration, from paternalism to independence requires continued shifting at the policy level if this change is to be realized. The place where one lives will have a critical influence on how we achieve full participation of people with intellectual disabilities.

The rate of developmental disability among Canadians aged 15 years and over in 2001 was 0.5% or 120,140 persons. Of these, an estimated 44,770 persons are aged 45 - 64 and 11,080 are aged 65 - 74.<sup>1</sup> These figures are considered to be an underestimation because they exclude persons who are institutionalized or living in nursing homes as well as those residing in the territories and reserves. Seltzer and Essex suggest that cite references that estimate the population of people with disabilities in the general population of the United States ranging from 1.20% to 1.65% in 1992, and that in general, estimates of the prevalence of developmental delays range from 1% to 3% of the population, with epidemiological studies lending support for the lower estimates.<sup>2</sup>

Since the early 1980's, there has been recognition that institutions were no longer acceptable as a practice for housing people with developmental disabilities. Thus began the shift in social policy away from institutional placement and the move towards community living.

This shift continues today, and although there are still thousands of people with developmental disabilities in Canada that reside in institutions, the larger majority of institutions have been closed. In the few remaining provinces that have institutions, efforts are being made to move residents back to the community.<sup>3</sup>

For families who have come to rely on institutional care, or for those whom the community has failed, the prospect of community support can be daunting and terrifying. There is apprehension about a possible uncertain future, security, quality of care, impact on family life and the potential change in family responsibility.

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<sup>1</sup> Cossette, L. & Duclos, E. (2002). A Profile of Disability in Canada 2001 (No. 89-577-XIE). Ottawa, Statistics Canada: Housing, Family and Social Statistics Division.

<sup>2</sup> Seltzer, Gary B.; Essex, Elizabeth Lehr, Service Needs of Persons With Mental Retardation and Other Developmental Disabilities in Allen, Susan M and Mor, Vincent, Ed.) Living in the Community with Disability, pp 197 – 240, Springer Publishing Company. 1998

<sup>3</sup> There are many types of institutional facilities that exist in the community ranging from large residential type facilities, mid-range congregate care facilities for people with developmental disabilities and smaller facilities like 5+ bedroom group homes which can still be institutionalized environments.



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## 2. Methodology

The methodology for this literature review focused primarily on North American sources, most of which are Canadian sources. An Internet search using key words related to housing for people with developmental disabilities generated many publications, however, most were non-Canadian sources. Key words included:

- developmental disability and housing
- intellectual disability and housing
- normalization theory
- social role valorization theory
- developmental disability and aging

Other materials were generated through discussions with individuals working in the field of developmental disability with responsibility for supporting people with their residential needs, and engaged in creative developments in this field.

## 3. Definition of Intellectual Disability

The terminology used for persons with intellectual disabilities has evolved over the past number of decades from reference to persons with “mental retardation”, “developmental handicaps”, “developmental disability” and more recently to the terminology “intellectual disability”. Seltzer and Essex identify two main classifications systems or approaches that are used to classify persons with an intellectual disability – the categorical approach and the social systems approach. “The categorical approach uses the presence of intellectual impairments, as measured by IQ tests, as the primary diagnostic criterion for mental retardation. The level of intellectual impairment is based on the standard deviation of the IQ test that is administered.”<sup>4</sup> Using the Wechsler scales of intelligence, persons are assumed to have mental retardation or an intellectual disability when they score more than 2 standard deviations, 30 points below the mean IQ scores of 100. Seltzer and Essex suggest that this approach fails to describe an individual’s functional abilities. The social systems approach considers the role played by a person in some but not all social systems and tends to contribute most when determining the level of disability, not the presence of disability. The functional approach is an alternative to these two that considers the behavioural or functional limitations to having an impairment. Seltzer and Essex suggest “this approach stresses the importance of functional limitations on the daily routines and role performance of persons with disabling conditions”<sup>5</sup>.

Seniors on the Margins - Aging with a developmental disability defines developmental disability as a condition that originated prior to birth, at birth or in early adulthood, but the primary disability is intellectual. The condition presents varying degrees of

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<sup>4</sup> Ibid

<sup>5</sup> Ibid

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intellectual deficiency, along with other physical and/or sensory incapacities and health risks. Developmental disability can be classified into three broad categories:

- genetic syndromes such as Down Syndrome, Fragile X Syndrome and Prader-Willi Syndrome;
- problems with the central nervous system which result in epilepsy, cerebral palsy and visual impairments; or
- milder developmental disabilities.<sup>6</sup>

#### **4. The Housing Challenge for Persons with Intellectual Disabilities**

Housing Issues for Albertans with Developmental Disabilities – A Discussion Paper<sup>7</sup> indicates there are many challenges that people with intellectual disabilities face in obtaining housing that enhances their quality of life, both as renters and home owners. Some of these challenges are increased when the intellectual disability is accompanied by sensory or motor limitations and/or health problems, behavioural difficulties or mental health issues. For example, shared accommodation, while reducing the costs of housing for persons with intellectual disabilities, may increase their need for support to deal with behavioural challenges. Such accommodation might also limit their freedom to make choices about how they live their lives. Most people with developmental disabilities are poor with low and relatively fixed incomes, have either no employment or minimum wage employment where the availability of affordable housing is critical. There are some, but very few who have access to substantial trust funds set up by family to assist with housing needs.

This paper summarizes the primary housing issues for Albertans with developmental disabilities as follows:

“The lack of affordable, suitable and adequate housing due to low vacancy rates and disincentives to build low-cost housing;

- accessible housing for those who have physical disabilities is limited;
- competition for affordable housing favours other groups, such as single parents;
- individuals who also have behavioural challenges or whose signatures on legal forms may not hold up in court are unattractive to landlords;
- the number of individuals with developmental disabilities seeking accommodation has increased due initially to deinstitutionalization and more recently to agencies selling off group home properties and also to increased numbers of adults with developmental disabilities in Alberta.

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<sup>6</sup> National Advisory Council on Aging, Seniors on the Margins – Aging with a developmental disability, Minister of Public Works and Government Services Canada, 2004.

