



No Place Like Home:

A Report on the Housing Needs of People with Intellectual Disabilities

Researched and written by
Cameron Crawford
Director, Research and Knowledge Management

Canadian Association for Community Living
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I. Overview

This report looks at housing issues for people with intellectual disabilities. It provides a working definition of this population and looks at the nature and extent of their need for housing. The focus of the report is on non-institutional housing options beyond the family (e.g., parental) home.

Overall the report shows that relatively few people with intellectual disabilities are living within the formal system of ‘residential care facilities’, which includes large congregate care institutions and group homes of various sizes. Instead, they are disproportionately more likely than adults without disabilities to be living with one or both parents or to be living as ‘unattached’ persons, that is, alone or with others who are not related by ties of kinship. They are more likely to be living in places that are rented rather than owned and more likely to be living in places that need major repairs.

While the demand for housing for people with intellectual disabilities has been increasing of late, the supply of appropriate housing options has not kept pace. The report discusses factors that help explain why people with intellectual disabilities are not moving to preferred options, discusses housing options typically made available to them and some of the pros and cons of those options, and provides principles for informing the development of housing options to better meet the needs of this population. Ideally, such housing would be adequate, suitable, and affordable. It would be accessible and would be linked to but separate from supportive services for disability, which would be provided as required and in ways consistent with the federal-provincial-territorial accord on disability issues, *In Unison*. As well, the housing would facilitate the social inclusion of people with intellectual disabilities rather than reinforcing their marginalization from society.

II. Defining ‘Intellectual Disability’

The present report uses the term ‘intellectual disability’ to refer to people who have been variously classified as having a developmental disability, developmental delay, mental handicap, and until quite recently in the United States, ‘mental retardation’.

Definitions of intellectual disability tend to involve measures of intelligence and adaptive behaviour, but are contested ground. For instance, IQ cut-offs can range from 70 to 75. There is variation in whether environmental factors are taken into account (e.g., availability of support systems) and whether measures of adaptive behaviours or aetiology (familial/cultural and organic) are factored into the definition. Horwitz, Kerker, Owens, and Zigler (2000) provide a helpful discussion.

Generally, however, people with intellectual disabilities are considered to be those who have significantly greater difficulty than most people with intellectual and adaptive functioning due to a long-term condition that is present at birth or before the eighteenth birthday. ‘Adaptive functioning’ includes carrying out everyday activities such as communicating and interacting with others, managing money, doing household activities and attending to personal care. While the term ‘intellectual disability’ is technically distinct from other ‘developmental disabilities’ (see American Psychiatric Association, 1994), these terms are often used interchangeably.

III. Prevalence of Intellectual Disability

Prevalence estimates of intellectual disability vary from about 0.7% to about 3% of the general population. While there are no ‘official’ data for Canada, Bradley *et al* (2002) found a prevalence rate of 7.18 per thousand in Ontario, a figure similar to Scandinavian countries but that the researchers believe probably understates the actual prevalence. The figure used by the Ministry of Children and Family Development in British Columbia has been 1% in recent years (British Columbia. Ministry of Children and Family Development, 2001), which is similar to figures recently found by research conducted by the Centres for Disease Control and Prevention (2008) in the United States. An official from the Ontario Developmental Services Branch of the Ministry of Community and Social Services told the author of the present paper that the Branch estimated a total of about 90,000 people with intellectual disabilities in the province. That figure works out to about 1% of the total population. In contrast, a senior government official who worked in developmental services in Alberta recently told the present author that Alberta was using prevalence estimates that ranged from about 2% to 2.5%.

The US President's Committee for People with Intellectual Disabilities uses the following language to discuss prevalence, with ‘MR’ as shorthand for ‘mental retardation’, the term used pervasively in the US instead of ‘intellectual disability’ until quite recently:

The US Census does not collect national data on people with intellectual disabilities (mental retardation). Data is based on best estimates from various authorities in the field. The usual national percentages are estimated to be 1% (which usually includes all or most persons currently receiving services in the MR service system), 2% (includes the preceding plus those who were once served in the MR service system but are no longer in it), 3% (includes the preceding plus the “unknown” cases discovered through epidemiological or other studies in the search for people with mental retardation. For example, they may include those residing in rural isolated areas where MR services may not exist, or in poverty areas of inner cities where people may not know about resources available to them, or not know how to access services, and other populations not usually counted). In some rare circumstances, a few parents may hide or even deny the existence of an intellectual disability in their child or not even know that their child with “mild”

mental retardation has a disability (US Department of Health and Human Services, 2008).

IV. Population Estimates

Data from Statistics Canada's Participation and Activity Limitation Survey (PALS) indicate an intellectual disability prevalence of about 0.7% (Table 1), which may mean that the survey is picking up people with intellectual disabilities who have a relatively severe level of functional limitation. PALS is Statistics Canada's 'flagship survey' on disability issues. Non-responses, contrary responses and other survey design issues may have been other factors that resulted in low reporting of intellectual disability in PALS.

Table 1. Participation and Activity Limitation Survey (PALS) 2006 data on people with intellectual disabilities in Canadian households

Age group	People with intellectual disabilities (numbers)	All Canadians (numbers)	People with intellectual disabilities as a percentage of total population
0-14*	17,090 *	1,656,040	1.0%
5-14**	53,740 **	3,815,310	1.4%
15+**	136,570 **	25,422,280	0.5%
Total	207,400	30,893,640	0.7%

*Developmental delay: Child younger than 5 years has a delay in his/her development, either a physical, intellectual or another type of delay.

