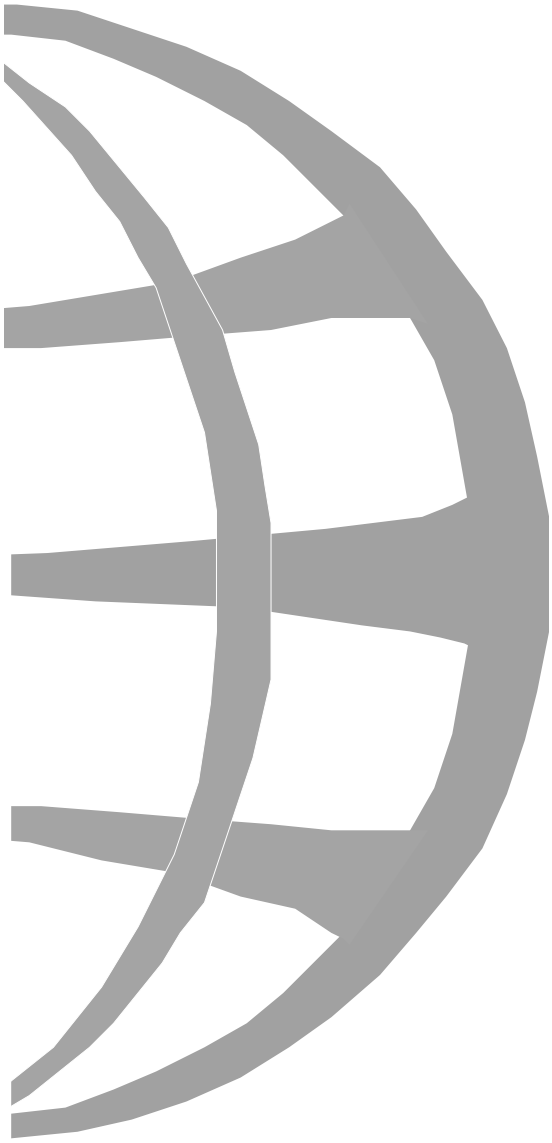

Mixed Progress in Closing Institutions: Patterns in the Use of Residential Care Facilities for Canadians with Intellectual Disabilities

(Technical Paper)

L'Institut Roeher Institute
Researched and written by
Cameron Crawford

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About The Roeher Institute

The Roeher Institute is a leading policy-research and development organization. Its mission is to generate knowledge, information and skills to secure the inclusion, citizenship, human rights and equality of people with intellectual and other disabilities. It's research spans many areas: education, learning and literacy; income security and employment; disability supports; supports for children and families; values and ethics; community/social inclusion; health and well-being; and personal safety and security. Roeher has conducted research for federal and provincial governments, international organizations and non-governmental organizations in the voluntary and private sectors.

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Contents

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Overview

This report shows the numbers of people living in residential care facilities for people classified by Statistics Canada as “developmentally delayed”.

The purpose of the report is to answer whether and to what extent progress has been achieved over the years in enabling people with intellectual disabilities to take up residence in small living arrangements instead of large congregate care facilities. In other words, has the deinstitutionalization movement in Canada benefited people with intellectual disabilities over the past couple of decades, and if so, to what extent?

The report answers that question by drawing from administrative data that show general numbers and trends across facilities of various sizes from the mid-1980s up to 2002.

Overall we found that the entire ‘system’ of group homes and other facilities that serve 4 or more people with intellectual disabilities actually serves about 4,000 fewer people now than in the mid-1980s. Within that smaller system:

- Places with 4 to 9 people are more commonly used of late than in the mid-1980s, but nowhere near as commonly as in the early 1990s.

- There are far fewer facilities with 100 or more residents, fewer people and a lower percentage of people living in such places.

- There has been a significant increase in the percentages and numbers of people living in places that serve from 20 to 49 people and from 50 to 99 people. The numbers of facilities this size also increased across the reference years. Patterns vary somewhat by region of the country.

Given that this is a technical report and not a policy analysis, the report does not explain in detail the factors that account for the numbers and trends reported. However, the report does raise a few questions and presents a few reasoned hypotheses that point towards further research that may be warranted for people seeking a fuller understanding.

The Roeher Institute thanks Dr. Michael Prince (Acting Dean and Lansdowne Professor of Social Policy, Faculty of Human and Social Development, University of Victoria) and Dr. John Rietschlin (Manager, Knowledge Development, Office for Disability Issues, Department of Social Development Canada) for their helpful and detailed input to drafts of this report

Notes on Method

Years Covered

This report explores a span of about fifteen years in selected intervals from fiscal 1986-1987 through 2001-2002.

Data Sources

Data on residential care facilities for fiscal years 2000-2001 and 2001-2002 are from a custom retrieval of raw data that The Roeher Institute requested from Statistics Canada based on the latter organization's *Survey of Residential Care Facilities.* Figures for previous years (1986-1987, 1990-1991 and 1992-1993) are from published reports by Statistics Canada (1989, 1993 and 1994).

We have also used some data on people with intellectual disabilities from the Participation and Activity Limitation Survey (PALS) of 2001 and from the Health and Activity Limitation Survey (HALS) of 1991. These are large Statistics

Canada surveys that provide a wealth of information on the social and economic situations of people with disabilities.

Principles of Selection

The data presented in this report do not include Quebec. Those data are not available because, to date, Quebec has not reported to Statistics Canada on residential care facilities for people classified as developmentally delayed.

The selected reference years were chosen because:

a) The Roeher Institute has been receiving requests for information on the numbers of people living in various sized facilities. The 2001-2002 data were the most recent available from Statistics Canada when this report was written;

b) 1986-1987 corresponds roughly with the early days of a major drive of the Canadian Association for Community Living and its provincial / territorial affiliates to assist people living in large institutions to return to their communities and take up smaller, more personalized living arrangements, there. We took that year as a baseline;[1]

c) Leaving aside 1996, for which no published information is available on Residential Care Facilities for people with intellectual disabilities, the years explored correspond with years in which the Census was conducted and in which Statistics Canada conducted major disability surveys (1986, 1991, 2001)[2]. Roeher considered that other researchers might perhaps be

[1] Deinstitutionalization was a major objective in Canadian Association for Community Living (1985). *Community Living 2000*. Toronto: Author. Several member organizations within the community living federation had been pursuing institutional closures before 1985.
[2] These were the Health and Activity Limitation Surveys of 1986 and 1991 and the Participation and Activity Limitation Survey of 2001.

able to find linkages between data provided in this report and other data stemming from the disability surveys of those years.

d) Roeher was concerned that the available data for any given year in isolation might involve anomalies of reporting and other data quality issues. Accordingly, we included two adjacent reporting years for the fiscal years around the major Statistics Canada disability surveys of 1991 and 2001. We did not have that luxury for 1986 –1987 as we did not have the published data on either side of that fiscal year and those early reports are difficult to obtain.

e) Published *Residential Care Facilities* reports by Statistics Canada with information about facilities for people classified as "developmentally delayed" have been infrequent; Statistics Canada discontinued the series of publications with this information in 1994. As Roeher had documents for fiscal years 1986-1987, 1990-1991 and 1992-1993,[3] and obtaining data for the years beyond 1993 to 2000 would have involved further custom retrievals from Statistics Canada and potential costs, convenience and costs were factors in the selection of reference years; and

f) Roeher did not consider that it would have been particularly useful to seek out further material. General trends seemed clear enough on the basis of the information that we have used.