<sup>7</sup> Heemeryck, Barrie and Biersdorff, Kathleen K., Housing Issues of Albertans with Developmental Disabilities A Discussion Paper, Persons with Developmental Disabilities Board in collaboration with the Vocational and Rehabilitation Research Institute, November 2001.

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In addition, those who seek to own their home may face the following challenges:

- little money can be saved from fixed incomes for down payments
- few properties are available in the low-cost end of the market
- lack of credit rating makes getting a bank loan difficult
- public trustee policies favour liquidity of assets over home ownership.”<sup>8</sup>

In The Community Participation Series Volume 2, Housing, Support, and Community<sup>9</sup>, the authors highlight a range of barriers that exist on all levels in the area of housing for people with severe disabilities in the United States including suggested strategies and practices that would help to address these barriers. The list of barriers, although not exhaustive, include lack of accessible community housing, lack of decent affordable housing, lack of choice in housing, state barriers to home ownership by parents and people with disabilities, lack of money for housing expenses or rent deposits, attitudinal barriers regarding people with severe disabilities living in typical homes, the heavy investment by the state in agency run facilities, lack of choice in roommates, lack of knowledge by policy makers and community agencies on community housing, etc.

## **5. Models and Approaches to Housing for Persons with Intellectual Disabilities**

The Community Participation Series Volume 2, Housing, Support, and Community<sup>10</sup> suggests that residential services or community living arrangements were conceptualized according to a continuum of facilities. This continuum was based on the assumptions that community living arrangements are generally agency-owned, operated and/or licensed facilities. Furthermore, it is assumed that housing and services are linked together; people with disabilities are expected to make the transition to less restrictive settings as they acquire additional skills or to move to more restrictive settings if problems occur. The perceived severity of a disability determines the type of facility in which an individual will be placed. The authors also note that the field of developmental services is moving away from the notion of a continuum of residential facilities to more flexible and responsive approaches that are “non-facility based,” “person-centered,” or a “housing and support” approach for adults. The range of models presented in this literature review reflects this change to approaches that are more person-centered and housing support that is non-facility based.

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<sup>8</sup> Ibid

<sup>9</sup> Racino, Julie Ann; Taylor, Steven J.; Walker, Pamela; and O’Connor, Susan, The Community Participation Series. Volume 2, Housing, Support and Community, Chapter 1, Brookes Publishing, Baltimore, 1993.

<sup>10</sup> Ibid

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## 6. The Group Home Model

John O'Brien wrote that "the recent experience of a large number of people with mental retardation [sic] is better described as movement from one kind of institution to another than as community integration. Many community alternatives perpetuate undesirable practices such as deprivation of purposeful activity, isolation from ordinary places and people, crowding, lack of choices and failure to provide for individualization".<sup>11</sup>

The most common image of a community residence for people with intellectual disabilities is a group home. There are debates about who can suitably be housed in a group home, how group homes might best be financed, who should sponsor and staff them, etc. O'Brien states "underlying these important differences in policy and practice are some common assumptions.

- An agency acquires and manages the building
- Staff are employed by the agency.
- Housing is offered along with other services such as instruction, supervision, and personal assistance in a tightly connected package....
- Usually the person with mental retardation (sic) contributes only a small part to the program's costs from discretionary income. Most program costs are paid by a third party who may bundle several funding sources to make up a daily rate per person.
- Reimbursement rates are often justified by a scheme for determining a person's level of [need for] care. This frequently results in grouping people with similar needs in the same place and paying more to serve people who are less able.
- People often assume that different types of building match different degrees of handicaps. The most able people live in apartments. The least able people live in congregate health care facilities. The people in between belong in group homes.
- People are "admitted" to a "bed" as "residents" or "clients" and receive "residential care" or "active treatment" are "demitted" or "graduated" or "referred or transferred to a more appropriate program".<sup>12</sup>

People with developmental disabilities are essentially a guest in someone else's home.

Pedlar, et al<sup>13</sup> describe the process once a decision is made to seek a home within the traditional service system. The authors seek to understand texture in the lives of people with developmental disabilities by exploring aspects of everyday life that most profoundly affect our general well-being, namely our home and family life.

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<sup>11</sup> O'Brien, John, Discovering Community Living Learning from Innovations in Services to People with Mental Retardation, 1987

<sup>12</sup> Ibid

<sup>13</sup> Pedlar, Allison; Haworth, Larry; Hutchison, Peggy; Taylor, Andrew, A Textured Life - Empowerment and Adults with Developmental Disabilities., Wilfrid Laurier University Press, 1999.

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The path to community living often leads families and individuals to the group home model. Group homes are still the most common form of housing services for adults with developmental disabilities. Criticism of group homes suggests that this model offers people a less than desirable home situation. The group home model has a tendency to group people who have a similar disability and the complexity of one's disability acts as a determinant of where and with whom a person lives. The model is basically organized as a "program" that places priority on functionality and administrative ease whereby decision-making is often driven by economic considerations. Group home models tend to be a place to live, rather than an individual's home and are not viewed as the "optimal" living arrangement. Group home living presents difficulties for people who express a desire to relocate, primarily due to the manner in which funding is allocated as well as minimal options in the community. Nevertheless, for some families, there is an enormous gratitude for the fact that their family member was in a community setting rather than an institution. Some see this as indeed a place to live that is better than an institution, others accept this as their "lot". Individuals with developmental disabilities and their families do experience a fear of reprisal if they attempt to address difficulties or concerns they may have concerning the quality of service in a group home. Group homes have responded to very real needs for decent housing in many communities. They have allowed people to move from institutions and to come one step closer to living more normal lives in everyday residential settings and take a first step towards an adult home life. For many families, group homes offer a solution to an extremely difficult circumstance.

John Lord, Judith Snow and Charlotte Dingwall in their commentary state that recent research "shows that a significant number of group homes across Canada have many of the features of mini-institutions, where people's lives are controlled".<sup>14</sup>

The shift to community living continues to evolve. In the earlier development of community living models, the agency owned and operated group home was the predominant model of housing support for people with developmental disabilities. Service providers were both the landlord and the provider of personal care and support services.

