

# National Intellectual Disability Database Committee

Annual Report 2002



Fiona Mulvany and Steve Barron

Health Research Board An Bord Taighde Sláinte





National Intellectual Disability Database

**Annual Report  
of the National Intellectual  
Disability Database Committee  
2002**

**Fiona Mulvany and Steve Barron**

## Acknowledgements

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- the Intellectual Disability Services Section of the Department of Health and Children;
- the health boards, in particular the Regional Database Co-ordinators, the Database Administrators and the Regional Database Committees;
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# Chairman's Statement

It gives me great pleasure to introduce the fifth Annual Report from the Intellectual Disability Database. This report provides a profile of the population with intellectual disability and sets out details of the existing level of service provision for this group. It outlines the pattern of care required over the coming years in both residential and day care services and highlights some of the issues which must be addressed in planning and delivering services.

The Intellectual Disability Database enables those involved with the planning and delivery of services to identify not only the level of need amongst those awaiting placement in services, but also the service changes required by those already in receipt of services. As stated in previous reports, this continues to be particularly important in relation to this population, which is now predominantly an adult one with a growing need for both residential and day services that are flexible and can change to meet long-term needs.

In the fourth Annual Report, the National Intellectual Disability Database Committee (NIDDC) emphasised the need for health boards and other service providers to address specific data-quality issues which were highlighted in that report. This work, together with the timely return of information to both the regional databases and the national database, continues to be a priority for the NIDDC. The 2002 data reflect some of the work undertaken by health boards and service providers in this area. However, this report continues to highlight particular data-quality issues such as the need to review, on an ongoing basis, the considerable number of people registered on the database in 2002 who were not availing of services and had no identified service needs. One possible explanation is that some of this group who have a more severe degree of intellectual disability are appropriately registered on the database but have not had their need for specialised services adequately assessed. Another possibility is that those with a mild degree of intellectual disability in this group do not require specialised disability services and in that case should not be registered on the database. While acknowledging the efforts being made to review and refine the database, as Chairperson of the National Intellectual Disability Database Committee, I urge health boards to prioritise the review of these cases.

Arising from the Government decision of June 2000 to mainstream services for people with disabilities, responsibility for vocational training and employment support measures for people with disabilities was transferred from the Department of Health and Children (and health agencies) to the Department of Enterprise, Trade and Employment (and FÁS). Responsibility for rehabilitative training remains with the Department of Health and Children. Future database reports will take account of this distinction when detailing programme codes and descriptions and day service groupings.

The contribution of my colleagues on the National Intellectual Disability Database Committee in steering the development of the database is much appreciated. The ongoing enhancement of the range of information available to us will continue to ensure that the resources allocated to the services are targeted at the areas of most need. I would particularly like to acknowledge the contribution made by Ms Fiona Mulvany and Mr Steve Barron to the preparation of this report.

Brendan Ingoldsby  
Chairman  
National Intellectual Disability Database Committee

# Executive Summary

## Demographic Profile

There were 25,448 people registered on the National Intellectual Disability Database in 2002, representing a prevalence rate of 6.49 per 1,000 population. The administrative prevalence rate for mild intellectual disability is 2.40 per 1,000 and the prevalence rate for moderate, severe, and profound intellectual disability is 3.71 per 1,000. The numbers registered on the database have decreased by 1,220 since 2001 largely due to the ongoing refinement of the dataset and, in particular, the removal from the record of people with mild intellectual disability who are not accessing specialised services and do not require such services in the period 2003-2007. There are more males than females at all levels of intellectual disability, with an overall ratio of 1.27 to 1. The total number with moderate, severe, and profound intellectual disability has increased by 29% since the first Census of Mental Handicap in the Republic of Ireland was carried out in 1974; since 1996 this increase in numbers is confined to those over 35 years of age. This increase is attributed to the general population increase over the period, improved standards of care, and an increase in the lifespan of people with intellectual disability. There has been a steady increase in the proportion of people with moderate, severe, and profound intellectual disability aged 35 years and over from 29% in 1974, to 38% in 1996, and increasing to 45% in 2002. This changing age profile observed in the data over the past three decades has major implications for service planning, including an ongoing high level of demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability, and helps to explain the ongoing demand for additional resources for this sector.

## Service Provision in 2002

In 2002 there were 23,050 people with intellectual disability in receipt of specialised services, representing 90.6% of the total population registered on the National Intellectual Disability Database. There are 468 people (1.8% of those registered) who are without services at present and are identified as requiring appropriate services in the period 2003-2007. This number has reduced by 47, or 9%, since 2001. The remaining 1,930 people (7.6%) are not availing of services and have no identified requirement for services during the planning period 2003-2007. Most of this group (67%) are in the mild and 'not verified' ranges of intellectual disability and their continued registration on the NIDD is being reviewed. However, the remaining 33% of this group have a moderate, severe, or profound degree of intellectual disability and the need for continued monitoring of the circumstances of these people is highlighted.

There are 8,102 people in receipt of full-time residential services, a net decrease of 194 since 2001. The number of people with intellectual disability accommodated in psychiatric hospitals continues to fall, down by 162 since 2001, to 515. Day programmes are availed of by 22,443 people. Of this group, 7,542 are in full-time residential placements and the remainder attend services on a day basis. Over 60% of all children and adults with intellectual disability live in a home setting with parents, siblings, relatives, or foster parents.

Since 1996 there has been significant growth in the level of provision of full-time residential services, residential support services, and day services recorded on the National Intellectual Disability Database reflecting, in particular, the significant investment programme in the intellectual disability sector between 2000 and 2002. Key developments noted in this report include:

- a 37% growth in the number of people with intellectual disability living in full-time residential placements within local communities;
  - a 165% increase in the provision of intensive placements designed to meet the needs of individuals with challenging behaviours;
  - a 47% reduction in the number of people accommodated in psychiatric hospitals;
  - a continued expansion in the availability of residential support services, in particular service-based respite services, which have grown by 255%, with an additional 443 people reported as being in receipt of these services between 2001 and 2002 alone;
- and
- increased provision in almost all areas of adult day services and in the level of provision of support services delivered as part of a package of day services to both children and adults.

## Service Requirements

In 2002 there were 2,262 people who were either without services or without a major element of service. The provision of 1,633 full-time residential placements and 682 day programmes is required to meet the needs of this group in the period 2003-2007. In addition, 1,446 people will require residential support services during this period. Most service needs arise immediately. A group of 380 individuals living in psychiatric hospitals in 2002 has been identified as needing to transfer from these locations to more appropriate accommodation over the five-year period.

In 2002 a further 12,516 people were receiving services but require alternative, additional, or enhanced services within the next five years. This group includes people who require an increased level of service provision, increased support within their existing services, transfers to more appropriate placements, or service changes to coincide with transition periods in their lives, for example movement from child to adult services, or from training to employment services. Individuals who already avail of services have significant funding allocated to them and in most instances changes to their existing placements will incur minimal costs.

Despite the significant investment in intellectual disability services in recent years and a corresponding growth in the level of service provision, the demographic factors outlined above are contributing to long waiting lists for services, and in particular for full-time residential services.



# Chapter one

# 1. The National Intellectual Disability Database

## Background

The National Intellectual Disability Database was established in 1995 to ensure that information is available to enable the Department of Health and Children, the health boards and the voluntary agencies in the Republic of Ireland to provide appropriate services designed to meet the changing needs of people with intellectual disability (mental handicap) and their families. The database is intended to provide a comprehensive and accurate information base for decision-making in relation to the planning, funding, and management of services for people with an intellectual disability.