**Developmental disability or disorder: People older than 4 years who have cognitive limitations due to the presence of a developmental disability or disorder, such as Down syndrome, autism or mental impairment caused by a lack of oxygen at birth.

Source: Statistics Canada, 2007a.

Given the variability in population estimates on intellectual disability, and that PALS seems to understate prevalence, three estimates are provided, here, that correspond with prevalence rates of 1%, 2% and 3% of the adult population 15 years and older. Table 2 shows the results. The three estimated numbers of adults with intellectual disabilities are about 225,000, 510,000 and 766,000 people, respectively.

Table 2. Canadian adult population (15 years and older) and three estimates of intellectual disability, 2006

Number of Canadian adults:	25,522,280		
<hr/>			
Estimated percentages of the general adult population with intellectual disabilities:	1%	2%	3%
<hr/>			
Estimated numbers of adults with intellectual disabilities:	255,000	510,000	766,000

Source for total adult population: Statistics Canada (2007a).

V. Where Are People with Intellectual Disabilities Living?

A. Residential Care Facilities

Based on 2002 data from Statistics Canada's *Residential Care Facilities Survey*, research conducted by Crawford (2005c) found that fewer than 15,000 people with intellectual disabilities were living in the residential care facilities system. Statistics Canada (2007b) defines residential care facilities as:

facilities which have four beds or more and which are approved, funded or licensed by provincial/territorial departments of health and/or social services. Among the facilities included are homes for the aged, persons with physical disabilities, persons who are developmentally delayed, persons with psychiatric disabilities, persons with alcohol and drug problems, emotionally disturbed children, transients, young offenders and others.

Some of these facilities are maintained for chronically ill or disabled people who reside there more or less permanently. This is in contrast, for example, to a hospital where patients are accommodated on the basis of medical need and are provided with continuing medical care and supporting diagnostic and therapeutic services. Generally, residential care facilities provide a level of care that is below that found in hospitals, although there is some overlap.

Other residential care facilities keep their patients for shorter periods, though they still provide a care program.

'Group homes' and larger congregate care arrangements for people with intellectual disabilities would typically fall within the class of residential care facilities. A limitation of the *Residential Care Facilities Survey*, however, is that it does not enquire about provincially approved, funded or licensed places with fewer than four people with intellectual disabilities. In some jurisdictions, such smaller arrangements are becoming more common (Stainton et al., 2008), although publicly available data about such arrangements are scarce in Canada.

That said, if only about 15,000 people with intellectual disabilities are in the residential care facilities system with four or more 'beds', this leaves the question: where

are all the others? Reasonable inferences are that some are in residential care facilities that do not focus primarily on people with intellectual disabilities and that the vast majority are in various non-institutional living arrangements.

B. Institutions for Seniors and Others

Customized data received from Statistics Canada indicate that about 1,200 people with intellectual disabilities were living in residential care facilities designated for seniors in 2001-2002. Some 273 were living in various other residential care facilities. Data from the Institutions component of the 1998 National Population Health Survey indicate that about 3,900 people with a developmental disability were residing in facilities for seniors that year, which would have included extended care facilities attached to hospitals. The latter were not covered under the *Residential Care Facilities Survey*. If either of the figures are taken at face value, it would appear that a relatively small number of people with intellectual disabilities reside in facilities for seniors.

A recent conference in Winnipeg on aging and intellectual disability brought together residential service providers, people with intellectual disabilities, family members and government officials. It was reported that the residential ‘system’ for people with intellectual disabilities is, in effect, becoming the residential system for these people as they enter into their senior years and approach the end of life (Crawford, 2005b). That is, people with intellectual disabilities do not seem to be migrating in large numbers over to the residential system for seniors.

C. Non-institutional Arrangements Beyond Residential Care Facilities

Table 3 shows the economic family situations of adults by disability status.¹ The table shows that, compared with adults who do not have disabilities, those with intellectual disabilities are:

¹ The figures are from PALS 2001 because the 2006 PALS data on family arrangements for people with intellectual disabilities had not yet been released when the present report was written.

- Much more likely (38% compared with 18%) to be living as never-married adult sons or daughters with one or both parents;
- More than twice as likely (29% compared with 14%) to be living as ‘unattached’ persons, i.e., people living alone or with one or more people who are not members of the same family, which would include unrelated people sharing the same house/apartment, residents of a rooming house, people in a non-institutional private care arrangement (e.g., living as a tenant with, and perhaps receiving support from, a family but not linked by kinship ties), and various other non-institutional arrangements;
- Somewhat more likely (6% compared with 4%) to be living with extended family members beyond the biological or adoptive family unit; and
- Slightly over a third as likely (23% compared with 60%) to be living with a spouse.

The rest of people with intellectual disabilities (5%) are lone parents.

In other words, if adults with intellectual disabilities are not in the formal residential care facilities system, they are most likely to be living as never-married adult ‘children’ with one or both parents, or alone, or with others with whom they do not share ties of kinship.

Table 3. Economic family status of adult Canadians 15 years and older without disabilities, with intellectual disabilities and with other disabilities

	Non-disabled	Intellectual disabilities	Others w/ disabilities
Spouse or partner	60%	23%	55%
Lone parent	4%	5%	7%
Never married adult children	18%	38%	5%
Other members of family	4%	6%	6%
Unattached	14%	29%	26%
Total	100%	100%	100%

Source: PALS 2001

The housing of people with learning difficulties inclusive of intellectual disability is more likely (39%) than that of non-disabled persons (26%) to be rented rather than owned by someone in the same household (Crawford, 2008, in press).