Families are seeking alternatives to the traditional group home model where the individual with a developmental disability has no say in the ownership of their home, relationships are limited to staff, staff turnover is problematic and residents are often not living in familiar communities. The view is that group homes are structured around the people who work there. L'Arche Communities are seen as an exception whereby there is an intense focus on relationships that create a welcoming and nurturing environment that qualify as home.

David Wetherow's article Reflections on Group Homes and Supported Living<sup>15</sup> presents a picture of group home living and proposes that the system doesn't understand supported

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<sup>14</sup> Lord, John; Snow, Judith; Dingwall, Charlotte, Building a New Story – Transforming Disability Supports and Policies, Individualized Funding Coalition, September 2005.

<sup>15</sup> David Wetherow, A Reflection on Group Homes and Supported Living, [www.communityworks.info/articles/group\\_homes.htm](http://www.communityworks.info/articles/group_homes.htm).

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living. He questions what does group home living really mean for people and proposes that a five bedroom group home with a 1:1 staff/client ratio likely results in 48 minutes of engagement out of an 8 hour shift for individualized personal attention that is often spread over the course of the shift.

## **7. Living independently, in one's own home or in an apartment**

Pedlar, et al suggest that “living independently, in one's own home or in an apartment, is a dream that has been realized by few Canadians with developmental disabilities”<sup>16</sup>. This dream is realized for some when family support, funding structures and service arrangements have worked together to form a common, empowerment-driven paradigm. People without access to strong advocacy supports can rarely exert control over their residential situation.

The ideal living arrangement is a typical house or apartment in a typical neighbourhood. Not available to many, this option allows the greatest freedom to set the rules and determine one's own life as opposed to settings in which others are in charge. Fear for the safety and security of the person with severe disabilities remains one of the biggest obstacles in achieving more independent living. A shift towards supporting people in their own apartments, and finding ways to do so, requires a shift in philosophy and a willingness to let individuals with disabilities take the risks inherent in making choices for themselves.

Supportive apartments, whereby two, three or four individuals live independently with some assistance provides for the highest level of independence apart from living independently in one's own apartment. It provides for a greater ability to exercise control over one's life and make choices, living as adults. This approach works best when there is a separation of housing and support.

## **8. Family Home Arrangement**

Foster Family Care is a service provided in private homes for individuals with special needs who receive room and board as well as training – Pedlar, et al.<sup>17</sup> A family home arrangement offers a person with a disability the opportunity to live in the home of a family other than his or her own where the family receives payment or reimbursement for the support they provide to the individual. This provides an opportunity to experience family life and is often viewed as an option for individuals requiring higher levels of support rather than or before a move to more independent living sites. It is viewed as an effort to support the development of natural family-like relationships between the “home

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<sup>16</sup> Pedlar, et al. 1999

<sup>17</sup> Pedlar, et al. 1999

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provider” and the “home sharer” and is not conceived purely as a residential program but rather a means to provide a home for the individual. The success of this model is related to the philosophy of practice of both the families that open their homes and the agencies that facilitate this type of arrangement.

## **9. Shared accommodation with a live-in caregiver and companion**

Pedlar, et al describe one variation of the Family Home Arrangement Model as an option for the “adult with the disability to share accommodation with a live-in caregiver and companion”<sup>18</sup>. Typically a full-time support person, the caregiver is also encouraged to become a friend or companion and less like a staff member. This option creates greater opportunity to increase the degree of autonomy and choice in determining living arrangements and in the choice of fellow residents.

## **10. Microboards**

The establishment of Microboards to support people to find and sustain housing arrangements is a growing model for the development of personal support services for individuals with disabilities. Microboards can assist someone to purchase a home, adapt a home, build a home and manage the range of both paid and unpaid care and support to allow the person to live a full life in the community.

David and Faye Wetherow in their article Microboards and Microboard Association Design, Development and Implementation<sup>19</sup> define a Microboard as a small (micro) group of committed family and friends joining together with a person who lives with challenges to create a non-profit society (board). Together this small group of people address the person’s planning and support needs in an empowering and customized fashion. A Microboard comes from the person centered planning philosophy and is therefore created for the sole support of one individual.

The qualities of a Microboard that define purpose and identity include:

- “an unencumbered focus on the identity, needs and express wishes of the person who is supported;
- development and maintenance of an active, diverse and fully engaged citizen-based circle of support;
- retaining all possible elements of control, especially including the role of employer-of-record”<sup>20</sup>.

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<sup>18</sup> ibid

<sup>19</sup> Wetherow, David and Wetherow, Faye; Microboards and Microboard Association Design, Development and Implementation, <http://www.communityworks.info/articles/microboard.htm>

<sup>20</sup> Ibid



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The first Microboards in Canada were created in Manitoba in 1984. The objectives of Microboards were to:

- “establish a mechanism for direct individualized funding (which was not available in Manitoba at that time),
- provide a mechanism for bringing effective control of support services into the hands of the person who was being supported and the people who were closest to him or her,
- develop an understandable pattern for drawing together an intentional citizen-based personal support network,
- develop a pattern that would define and maintain the identity and efforts of the support network (the Microboard members and allied others)”<sup>21</sup>.

The Manitoba government accepted two new operating strategies in service funding and organization: the first being a move to individualized funding related to a specific person’s support needs and segregating the funds that were received on behalf of that person and secondly to separate the provision of housing from the provision of support services.

Wetherow states that Microboards are intended to allow people to move:

- “from agency funding to funding individual support services;
- from agency-type governance structures to supports directly governed by the individual person being supported and their friends and family members;
- from relatively inflexible service structures to supports that could adapt rapidly to changes in a person’s needs, interests, relationships and environments; and
- from lives defined by services to lives increasingly defined by companionship, connection and contribution in the broader community”<sup>22</sup>.