The database was established on the principle that minimum information with maximum accuracy was preferred, hence it incorporates only three basic elements of information: demographic details, current service provision, and future service requirements. The objective is to obtain this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service. Information as to diagnosis is specifically excluded, as the database is not designed as a medical epidemiological tool. The data held in any individual record represent the information available for that person at a specified point in time only. The record is updated whenever there are changes in the person's circumstances or during the annual review process in the spring of each year.

The information now available from the National Intellectual Disability Database provides a much better basis for decision-making than was previously the case. Priorities can be set based on an objective evaluation of the needs of people with intellectual disability, and services that are sensitive to these needs can be delivered. The commitment of all services and agencies involved in the maintenance of the database is significant and their continuing commitment and co-operation is crucial in ensuring the ongoing availability of accurate information.

## Structure

The relevant Programme Manager in each health board region is responsible for the administration of the database in the region. This includes the implementation and maintenance of structures for the identification of individuals and the collection, review and updating of data. In practice, this responsibility is delegated to the Regional Database Co-ordinator, whose function is to ascertain the persons concerned. The initial step in the generation of the national dataset is the completion of a database form for each identified individual (Appendix A). Responsibility for providing this information to the health board lies primarily with the service providers, community care personnel and school principals. The designated data providers supply this information to their health board and a regional database is compiled. Data from the regional databases enable more sophisticated service planning at health board level and promote effective co-ordination of local services. Regional Intellectual Disability Database Committees, consisting of the Regional Database Co-ordinator,

the Regional Database Administrator and representatives from the health board and the voluntary services, monitor the operation of the regional database in each health board region.

The Eastern Regional Health Authority and the seven health boards transfer their regional dataset, excluding personal details such as name and address, to the Department of Health and Children and this information is then merged to form the National Intellectual Disability Database. The Health Research Board (HRB), on behalf of the Department of Health and Children, manages the national dataset.

## Data Quality

The HRB oversees a system of ongoing validation which aims to identify and correct gaps and inconsistencies in the data. The National Intellectual Disability Database software contains a series of technical checks which enable routine data validation to be carried out at health board level. In addition, the database guidelines and protocols are revised and refined in response to issues highlighted by the HRB, the health boards and service providers. Such refinements ensure greater standardisation of data collection throughout the country. There are ongoing efforts to ensure continued improvement of data quality at local, regional and national levels.

## 2002 Annual Report

This is the fifth report of the National Intellectual Disability Database Committee. The report is based on validated data received from seven of the regional databases in June 2002 and from the eighth in February 2003, eight months after the scheduled export date. The importance of adhering to scheduled export dates is once again emphasised by the NIDDC to ensure timely reporting of data by the HRB and to enable accurate comparisons between regional datasets.

Prevalence rates per thousand population are based on the up-to-date data from the Central Statistics Office, the 2002 Census of Population (Central Statistics Office, 2003).

The extent of current service provision in Ireland ensures that an almost 100% ascertainment of all persons with a moderate, severe or profound intellectual disability is possible and expected. Inclusion of persons with a mild level of intellectual disability is sought if they are in special classes or special schools for children with intellectual disability, attending an intellectual disability service as adults, or if they are considered likely to require such a service within the next five years. Those in the average ability and borderline intellectual disability categories have been excluded from analyses because services for this group are not usually provided within intellectual disability services.<sup>1</sup> In the 2002 dataset, there are 146 people recorded as being of average ability and 666 people in the borderline intellectual disability categories, an increase of 5 and reduction of 37 respectively since 2001. The health boards are involved in an ongoing appraisal of such registrations on the database. The disability category described as 'not verified' has been included in the analyses as members of this group have an intellectual disability, but the level of disability has not been confirmed. Accordingly, the data presented include those with a mild, moderate, severe or profound intellectual disability, in addition to the 'not verified' category.

<sup>1</sup> Largely for historical reasons some persons in these categories continue to avail of a placement within the intellectual disability services.





# Chapter two

## 2. Profile of the Population

### National Level

#### NUMBERS AND PREVALENCE

In 2002 there were 25,448 people registered on the National Intellectual Disability Database. Table 2.1 summarises the numbers and prevalence rates at each level of intellectual disability. The administrative prevalence rate for mild intellectual disability in 2002 is 2.40/1000, compared to 2.91/1000 in 2001, and the prevalence rate for moderate, severe and profound intellectual disability in 2002 is 3.71/1000, compared to 4.06/1000 in 2001.

Table 2.1. National Intellectual Disability Database, Ireland 2002.

#### Prevalence of intellectual disability by degree of intellectual disability.

	<b>n</b>	<b>%</b>	<b>rate</b>
Mild	9412	37.0	2.40
Moderate	9495	37.3	2.42
Severe	4004	15.7	1.02
Profound	1058	4.2	0.27
Not Verified	1479	5.8	0.38
<b>All levels</b>	<b>25448</b>	<b>100.0</b>	<b>6.49</b>

Overall, the numbers registered on the National Intellectual Disability Database have decreased by 1,220 since 2001 (Mulvany, 2003). During the review and update period prior to the 2002 export of data from the health boards to the national dataset, 1,634 people were removed from the database. This total consisted of 299 people who had died, 37 people who it was deemed would be more appropriately registered on the National Physical and Sensory Disability Database, 31 people who had emigrated, 1,131 who no longer required intellectual disability services (1,068 of whom were in the mild range of intellectual disability, 62 of whom were recorded as level of disability 'not verified', and one was in the moderate range of intellectual disability), and 136 individuals where the reason for removal was either not stated or described as 'other'. The large reduction in numbers with mild intellectual disability registered on the database is due to a national emphasis on including and retaining on the National Intellectual Disability Database only those people with mild intellectual disability who are in receipt of, or in need of, intellectual disability services.

Table 2.2 summarises the age and gender distribution of those registered on the database by degree of disability.

#### GENDER DIFFERENCES

As Table 2.2 indicates, the number of males at all levels of intellectual disability exceeds the number of females, with an overall male to female ratio of 1.27:1. This represents a prevalence rate of 7.27/1000 males and 5.74/1000 females.

Table 2.2. National Intellectual Disability Database, Ireland 2002.  
Age, gender and degree of intellectual disability.