Owing to different survey methodologies, data from PALS 2001 are not, strictly speaking, comparable with those from its predecessor, the Health and Activity Limitation Survey (HALS) of 1991 (Statistics Canada, 2004). However, the questions about intellectual/developmental disability are similar across both surveys. Focusing on the adult population 15 years and older, PALS indicates that in 2001, 38% of adults with intellectual disabilities were never-married sons or daughters living with one or both parents. For 1991, the HALS figures indicated that only 31% met this description. About the same proportion of people with intellectual disabilities in both reporting years (29% in 2001 and 30% in 1991) were 'unattached' individuals.

It may be the case, then, that adults with intellectual disabilities are more apt in recent years to be living with their parents than was the case in the early 1990s. Section VII of the present report suggests that this may indeed be the case; the system of community living supports has been under considerable stress and waitlists have been commonplace in recent years.

VI. Demand for Housing

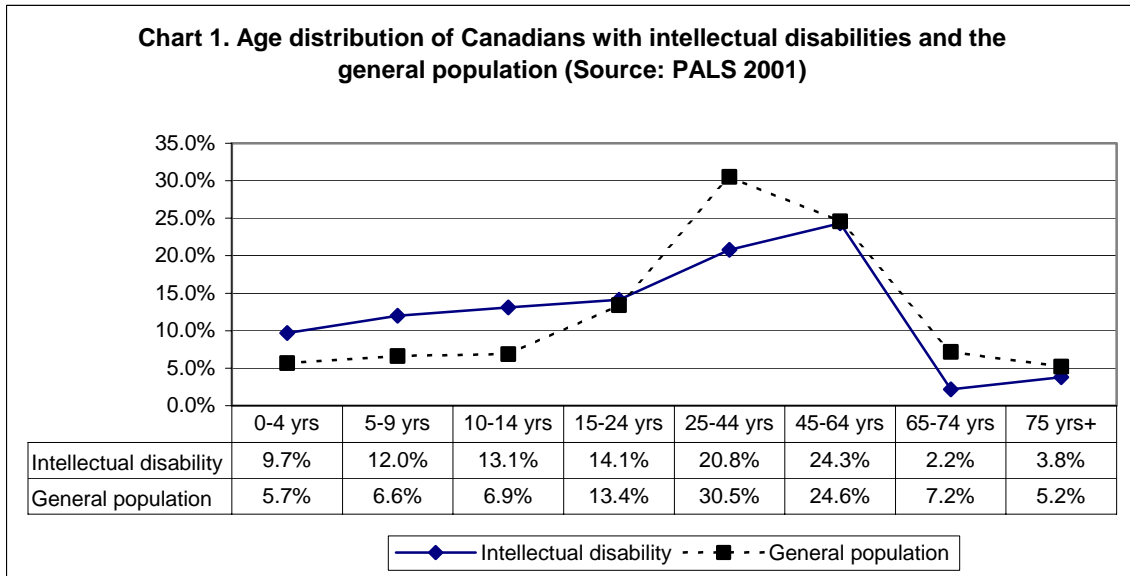
Emerson (1999) has pointed out that the ability to effectively support adults with developmental disabilities will become increasingly important as the demand for community living arrangements rises. Demographic factors contributing to this demand include: increased prevalence of people with developmental disabilities from the baby boom generation who are currently cared for by elderly parents; increased life expectancy and lower mortality rates; and increased survival rates of young people with severe and complex disabilities.

Compared with people who do not have a disability, people with intellectual disabilities are over-represented as never-married adult 'children' living with parent(s) (38% vs. 18%). If that percentage were to be reduced by 20 percentage points to bring it into line with the percentage for non-disabled adults, then, taking the very conservative PALS adult population count (Table 1) on face value as the 'true count', some 27,000 more people with intellectual disabilities would be living somewhere other than their parents' homes (20% x 136,570). If a 1% prevalence estimate were used for intellectual disability (Table 2) instead of the PALS count, about 51,000 more adults with intellectual disabilities would be living somewhere other than the family home (20% x 255,000); if 2% prevalence were used, the figure would be 102,000 people (20% X 510,000).

An underlying assumption for those calculations is that the age distribution of people with intellectual disabilities is similar to that of the general population, and that people with intellectual disabilities, like others, would ideally move into housing beyond their parents' homes sometime fairly early in their adult years. Chart 1² shows that the age distributions for people without disabilities and those with intellectual disabilities are indeed similar. The finding is consistent with reports in recent years that indicate much

² Chart 1 draws from PALS 2001 because those data were available for finer age groupings than the published PALS data for 2006 (Statistics Canada, 2007a), the latter being the only pertinent data from PALS 2006 that were publicly available when the present report was written.

the same life expectancy for people with intellectual disabilities as for the general population and much the same in terms of age-related and other health issues (AAMR 2005; Horwitz et al., 2000; Harum 2006). That people with intellectual disabilities want to live more independently as they enter into adulthood has also been confirmed by recent Canadian research (Beals et al., 2006).



VII. Where do People Want to Live and Why Aren't They Moving There?

A recent CMHC research project (Beals et al., 2006) found that people with intellectual disabilities want to live independently, make their choices about who to live with and make their own decisions and how to spend their time. Why, then, are they not moving into places beyond the family home? There are at least four inter-related reasons: a supply 'crunch', the high cost of housing, difficulties securing the needed supports for disability beyond the family home and other issues of a financial nature.