Wetherow states that the development of Microboards can be supported on a larger scale with access to the underlying supports such as training, technical support and practical assistance in areas such as initial formation, planning, managing resources, recruiting, screening and training of staff, handling difficult human resource situations, budgeting, evaluation, accountability, representing the person’s needs to government, etc. In British Columbia, the Vela Microboard Association has supported the development of over 170 Microboards over a 10 year period. This initiative reflects 170 people with disabilities with funding from the state being supported by and engaged with over 800 citizen supporters.

In the United States, the Tennessee Microboard Association is a more recent development and has been successful in making Microboards eligible for Medicaid, residential, vocational, family support and health support funding in a U.S. context.

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<sup>21</sup> Ibid

<sup>22</sup> Ibid



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## 11. Home Ownership

Housing for People with Severe Disabilities: A Collection of Resource Materials<sup>23</sup> <http://thechp.syr.edu/housereres.htm> suggests that the development of a housing trust is one method of developing home ownership for individuals with disabilities. The article indicates the number of housing trusts that have been established since 1985 has increased more than fivefold (Centre for Community Change, 1989. US). There is a range of housing trusts that includes private trusts that may be established for the benefit of an individual or group that would include a housing component. Other examples of trusts are those established by one or more levels of government where there is an ongoing commitment of revenue to support home ownership.

Etmanski in his book A Good Life<sup>24</sup>, presents a chapter Creating a Home Life, which focuses on assisting parents plan for their family member with a disability to continue to live in a familiar community after their parents die. This chapter identifies the differing financial arrangements that could assist someone with a disability to achieve home ownership.

Nesbit and Hagner<sup>25</sup> indicate that there are three major barriers to homeownership in the United States for people with disabilities: federal policy that offers substantial incentives that favour funding for service providers over individuals, mortgage lending criteria used to underwrite mortgage loans that disqualify the majority of people with disabilities and the limited financial resources of people with disabilities who are either unemployed, underemployed and receive poverty level income. In chapter seven, the authors present the New Hampshire Home of Your Own Project as one example of a best practice that received an award on homeownership and control from the U.S. Administration of Developmental Disabilities in 1991.

The Home of Your Own Project, led by the University of New Hampshire's Institute on Developmental Disability was a project that pooled together the resources of both the public and private sectors, creating collaboration and partnerships among agencies, businesses, organizations and people with broad based home ownership concerns. At the end of the three year demonstration project, there were 20 Home of Your Own Project participants who had purchased their own homes and the project's success generated funding for an additional three years. Chapter seven illustrates the changes that are taking place and are required if homeownership is to become a reality for more people with developmental disabilities. Assistance has become more personalized when it is not

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<sup>23</sup> Housing for People with Severe Disabilities: A Collection of Resource Materials <http://thechp.syr.edu/housereres.htm>

<sup>24</sup> Etmanski, A, A Good Life, Planned Lifetime Advocacy Network, 2000

<sup>25</sup> Nisbet, Jan; and Hagner, David, Part of the Community – Strategies for Including Everyone, Brookes Publishing, 2000.

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dictated by the rigid protocols required when numerous people live together in one facility. Lenders are beginning to recognize public benefits as income. Agency budgets are being structured and personalized whereby a line item for housing becomes a budget for mortgage payments. There is an acknowledgement that people on public benefits do not have funds from savings and are not penalized because of resource limitations that prevent them from accumulating significant savings.

## **12. Cooperative Ownership Models**

We Come Bearing Gifts - The Story of Deohaeko Support Network<sup>26</sup> presents the story of Rougemount Co-operative Homes, Inc. and Deohaeko Support Network. Rougemount Co-operative Homes, Inc., is a housing cooperative envisioned, planned and brought to reality by a group of Durham Region families in Ontario who wanted to ensure a future for each of their sons and daughters with a disability within the heart of a welcoming community. These families formed the Founding Board of Rougemount until its transition to a Board of members who live in the cooperative.

Deohaeko Support Network is the group that exists to consciously think about how the sons and daughters of the founding families of Rougemount Cooperative Homes might best be supported to fully participate in the events and activities of their own lives within the Rougemount and the broader communities. Deohaeko's Board is separate from the Rougemount Board, but is made up of the same families who designed and built Rougemount.

Ten young adults live in Rougemount Co-operative, each with an intellectual disability or impairment such that some degree of support is required to assist them to achieve their hopes, dreams and endeavours to be active. This book is an example of many of the identified best practices in action and the steps one group of families took to bring their shared vision to reality. It addresses issues of home ownership, inclusion, integration, relationships - both paid and natural, support needs and the role of families and natural relationships, and funding. It provides an opportunity for an expression of learnings from building the project to sustaining the homes of the young adults with intellectual disabilities.

Housing for People with Severe Disabilities: A Collection of Resource Materials<sup>27</sup> suggests that Housing Associations and Housing Cooperatives are definite models that are on the rise as another option for people with disabilities. These models have a great untapped potential for integration of persons with disabilities and separates housing from the provision of services so that if the relationship with the service providing agency changes, the person can continue to live in their own home.

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<sup>26</sup> Klees, Janet, Copywell, We Come Bearing Gifts, 1996

<sup>27</sup> Housing for People with Severe Disabilities: A Collection of Resource Materials <http://thechp.syr.edu/houseress.htm>

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### 13. The Cluster Model

The Cluster model is characterized by a single location for a number of individuals with developmental disabilities such as a series of apartments in a single apartment building, a number of houses on a block or a row of town homes in a community. Racino and Taylor<sup>28</sup> indicate there are some advantages to the cluster model that include less susceptibility to regimentation, administrative and logistical advantages, potential for greater physical integration in the community than group homes and a smaller size of living situation leading to a greater likelihood that the people living together would get along with each other. They also indicate there are several drawbacks to the cluster model including the potential to limit people's choices in housing options, they are often transitional in nature, are sometimes inflexible in nature with respect to neighbourhood choice and number of roommates, they typically belong to an agency and are not considered people's own homes, similar to group homes there is a rigid distinction between staff and clients and there is a tendency to become insular and self-reliant thereby inhibiting community integration.