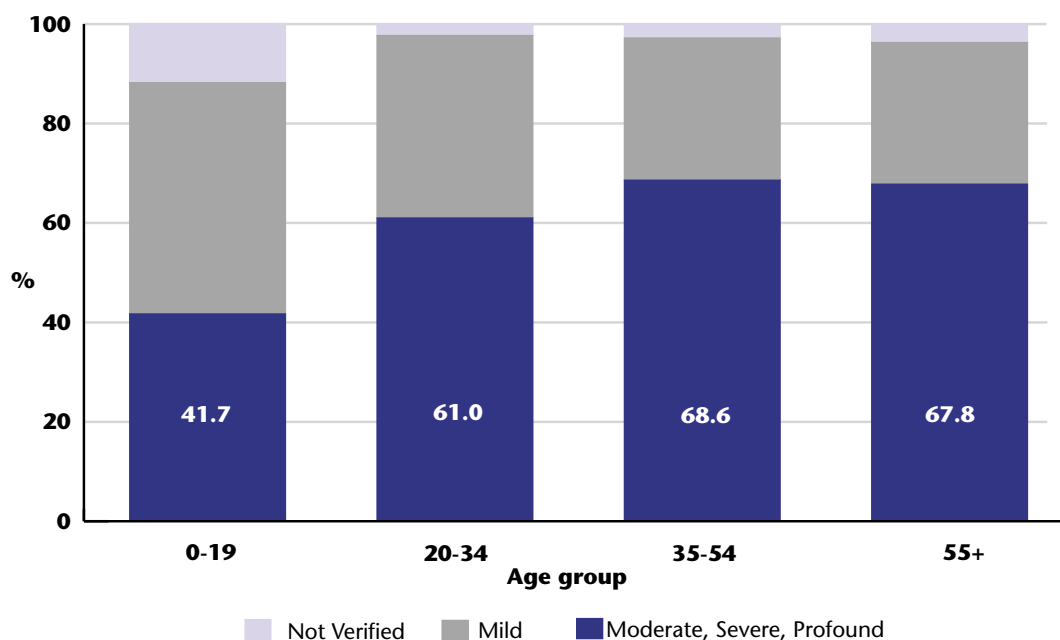
Age Group	Numbers											
	Not Verified			Mild			Moderate			Severe		
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
0-4	263	377	640	58	71	129	58	87	145	21	36	57
5-9	91	149	240	258	397	655	211	434	645	107	150	257
10-14	36	52	88	533	886	1419	326	480	806	110	161	271
15-19	16	43	59	690	1127	1817	388	559	947	118	169	287
20-34	78	88	166	1199	1462	2661	1331	1581	2912	467	691	1158
35-54	96	100	196	977	1053	2030	1429	1507	2936	698	802	1500
55 & over	48	42	90	388	313	701	597	507	1104	243	231	474
All ages	628	851	1479	4103	5309	9412	4340	5155	9495	1764	2240	4004
Prevalence Rates												
0-4	1.94	2.65	2.31	0.43	0.50	0.46	0.43	0.61	0.52	0.15	0.25	0.21
5-9	0.71	1.10	0.91	2.01	2.92	2.48	1.65	3.19	2.44	0.83	1.10	0.97
10-14	0.26	0.36	0.31	3.82	6.06	4.97	2.34	3.29	2.82	0.79	1.10	0.95
15-19	0.10	0.27	0.19	4.52	7.03	5.80	2.54	3.48	3.02	0.77	1.05	0.92
20-34	0.17	0.19	0.18	2.54	3.09	2.81	2.82	3.34	3.08	0.99	1.46	1.22
35-54	0.18	0.19	0.19	1.87	2.02	1.95	2.74	2.89	2.81	1.34	1.54	1.44
55 & over	0.11	0.11	0.11	0.92	0.85	0.89	1.42	1.38	1.40	0.58	0.63	0.60
All ages	0.32	0.44	0.38	2.08	2.73	2.40	2.20	2.65	2.42	0.89	1.15	1.02
										0.24	0.30	0.27
										5.74	7.27	6.49

## AGE DIFFERENCES

Of the persons recorded on the National Intellectual Disability Database, 34.0% are aged 19 years and under, 28.5% are aged between 20 and 34 years, 27.8% are aged between 35 and 54 years, and 9.7% are 55 years of age and over. Figure 1 illustrates the proportion in each age group at each level of intellectual disability. The larger proportion with mild intellectual disability in the 0-19 year age group reflects the numbers of children in special education who receive support services from the intellectual disability sector, many of whom do not transfer to the intellectual disability services after school. There is also a higher proportion in the 'not verified' category in this age group, as many young children do not receive a definitive diagnosis of their level of intellectual disability in their earlier years.

Figure 1. National Intellectual Disability Database, Ireland 2002.

**Age profile of total population, showing proportion at each level of intellectual disability in each age group.**



## TRENDS OVER TIME

### Recent trends

Prevalence rates for moderate, severe and profound intellectual disability for 1996 and 2002 are compared as these are the two most recent years in which a national census of the Irish population was taken and for which data from the National Intellectual Disability Database is available. Compared to the 1996 data (National Intellectual Disability Database Committee, 1997), the 2002 data in Table 2.3 demonstrate the following trends:

- A reduced prevalence rate for the 0-4 year age group.
- An upward trend in prevalence in the 5-9 year and 10-14 year age groups. This increase in prevalence is observed despite a fall in numbers in these age groups.

- A downward trend in prevalence in the 15-19 year, 20-34 year and 35-54 year age groups. This decrease in prevalence is observed in the 35-54 year age group despite a 17% increase in numbers since 1996.
- An almost unchanged prevalence rate for the 55 years and over age group which exhibited a 16% increase in numbers in the period.

The prevalence rate for the 0-4 year age group, at 0.79/1000, is considerably lower than expected. Applying the prevalence rate of 3.94/1000 for the 10-14 year age group, which is the internationally accepted rate for maximum ascertainment, it is estimated that the number of children aged 0-4 years recorded on the database may be underestimated by somewhere in the region of 875 cases. In compiling the database, attempts are made to discover every child with intellectual disability at the earliest possible age so as to plan the most comprehensive treatment and education possible, but respect is also given to the growing number of situations where parents are reluctant to register their child on the database at a very early age.

It is felt that the 2002 census of population data, which is used as the denominator for calculating prevalence rates for intellectual disability, is having a significant impact on the observed rates. The 2002 Census for the Republic of Ireland reports the highest population recorded in the state since 1996 and this growth is attributed by the Central Statistics Office to the natural increase in the population (more births than deaths) and historically high net inward migration. The general population growth is confined to the 0-4 year age group, which experienced growth of 10.9%, and the 20-34 year, 35-54 year, and 55 years and over age groups, which experienced growth rates of between 11.6% and 16.3%. The three age groups 5-9 years, 10-14 years, and 15-19 years experienced a decline in population of between 6.7% and 12.4%. As the numbers of individuals with intellectual disability have not experienced similar reductions, the data are now showing increased prevalence in the 5-9 and 10-14 year age groups. The 20-34 year and 35-54 year age groups are now showing decreased prevalence as the general population in these age groups has increased substantially but the numbers of people with intellectual disability in these age groups has not exhibited a corresponding growth rate. The Central Statistics Office reports that the 25-54 year age groups are most affected by immigration of non-Irish nationals and by returning Irish-born migrants but it is unlikely that there would be significant numbers of adults with intellectual disability within this group. The general population growth in the 0-4 year age group may reflect the children of either or both of these migrant groups and it is possible that some of these children may have an intellectual disability.

The demographic trends in the general population make interpretation of these results more complicated. The decrease in prevalence observed in the older adult age groups is considerably affected by marked demographic population changes and is masking a real increase in the number of adults with intellectual disability. Furthermore, as the primary purpose of the database is to plan services, the overall number of people affected is a more useful measure than the prevalence rate.

### **Past three decades**

Data from the 1974 and 1981 Censuses of Mental Handicap, carried out by the Medico-Social Research Board (Mulcahy, 1976; Mulcahy and Ennis, 1976; Mulcahy and Reynolds, 1984), enable us to monitor trends in this group over the past 28 years (Table 2.3).