Definition of Residential Care Facilities

Statistics Canada (2005a) 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

[3] Roeher also had data for some years before 1986-97. However, we decided not to extend the research backwards to before 1986 as this would have involved more time and resources than Roeher had available to complete the present research.

> 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 to, for example, 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.
>
> The other categories of residential care facilities provide shelter for a shorter period of time, often combined with a program of service.

'Group homes' and larger congregate care arrangements for people with intellectual disabilities would typically fall within the class of residential care facilities.

'Developmental Delay' and Intellectual Disability

Statistics Canada classifies facilities by principal characteristics of residents at March 31 of the reporting year. The term "developmentally delayed" is one of several such descriptors in the *Residential Care Facilities Survey* (2001). Statistics Canada does not define the term in the survey.

We take the term to connote people who have been variously classified as having a developmental disability, developmental delay, mental handicap, or (less acceptable in most jurisdictions except the United States) 'mental retardation'.

Internationally the term 'intellectual disability' is now widely used and is a term that people so identified tend to find more acceptable than previous descriptors. Accordingly, 'intellectual disability' is used throughout the body of this report.

See Appendix 3 for more detailed information on intellectual disability.

In the Appendix Tables we use the term ‘developmental delay’ to keep the terminology consistent with that used by Statistics Canada in the data supplied for this research.

Estimates of Numbers of Residents

In any given year, the total number of residential care facilities may exceed the number of facilities that actually report to Statistics Canada. Accordingly, the actual number of people with intellectual disabilities living in such facilities can be more than the number of people reported.

We estimated the number of people residing in non-reporting facilities. To do so we calculated occupancy rates for facilities of various sizes.

The occupancy rate is defined as the total number of people living in reporting facilities of a given size divided by the total number of approved beds in those facilities.

The occupancy rates for various sized facilities were then multiplied by the number of beds in non-reporting facilities to yield estimates of the numbers of people likely residing in non-reporting facilities. Appendix Tables 1 – 5 show the detailed figures.

Approaches to Occupancy Rates

Occupancy rates shown on Appendix Tables 3 – 5 are a little different than those shown in Statistics Canada publications (1989, 1993 and 1994).

Statistics Canada seems to have taken the total number of resident days in facilities for people with intellectual disabilities and divided by 365 (366 in leap years) to produce estimated numbers of people with intellectual disabilities residing in facilities of various sizes. Statistics Canada then took those numbers and divided by the number of *staffed* beds in facilities for people with intellectual disabilities to yield the percentage occupancy for reporting facilities of various sizes.

The present report used the number of people with intellectual disabilities "on the books" on March 31 in facilities of various sizes in a given reporting year. We calculated occupancy rates by dividing the numbers of people on the books by the total numbers of *approved* beds in reporting facilities of various sizes.

Because residential care facilities tend to operate near to maximum capacity (i.e., most approved beds are staffed and in operation), the total estimated numbers of people residing in non-reporting facilities are similar using both approaches to calculating occupancy rates.

Facility Size

The size of facility is defined as its number of beds. Statistics Canada has grouped the data (e.g., 4 to 9 beds, 10 to 19 beds and so on).

Grouping of Data for Large Facilities

In the Statistics Canada publication on residential care facilities for fiscal 1986-1987, no figures were provided for facilities with more than 200 beds. Instead, Statistics Canada used “100 +” as the upper limit for facility size. Later data were available for facilities with 100 to 199 beds and 200 or more beds.

For the sake of simplicity and comparability across reference years, we have grouped figures for facilities with 100 or more beds, but provide break out figures for large facilities where these seemed useful.

Results

Tables 1 – 6 are summary tables based on Appendix Tables 1 – 5. The reader is encouraged to consult the Appendix Tables for fuller details.

Number of Facilities

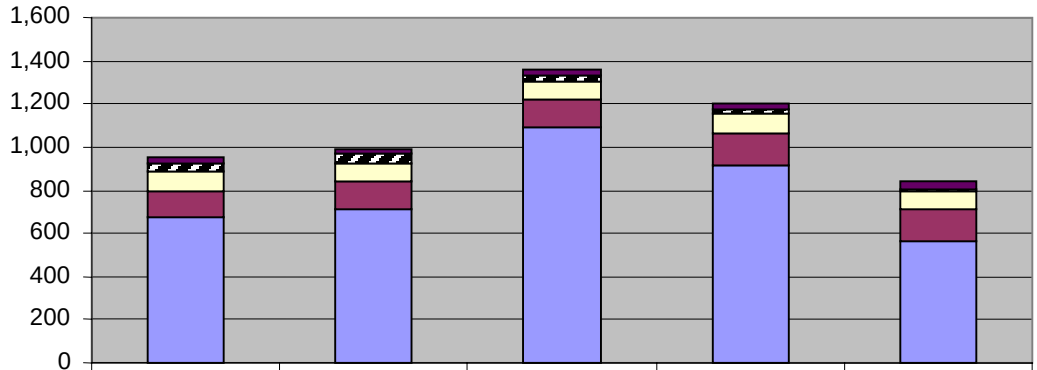
Table 1 shows that overall there has been an increase since 1986-1987 in the number of residential care facilities for people with intellectual disabilities, rising from 840 to 948. A period of significant growth occurred from 1986 through 1993. Figures for more recent years suggest a downward trend since the early 1990s.

Table 1. Numbers of residential care facilities for people with intellectual disabilities, by facility size, in selected years

Facility size (number of beds)	**2001-2002**	**2000-2001**	**1992-1993**	**1990-1991**	**1986-1987**
4 to 9	679	709	1,088	918	562
10 to 19	119	129	132	145	151
20 to 49	87	90	86	89	79
50 to 99	44	46	26	24	17
100 +	19	19	27	28	31
Total	948	993	1,359	1,204	840
100 to 199	10	10	16	14	
200+	9	9	11	14	

Chart 1 shows the patterns based on Table 1.

Chart 1. Numbers of residential care facilities for people with intellectual disabilities, by facility size, in selected years



	2001-2002	2000-2001	1992-1993	1990-1991	1986-1987
100 +	19	19	27	28	31
50 to 99	44	46	26	24	17
20 to 49	87	90	86	89	79
10 to 19	119	129	132	145	151
4 to 9	679	709	1,088	918	562

Trends in Facility Size

Table 2 shows that there was a sharp upward shift in the proportion of facilities with 4 to 9 beds (rising from 67% to 80%) from 1986 to 1993. However, after the year 2000 such facilities comprised only 71% to 72%.