In the U.S., farm communities as a type of cluster model have developed and grown in popularity over the last couple of decades for individuals with autism. Margaret A. Schneider's<sup>29</sup> published article notes that the process of deinstitutionalization realized from the sixties has brought everyone to think about a better way to develop suitable residential options for the benefit of individuals with autism. In fact, these individuals used to live in institutions where their situation often deteriorated due to the lack of appropriate assistance. The precariousness of their life conditions in institutions linked to the escalating costs of housing created a huge civil rights movement where they could return to the community to live with dignity, respect and freedom.

Schneider indicates that a common finding in the literature pertaining to residential alternatives for individuals with autism is that they are often excluded from traditional group homes. They are viewed as incapable of functioning independently at home because of the extent and nature of their disability. For all these reasons, they are perceived as a vulnerable group who do not easily fit in the existing services and as such, require special attention to assist with skill development.

During the past decades, farm communities have become an adapted environment where individuals with autism can accomplish tasks according to their incapacities. These communities constitute an alternative that takes into account the needs of the person in relation to the ability to facilitate their social integration. Because people with autism present language, attentional and cognitive deficits, staff members of the traditional group homes

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<sup>28</sup> Racino et al, Chapter 2, 1993.

<sup>29</sup> Journal of Leisurability, Vol 27, Number 1, Winter 2000. Schneider, Margaret A., In Response to Deinstitutionalization: Farm Communities as a housing alternative for individuals with autism

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settings often lack appropriate knowledge of people with autism and have difficulties dealing with presenting behavioural challenges.

As an example, Bittersweet farms in Ohio offer to people with autism the opportunity to grow by making their own food and products and learning life skills. They receive support from staff members that are in fact seen as partners. This community has been developed with the support of parents, teachers and professionals in order to establish an environment where individuals with autism could live with staff members of Bittersweet farms. For Mesibov, the three keys of this program consist of:

- The possibility for the people with autism to develop their ability on the farms,
- The opportunity to implement the skills they are taught, and
- The physical nature of the work on the farms.

In these community farms, the emphasis is placed on quality of life issues and recreational activities as a way to satisfy the needs of the residents. Programs are appropriate to the capacity of people with autism in order to improve their self-esteem and their ability to participate in the community life.

Margaret A. Schneider proposes that farm community housing offered to individuals with autism the opportunity to have a community life, in response to the weaknesses of deinstitutionalization. The experience of Bittersweet farms is presented as a good example of the advantages of these accomplishments.

#### **14. Intellectual Disability and Aging**

Older Adults with Developmental Disabilities<sup>30</sup> discusses an emerging and growing segment of older Americans that is still largely hidden and often neglected in the provision of services - namely, older persons with developmental disabilities. With the growth in the numbers of individuals with developmental disabilities is the growth in the variety of settings available to them. Fifty years ago, there were only two options, home or institutional care. Today, large institutions are a thing of the past and there is a range of community living options.

The National Advisory Council on Aging (NACA) publication Seniors on the Margins - Aging with a developmental disability<sup>31</sup> suggests that by 2021, seniors will form 18% of Canada's population as compared with 12.5% in 2000. As a result of medical science

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<sup>30</sup> Lavin, Claire and Doka, Kenneth J., Older Adults with Developmental Disabilities, Baywood Publishing Company, New York. 1999

<sup>31</sup> National Advisory Council on Aging, Seniors on the Margins – Aging with a developmental disability, Minister of Public Works and Government Services Canada, 2004.

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and health care, Canadians with a developmental disability now have a life expectancy that extends well beyond mid-life.

The living arrangements of Canadian seniors with developmental disabilities are not fully known, however a recent national Canadian survey<sup>32</sup> suggests that most continue to have group homes as their dominant model of residential services, followed by independent apartment living and then other settings such as foster families, home with parents, homes with house parents and boarding homes. The survey did not include people living in institutions.

The NACA publication indicates that in Canada, there is a movement toward smaller, home-like housing that allows adults with developmental disabilities to age in place rather than move to institutions. However, waiting lists are long, and many settings require physical adaptation to accommodate seniors with a developmental disability. Meeting the needs of developmentally disabled seniors becomes more complex because services for seniors are delivered as group programs and are not designed to adapt to individual needs and circumstances.

The publication also suggests there is a need for an increase in the number and variety of housing options for older adults with a developmental disability including options with access to community services and facilities. Permanency planning is required to respond to the needs of housing for older adults with developmental disabilities including estate planning and options for housing arrangements. In addition, there is a need for collaboration between service providers in the disability sector and seniors sector to develop the capacity of both sectors to respond to the needs of aging persons with developmental disabilities.

A retirement type congregate care community for aging persons with a developmental disability is one option. Some of the advantages include staff trained in the needs of aging and developmental disability, the setting would be designed to be physically accessible and opportunities for the continuation of leisure activities to maintain and enhance physical, social and personal well-being would be created.

Aging in place is another alternative presented in the publication of the NACA. This option may require modifications to the physical environment. It allows for the continuity and preservation of existing relationships. It minimizes any stress of dislocation, and it provides for the ongoing stimulation and support offered in an intergenerational setting.

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<sup>32</sup> Pedlar, A., Hutchison, P., Arai, S., & Dunn, P. (2000). Community Services Landscape in Canada : Survey of Developmental Disability Agencies. *Mental Retardation*, 38 (4), 330 – 341.

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Research<sup>33</sup> in the United States demonstrates that there is a trend towards small-scale living options regarding housing for older adults with developmental disabilities. There has also been a vision since the 1980's that older adults with developmental disabilities are entitled to choices about how and where they want to live. In 1987, the United States adopted the Older Americans Act Amendments, which recognized that having a real home was as important to people with developmental disabilities as it was to others. In the United States, there are many different options for community living and the focus is on individualized planning and management. Small scale living options are considered best practice in the provision of community living options and supports for older adults with developmental disabilities. Unfortunately, the availability depends on funding.