The total number of those more severely affected is 14,557 in 2002, compared to 11,256 in 1974 (an increase of 29%). The prevalence rate in 1974 was 3.80 per thousand and is now 3.72 per thousand (Table 2.3). Of particular interest, from the point of view of service delivery, is that since 1996 this increase in numbers is confined to the two older age groups, the 35-54 year age group and the 55 years and over age group. The older age group, 55 years and over, which showed continued growth since 1996, shows a very slight decrease in numbers in 2002 when compared to 2001. The overall increase in numbers is influenced by a number of factors, including the general population increase during this period, improved standards of care, and an increase in the lifespan of people with intellectual disability.

The graphical representation of the combined data for moderate, severe and profound intellectual disability shown in Figures 2 and 3 indicates a distinct changing age profile over the 28-year period, with fewer children and young adults and more older adults availing of, or in need of, intellectual disability services.

#### *COHORT EFFECT*

There is a population bulge originating in the 1960s and lasting until the mid-1970s currently moving through the intellectual disability services. The growth in numbers with intellectual disability during the 1960s and 1970s is attributed to a high birth rate and improved obstetric and paediatric care. Data from the previous Censuses of Mental Handicap allow us to monitor the progress of this group through the services. In 1974 there was a high prevalence rate in the 10-14 year age group, which was observed as the peak prevalence rate in 1981 in the 15-19 year age group and in the 20-34 year age group in 1996 and 2002. Closer examination of Figure 2 shows that the concentration of this cohort in the 20-34 year age group has peaked and that the prevalence rate for the 35-54 year age group, which had been considerably lower, is now similar to that found in the 20-34 year age group.

### **Ageing population**

Figure 4 provides further evidence that the population of people with intellectual disability in the Republic of Ireland is an ageing population. By grouping people with moderate, severe and profound intellectual disability in the 35-54 and the 55-and-over age groups, it can be seen that in 1974, 29% of this population, and in 1981, 27% of this population, were aged 35 years and over. A steady increase in the proportion aged 35 and over has been observed in each dataset since 1996, from 38% in 1996 to 45% in the 2002 dataset. Increased longevity in this population is attributed in the research literature to improved health and well-being, the control of infectious diseases, the move to community living, improved nutrition, and the quality of health care services.

Table 2.3. National Intellectual Disability Database, Ireland 2002.  
**Age and degree of intellectual disability (moderate, severe and profound): 1974, 1981, 1996, 2002.**

Numbers												
Age Group	Moderate				Severe				Profound			
	1974	1981	1996	2002	1974	1981	1996	2002	1974	1981	1996	2002
0-4	189	214	226	145	143	92	83	57	99	26	30	17
5-9	809	955	736	645	617	330	260	257	224	99	77	52
10-14	752	1035	948	806	583	428	305	271	292	117	93	48
15-19	698	1203	1072	947	445	508	378	287	241	154	132	75
20-34	1498	2419	2997	2912	1017	1129	1350	1158	441	340	460	353
35-54	1321	1559	2626	2936	626	612	1183	1500	201	97	343	425
55 & over	669	715	987	1104	307	248	394	474	84	24	53	88
All Ages	5936	8100	9592	11497	3738	3347	3953	4004	1582	857	1188	1058
Prevalence Rates												
0-4	0.60	0.62	0.83	0.52	0.45	0.27	0.30	0.21	0.31	0.07	0.11	0.06
5-9	2.55	2.73	2.31	2.44	1.95	0.94	0.82	0.97	0.71	0.28	0.24	0.20
10-14	2.52	3.08	2.72	2.82	1.95	1.27	0.88	0.95	0.98	0.35	0.27	0.17
15-19	2.61	3.79	3.20	3.02	1.66	1.60	1.13	0.92	0.90	0.48	0.39	0.24
20-34	2.78	3.33	3.93	3.08	1.88	1.56	1.77	1.22	0.82	0.47	0.60	0.37
35-54	2.13	2.43	3.25	2.81	1.01	0.95	1.46	1.44	0.32	0.15	0.42	0.41
55& over	1.08	1.09	1.45	1.40	0.50	0.38	0.58	0.60	0.14	0.04	0.08	0.11
All Ages	1.99	2.35	2.72	2.94	1.25	0.97	1.12	1.02	0.53	0.25	0.34	0.27
					3.80	3.60	4.18	3.72				



Figure 2. National Intellectual Disability Database, Ireland 2002.

**Prevalence of moderate, severe and profound intellectual disability (combined) by age group: 1974, 1981, 1996, 2002.**

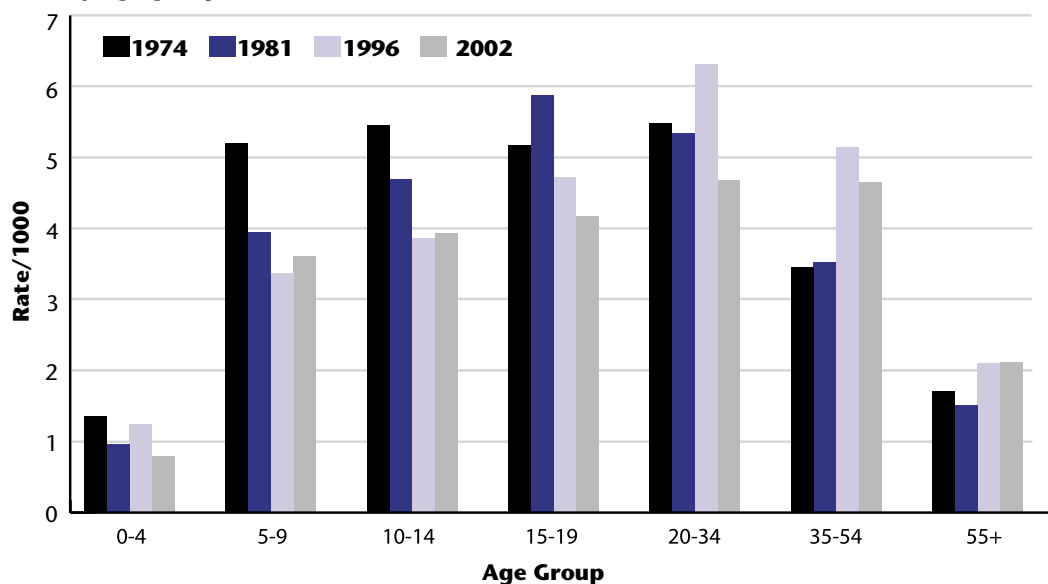
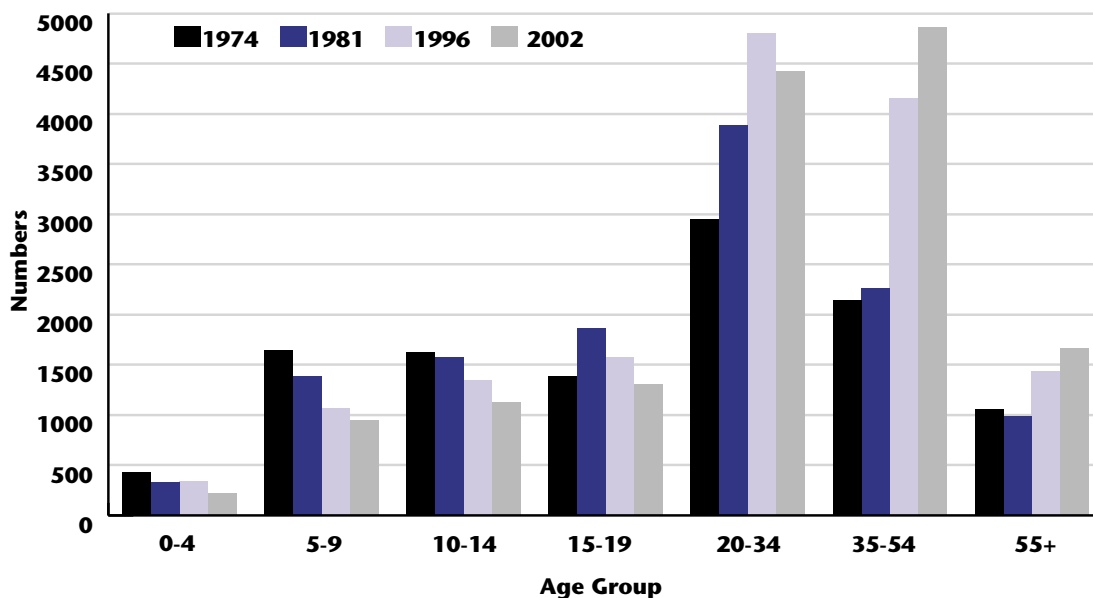