Table 2. Percentage distribution of residential care facilities for people with intellectual disabilities, by facility size, in selected years

Facility size (number of beds)	**2001-2002**	**2000-2001**	**1992-1993**	**1990-1991**	**1986-1987**
4 to 9	72%	71%	80%	76%	67%
10 to 19	13%	13%	10%	12%	18%
20 to 49	9%	9%	6%	7%	9%
50 to 99	5%	5%	2%	2%	2%
100 +	2%	2%	2%	2%	4%
Total	100%	100%	100%	100%	100%
100 to 199	1%	1%	1%	1%	
200+	1%	1%	1%	1%	

There was a sharp downward shift in the proportion of facilities with 10 to 19 beds (from 18% to 10%) from 1986 to 1993. After the year 2000 the percentage of facilities this size rose to 13% (Table 2).

There was a modest downward shift in the proportion of facilities with 20 to 49 beds from 1986 through 1993, after which the proportion returned to comprise 9% (Table 2).

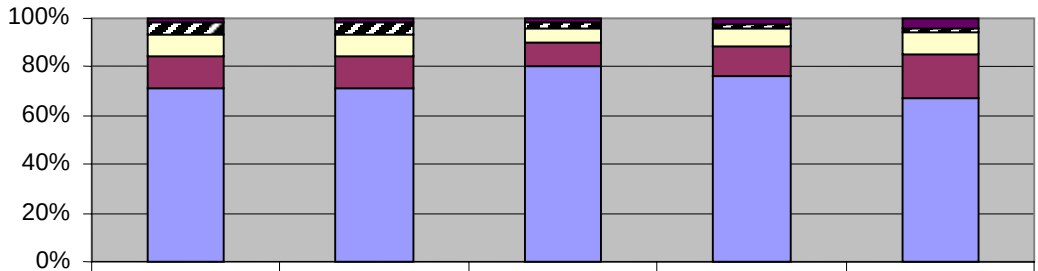
Facilities with 50 to 99 beds made up a larger proportion of residential care facilities in recent years than before 1994 (5% compared with 2%).

The figures for facilities with fewer than 20 beds reveal clear trends towards smaller facilities from 1986 to 1993, then a reversal of direction somewhere after 1993. Having said this, facilities with 4 to 9 beds comprised a greater share of all facilities for people with intellectual disabilities in 2001-2002 than was the case in 1986-1987.

Large facilities with 100 or more beds decreased from 4% in 1986-1987 to 2% from 1990 afterwards. Large facilities with 100 to 199 beds and 200 or more beds have held constant since 1990, each comprising 1% of all residential care facilities for people with intellectual disabilities.

Chart 2 shows the patterns based on Table 2.

Chart 2. Percentage distributions of residential care facilities for people with intellectual disabilities, by size of facility, in selected years



	2001-2002	2000-2001	1992-1993	1990-1991	1986-1987
100 +	2%	2%	2%	2%	4%
50 to 99	5%	5%	2%	2%	2%
20 to 49	9%	9%	6%	7%	9%
10 to 19	13%	13%	10%	12%	18%
4 to 9	72%	71%	80%	76%	67%

Numbers of People Overall

Tables 3 and 4 show the numbers of people living in various sized facilities for people with intellectual disabilities. Fewer people are in the residential system with 4 or more beds (14,623 people in 2001-2002 compared with 18,780 people in 1986-1987).

Table 3. Numbers of people in residential care facilities for people with intellectual disabilities, by facility size, in selected years

Facility size (number of beds)	**2001-2002**	**2000-2001**	**1992-1993**	**1990-1991**	**1986-1987**
4 to 9	3,325	3,492	5,720	4,951	3,398
10 to 19	1,472	1,555	1,606	1,796	1,851
20 to 49	2,843	2,419	2,588	2,664	2,284
50 to 99	2,203	2,636	1,622	1,492	993
100 to 199	1,388	1,340	1,912	1,582	
100 +					10,254
200 +	3,393	3,418	5,810	6,703	0
Total	14,623	14,861	19,258	19,187	18,780

Table 4. Numbers of people in residential care facilities for people with intellectual disabilities, by facility size, in selected years

Facility size (number of beds)	2001-2002	2000-2001	1992-1993	1990-1991	1986-1987
4 to 9	3,325	3,492	5,720	4,951	3,398
10 to 19	1,472	1,555	1,606	1,796	1,851
20 to 49	2,843	2,419	2,588	2,664	2,284
50 to 99	2,203	2,636	1,622	1,492	993
100 +	4,780	4,758	7,722	8,285	10,254
Total	14,623	14,861	19,258	19,187	18,780
Total 10 beds +	11,298	11,369	13,538	14,237	15,381

Numbers and Percentages of People by Size of Facility

The proportion of facilities with 4 to 9 beds has increased over the years (Table 2). So has the proportion of people living in such arrangements. In 2001-2002, 23% of people in residential care facilities for people with intellectual disabilities were in 4 to 9 bed arrangements compared with 18% in 1986-1987 (Table 5).

The number of people in facilities with 4 to 9 beds nearly doubled from 1986 to 1993 (from 3,398 to 5,720 people), then reverted to levels similar to 1986 (Table 4).

Table 5. Percentages of people in residential care facilities for people with intellectual disabilities, by facility size, in selected years

Facility size (number of beds)	2001-2002	2000-2001	1992-1993	1990-1991	1986-1987
4 to 9	23%	24%	30%	26%	18%
10 to 19	10%	10%	8%	9%	10%
20 to 49	19%	16%	13%	14%	12%
50 to 99	15%	18%	8%	8%	5%
100 +	33%	32%	40%	43%	55%
Total	100%	100%	100%	100%	100%
Total 10 beds +	77%	76%	70%	74%	82%

While the proportion of facilities with 20 to 49 beds was 9% in 1986-1987 and again in 2001-2002 after some fluctuations in intervening years (Table 2),

the proportion of people living in such arrangements increased overall from 12% to 19% (Table 5).

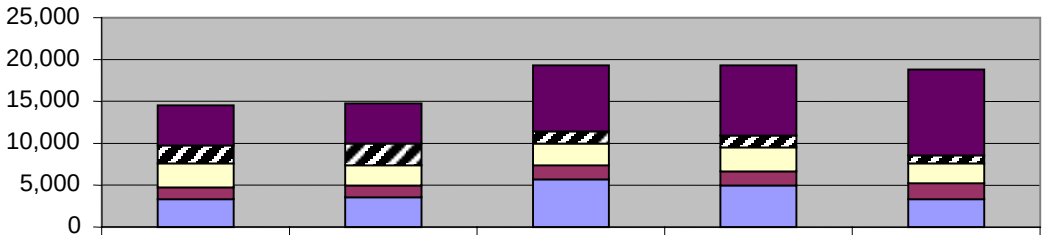
The percentage of people living in facilities with 50 to 99 beds also increased, from 5% in 1986-1987 to 15% in 2001-2002 (Table 5). The percentage of facilities this size rose from 2% to 5% of all facilities for people with intellectual disabilities (Table 2). The number of people living in facilities this size more than doubled, increasing from 993 to 2,203 (Table 4).