A. Supply 'Crunch' Within the Developmental Services Residential System

People with intellectual disabilities are not moving out of the family home in part because the developmental services residential 'system' as a whole for people with intellectual disabilities has been hard pressed to keep pace with ever-increasing demands for service in recent years. For example, a discussion paper co-authored by Ontario's Ministry of Community and Social Services, released as a report by the Joint Developmental Services Sector Partnership Table (2004), recently said:

Government continues to spend more and more money to provide supports to people who have a developmental disability ... The available supports are still inadequate to enable families and individuals to cope with the challenges that they face every day of their lives (p. 1).

...The current support system is under extraordinary stress. Demands for services continue to grow, as do waiting lists, and funding for wages and other costs have not kept pace with inflation (p. 14).

Similarly, in its *Annual Report* for 2001-2002, British Columbia's Ministry for Children and Family Development (2002, pp. 29-30) reported per person costs of about \$59,000 on average for adults in the 'community living' services system at the time. The numbers of people receiving such services had risen steadily since 1997. The *Annual Report* said, "A reduction in the average cost per client is essential to ensuring the

sustainability of the new system” (p. 29). When the *Annual Report* was written, wait lists had been a longstanding problem (Crawford, 2004).

Comparable problems have been reported for Alberta (Heemeryck, B. & Biersdorff, K., 2001).

Based on focus groups in Victoria, Ottawa, and Halifax and interviews with knowledgeable informants in all provinces except the northern territories, Beals et al. (2006) recently found significant unmet need for suitable housing for adults with intellectual disabilities across the country. That research found that the present ‘system’ seldom plans for a smooth transition from the family home to a more independent living environment. The gap is due to lack of funding for physical facilities and for disability-related personal supports. Often, individuals are housed where space is available, rather than in dwellings suited to their specific needs.

It is too early to tell whether major initiatives such as bilateral agreements between the federal government and the province/territories under the federal Affordable Housing Initiative (AHI) are making a positive difference in easing the shortage of housing within the developmental services sector.

Beginning in 2001, under the AHI the federal government, through the Canada Mortgage and Housing Corporation (CMHC), has provided contributions to increase the supply of off- reserve affordable housing, in partnership with each province and territory. Within the terms and conditions set out in the bilateral agreements, provincial and territorial housing agencies design their own housing programs and are responsible for program delivery, including the selection of housing projects that receive AHI funding (CMHC, 2008a).

The first phase of the AHI has been providing \$680 million for the creation of new rental housing, major renovation and conversion within the non-profit, private and public sectors (e.g. municipal non-profit housing corporations). Homeownership is

eligible in remote areas and in urban redevelopment areas, subject to a maximum funding amount.

The second phase of the AHI, announced in 2003, includes an additional federal commitment of \$320 million for housing for low-income households, i.e., households qualified to be on social housing waiting lists. Provinces and territories have been encouraged to consider Aboriginal people, persons with disabilities and recent immigrants as priorities.

Table 4 shows the amounts committed and/or announced up to December 2007.

Table 4. Affordable Housing Initiative					
Allocations and Progress as at December 31, 2007					
	Total (\$M)	Phase I Allocation (\$M)	Phase II Allocation (\$M)	Committed and / or Announced (\$M)	Committed and / or Announced (Units)
Newfoundland and Labrador	\$20.45	\$15.14	\$5.31	\$9.04	322
Prince Edward Island	\$4.16	\$2.75	\$1.41	\$2.95	120
Nova Scotia	\$28.09	\$18.63	\$9.46	\$20.26	947
New Brunswick	\$22.55	\$14.98	\$7.57	\$22.08	1,049
Quebec	\$236.51	\$161.65	\$74.86	\$231.34	8,831
Ontario	\$366.29	\$244.71	\$121.58	\$222.84	12,672
Manitoba	\$36.93	\$25.39	\$11.54	\$34.75	2,095
Saskatchewan	\$33.02	\$22.93	\$10.09	\$33.02	1,328
Alberta	\$98.62	\$67.12	\$31.50	\$98.62	3,683
Northwest Territories	\$7.95	\$7.54	\$0.41	\$7.95	297
Nunavut	\$5.25	\$4.96	\$0.29	\$5.25	212
Yukon	\$5.80	\$5.50	\$0.30	\$5.27	194
British Columbia	\$130.38	\$88.70	\$41.68	\$130.18	4,304
CMHC Overhead	\$4.00		\$4.00		
TOTAL	\$1,000.00	\$680.00	\$320.00	\$823.59	36,054

Source: Canada Mortgage and Housing Corporation (2008a).

B. Low Income and the High Cost of Housing on the Open Market

Another reason why people with intellectual disabilities are not moving into places beyond the family home is because they cannot afford to do so. The employment rate for people with intellectual disabilities is very low: 26.6% were employed when PALS 2001 was conducted compared with 71% for people without disabilities. Their employment earnings are quite low – in the \$10,000 to \$15,000 range. Nearly 70% of those with intellectual disabilities are not in the labour force, i.e., they are neither seeking nor available for employment. (Crawford 2008, in press; Crawford, 2005a)

More than one-third (36.9%) of people with intellectual disabilities were in low-income families in 2001, compared with 14.2% of adults without disabilities (Crawford, 2008, in press). These are people with total family incomes below Statistics Canada's 'low income cut-off', a widely used if unofficial measure of poverty. The low-income cut-off is defined as the income level below which families spend 20% more than the average family of similar size, in a similarly sized community, on food, shelter and clothing (Statistics Canada, 2006). Using PALS and its forerunner Health and Activity Limitation Survey of 1991 (HALS), the present research also found that about half of people with intellectual disabilities and not in the labour force were receiving social assistance in 1991 and 2001.³ However, social assistance is not keeping pace with rising shelter costs, making it difficult for people with intellectual disabilities to make the transition from their parents' home to greater independence.