Figure 3. National Intellectual Disability Database, Ireland 2002.

**Numbers with moderate, severe, and profound intellectual disability (combined) by age group: 1974, 1981, 1996, 2002.**



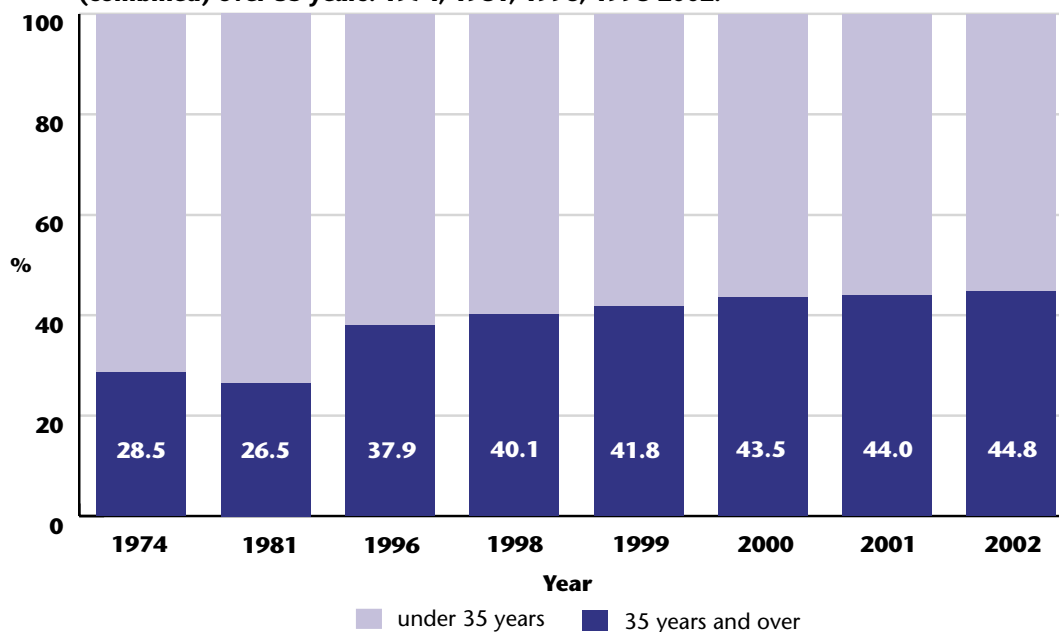
### Impact of observed trends

As previous reports from the National Intellectual Disability Database have highlighted, the changing age structure among those with moderate, severe and profound intellectual disability has major implications for service planning in the years ahead as this is where the demands on the health services are most acute:

- Increased pressure will be experienced by residential services and is reflected in the current waiting lists for full-time residential services.

Figure 4. National Intellectual Disability Database, Ireland 2002.

**Proportion of people with moderate, severe, and profound intellectual disability (combined) over 35 years: 1974, 1981, 1996, 1998-2002.**



- Improved life expectancy among adults with severe intellectual disability will place an increased demand on the health services and pose new challenges to health care professionals.
- The majority of adults with intellectual disability continue to live with their families and as these caregivers age beyond their care-giving capacity, residential supports will be required.
- Additional therapeutic support services will also be required for people who wish to continue to live with their families to enable this caring arrangement to continue.
- Another implication of ageing and the increase in the severely disabled population will be the demand for a higher degree of support within day and residential services and the need to develop specific geriatric support services.

Taken together, the combined effects of the baby-boom generation and increased longevity will result in significant demand for additional resources. This demand is now presenting, and will continue to present, major challenges to service planners and providers.

## Health Board Level

### *NUMBERS ON EACH REGIONAL DATABASE*

Table 2.4 details the number of individuals included on each of the regional databases in April 2002. Each health board has responsibility for collecting the required information for all individuals who are in receipt of, or in need of, intellectual disability services within their health board region.

Table 2.4. National Intellectual Disability Database, Ireland 2002.

**Number of people included on each Regional Intellectual Disability Database.**

	<b>n</b>	<b>%</b>
Eastern Regional Health Authority	8404	33.0
Midland Health Board	1410	5.5
Mid-Western Health Board	2383	9.4
North-Eastern Health Board	1980	7.8
North-Western Health Board	1777	7.0
South-Eastern Health Board	3170	12.5
Southern Health Board	3765	14.8
Western Health Board	2559	10.1
<b>Total</b>	<b>25448</b>	<b>100.0</b>

Table 2.5 summarises the number and proportion of people at each level of intellectual disability in each health board.

Table 2.5. National Intellectual Disability Database, Ireland 2002.

**Degree of intellectual disability by health board area.**

	<b>Not Verified</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Profound</b>	<b>All Levels</b>
	<b>n %</b>	<b>n %</b>	<b>n %</b>	<b>n %</b>	<b>n %</b>	<b>n %</b>
Eastern Regional Health Authority	652 7.8	2941 35.0	3208 38.2	1262 15.0	341 4.1	8404 100.0
Midland Health Board	32 2.3	470 33.3	652 46.2	213 15.1	43 3.0	1410 100.0
Mid-Western Health Board	59 2.5	1012 42.5	876 36.8	348 14.6	88 3.7	2383 100.0
North-Eastern Health Board	120 6.1	708 35.8	777 39.2	304 15.4	71 3.6	1980 100.0
North-Western Health Board	180 10.1	628 35.3	636 35.8	280 15.8	53 3.0	1777 100.0
South-Eastern Health Board	212 6.7	1288 40.6	1038 32.7	449 14.2	183 5.8	3170 100.0
Southern Health Board	143 3.8	1433 38.1	1374 36.5	602 16.0	213 5.7	3765 100.0
Western Health Board	81 3.2	932 36.4	934 36.5	546 21.3	66 2.6	2559 100.0
<b>Total</b>	<b>1479 5.8</b>	<b>9412 37.0</b>	<b>9495 37.3</b>	<b>4004 15.7</b>	<b>1058 4.2</b>	<b>25448 100.0</b>

## REGIONAL VARIATION IN PREVALENCE

The 1981 Census revealed considerable differences between health board areas in the prevalence rates of moderate, severe and profound intellectual disability. The data collection method used by the National Intellectual Disability Database does not seek information as to place of birth so it is not possible to compare prevalence in different areas for all age groups. However, for an individual aged under 25 years, the health board with responsibility for providing services to that person is recorded and, as this would generally be the health board in which the person was born, the prevalence rates for the 0-19 year age groups are compared with some confidence (Table 2.6). There is some variation in prevalence rates between health board areas. The prevalence of moderate, severe and profound intellectual disability in the 0-19 year age group is highest in the Midland Health Board and lowest in the North-Eastern Health Board. There is a geographical pattern observable in this table, with the highest rate in the Midland Health Board, followed in sequence by the health boards along the western seaboard and the lowest rates being observed in the health boards along the eastern seaboard. These variations are most likely due to demographic factors such as higher migration from rural areas and older maternal age, and may also be due to differences in ascertainment and classification practices.