The percentage of people living in large facilities with 100 or more beds decreased, from 55% in 1986 to 33% in 2002 (Table 5). The number of people shrank by more than half, decreasing from 10,254 to 4,780 people (Table 4).

Subtracting the percentage of people in facilities with 1 to 9 beds from 100%, Table 5 shows that the percentage of people living in facilities with 10 or more beds dropped from 82% in 1986 to 70% in 1992 then rose to between 76% and 77% more recently.

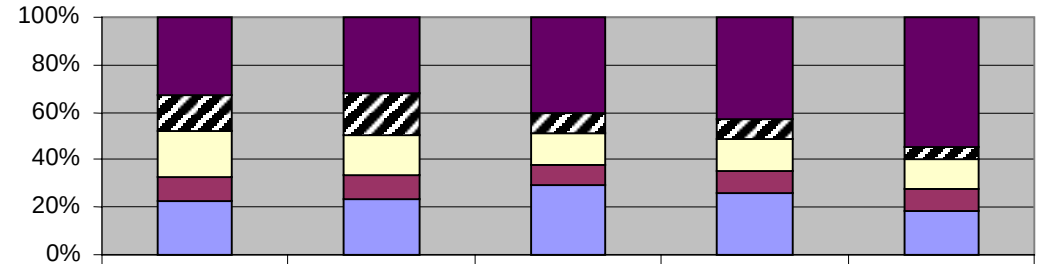
Charts 3 and 4 show the patterns based on Tables 4 and 5.

Chart 3. Numbers of people in residential care facilities for people with intellectual disabilities, by facility size, in selected years



	2001-2002	2000-2001	1992-1993	1990-1991	1986-1987
100 +	4,780	4,758	7,722	8,285	10,254
50 to 99	2,203	2,636	1,622	1,492	993
20 to 49	2,843	2,419	2,588	2,664	2,284
10 to 19	1,472	1,555	1,606	1,796	1,851
4 to 9	3,325	3,492	5,720	4,951	3,398

Chart 4. Percentage distributions of people in residential care facilities for people with intellectual disabilities, by facility size, in selected years



	2001-2002	2000-2001	1992-1993	1990-1991	1986-1987
100 +	33%	32%	40%	43%	55%
50 to 99	15%	18%	8%	8%	5%
20 to 49	19%	16%	13%	14%	12%
10 to 19	10%	10%	8%	9%	10%
4 to 9	23%	24%	30%	26%	18%

Density of Living Arrangements

Table 6 shows the average number of people per various sized residential care facility for people with intellectual disabilities.

Table 6. Average numbers of people in residential care facilities for people with intellectual disabilities, by facility size, in selected years

Facility size (number of beds)	**2001-2002**	**2000-2001**	**1992-1993**	**1990-1991**	**1986-1987**
4 to 9	4.9	4.9	5.3	5.4	6.0
10 to 19	12.4	12.1	12.2	12.4	12.3
20 to 49	32.7	26.9	30.1	29.9	28.9
50 to 99	50.1	57.3	62.4	62.2	58.4
100 +	251.6	250.4	286.0	295.9	330.8
Average	15.4	15.0	14.2	15.9	22.4

The table shows a reduction over the years in the average number of people in facilities with 4 to 9 beds. Here, the average dropped from 6 to 4.9 people from 1986 to 2002 (Table 6).

There was little change in the average number of people living in facilities with 10 to19 beds: about 12 people on average across the reference years (Table 6).

The average number of people living in places with 20 to 49 beds increased, with some fluctuations, from 28.9 to 32.7 people between 1986 and 2002 (Table 6).

In contrast, there was a decrease in the average number of people with intellectual disabilities living in residential care facilities with 50 to 99 beds, declining from 58.4 to 50.1 people on average over the reference years and tracking generally downwards after 1992-1993 (Table 6).

The numbers of people with intellectual disabilities living in large facilities with 100 or more beds tracked downwards from 1986 to 2002, declining from 330.8 to 251.6 people on average (Table 6).

The average number of people living in *all* residential care facilities (irrespective of size) for people with intellectual disabilities dropped from 22.4 to 14.2 from 1986 to 1993 then rose to 15.4 people more recently (Table 6).

That finding suggests a reversion to higher density living arrangements in residential care facilities for people with intellectual disabilities, especially in facilities with 20 to 49 beds.

Appendix Table 1 shows that the occupancy rate in reporting facilities with 20 to 49 beds exceeded 100% in fiscal 2001-2002, suggesting demand for service that exceeded service availability and high density of people with intellectual disabilities living in facilities of this size.

Regional Patterns

Appendix Charts A1 – A6 show regional patterns. Chart A1 shows that British Columbia/Territories[4] and Ontario have similar numbers of residential care facilities even though Ontario has nearly three times the household population. British Columbia/Territories has more facilities than Ontario with 4 to 9 beds (226 compared with 174 in 2001-2002).

In all regions shown on Chart A2 there were increases in the numbers of facilities with 4 to 9 beds from 1986 to 1993, then a decrease after that year. In all regions except Ontario, the number of facilities this size was greater in 2001-2002 than in 1986-1987. In Ontario there were only 174 facilities this size in 2001-2002 compared with 248 in 1986-1987. In contrast, in British Columbia/Territories, there were more than twice as many facilities this size in 2001-2002 as in 1986-1987 (226 compared with 109).

[4] Owing to very small numbers of facilities and residents in the Yukon, Northwest Territories and Nunavut, Statistics Canada collapsed those data into a single group with data for British Columbia. Statistics Canada also collapsed the data for Alberta, Saskatchewan and Manitoba into one group representing the Prairies.

Chart A6 shows that the number of large facilities with 100 or more beds decreased in Ontario (from 20 to 12) over the reference years. There was also a decrease in the Prairies in the numbers of very large facilities between 1986 and 1993 (from 8 to 4), after which the number has held constant. In the Maritimes there was an increase from 2 to 4 large facilities from 1986 to 1993, then a decrease to 3 facilities. A similar pattern occurred in British Columbia/Territories, except that there are no longer any facilities with 100 or more beds in operation, there.

Charts A3 – A 5 present a more complicated story for facilities with 10 to 99 beds.

- In the Maritimes there have been increases in the numbers of facilities with 10 to 19 beds, 20 to 49 beds and 50 to 99 beds.

- In Ontario there were decreases in the numbers of facilities with 10 to 19 beds and 20 to 49 beds, but a significant increase in the number of facilities with 50 to 99 beds.

- In the Prairies there has been a decrease in the number of facilities with 10 to 19 beds. In contrast there have been increases in the in the numbers of facilities with 20 to 49 beds and 50 to 99 beds.

- The picture in British Columbia/Territories shows less change, with slight overall growth in the number of facilities with 50 to 99 beds and slight decreases in the numbers of facilities with 10 to 19 beds and 20 to 49 beds.