Table 5 shows the maximum allowable social assistance (welfare) income for single persons with disabilities in Canada in 2005 and the average cost of housing across

³ Data on social assistance from Statistics Canada population surveys are somewhat imprecise owing to the tendency of survey respondents to under-report (Kapsalis, 2001). We have used 50% as a reasonable approximation. The remainder would have received financial support from family members and may have received some limited financial support from various other sources.

the provinces in 2006 (rental and owned). If living in the kinds of housing typically available to Canadians, average shelter costs alone would have consumed most and in some instances all of the allowable social assistance incomes of people with intellectual disabilities who relied on such income. The figures on Table 4 do not take into account the cost of utilities, furniture, food, clothing, other basic necessities and disability-specific costs.

Table 5. Average shelter costs for Canadians, and maximum social assistance incomes for persons with disabilities, by province, 2005 – 2006 *

	Average cost of shelter per household (rented and owned)	Average number of people per household	Average number of children at home	Average number of adults	Average cost of shelter per adult**	Maximum welfare rates for single persons with disabilities (2005) ***	Average housing per adult as % of welfare
Newfoundland	\$12,986	2.5	1.0	1.5	\$8,657	\$9,728	89.0%
Prince Edward Is.	\$9,966	2.5	1.1	1.4	\$7,119	\$8,084	88.1%
Nova Scotia	\$10,234	2.4	1.0	1.4	\$7,310	\$8,897	82.2%
New Brunswick	\$9,093	2.4	1.0	1.4	\$6,495	\$7,995	81.2%
Quebec	\$10,048	2.3	1.0	1.3	\$7,729	\$10,063	76.8%
Ontario	\$15,163	2.6	1.2	1.4	\$10,831	\$12,057	89.8%
Manitoba	\$10,176	2.5	1.2	1.3	\$7,828	\$8,601	91.0%
Saskatchewan	\$10,337	2.4	1.1	1.3	\$7,952	\$8,893	89.4%
Alberta	\$14,690	2.6	1.1	1.5	\$9,793	\$7,851	124.7%
British Columbia	\$14,521	2.5	1.0	1.5	\$9,681	\$10,656	90.8%

* Data were not available at Statistics Canada's website for average shelter costs in the northern territories.

** Figures in this column are based on the assumption that all adult household members pay for housing.

*** 2006 data on maximum welfare amounts were not available when the present research was conducted.

Sources: Statistics Canada (2008a; 2008b; 2008c); National Council on Welfare (Summer 2006).

It would be financially near to impossible for people with an intellectual disability who receive social assistance to live completely on their own in housing priced at 'average' levels. However, depending on the jurisdiction, social assistance may not encourage rent sharing; social assistance income may be lost or clawed back when people live together and share rent. Beals et al. (2006) have identified restrictive 'claw-back' provisions in disability income programs, including social assistance, as factors that effectively keep people with intellectual disabilities locked in poverty. Even where employed, with earnings in the \$10,000 to \$15,000 range on average, people with intellectual disabilities would have difficulty affording to live in 'average' housing.

C. Securing Needed Disability Supports *and* Housing

As discussed earlier in this report, PALS is likely picking up a fairly severely disabled segment of the population with intellectual disabilities. Accordingly, those captured by PALS are extensively reliant on help from others; some 86.4% of adults with intellectual disabilities require some level of personal assistance with one or more activities of everyday living. These activities include preparing meals, light or heavy housework, running appointments and errands, addressing personal finances (e.g., banking, paying bills), specialized nursing/medical support at home (e.g., for injections, therapy, blood, urine testing or catheter care) and moving about at home. Family members are involved in most cases as informal providers of support. Even then, unmet need is considerable: about a third (31%) of adults with intellectual disabilities needed more support with everyday activities than what they were receiving when PALS 2001 was conducted (Crawford, 2008, in press).

The most significant factor that accounts for unmet need for help in everyday activities for persons with disabilities is that the help is too expensive, which affects 48.4% who require more help than they receive. Lack of insurance coverage – another dimension of cost – is the next-most pervasive factor, affecting 24.8%.

D. Other Financial Issues

Beals et al. (2006) have identified several other financial issues that affect the ability of people with intellectual disabilities to move into housing where they would have greater independence from their families. These include:

- Estate planning regulations that make it difficult for parents to provide for their children without losses from taxation;
- Lending criteria that do not consider social assistance and other disability income support as assurance for mortgages;

-
- Municipal zoning policies and, it might be added, provincial laws and regulations, that can require prohibitively expensive institution-like features in group homes and other shared living arrangements.

As well, interpretation of zoning bylaws may deem even small, shared living arrangements to be ‘group homes’, which may be restricted in terms of the number permitted in a given area of a municipality (Tomalty & Cantwell, 2006).

VIII. What Are Some Typical Housing Options for People with Intellectual Disabilities?

Literature in the area of residential options for adults with intellectual disabilities is fraught with disparities in the terminologies used and the associated definitions. Similar terms are used in various parts of the world, but with considerably different meanings, which makes it difficult to compare findings across studies. Furthermore, a given residential option may have a range of characteristics that make a definition problematic even within in a given country. For example, life sharing (also referred to as shared care, adult foster care, and family model homes) can involve the person with an intellectual disability living with a family or a roommate. A variety of parties may provide support to the individual, i.e., the family, the roommate or another individual from beyond the home, such as a paid staff person. In addition, individuals in a life sharing situation may live in various places: in the home of the family or roommate; or in a jointly rented apartment or home; or in a home owned by the adult with the intellectual disability. This type of arrangement often has a minimum time commitment required of support providers, which also varies. Thus, any particular housing option may have many features.