Table 2.6. National Intellectual Disability Database, Ireland 2002.

**Prevalence rates for 0-19 year age groups by geographical region (moderate, severe and profound intellectual disability combined).**

	<b>0-4 years</b>	<b>5-9 years</b>	<b>10-14 years</b>	<b>15-19 years</b>	<b>0-19 years</b>
	<b>n</b>	<b>n</b>	<b>n</b>	<b>n</b>	<b>n</b>
	<b>rate</b>	<b>rate</b>	<b>rate</b>	<b>rate</b>	<b>rate</b>
Eastern Regional Health Authority	34 0.35	296 3.33	346 3.67	411 3.84	1087 2.81
Midland Health Board	19 1.09	61 3.69	96 5.37	92 4.91	268 3.80
Mid-Western Health Board	16 0.67	81 3.49	112 4.51	113 4.04	322 3.22
North-Eastern Health Board	6 0.22	86 3.44	101 3.74	103 3.64	296 2.75
North-Western Health Board	14 0.88	54 3.37	71 3.99	91 4.92	230 3.37
South-Eastern Health Board	35 1.13	116 3.89	112 3.40	140 4.07	403 3.14
Southern Health Board	51 1.29	144 3.70	169 4.03	225 4.88	589 3.53
Western Health Board	44 1.73	116 4.51	118 4.07	134 4.18	412 3.67
<b>All Regions</b>	<b>219</b>	<b>954</b>	<b>1125</b>	<b>1309</b>	<b>3607</b>
<b>Rate</b>	<b>0.79</b>	<b>3.61</b>	<b>3.94</b>	<b>4.18</b>	<b>3.16</b>



# Chapter three

# 3. Service Provision in 2002

## National Level

### SUMMARY OF SERVICE PROVISION

In 2002, 23,050 people with intellectual disability were receiving services, which accounted for 90.6% of the total population registered on the National Intellectual Disability Database, compared to a service provision level of 89.6% in 2001. A further 2,398 people were identified as not being in receipt of services, of whom 468 expressed a need for services in the period 2003-2007. A summary of the overall level of service provision in 2002 is provided in Table 3.1.

Table 3.1. National Intellectual Disability Database, Ireland 2002.  
**Summary of service provision in 2002.**

	<b>n</b>	<b>%</b>
Receiving day services	14901	58.6
Receiving 5- or 7-day residential services	7587	29.8
Resident in a psychiatric hospital	515	2.0
Receiving residential support services only	47	0.2
Receiving no service	468	1.8
No identified service requirements	1930	7.6
<b>Total</b>	<b>25448</b>	<b>100.0</b>
<b>Note:</b> 3,619 day attenders and 278 full-time residents receive residential support services in addition to their principal service. 7,542 full-time residents receive a day service in addition to their full-time residential service.		

Table 3.2 summarises service provision in 2002 by degree of intellectual disability and age group.

### Without services

In 2002 there were 468 people (1.8%) without services and who had identified service needs in the period 2003-2007, details of which are presented in Chapter 4. This figure represents a reduction of 47, or 9%, in the number of people in this category since 2001. Almost two-thirds of this group are in the 'not verified' (11%) and mild (52%) categories of intellectual disability and 37% have a moderate, severe or profound level of intellectual disability. Eighty-seven per cent are aged 19 and over.

Table 3.2. National Intellectual Disability Database, Ireland 2002.

**Summary of service provision in 2002 by degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Receiving day services	923	230	1153	3550	3181	6731	2975	4042	7017	7448	7453	14901
Receiving 5- or 7-day residential services	10	42	52	80	1114	1194	292	6049	6341	382	7205	7587
Resident in a psychiatric hospital	0	8	8	0	137	137	0	370	370	0	515	515
Receiving residential support services only	0	3	3	2	20	22	1	21	22	3	44	47
Receiving no service	14	35	49	22	222	244	17	158	175	53	415	468
No service requirements in 2002	60	154	214	89	995	1084	50	582	632	199	1731	1930
<b>Total</b>	<b>1007</b>	<b>472</b>	<b>1479</b>	<b>3743</b>	<b>5669</b>	<b>9412</b>	<b>3335</b>	<b>11222</b>	<b>14557</b>	<b>8085</b>	<b>17363</b>	<b>25448</b>



A further 1,930 people (7.6%) were also without services but had no identified requirement for services within the five-year period 2003-2007. This number has reduced by 335 since 2001. Of this group with no identified service requirements, 602 have their circumstances formally reviewed annually and 397 have contingency service plans identified on the database. Ninety per cent are aged 19 and over.

Over two-thirds of this group are in the 'not verified' (11%) and mild (56%) categories of intellectual disability. The appropriateness of registering people with mild intellectual disability who have no identified need for services on the database is being monitored on an ongoing basis, as the primary function of the database is to register only people who are in receipt of intellectual disability services or who require such services within a five-year period. It is reasonable to assume that the group with mild intellectual disability genuinely do not require services at this time.

However, one-third of the group (632 people) who were without services but had no identified need for services between 2003 and 2007 have either a moderate, severe or profound degree of intellectual disability. Of this group, 263 have their circumstances formally reviewed annually and 200 have contingency service plans identified on the database. While these people may not wish to avail of services at this time, it is essential that their needs are monitored on a regular basis so that changing circumstances can be identified and responded to in a timely manner. Failure to anticipate the needs of this group can result in emergency admissions to services which may not be tailored to the specific needs of the individual. The National Intellectual Disability Database Committee remains concerned about the circumstances of 50 children within this group who have a moderate, severe, or profound intellectual disability and are not availing of services and have no identified need for services in the period 2003-2007. The Committee again urges health boards to monitor the circumstances of these children.

### **Availing of services**

There is a clear relationship between level of disability, age and the type of service availed of. Individuals attending services on a day basis tend to be younger and in the less severe range of intellectual disability, while residential services are used primarily by adults with moderate, severe and profound levels of intellectual disability.

In 2002, 14,901 individuals were accessing services on a day basis. Forty-five per cent had a mild level of intellectual disability and 50% were aged 18 years and under. There were 7,587 full-time residents in intellectual disability services in 2002, of whom 84% had a moderate, severe or profound degree of disability, and 95% were aged 19 years and over. All 515 individuals with an intellectual disability residing in psychiatric hospitals in 2002 were aged 19 years and over and 72% had a moderate, severe or profound degree of intellectual disability. A further 47 individuals registered on the database in 2002 were availing of residential support services only.