Sutton, et al report on a US national survey of community living options for individuals 60 years of age or older with developmental disabilities which identified and defined several options for small scale living, taking into consideration the individual's needs and preferences as follows:

- The Intermediate care facility for people with mental retardation (ICF/MR) is an intermediate care facility for people who require 24 hour supervision and includes some nursing care. There are usually 15 residents or fewer.
- A Group Home setting provides care, supervision and training and limits the number of residents to eight.
- Supervised homes or apartments allow residents the choice to live alone or with a roommate and a staff person lives in a separate unit at the same location.
- Adult foster care allows one to three people to live together in a rented home with a surrogate family to provide care.
- Demonstration housing allows for a temporary housing unit to be built on the same property as a family home, and the family can then look after the resident in need.
- The Individualized Support Living Arrangement (ISLA)/Supportive Home Care option allows the resident to live with a relative, who is the primary caregiver and community workers assist the primary caregiver in providing necessary care.
- Independent, semi-independent and personal care living allows the person to live in their own home with the necessary supports coming to them as needed.
- Board and care homes provide meals, sleeping rooms and supervision, with no nursing care provided.

In a U.S. national survey of state agencies responsible for services to older adults with mental developmental disabilities, over 50% of older adults with developmental disabilities reported on are using the ICF/MR model for community living<sup>34</sup>.

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<sup>33</sup> Lavin, Claire and Doka, Kenneth J., Older Adults with Developmental Disabilities, Baywood Publishing Company, New York. 1999

<sup>34</sup> Sutton, E., Ractor, A., Hawkins, B., Heller, T., Seltzer, G. Older Adults with Developmental

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The trend right now is for agencies to use state funding rather than federal funding and case managers are expected to ensure that supported living funds are used only when there are no other funding sources available. The state of Ohio ensures that funds are provided directly to the resident so they can make their own choices regarding their home; and there is certification, monitoring and evaluation of all homes to ensure safe and secure housing and care. Since the 1980's there is a push for financing to be tied to the person, rather than the programs and that it be flexible and linked to the individual's choices.

The trend for small-scale living options will continue to grow as the population of older adults with developmental disabilities continues to grow. The benefits are clear and include: flexibility, the option to stay in a familiar setting, individualization, community participation, family and social involvement, and the freedom and opportunity to make choices.

There are also two major types of supports being offered to older adults with developmental disabilities: habilitation and personal care. The habilitation model involves active intervention that teaches the individual how to do needed tasks. This allows the individual to gain more independence and lessens the need for the same number of supports in the future. The personal care model focuses on maintenance, assistance and supervision of care and is a more long-term type of support.

## **15. Additional Research**

In 1979, the State of Vermont undertook a study of the question: "How well has the state been accomplishing its social-policy objectives of normalization of services to those with disabilities." In particular the study addressed community members with "mental retardation" (developmental or intellectual disabilities). It defined the normalization philosophy as that which "enhances the inclusion of persons with disabilities in recreation, leisure, work, education, and other services in their community, supporting them to gain and maintain respect, social supports and friendships, and autonomy and independence, and to have access to lifestyles of their choice..."<sup>35</sup> It described the transition of public policy from one in which people with mental health, educational, or social needs were segregated from those without disabilities in order to "fix" or "contain" them, to one in which supports and services were brought to the consumer and his/her family in an attempt to assist them in participating as fully as possible in community.

The study was longitudinal, covering a period of three years and comparing three community residential settings: group homes of 4 to 6 residents; supervised apartments;

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Disabilities Optimizing Choice and Change, Paul Brookes Publishing, Baltimore, 1993.

<sup>35</sup> Burchard, S.N. (1999). Normalization and residential services: The Vermont studies. In R.J. Flynn & R. A. Lemay (Eds.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact*. Ottawa, ON: University of Ottawa Press. (N)



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and natural family settings. In terms of lifestyle normalization (individualization, autonomy, personal responsibility, choice, age-appropriate activities, and daily and seasonal rhythms) and personal adjustment it was found that outcomes were not related to any previous institutionalization of the residents. It also found that the group home and the family home residents were most alike in terms of lifestyle normalization and that supervised apartment residents experienced greater independence, residence-lifestyle normalization, and physical and social integration than those in the other settings. Those living in supervised apartments were most like individuals living in a family home setting in terms of residence satisfaction (79.8% & 76.8% respectively) and well being (82.4% & 84.3% respectively). In terms of social support, residents in all three settings expressed a high level of satisfaction (87%) with the group home settings having the largest networks and the most peers in their networks. People living in family home settings had the fewest staff and peers in their support networks. One conclusion drawn by the study was that residents in group home settings experienced less autonomy, choice, community integration, and personal satisfaction and no greater social support than the other two settings. Individuals living in supervised apartment settings appeared to experience the greatest residence-lifestyle normalization, community access and integration, and independent performance of skills.

This research also looked at elements that predicted lifestyle normalization as set out by Wolfensberger (1972). In the three settings being studied it was found that *location*, *residence-lifestyle normalization*, and *opportunity* (having environmental opportunities and the autonomy to choose to engage in the activities available) were important predictors with *opportunity* being the most consistent. In terms of *social integration* (activities outside the home in the company of at least one non-disabled friend) the scores for people living in group homes and family homes were very low and so no predictors were assigned. Resident-lifestyle normalization, on the other hand, was shown to be a predictor for those living in supervised apartments where the location was “accessible to downtown and community sites.”

Burchard felt that because few people in the non-disabled community live either with their parents (family home) or in groups of 4 to 6 (group homes) that the Vermont Studies research did not reflect a true comparison with the non-disabled community. Thus, she quoted a study carried out by Julie Rosen (Rosen & Burchard, 1990) that demonstrated that people with developmental or intellectual disabilities living in supervised apartments compared very well with non-disabled people in the community living in similar settings when compared on the basis of access to the community, social activity with friends, lifestyle satisfaction, well-being, and satisfaction with social support. Differences occurred basically in terms of the friends in these two groups, where *friends* of the people with disabilities included staff (40%) and other people with disabilities (35-40%).