Looking at the trends from 1992-1993 to 2001-2003, Ontario has used more facilities with 50 to 99 beds and fewer of facilities of other sizes. The Maritimes have used more facilities with 10 to 49 beds and fewer facilities of other sizes. The Prairies have used more facilities with 20 to 99 beds, the same

number of facilities with 4 to 9 beds and of large facilities with 100 or more beds, and fewer facilities of other sizes. British Columbia has used slightly more facilities with 50 to 99 beds, the same number of facilities with 20 to 49 beds and slightly fewer facilities of other sizes.

Table 7 shows the regional trends from 1992-1993 to 2001-2002.

Table 7. Overall increase (+), decrease (–) or no change (nc) in the numbers of residential care facilities from 1992 to 2002, by size of facility and region

Facility Size (Number of Beds)	Maritimes	Ontario	Prairies	BC and Territories
100+	–	–	nc	–
50 to 99	–	+	+	+
20 to 49	+	–	+	nc
10 to 19	+	–	–	–
4 to 9	–	–	nc	–

Accounting for the Trends

The data from Statistics Canada do not in themselves tell us whether fewer people are actually receiving residential supports now than previously. In part this is because Statistics Canada's figures do not shed light on the numbers of people residing in provincially/territorially licensed, funded or regulated situations with fewer than 4 beds; the *Residential Care Facilities Survey* does not gather data concerning people in those situations. It is known anecdotally, however, that people with intellectual disabilities and their families have been striving to achieve small living arrangements with 3 and fewer people in recent years.

Other information suggests that the residential system as a whole for people with developmental 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. As the average was based on total costs for adult community living services divided by the total number of open files, i.e., people receiving residential services or day programs (pp. 12 and 29), the average per person cost of residential services would have been even higher.[5] 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).

In research recently conducted by The Roeher Institute (Crawford, 2004), some people who were interviewed characterized the 1980s and early 1990s as an "era of plenty" for the community living sector. In part the plenty was the result of funding that governments were refocusing from institutional care to the expansion of community support options. As institutions closed, however, there were no further public funds to shift from institutions to the community.

[5] The Roeher Institute was informed that people receiving residential services make up about half of all people receiving adult community living services in BC. Residential services are generally more labour intensive than day programs.

Aggravating the problem was the change in federal-provincial fiscal arrangements under the *Canada Health and Social Transfer* (CHST) in 1996 and the repeal of the *Canada Assistance Plan Act* (CAP) and of other fiscal arrangements. These changes meant a significant reduction in cash transfers from the federal to provincial governments for social programs in Canada, resulting in a “squeeze” in all jurisdictions on social programs, including residential programs. Figures from the National Council on Welfare (1997, Table 1) show a reduction of $4.4 billion in federal funding under the CHST over previous arrangements from 1995-1996 to 1997-1998.

Increases in the numbers of facilities with 20 to 99 beds may have been driven by fiscal necessity, i.e., the economies of scale for these arrangements may have been more attractive to governments than other arrangements. To establish whether that is indeed the case, region-by-region analysis of costs per person would be required by facility size. That research is beyond the scope of the present report.

Decreases in the number of facilities with 100 or more beds, and decreases in the number of people living in such facilities, were likely driven in part by the deinstitutionalization movement in Canada. Economies of scale may also have been a factor: per person costs in large facilities will increase as the numbers of residents decrease because capital costs tend to remain constant, which creates financial incentives for governments to shift people into more cost-efficient arrangements. Again, detailed analysis of costs and numbers of people served over time would be required to show how economies of scale for various sized facilities have changed.

Where Are All the Other People with Intellectual Disabilities?

Common estimates of the prevalence of intellectual disability range between 1% and 3% of the general population (See Appendix 3). Table 8 shows how those estimates translate to numbers of people. We have used the Participation and Activity Limitation Survey (PALS) Public Use Microdata File and other Statistics Canada data (2002a) to calculate the total Canadian population living in households (i.e., not in institutions) in 2001.

Table 8. Estimated total numbers of people with intellectual disabilities based on three population estimates

Total population in households, 2001		28,993,000
Estimated numbers of people with intellectual disabilities at:		
	1%	290,000
	2%	580,000
	3%	870,000

Source: PALS 2001

A conservative (1%) estimate suggests that about 290,000 Canadians have intellectual disabilities (Table 8). The present report indicates that less than 15,000 people with intellectual disabilities are in the residential care facilities system. This leaves the question: where are all the others?

The vast majority are in various non-institutional arrangements and a few others are in residential facilities that do not focus primarily on people with intellectual disabilities.

Non-institutional Arrangements

Table 9 shows the economic family situations of adults by disability status. The figures are from PALS 2001. The table shows that, compared with adults without disabilities, people with intellectual disabilities are:

- Much more likely (25% compared with 14%) to be living as never-married adult sons or daughters (15 years and older) with one or both parents;

- Considerably more likely to be children less than 15 years (35% compared with 21%);

- Nearly twice as likely (19% compared with 11%) 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 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 (4% compared with 3%) to be living with extended family members beyond the biological or adoptive family unit; and

- About a third as likely (15% compared with 46%) to be living with spouses.

The rest of people with intellectual disabilities (3%) are lone parents.

In other words, if adults with intellectual disabilities aren’t in the residential care facilities system they are likely to be living in a variety of non-institutional arrangements as never-married children, extended family members, or alone or with others who do not share ties of kinship.

Table 9. Economic family status of Canadians without disabilities, with intellectual disabilities and with other disabilities

	Non-disabled	Intellectual disabilities	Others w/ disabilities
Spouse or partner	46%	15%	53%
Lone parent	3%	3%	7%
Never married adult children	14%	25%	5%
Children < 15 years	21%	35%	3%
Other members of family	3%	4%	6%
Unattached	11%	19%	25%
Not applicable or invalid data	1%	0%	0%
Total	**100%**	**100%**	**100%**

Source: PALS 2001

Owing to different survey methodologies, data from PALS 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 on intellectual disability are similar in both surveys. Appendix 4 provides the wording for these questions.

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. In 1991, the HALS figures indicate that only 31% met this description. About the same proportion 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 a decade or so ago. The information in the section of the present report on “Accounting for the Trends” suggests that this may indeed be the case; the system of community living supports has been under considerable stress and waitlists have been commonplace.

Institutions for Seniors and Others

Information provided by Statistics Canada indicates that 1,177 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.

Summary and Conclusion

As of fiscal 2001-2002 there were 948 residential care facilities with 4 or more beds for people with intellectual disabilities in Canada. There was a period of growth in the numbers of such facilities from 1986 to 1993 (from 840 to 1359), after which the number decreased to the present level.

Nearly 15,000 people lived in residential care facilities for people with intellectual disabilities in 2002, down from nearly 19,000 in 1986.

Within that smaller system, large facilities with 100 or more beds decreased from 4% of all facilities for people with intellectual disabilities in 1986 to 2% from 1990 afterwards. In British Columbia there no longer any facilities this size.

The figures for facilities with fewer than 20 beds reveal clear trends towards increased use of smaller facilities from 1986 to 1993, then a reversal of direction somewhere after 1993. Having said this, facilities with 4 to 9 beds comprised a greater share of all facilities for people with intellectual disabilities in 2002's smaller system than was the case in 1986. The proportion of people living in facilities this size was 23% in 2002, up from 18% in 1986. Density in places this size decreased from 6 people on average in 1986 to 4.9 people in 2002.