Much of the existing literature on housing and intellectual disability centres on institutional and group home comparisons. Such research is of little value to jurisdictions such as British Columbia, which no longer operates institutions, or Ontario, which is moving quickly towards closing its largest facilities. Research on options beyond institutions and group homes is quite limited.

Stainton et al. (2006) have developed a useful typology and set of standardized definitions that can be used as a heuristic lens for looking at various housing options.

- The *Family Home/ Family Support* model involves providing the person with an intellectual disability various social supports within the context of the home that is

owned or rented and occupied by one or more of his/her family members, e.g., the parental home. Those who are paid to provide support are typically people other than family members, such as under the Special Services at Home program in Ontario. However, family members may in some instances receive such payments directly (e.g., in Nova Scotia under the Direct Family Support program).

This model – with or without the provision of supportive services in the family home to people with intellectual disabilities – is widely used in Canada; it is like the ‘default’ model. In some jurisdictions, out-of-family alternatives are made available only when health and safety issues have become so aggravated that it is clear that the family can no longer cope with the individual continuing to live in the family home (Crawford, 2004; Joint Developmental Services Sector Partnership Table, 2004). The present research does not provide an analysis of the strengths and limitations of this model because the focus of the research is on housing arrangements beyond the family home.

- The *Group Home* model provides both housing and support services to people with disabilities. Typically the place is a regular home in the community, although some have specialized modifications specific to disability (e.g., ramps; widened doorways and halls to meet fire codes and other regulations). Usually, support services are provided full-time to residents when they are physically present, e.g., after returning in the evening from a day program, employment centre or regular job in the community. Such homes can range in size up to 15 people and can be publicly or privately owned and operated (Hewitt & O’Neill, 1998). Historically in Canada, not-for-profit organizations have played a major role in operating group homes. Some research studies use slightly different definitions of ‘group home’.

Aside from the family home, group homes continue to dominate in terms of housing models in the field of developmental services. However, this ‘one size fits all’ approach for people with different levels of disability, diverse needs and unique personalities is being scrutinized; many consider it an unacceptable standard of care.

Emerson (2001) has found that small vs. larger group homes contribute to larger and more variegated social networks for residents. That said, inflexible schedules, high levels of staffing, concentration of power and control amongst staff, disputes and incompatibility between residents, lack of responsiveness to residents' changing needs and preferences, and low levels of personal choice and autonomy for residents regarding group activities and in other decisions persist in group homes, regardless of their size (Emerson et al., 2001; Emerson, 1999; Howe et al., 1998; Stancliffe & Lankin, 2005; Stancliffe & Keane, 2000).

- *Cluster Housing* has several variations. *Campus Type Living* involves individuals with intellectual disabilities living in close proximity to each other and forming a micro-community distinct from the surrounding community. It could be part of a campus development (three or more houses with an on-site day center) or a cluster of houses specifically for people with intellectual disabilities (Emerson, 2004). This type of living is the opposite of dispersed housing schemes. *Village Communities* "...typically consist of a cluster of living units and other resources (e.g., day centers, shops, churches) that are physically segregated from the local community. They often aim to provide an intentional community of attachment in which people with mental retardation can be supported and provide support to their peers" (Emerson et al., 2000, p. 83).⁴

Research in the U.K. has found that, compared with dispersed housing, cluster housing is associated with a poorer quality of care and a poorer quality of life (Emerson, et al., 2000). In cluster housing, people tend to live in larger settings, receive less staff support, experience greater changes and irregularity in living arrangements, are more exposed to restrictive management practices (i.e. seclusion, sedation), are more sedentary and more likely to experience restrictive leisure, social, and friendship activities. Financial costs, however, were found to be lower on average than in dispersed housing schemes (Emerson et al., 2000).

⁴ McConkey, Sowney, Milligan, and Barr (2004) use the term "cluster centres" to refer to "small institutions" (p. 420) that provide 24 hour support to 12 to 25 residents. This type of cluster setting is quite different than the cluster settings described in this report and is not presented as a desirable housing option.

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- *Semi-Independent Living Services* provide support to people with intellectual disabilities to live quite independently with a few hours of supportive services each week from paid staff. Support may be in the form of help with grocery shopping, paying bills or budgeting. Individuals receiving these services may live alone or with roommates in their own home or apartment (Hewitt & O’Neill, 1998).

A range of studies have shown that semi-independent living is a more cost-effective alternative to group homes and also yields more favourable outcomes in terms of personal control and choices (Emerson, et al., 2001; Emerson, 1999; Howe et al., 1998; Stancliffe, 2005; Stancliffe & Keane, 2000; Stancliffe & Lankin, 2004). Stancliffe and Keane (2000) found that, in comparison to people living semi-independently, group home residents did not obtain better scores on any measured outcomes and that, overall “most outcomes were similar, but where differences were evident they consistently favoured semi-independent participants” (Stancliffe & Keane, 2000, p. 298).