Overall, the Vermont Studies has shown that living environments such as supervised apartments that include “greater opportunities, autonomy, independence, fewer housemates, and less restrictive supervision and control” compare better than other living environments to the goals of public policy in terms of normalization philosophy. Well-being and satisfaction are greater in these environments than in large institutional



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settings. Individual living settings or settings of “one to two” friends were shown to promote a greater taking of responsibility and exercising of independence and choice, as well as creating greater personal satisfaction in people with developmental or intellectual disabilities. Although individual living settings appear to be the more ideal settings for community living it was shown that in small group settings staff and management competencies played an important role in the normalization process. In small community residences housing two to six people with varying degrees of disability the study concluded that staff and manager attitudes, values and practices were also determinants in the promotion of normalization goals and the residents’ level of satisfaction in his /her activities and living situation.

The Vermont Studies conclude that many individuals with disabilities, if given the opportunity and support from the community, will adapt successfully to living in the community and that although their financial situation may be an indicator of poverty they don’t necessarily view themselves as “impoverished.” Social policy needs to reflect the real needs of these individuals, which Burchard (1999) outlines as the provision of living and working opportunities that provide “as much individualization, choice, and personal control as possible and, for service systems, to have more respect and faith in individuals’ abilities to make and exercise choices including lifestyle-related ones”<sup>36</sup>.

## **16. Other Considerations**

For many individuals without disabilities, only significant crises or changes challenge day-to-day adaptation. The small changes, such as a move to a new office or everyday transportation difficulties that may cause one to modify his or her route, are taken in stride. For many persons with developmental disabilities, one of the major adaptive mechanisms is routinization. It also means that any change, however minor, may be perceived as a crisis. Often, the lack of control over their lives can make small changes have a great impact.

Maintaining continuity in housing represents a critical need for aging persons with developmental disabilities. For those living with family members, there is a need for permanency planning. For those living independently, it may require additional support or creative solutions - possibly house or apartment sharing. For others living in congregate or other non-institutional options, other alternatives are worth considering.

John O’Brien and Connie Lyle O’Brien in Members of Each Other - Building Community in Company with People with Developmental Disabilities<sup>37</sup> write a collection of essays and reflections on practice that explores work at the boundaries between people with developmental disabilities and other community members who, except for this work, would not meet and become a part of one another’s lives. Good lives for people with

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<sup>36</sup> Ibid

<sup>37</sup> O’Brien, John and O’Brien, Connie. Members of Each Other - Building Community in Company With People With Developmental Disabilities, Inclusion Press, Toronto, 1996.

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severe disabilities depend on whether they are recognized as members of the social networks and associations that constitute community. People recognized as members benefit from everyday exchanges of support that create opportunities to play socially valued roles and chances to form personally significant relationships. People excluded from membership risk loneliness, isolation and powerlessness.

Because people with severe disabilities cannot take membership for granted, those concerned with building stronger, more inclusive communities must consider how some people deny other people membership, the resources that membership can offer, and the ways membership can be established.

Human services can help reduce barriers and create opportunities for people with severe disabilities to gain greater membership in a number of ways. With respect to creating opportunity to develop secure homes, the human service system can support individual or cooperative home ownership for adults with severe disabilities. There is a need to break programmatic links that tie people who need a particular type or amount of support to an agency owned building.

Services to people with developmental disabilities need to gradually shift attention and investment away from congregate services. As this happens, small but growing and visible numbers of people with substantial disabilities will come to live in ordinary housing, have support for ordinary employment and attend ordinary schools.

A Place Called Home<sup>38</sup> is the story about a family with a son (David) who has significant disabilities including a developmental disability and their journey to assist him to live independently. The story speaks to issues of inclusion, home ownership, paid support, housemates, location of a home, etc. Learnings include the need to: form a circle or group of supportive friends, seek out resources, consider how your family member will live on their own, and considerations when choosing where your family member should live and the outcomes you want to achieve.

## **17. Summary**

Group homes are still the most common form of housing services for adults with developmental disabilities outside of the family home. Criticism of group homes suggests that this model offers people a less than desirable home situation. Residents of group home settings experienced less autonomy, choice, community integration, and personal satisfaction and no greater social support than other settings. Families are seeking alternatives to the traditional group home model for their family member with a developmental disability. Living independently, in one's own home or in an apartment, is a dream that has been realized by few Canadians with developmental disabilities. Best

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<sup>38</sup> Ouellette, Allison C., A Place Called Home, 2002

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practices include home ownership that addresses issues of inclusion, integration, relationships - both paid and natural, support needs and the role of families and natural relationships, and funding. The benefits of small-scale housing include: flexibility, the option to stay in a familiar setting, individualization, community participation, family and social involvement, and the freedom and opportunity to make choices. There is a need to break programmatic links that tie people who need a particular type or amount of support to an agency owned building. This de-linking of services and supports will contribute to increased flexibility and opportunity for choice. The establishment of Microboards to support people to find and sustain housing arrangements is another growing model for assistance individuals with disabilities obtain personal supports.

There is a trend towards smaller scale housing for people with developmental disabilities that is widespread throughout North America and Canada.

Characteristics of successful models of housing include:

- housing with supports that are flexible and individualized;
- housing that typifies North American living arrangements for people who do not have disabilities;
- housing that provides a person with more control over where they live, who they live with and how they live;
- housing with supports that are more adaptable and able to innovate on an ongoing basis as situations changes
- housing whereby the personal supports an individual receives are separate from the housing support.

Emerging models include:

- home ownership
- cooperative housing
- apartment rental
- a separation of personal care services and landlord services
- the establishment of microboards for individuals or groups of individuals.

Successful housing policy starts with the person first. The implications for successful housing policy related to people with intellectual disabilities is about much more than bricks and mortar. Successful housing policy will implicate both the public and private sectors and call for strong partnerships and collaboration.