### **RESIDENTIAL CIRCUMSTANCES**

Table 3.3 outlines the main residential circumstances of those registered on the National Intellectual Disability Database in 2002. Almost two-thirds (61%) live in a home setting with parents, relatives, or foster parents. The remainder of the population live in full-time residential services (34%), mainly residential centres, community group homes, and psychiatric hospitals,

or they live independently or semi-independently (3%). There are 12 people registered on the database who have no fixed abode, a decrease of one since 2001. There is insufficient information on the residential circumstances of 1,231 people registered on the database (5%), a reduction of 80 people since 2001. This group needs to be further reviewed as a matter of urgency to improve the overall quality of data available from the National Intellectual Disability Database. Of the 1,231 records with insufficient information, 1,198 (97%) were returned by the Eastern Regional Health Authority.

There were 8,102 people in receipt of full-time residential services in 2002, a net reduction of 194 people since 2001. A reduction in full-time places since 2001 was evident in four health boards. This finding was followed up with the relevant health boards and the reduction is attributed to the deaths of individuals in inappropriate full-time residential placements that are not being refilled, individuals described in the 2001 data as full-time residents but who, it has been established on further evaluation of their information, were incorrectly recorded and many of whom are in receipt of residential support services only, and the previous registration on the database of individuals with mild intellectual disability who were living in non-specialised services, such as nursing homes, but were removed from the database during recent refinements as they did not meet the registration criteria for the database.

Of those in receipt of full-time residential services, 3,267 live in community group homes (up from 3,097 in 2001), 3,461 live in residential centres (up from 3,444 in 2001), 503 receive special intensive placements, either because they have profound or multiple disabilities or because they have special requirements due to challenging behaviour (up from 402 in 2001), and 54 reside in nursing homes. As part of the 2002 review and update of the National Intellectual Disability Database, health boards were requested to assign individuals previously described as being resident in de-designated units to the appropriate residential centre or community group home category that best described their residential circumstances.

The 2002 data indicate that 103 of the full-time residents were occupying residential support places on a full-time basis, thereby blocking these services from their intended use. A further 199 people were described as receiving full-time residential services described as 'other'. As part of the 2003 review and update of the National Intellectual Disability Database, the Health Research Board has asked health boards to validate records which indicate that the individual is occupying a residential support place on a full-time basis. Health boards were also asked to review records where the service description is 'other' to establish if an existing residential service code could be used to describe the placement.

In 2002 there were 515 people with intellectual disability accommodated in psychiatric hospitals, a reduction of 162 (24%) since 2001.

Table 3.3. National Intellectual Disability Database, Ireland 2002.

**Main residential circumstances.**

	<b>n</b>	<b>%</b>
<b>Home Setting</b>	<b>15448</b>	<b>60.7</b>
At home with both parents	10806	42.5
At home with one parent	3236	12.7
At home with sibling	834	3.3
At home with other relative	281	1.1
Living with non-relative	41	0.2
Adoption	28	0.1
Foster care and boarding-out arrangements	222	0.9
<b>Independent Setting</b>	<b>655</b>	<b>2.6</b>
Living independently	460	1.8
Living semi-independently	195	0.8
<b>Community Group Homes</b>	<b>3267</b>	<b>12.8</b>
5-day community group home	580	2.3
7-day (48-week) community group home	725	2.8
7-day (52-week) community group home	1962	7.7
<b>Residential Centres</b>	<b>3461</b>	<b>13.6</b>
5-day residential centre	140	0.6
7-day (48-week) residential centre	703	2.8
7-day (52-week) residential centre	2618	10.3
<b>Other full-time services</b>	<b>1374</b>	<b>5.4</b>
Nursing home	54	0.2
Psychiatric hospital	515	2.0
Intensive placement (challenging behaviour)	284	1.1
Intensive placement (profound or multiple handicap)	219	0.9
Occupying a residential support place	103	0.4
Other full-time residential service	199	0.8
<b>No fixed abode</b>	<b>12</b>	<b>0.0</b>
<b>Insufficient information</b>	<b>1231</b>	<b>4.8</b>
<b>Total</b>	<b>25448</b>	<b>100.0</b>

**Main residential circumstances: age group and degree of intellectual disability**

Table 3.4 provides an overview of the type of main residential circumstances by degree of intellectual disability and age group. A detailed breakdown of the information in this table is presented in Table B1 in Appendix B.

Table 3.4. National Intellectual Disability Database, Ireland 2002.

**Main residential circumstances, degree of intellectual disability and age group.**

	Not Verified					Mild					Moderate, Severe & Profound					All Levels				
	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total
Home setting	972	114	106	30	1222	3864	1944	916	140	6864	3205	2502	1393	262	7362	8041	4560	2415	432	15448
Independent setting	0	9	22	14	45	3	131	264	84	482	0	21	75	32	128	3	161	361	130	655
Community group home	3	2	12	6	23	65	189	374	168	796	122	692	1300	334	2448	190	883	1686	508	3267
Residential centre	5	3	4	2	14	11	47	106	115	279	167	800	1524	677	3168	183	850	1634	794	3461
Other full-time services	3	3	8	9	23	11	55	88	102	256	71	304	428	292	1095	85	362	524	403	1374
No fixed abode	0	1	0	0	1	0	6	2	0	8	0	1	2	0	3	0	8	4	0	12
Insufficient information	44	34	44	29	151	66	289	280	92	727	42	103	139	69	353	152	426	463	190	1231
<b>Total</b>	<b>1027</b>	<b>166</b>	<b>196</b>	<b>90</b>	<b>1479</b>	<b>4020</b>	<b>2661</b>	<b>2030</b>	<b>701</b>	<b>9412</b>	<b>3607</b>	<b>4423</b>	<b>4861</b>	<b>1666</b>	<b>14557</b>	<b>8654</b>	<b>7250</b>	<b>7087</b>	<b>2457</b>	<b>25448</b>

### *AGE DIFFERENCES*

There are striking differences in the age profile of individuals in the various categories of accommodation. The proportion of people living in a home setting decreases with age – 93% of all 0-19-year-olds live in a home setting, declining to 63% of those aged between 20-34 years, 34% of those aged 35-54 years, and 18% of those aged 55 years and over.

The data indicate that, among those aged 35 years and over, 30% of all people with intellectual disability, and 26% of those with moderate, severe and profound intellectual disability, continue to live with their families. Planning for the future care of these individuals and avoiding crisis situations when family carers can no longer provide care is of paramount importance.

The proportion of people in the different age categories who are living in full-time residential services increases with age – 5% of all 0-19-year-olds are in receipt of full-time residential services, compared to 29% of 20-34-year-olds, 54% of 35-54-year-olds, and 69% of those aged 55 years and over.

### *DEGREE OF INTELLECTUAL DISABILITY*

There are also noticeable variations between level of ability and type of accommodation. Of those people with a mild intellectual disability, 73% live in a home setting, compared to 51% of those with a moderate, severe or profound intellectual disability. In the more severe categories of disability, the proportion of people in full-time residential services is increased. Only 14% of people with a mild intellectual disability live in full-time residential services but this increases to 46% in the case of those with a moderate, severe or profound disability.

Where individuals are in full-time residential services, the type of service varies according to level of intellectual disability. Of those in the mild range of intellectual disability who are in full-time residential services, 60% are in community group homes, 21% are in residential centres, and 19% are in other full-time residential services. Of those in full-time residential services who have a moderate, severe or profound intellectual disability, 36% are in community group homes, 47% are in residential centres and 16% are in other full-time residential services.

### *DAY SERVICES*

In 2002, 22,443 people, representing 88.2% of all those registered on the National Intellectual Disability Database, were availing of day services. This represents a decrease of 305 people availing of day services since 2001.