- *Supported Living* is a residential service model that is based on the provision of only those supports required by the individual who lives in their own home, with supports tailored to meet individual needs (Hewitt & O’Neill, 1998). Service eligibility is not dependent on the individual being able to live independently. The individual with an intellectual disability has control over their home through home ownership, rent or lease. The individual’s support needs are addressed separately from their housing needs; if the individual’s support needs change and an adjustment is required in a support service, the person does not have to move out of their home in order to secure such an adjustment. The support services are person centered, i.e., individualized, flexible and centered around personal strengths and abilities. Natural supports (family, friends, community members, non-paid support) are encouraged. Overall, personal choice and control is vested in the individual with the disability, not in the housing provider or residential service program (Allen, Shea & Associates, 2002; Howe, Horner, and Newton, 1998).

An evaluation that compared supported living with group homes found higher levels of social and community-based activities amongst people living in supported living arrangements and that the costs were no higher (Howe et al., 1998). Although that research was criticized for its design limitations (Emerson, 2001), it found that people in supported living arrangements lived with fewer housemates on average, were better matched in terms of compatibility, had more personal attention from support staff, were more likely to be owners of their dwellings or to have their own names on rental agreements, had their personal preferences taken into account in support arrangements, made the decisions about their daily affairs and did not have to meet behavioural or other conditions in order to receive service (Howe et al.). Emerson et al. (2001) subsequently found much the same in the United Kingdom in terms of comparative benefits of supported living vs. group homes.

- The *Family Model Home/ Life Sharing/ Host Family/ Adult Foster Care* model involves a home owned or rented and occupied by an individual or family, in which they provide paid care and support for one or more unrelated persons with an intellectual disability (Bruininks, Byun, Coucouvanis, Lakin, Larson, and Prouty, 2005).

Although this model of housing has been used for many years, there has not been much research into it. The limited research indicates that adults who previously resided in institutions or group homes and have been placed in life sharing settings are experiencing positive changes (Walling et al., 2000).

This model is a major component of the restructuring of residential supports for people with intellectual disabilities in British Columbia. However, concerns have been raised about the safety and well-being of adults in such settings and the need for clearer, more systematic monitoring of outcomes has been flagged (Stainton et al., 2008).

Boarding House with Supervision. Not mentioned by Stainton et al. (2006), Beals et al. (2006) have defined boarding houses with supervision as 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 in such places, despite the fact that these facilities tend to be for people with severe disabilities.

Potential advantages are personal independence and empowerment, freedom of movement the availability of privacy and social involvement. Meals are provided and the environment may be friendly and caring.

While it is a relatively low cost option, there are drawbacks. One is that the model would seem quite antithetical to the desire of people with intellectual disabilities and their families for places to live other than large congregate care arrangements. Other pitfalls that have been identified (Beals et al., 2006) are the potential for incompatibility of residents and for the needed supports to be lacking. There is a risk of social isolation and loneliness and individuals may be vulnerable to exploitation and abuses by supervisors and other residents. The individual would have little control over who visits other residents and the physical place may be in need of repair.

IX. What Kinds of Housing do Canadians Want?

A. Meeting CMHC's Basic Requirements

The Canada Mortgage and Housing Corporation (CMHC) has articulated basic standards of housing for Canadians that draw from standards in place at the provincial/territorial level and from other criteria.

CMHC defines a dwelling as 'acceptable' when it meets three key criteria: it is *adequate* in condition, *suitable* in size and *affordable* in cost. Where a household's dwelling fails to meet those criteria, CMHC deems that household to be in *core housing need* (Canada Mortgage and Housing Corporation, 2008b).

1. Adequacy

CMHC defines housing as in *adequate* condition when it does not require major repairs to electrical or plumbing systems, or major structural repairs to walls, floors or ceilings. Recent research conducted for Human Resources and Social Development Canada (Crawford, 2008, in press) found that people with a disability are more likely than those without disabilities to live in inadequate housing (10.5% compared with 7.2%), all the more so if they have learning difficulties inclusive of intellectual disability (14.6%).

2. Suitability

CMHC deems a dwelling *suitable* in size when it when it adheres to the standards set by the National Occupancy Standard (NOS). The NOS was developed to encompass the common elements of provincial/territorial housing standards, and in this sense is politically acceptable to Canadians.

The NOS allows that a one-person household can occupy a bachelor unit. However, where two or more people live together in the same household, the NOS requires one bedroom for:

- Cohabiting adult couples;
- Same-sex pairs of children under age 18 and for each additional boy or girl, unless there are two opposite sex siblings under age 5, in which case, they can share a bedroom; and
- ‘Unattached’ household members 18 years old or older, i.e., household members not related to other household members by ties of kinship, such boarders.

3. Affordability

In order for housing to meet CMHC’s ‘*affordability*’ criterion, households must be able to pay for the following with less than 30% of total before-tax household income:

Renters – rent plus any payments for electricity, fuel, water and other municipal services;

Owners – mortgage payments (principal and interest), property taxes, and any condominium fees, plus payments for electricity, fuel, water and other municipal services.

4. Core Housing Need

CMHC defines a household as in *core housing need* if:

- Its dwelling falls below one or more of the adequacy, suitability, or affordability housing standards, and
- It would have to spend 30% or more of before tax household income to pay the median rent of alternative market housing that meets all three ‘acceptability’ housing standards.

X. What Kinds of Housing Should be Available to Canadians with Intellectual Disabilities?

A. Adequate, Suitable and Affordable

The present report takes it as axiomatic that people with any disability should be accorded the same rights and privileges as other citizens. In this regard, CMHC's basic housing standards that should apply for Canadians ought to apply for people with disabilities: their housing should be adequate, suitable and affordable.