Some progress has been achieved, then, in enabling people with intellectual disabilities to live in smaller rather than very large congregate care institutions.

However, while there were more facilities with 4 to 9 beds in 2002 than in 1986 (679 compared with 562), there were nowhere near as many as there were

in 1993 (1,088). About the same number of people lived in such facilities in 2002 as in 1986 (3,325 compared with 3,398 respectively).

As well, more people in 2002 than in 1986 were living in facilities with 20 to 49 beds and in facilities with 50 to 99 beds. These comprised greater percentages than previously of all residential care facilities for people with intellectual disabilities and the total numbers of such facilities have increased since 1986. The percentage of people living in facilities with 10 or more beds dropped from 82% in 1986 to 70% in 1992 then climbed back upwards and has hovered between 76% and 77% in recent years.

The decrease in the total number of people living in residential care facilities of all sizes suggests a constriction of the capacity of that system to respond to the housing and support needs of a population that other sources of information indicate have been on the rise. Constricted capacity is also suggested by the density of living arrangements, which has been on the rise since 1992, particularly in facilities with 20 to 49 beds. Fiscal pressures and economies of scale may be driving governments to use residential care facilities with more than 20 beds and fewer than 100 instead of the much smaller arrangements that champions of deinstitutionalization would prefer.

Appendices

1. Appendix Tables

Appendix Table 1. Estimated numbers of people in residential care facilities for people with "developmental delay" in fiscal 2001-2002

Size of facility (number of beds)		Number of facilities	Number of residents, reporting facilities	Total number of beds	Occupancy rate (reporting facilities)	Estimated number of residents, non-reporting facilities	Estimated total residents, reporting and non-reporting	Est. number of residents in facilities with 10 + beds	Summary
4 to 9	Non reporting	91		486		442	442		3,325
	Reporting facilities	588	2,883	3,171	90.9%		2,883		
10 to 19	Non reporting	23		303		280	280	280	1,472
	Reporting facilities	96	1,192	1,292	92.3%		1,192	1192	
20 to 49	Non reporting	7		192		192*	192	192	2,843
	Reporting facilities	80	2,651	2,414	109.8%		2,651	2651	
50 to 99	Non reporting	4		255		208	208	208	2,203
	Reporting facilities	40	1,995	2,450	81.4%		1,995	1995	
100 to 199	Non reporting	1		165		152	152	152	1,388
	Reporting facilities	9	1,236	1,342	92.1%		1,236	1236	
200 and more	Non reporting	1		313		239	239	239	3,393
	Reporting facilities	8	3,154	4,139	76.2%		3,154	3154	
Total		**948**	**13,111**	**16,522**	**88.5%**	**1,512**	**14,623**	**11,298**	**14,623**

* Estimate is top rounded at 100% occupancy

Source: Statistics Canada custom retrieval.

Appendix Table 2. Estimated numbers of people in residential care facilities for people with "developmental delay" in fiscal 2000-2001

Size of facility (number of beds)		Number of facilities	Number of residents, reporting facilities	Total number of beds	Occupancy rate (reporting facilities)	Estimated number of residents, non-reporting facilities	Estimated total residents, reporting and non-reporting	Est. number of residents in facilities with 10 + beds	Summary
4 to 9	Non reporting	117		601		544	544		3,492
	Reporting facilities	592	2,948	3,255	90.6%		2948		
10 to 19	Non reporting	29		407		369	369	369	1,555
	Reporting facilities	100	1,186	1,308	90.7%		1186	1186	
20 to 49	Non reporting	13		346		315	315	315	2,419
	Reporting facilities	77	2,104	2,308	91.2%		2104	2104	
50 to 99	Non reporting	9		598		531	531	531	2,636
	Reporting facilities	37	2,105	2,370	88.8%		2105	2105	
100 to 199	Non reporting	1		116		116*	116	116	1,340
	Reporting facilities	9	1,224	1,075	113.9%		1224	1224	
200 and more	Non reporting	0							3,418
	Reporting facilities	9	3,418	4,476	76.4%		3418	3418	
Total		**993**	**12,985**	**16,860**	**87.8%**	**1,876**	**14,861**	**11,369**	**14,861**

* Estimate is top rounded at 100% occupancy

Source: Statistics Canada custom retrieval.

Appendix Table 3. Estimated numbers of people in residential care facilities for people with "developmental delay" in fiscal 1992-1993

Size of facility (number of beds)		Number of facilities	Number of residents, reporting facilities	Total number of beds	Occupancy rate (reporting facilities)	Estimated number of residents, non-reporting facilities	Estimated total residents, reporting and non-reporting	Est. number of residents in facilities with 10 + beds	Summary
4 to 9	Non reporting	194		1,216		1,156	1,156		5,720
	Reporting facilities	894	4,564	4,799	95.1%		4,564		
10 to 19	Non reporting	8		207		197	197	197	1,606
	Reporting facilities	124	1,409	1,483	95.0%		1,409	1409	
20 to 49	Non reporting	15		520		493	493	493	2,588
	Reporting facilities	71	2,095	2,209	94.8%		2,095	2095	
50 to 99	Non reporting	2		173		168	168	168	1,622
	Reporting facilities	24	1,454	1,500	96.9%		1,454	1454	
100 to 199	Non reporting	1		368		334	334	334	1,912
	Reporting facilities	15	1,578	1,738	90.8%		1,578	1578	
200 and more	Non reporting	0		1,011		964	964	964	5,810
	Reporting facilities	11	4,846	5,082	95.4%		4,846	4846	
Total		**1,359**	**15,946**	**20,306**	**94.9%**	**3,312**	**19,258**	**13,538**	**19,258**

Source: Statistics Canada (1994). Tables 1 and 5.

Appendix Table 4. Estimated numbers of people in residential care facilities for people with "developmental delay" in fiscal 1990-1991

Size of facility (number of beds)		Number of facilities	Number of residents, reporting facilities	Total number of beds	Occupancy rate (reporting facilities)	Estimated number of residents, non-reporting facilities	Estimated total residents, reporting and non-reporting	Est. number of residents in facilities with 10 + beds	Summary
4 to 9	Non reporting	213		1,317		1,255	1,255		4,951
	Reporting facilities	705	3,696	3,879	95.3%		3,696		
10 to 19	Non reporting	24		377		362	362	362	1,796
	Reporting facilities	121	1,434	1,495	95.9%		1,434	1434	
20 to 49	Non reporting	17		644		602	602	602	2,664
	Reporting facilities	72	2,062	2,207	93.4%		2,062	2062	
50 to 99	Non reporting	4		292		283	283	283	1,492
	Reporting facilities	20	1,209	1,248	96.9%		1,209	1209	
100 to 199	Non reporting	0		210		186	186	186	1,582
	Reporting facilities	14	1,396	1,576	88.6%		1,396	1396	
200 and more	Non reporting	0		865		835	835	835	6,703
	Reporting facilities	14	5,868	6,076	96.6%		5,868	5868	
Total		**1,204**	**15,665**	**20,186**	**95.0%**	**3,522**	**19,187**	**14,237**	**19,187**

Source: Statistics Canada (1993). Tables 1 and 5.