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**APPENDIX D**  
**GLOSSARY OF TERMS**

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## GLOSSARY OF TERMS

- **Boarding house with supervision:** These are large, licensed facilities housing 20 - 30 consumers who pay for accommodations, with the addition of on-site staff who are there primarily to supervise, maintain order, and administer medications. There are no life skills programs delivered despite the fact that these facilities tend to be for people with severe disabilities.
- **Cooperative housing:** Cooperative housing is owned by a co-op corporation and is managed by a non-profit Board, which all residents/members have an opportunity to serve on. Co-op housing is usually in the form of apartment buildings or row-houses. All residents/members are expected to participate in the management and operation of the co-op.
- **Consumer:** this term is often used in lieu of the considerably more cumbersome “adult with intellectual disabilities” or “adult with developmental disabilities”.
- **Family Home:** The term “lives in the family home” is used to describe a consumer who either:
  - lives with blood relatives like parents or siblings, or
  - lives with unpaid others with whom he or she has a relationship like that typical (in Canadian society) of family members who are closely related.
- **Family Home Arrangement** is a term sometimes used for a Foster Family (see below).
- **Foster Family:** A foster family arrangement is intended to simulate a family home. The consumer lives with a family other than his or her own. The foster parents are paid to play the role they assume with the consumer.
- **Group Home:** A group home is an agency-owned (or leased) and operated facility which may be licensed, in which housing and support services are linked together. Group homes typically house three to twelve residents and have staff on-site 24 hours a day.
- **House owned by consumer(s):** These are residential facilities owned by a consumer, or a group of consumers, or a consumer’s family, or a group of consumers’ families. Despite the implications of the word “house” this term as used by practitioners can cover any residential facility not owned by an agency, ranging from an apartment, to a townhouse, duplex or a single family home.
- **Nursing homes:** Nursing homes are public or private facilities offering 24-hour health care and some recreation and leisure activities, but no skills development programming. Typically, two consumers share a room, though single rooms are sometimes available. The quality of accommodation varies widely depending on costs.



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- Small options model: This is a term used in Nova Scotia, to refer to an arrangement in which three or fewer consumers who require staff support live together and share support services provided either through shift-work or live-in staff, or a combination of both. It appears to be a province-specific term for a form of supportive independent living (see below).
  - Special Needs Housing: Housing stock geared specifically to individuals with disabilities, including accessible and subsidized housing.
  - Supportive independent living: Supportive independent living assumes that consumers are living on their own, but are provided with the support they need from agencies to sustain independence.

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**APPENDIX E**  
**PERSONS INTERVIEWED**

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Interviewee	Province
Lesley Lambert Team Leader Community Living B.C.	B.C.
Dominic Flanagan Manager of Tenant Services B.C Housing	B.C.
Shannon Mullen B.C. Corporate Policy and Planning	B.C.
Henry Kamphof Director of Services Capital Region Housing Corporation Victoria, B.C.	B.C.
Roy Ferguson Acting Department Chair University of Victoria School of Child and Youth Care	B.C.
Jim Franklin Academic/Network Advocate B.C. Aboriginal Network on Disability Society	B.C.
Lynda Vallee Executive Director Shekinah Homes Society	B.C.
Mike Griffen Supervisor, Supported Independent Living Program Victoria Association for Community Living	B.C.
Fred Ford University of Victoria Faculty Member– School of Social Work, School of Child and Youth Care Community Consultant	B.C.
Mike Storrier Integra Support Services Victoria, B.C.	B.C.
Paul Young Consultant. Founding president of People First NS; past- president of People First Canada; past chair of Council of Canadians with Disabilities Sydney, NS.	N.S.
Mary Rothman Executive Director, Nova Scotia Association for Community Living Dartmouth, NS.	N.S.

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Interviewee	Province
Bev Wicks Executive Director Regional Residential Services Society	N.S.
Donald Mullins President Disabled Individuals Alliance	N.S.
Barry Schmidl Executive Director, PEI Council of the Disabled Charlottetown, PEI	PEI
Gary Comeau Executive Assistant, Premier's Council on the Status of Disabled Persons Fredericton, NB	NB
Joan Russell More Services Mirimachi, NB.	NB
Dawn Leblanc Social Worker Izaak Walton Killam Hospital for Children Halifax, N.S.	NB
Kasia Tota Halifax Regional Municipality - Planning Halifax, N.S.	N.S.
Carol Tooton Executive Director Canadian Mental Health Assn Dartmouth, N.S.	N.S.
Jack Carlon Assistant Executive Director West Montreal Readaptation Centre Montreal, Quebec	Quebec
Lyse Beaudet Director of Client Services Centre CRDI Gabrielle Major Montreal, Quebec	Quebec
Jacques Pelletier Ottawa, ON	Ontario
Beth French, Executive Director Brockville Association for Community Living Brockville, ON	Ontario

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Interviewee	Province
Ray Lemay, Executive Director Services aux enfants et adultes de Prescott-Russell Services to Children & Adults Plantagenet, ON	Ontario
Leslie Peddie Director of Community Support Calgary Scope Society	Alberta
Robert Flynn Professor University of Ottawa	Ontario
Glen Rampton CEO, Kerry's Place Autism Services Toronto, ON	Ontario
Elizabeth Bloomfield co-founder of Autism Society of Ontario Toronto, ON	Ontario
Barrie Heemeryck Program Manager in housing and self-advocacy for people with developmental disabilities PDD Provincial Board Department of Social and Community Support, Government of Alberta	Alberta
Stan Fisher CEO, Chrysalis: An Alberta Society for Persons with Disabilities	Alberta
Forbes, Janet Executive Director Association for Community Living Winnipeg	Manitoba
Connie Woloschuk Manager for Residential and Support Services (for all homeless and at risk) with the Housing Branch at the City of Ottawa	Ontario
Dale Kendel Executive Director Community Living Manitoba	Manitoba
John Lord Consultant Waterloo ON	Ontario
Thierry Boyer Executive Director Pavillon du Parc Gatineau, Quebec	Quebec

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Interviewee	Province
Michael Milligan Social Worker Connections Club House	N.S.
Anne Wright Trinity House Saskatoon, SK	SK