In addition, it should be accessible, should be linked to and facilitate availability of the necessary supports that people may need because of disability, and should foster social inclusion.

B. Accessible

CMHC-sponsored research is being conducted based on PALS concerning the specific housing requirements of people with various disabilities. This research is slated for completion before April 2009 and will include a focus on people with intellectual disabilities. That said, there are particular housing considerations that depend on the nature of a person's disability. For example, a person with mobility impairments may require accessible entrances and more turn around room in bathrooms than a person without such a disability. He or she may need a lift to get from one floor to the next, lowered counters and a range of other accessibility features. A person with a seeing impairment may need audio warning devices or tactile signage, for example, in the elevator if s/he lives in an apartment complex. A person who is deaf may need visual alarms. Essentially, the person's dwelling should be fully accessible. Many people with intellectual disabilities have additional disabilities as well. The physical accessibility of dwellings can be a significant issue for such individuals.

For example, more than two-thirds of people with learning difficulties inclusive of intellectual disabilities also have disabilities in the areas of mobility or agility. Not surprisingly, then, a significant number of people in this group (more than 70,000) have or need one or more modifications to their personal residences to ensure physical accessibility.

C. With Disability Supports as Required per ‘In Unison’

People with intellectual disabilities may need further measures. As discussed earlier in this report, many are reliant on assistance from others in everyday activities and would need such assistance wherever they live. Yet, as Beals et al. (2006) have found, they typically want to live as independently as possible, to make choices about where and with whom they live and want to have major ‘say’ and choices with respect to the supportive services they receive. Those services should be flexible and portable, which requires that the service funding be de-linked from funding for physical dwelling places.

The federal/provincial/territorial (FPT) accord on disability – *In Unison* – lays out some criteria for disability supports that continue to be widely endorsed by Canadians with disabilities. These include that the supports should be portable, more widely accessible, de-linked in terms of eligibility from income and other programs, should provide greater assistance with costs, should be flexible and responsive to need, and should accord individuals consumer control (Federal/Provincial/Territorial Ministers Responsible for Social Services, 1998). In that leaders within the disability community have already agreed to such principles and policy directions – helped set them actually, those would ideally be brought to bear more systematically on the supportive services that people with intellectual disabilities require wherever they are living so they can live more independently.

D. Facilitating Social Inclusion

People with intellectual disabilities should be able to live in housing that, as would typically be sought out by most other people, facilitates their social inclusion.

That is, they should not find themselves disproportionately in living arrangements that, as a result of the physical features of their housing or its location, stigmatize them or marginalize them from the mainstream of the social, cultural or economic life of their community (Wolfensberger, 1972). Instead, their housing should support their participation as valued, appreciated equals in the social, economic, political and cultural life of their community, and should enable them to be involved in mutually trusting, appreciative and respectful interpersonal relationships at the family, peer and community levels (Crawford, 2003).

XI. Summary and Conclusion

This report has looked at housing issues for people with intellectual disabilities who comprise, conservatively, about a quarter million Canadians – probably more. The report has showed that they are disproportionately more likely than Canadian adults without disabilities to be living as never married adult ‘children’ with one or both parents, or alone or with others with whom they do not share ties of kinship. If people with intellectual disabilities were to be living beyond their family (parental) home at the same rate as non-disabled Canadians, somewhere around 50,000 more would have their own places or, at the very least, would be living with others with whom they are compatible.

Factors that help account for why they are not moving to their own places include a supply ‘crunch’ within the developmental services residential system; the formal residential services system for people with intellectual disabilities has simply not kept pace with increasing demand in recent years. Other factors include the high cost of housing on the open market and the low incomes of people with intellectual disabilities, difficulties securing the needed supports for disability beyond the family home and other issues of a financial nature. Presently, people with intellectual disabilities are more likely than people without disabilities to be living in places that are rented rather than owned and more likely to be living in places that need major repairs.

The report described several non-institutional housing models that are typically presented to people with intellectual disabilities: group homes, cluster housing, ‘life sharing’, semi-independent living, supported living and supervised boarding homes. Group homes and cluster housing present significant disadvantages in terms of community inclusion, choices and personal control. Supervised boarding homes are large institution-like arrangements and present risks of various harms. Life sharing is increasingly used in some jurisdictions, yet little research has been conducted on this model and it, too, presents some risks.

While no model is risk free, it would seem that semi-independent living and supported living hold strong promise of meeting the housing needs of people with intellectual disabilities in ways that are cost-effective and in keeping with their aspirations for independence, personal control and for having major ‘say’ about which supportive services they will receive at home and how these will be provided.

The paper makes the case that efforts to develop more housing to meet the needs of people with intellectual disabilities should be informed by six key principles. The first three are those that the Canada Mortgage and Housing Corporation, drawing in part from provincial/territorial standards, has set as basic standards for Canadians in general: housing should be adequate, suitable for the number of people who live in the household and affordable.

Three further principles are that the housing should:

- Be accessible for people who require modifications for mobility, seeing or hearing;
- Be linked with disability supports but distinct from disability supports that would be provided in ways consistent with the principles and policy directions laid out in the FPT accord, *In Unison*, i.e., the supports should be individualized, flexible, responsive to need and portable; and
- Should facilitate social inclusion rather than reinforcing stigma and marginalization.

Unless and until more such housing and supportive arrangements come on stream, too many families will continue to be responsible for providing housing and social support far past the time when most people leave the parental home and establish homes of their own. And until such a time, too few people with intellectual disabilities will have places that they can call homes of their own.

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