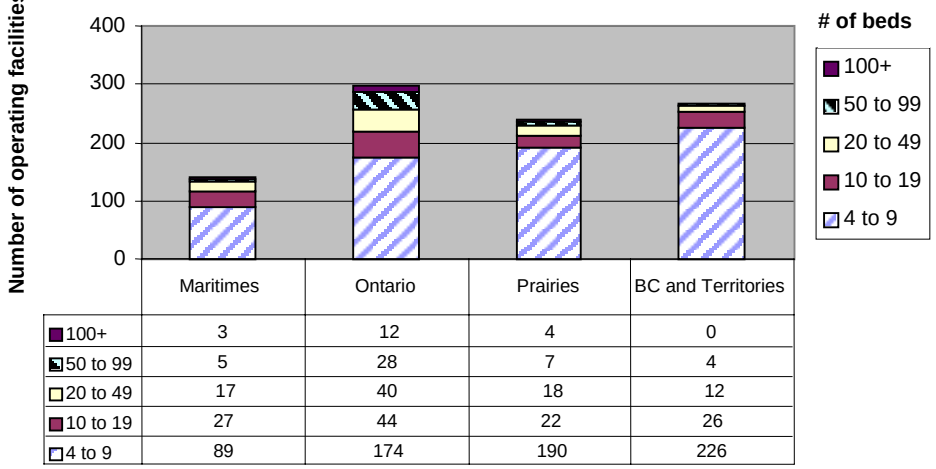
Appendix Table 5. Estimated numbers of people in residential care facilities for people with "developmental delay" in fiscal 1990-1991

Size of facility (number of beds)		Number of facilities	Number of residents, reporting facilities	Total number of beds	Occupancy rate (reporting facilities)	Estimated number of residents, non-reporting facilities	Estimated total residents, reporting and non-reporting	Est. number of residents in facilities with 10 + beds	Summary
4 to 9	Non reporting	51		453		439	439		3,398
	Reporting facilities	511	2,959	3,051	97.0%		2,959		
10 to 19	Non reporting	13		260		252	252	252	1,851
	Reporting facilities	138	1,599	1,653	96.7%		1,599	1599	
20 to 49	Non reporting	6		350		343	343	343	2,284
	Reporting facilities	73	1,941	1,983	97.9%		1,941	1941	
50 to 99	Non reporting	2		182		181	181	181	993
	Reporting facilities	15	812	815	99.6%		812	812	
100 to 199	Non reporting	2		1,650		1,658	1,658	1,658	10,254
	Reporting facilities	29	8,596	8,555	100.5%		8,596	8596	
200 and more	Non reporting								
	Reporting facilities								
Total		**840**	**15,907**	**18,952**	**98.3%**	**2,873**	**18,780**	**15,381**	**18,780**

Source: Statistics Canada (1989). Tables 1 and 10.

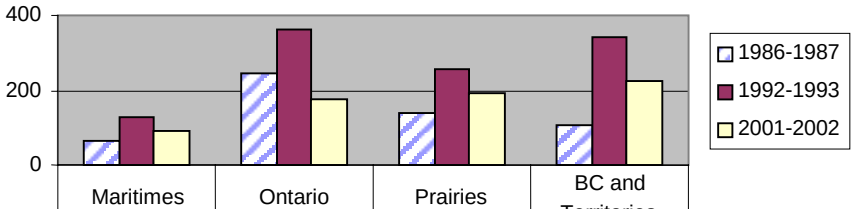
2. Appendix Charts

Chart A1. Numbers of operating facilities for people with intellectual disabilities, by size of facility and region, 2001-2002



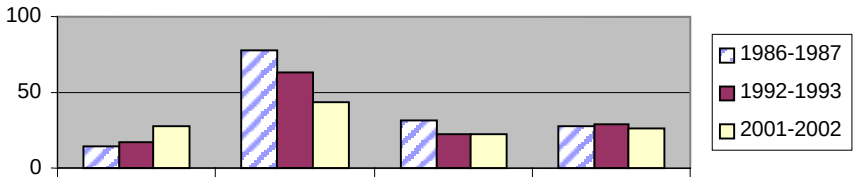
	Maritimes	Ontario	Prairies	BC and Territories
100+	3	12	4	0
50 to 99	5	28	7	4
20 to 49	17	40	18	12
10 to 19	27	44	22	26
4 to 9	89	174	190	226

Chart A2. Numbers of operating facilities with 4 to 9 beds for people with intellectual disabilities, by region and year



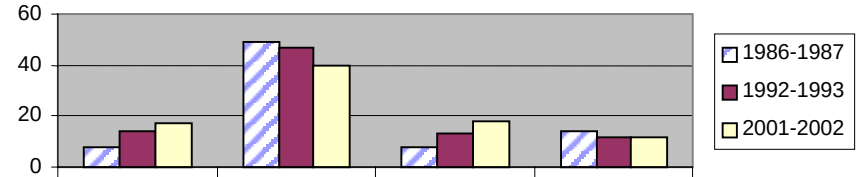
	Maritimes	Ontario	Prairies	BC and Territories
1986-1987	66	248	138	109
1992-1993	129	365	254	340
2001-2002	89	174	190	226

Chart A3. Numbers of operating facilities with 10 to 19 beds for people with intellectual disabilities, by region and year



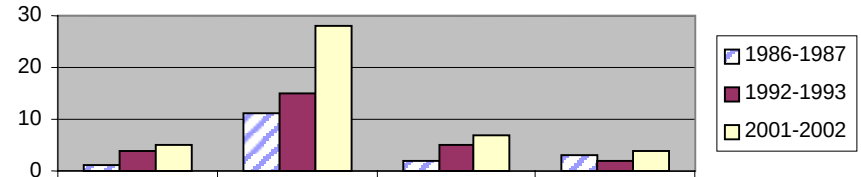
	Maritimes	Ontario	Prairies	BC and Territories
1986-1987	15	78	31	27
1992-1993	17	63	23	29
2001-2002	27	44	22	26

Chart A4. Numbers of operating facilities with 20 to 49 beds for people with intellectual disabilities, by region and year



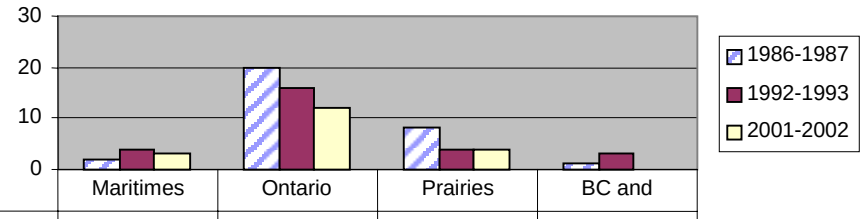
	Maritimes	Ontario	Prairies	BC and Territories
1986-1987	8	49	8	14
1992-1993	14	47	13	12
2001-2002	17	40	18	12

Chart A5. Numbers of operating facilities with 50 to 99 beds for people with intellectual disabilities, by region and year



	Maritimes	Ontario	Prairies	BC and Territories
1986-1987	1	11	2	3
1992-1993	4	15	5	2
2001-2002	5	28	7	4

Chart A6. Numbers of operating facilities with 100 or more beds for people with intellectual disabilities, by region and year



	Maritimes	Ontario	Prairies	BC and
1986-1987	2	20	8	1
1992-1993	4	16	4	3
2001-2002	3	12	4	0

3. Definition and Prevalence of 'Intellectual Disability'

Definition of 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 (less acceptable in most jurisdictions except the United States) 'mental retardation'. [6]

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, definitions of intellectual disability connote long-term conditions with onset before 18 years of age that involve significant cognitive limitations and difficulties in everyday activities that most people can do without major trouble. While the term 'intellectual disability' is technically distinct from other 'developmental disabilities' (see American Psychiatric Association, 1994), these terms are often used interchangeably.

[6] In Canada and internationally, 'intellectual disability' is becoming the preferred term. While the term 'mental retardation' is still widely used in the United States, the President's Committee on Mental Retardation was recently renamed the President's Committee for People with Intellectual Disabilities, suggesting that 'intellectual disability' is becoming the preferred terminology in that country as well.

See, for instance, the website entitled, "Administration for Children and Families – President's Committee for People with Intellectual Disabilities", dated May 3, 2005 at http://www.acf.hhs.gov/programs/pcpid/index.html, compared with the website entitled "Administration for Children and Families – President's Committee on Mental Retardation (PCMR)", dated September 2000 at http://www.acf.hhs.gov/news/facts/pcmrfspr.htm.

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) recently found a prevalence rate of 7.18 per thousand in Ontario, a figure similar to Scandinavian countries but that the researchers believed 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). An official from the Ontario Developmental Services Branch of the Ministry of Community and Social Services told The Roeher Institute in 2001 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 Roeher Institute 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. The Committee uses 'MR' as shorthand for 'mental retardation':

> 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 there child with "mild" mental retardation has a disability (US Department of Health and Human Services, 2004).

PALS Estimates

Data from Statistics Canada's Participation and Activity Limitation Survey indicate an intellectual disability prevalence of about 0.6% (Table A6), which may mean that the survey is picking up people with intellectual disabilities who have a relatively severe level of functional limitation. Non-responses, contrary responses and other survey design issues may have been other factors that resulted in low reporting of intellectual disability in PALS. Appendix 4 provides a discussion.

Table A6. Participation and Activity Limitation Survey (PALS) 2001 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
0-4*	17,820*	1,641,680	1.1%
5-14**	46,180**	3,904,330	1.2%
15+**	120,140**	23,445,760	0.5%
Total	184,140	28,991,770	0.6%

*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, 2002a.

4. Factors that May Account for Low Reporting of Intellectual Disability in PALS

Non Response and Contrary Responses

Non-responses and contrary responses may account for some of the low reporting of intellectual disability in PALS.

For example, in the lead up to the 1991 Health and Activity Limitation Survey (HALS), which was the forerunner of PALS 2001, Statistics Canada conducted field tests to determine likely response patterns to a 'point blank' question on intellectual disability. The testing stemmed from the experience with HALS 1986, in which there had been many difficulties classifying respondents as having intellectual disabilities using the 1986 survey's open-ended approach to identifying underlying conditions that accounted for disability. The field tests for the more structured question on intellectual disability in HALS 1991 were conducted with people living in various residential and day programs operated by local Associations for Community Living. The mission of those organizations included provision of direct services to people with intellectual disabilities.

The HALS question on intellectual disability followed a question on learning disability that set a general context of professional assessment. The HALS 1991 questions on learning disability (A24a) and intellectual disability (A24b) are as follows:

> A24
>
> (a) Has a teacher or health professional (such as a doctor, nurse, social worker or counsellor) ever told you or your family that you have a learning disability (such as dyslexia, a perceptual handicap, attention problems or hyperactivity)?
>
> (b) In the past, persons who had some difficulty learning were often told they had a mental handicap or that they were developmentally delayed or mentally retarded. Has anyone ever used these words to describe you?

It was found that many people with intellectual disabilities (or proxy respondents such as group home staff) were averse to answering the direct question on intellectual disability, or answered “no”, because of the stigma associated with answering “yes”. While Roeher was privy to this information because Roeher staff were involved in the analysis of the test results, to the best of Roeher’s knowledge Statistics Canada did not publish the results of those tests.

The question in PALS 2001 was similar to that asked in HALS 1991. The PALS question reads as follows:

> B88. Has a doctor, psychologist or other health professional ever said that you (. . . . .) had a developmental disability or disorder? These include, for example, Down syndrome, autism, Asperger syndrome, mental impairment due to a lack of oxygen at birth, etc.

Many PALS respondents with intellectual disabilities or their proxies may have had the same kinds of aversions as HALS respondents to answering “yes” to the question.

5. Possible Exclusion of Some People from PALS

Census – PALS Interface

A design feature of PALS is that it relies on the Census in order to sample people living in private households. A design feature of the Census is that some people with intellectual disabilities who were living in group homes in 2001 may have been classified as living in health care and related institutions and therefore may have been dropped from consideration for inclusion in household surveys such as PALS.

Health care and related institutions are defined as “general hospitals and hospitals with emergency, other hospitals and related institutions, treatment centres and institutions for persons with a disability, nursing homes and residences for senior citizens” (Statistics Canada, 2002b). People living in such places would not have been included in a survey such as PALS (Statistics Canada, 2004), which focuses on people in private households and people whose usual place of residence is in selected non-institutional collective dwellings such as hotels, motels and tourist homes, lodging and rooming houses, school residences and YM/YWCAs.

We do not know how many people may have been excluded from PALS owing to such survey design issues. However, several group home operators did bring to Roeher’s attention when HALS was conducted that their group homes had been classified as ‘institutions’ for the purpose of the Census of 1991. People living in those group homes would not have been included in HALS.

Elusive Identification

As pointed out in a recent report by the U.S. Department of Health and Human Services’ Surgeon General, the condition of most people with intellectual

disabilities is “relatively mild, and once they leave school, they disappear into larger communities, untracked in major national data sets” (2002).

In the Canadian context, we may well be dealing with the same challenge of not being able to capture many, and perhaps even most, people with mild levels of intellectual disability in a survey such as PALS. This is because, in order to be screened into PALS, respondents had to indicate difficulties hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities, or had to report a long-term health or mental health problem that reduced the amount or kind of activity that they could do at home, school or work, or in other activities such as transportation or leisure (Statistics Canada, 2004).

It is quite conceivable that a person with significantly lower than average intelligence may not have reported any of the difficulties that were used to screen people into PALS. Such people could have eluded being screened into PALS because of supportive circumstances at home, work, learning and other situations that enabled them to get on with their lives without feeling that they are dealing with significant difficulties or limitations in activities.

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