#### **Residential status of people availing of day services**

Day services are availed of by people who live at home or in independent living settings in the community and by people who are also receiving full-time residential services. Table 3.5 summarises the level of disability and age groups of people availing of day services according to their residential status.

Table 3.5. National Intellectual Disability Database, Ireland 2002.

**Residential status of people availing of day services by degree of intellectual disability and age group**

	<b>Not Verified</b>			<b>Mild</b>			<b>Moderate, Severe &amp; Profound</b>			<b>All Levels</b>		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Residents	8	42	50	78	1153	1231	283	5978	6261	369	7173	7542
Day Attenders	923	230	1153	3550	3181	6731	2975	4042	7017	7448	7453	14901
<b>Total</b>	<b>931</b>	<b>272</b>	<b>1203</b>	<b>3628</b>	<b>4334</b>	<b>7962</b>	<b>3258</b>	<b>10020</b>	<b>13278</b>	<b>7817</b>	<b>14626</b>	<b>22443</b>

Of those availing of day services, 34% (7,542) are also in full-time residential services, the majority of whom are in the moderate, severe or profound range of intellectual disability (83%) and aged 19 years and over (95%). The remaining 66% (14,901) attend services on a daily basis, of whom 45% are in the mild range of intellectual disability and 50% are aged 18 years and under.

The 2002 data indicate that 560 full-time residents have no day activity programme. The day service needs of this group, where identified, are documented in the fourth chapter of this report.

Table 3.6 presents details of the principal day services provided in 2002 both to residents and to those who attend services on a day basis.

The top five day activities availed of by people with intellectual disability in 2002, and accounting for 71% of day service provision, were: activation programmes, sheltered work, special schools, special vocational training, and supported employment (Table 3.6a). People who attend services on a day basis are availing mainly of educational, training and work programmes, reflecting both the higher level of ability and younger age profile of people in this category. Activation programmes are provided to 11% of day attenders. Those in full-time residential services are much more likely to avail of services such as activation programmes, sheltered work, special high-support programmes, and specific programmes for older people.

**Main day services by age group and degree of intellectual disability**

Table 3.7 provides details of the principal day services availed of in 2002, categorised by age group and degree of intellectual disability.

Table 3.6. National Intellectual Disability Database, Ireland 2002.

**Principal day service by category of persons availing of day services.**

	<b>Residents</b>	<b>Day Attenders</b>	<b>Total</b>
Home support	3	221	224
Home help	0	13	13
Early services	2	527	529
Mainstream pre-school	1	157	158
Special pre-school for intellectual disability	5	529	534
Child education and development centre	69	425	494
Mainstream school	3	735	738
Resource/visiting teacher	2	231	233
Special class - primary level	14	627	641
Special class - secondary level	11	242	253
Special school	278	3959	4237
Special vocational training centre	257	1171	1428
Activation centre	3348	1559	4907
Programme for the older person	329	95	424
Special high-support day service	369	79	448
Special intensive day service	175	44	219
Sheltered work centre - includes long-term training schemes	1893	2483	4376
Sheltered employment centre	21	99	120
Multidisciplinary support service	347	258	605
Centre-based day respite service	1	9	10
Other day service	167	259	426
Enclave within open employment	12	7	19
Supported employment	159	758	917
Open employment	24	107	131
Generic vocational training	27	251	278
Generic day services	25	56	81
<b>Total</b>	<b>7542</b>	<b>14901</b>	<b>22443</b>

Table 3.6a. National Intellectual Disability Database, Ireland 2002.

**Top five activities for people with intellectual disability.**

<b>Top five day activities All</b>	<b>%</b>	<b>Top five day activities Day attenders</b>	<b>%</b>	<b>Top five day activities Residents</b>	<b>%</b>
Activation centre	21.9	Special school	26.6	Activation centre	44.4
Sheltered work centre	19.5	Sheltered work centre	16.7	Sheltered work centre	25.1
Special school	18.9	Activation centre	10.5	Special high-support service	4.9
Special vocational training	6.4	Special vocational training	7.9	Multidisciplinary supports	4.6
Supported employment	4.1	Supported employment	5.1	Programme for older people	4.4

Table 3.7. National Intellectual Disability Database, Ireland 2002.

**Principal day service, degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Home support	21	6	27	14	58	72	15	110	125	50	174	224
Home help	1	2	3	0	4	4	0	6	6	1	12	13
Early services	362	0	362	73	0	73	94	0	94	529	0	529
Mainstream pre-school	79	0	79	41	1	42	37	0	37	157	1	158
Special pre-school for intellectual disability	172	0	172	113	0	113	246	3	249	531	3	534
Child education and development centre	29	0	29	32	1	33	379	53	432	440	54	494
Mainstream school	69	0	69	484	17	501	166	2	168	719	19	738
Resource/visiting teacher	65	1	66	133	2	135	28	4	32	226	7	233
Special class - primary level	23	2	25	393	21	414	194	8	202	610	31	641
Special class - secondary level	1	0	1	181	22	203	42	7	49	224	29	253
Special school	66	3	69	2041	118	2159	1922	87	2009	4029	208	4237
Special vocational training centre	0	31	31	26	569	595	19	783	802	45	1383	1428
Activation centre	1	57	58	2	529	531	25	4293	4318	28	4879	4907
Programme for the older person	0	17	0	0	85	85	0	322	322	0	424	424
Special high-support day service	4	2	6	5	27	32	25	385	410	34	414	448
Special intensive day service	1	0	1	9	9	18	12	188	200	22	197	219
Sheltered work centre	0	82	82	8	1614	1622	4	2668	2672	12	4364	4376
Sheltered employment centre	0	3	3	0	87	87	0	30	30	0	120	120
Multidisciplinary support service	32	11	43	14	135	149	14	399	413	60	545	605
Centre-based day respite service	0	1	1	1	3	4	0	5	5	1	9	10
Other day service	2	6	8	33	159	192	33	193	226	68	358	426
Enclave within open employment	0	0	0	0	10	10	0	9	9	0	19	19
Supported employment	0	18	18	1	571	572	0	327	327	1	916	917
Open employment	0	4	4	4	104	108	0	19	19	4	127	131
Generic vocational training	3	25	15	19	171	190	2	58	60	24	254	278
Generic day services	0	1	1	1	17	18	1	61	62	2	79	81
<b>Total</b>	<b>931</b>	<b>272</b>	<b>1203</b>	<b>3628</b>	<b>4334</b>	<b>7962</b>	<b>3258</b>	<b>10020</b>	<b>13278</b>	<b>7817</b>	<b>14626</b>	<b>22443</b>



### *AGE DIFFERENCES*

Of those availing of day services in 2002, 35% are aged 18 years and under, and 65% are 19 years and over.

In 2002 there were 7,817 individuals aged 18 years and under accessing day services. The majority are in mainstream or special education services at primary and secondary level, availing of early intervention and both mainstream and specialised pre-school services, or are attending Child Education and Development Centres. Some young adults at the upper end of the age group have moved into training and employment placements. A small group of those aged 18 years and under are availing of high-support or intensive services and activation programmes.

There were 14,626 adults availing of day services in 2002. Most adults attend either activation centres (33%) or sheltered work centres (30%). The next largest groups are concentrated in the areas of special vocational training (9%), supported employment (6%), multidisciplinary support services (4%), programmes for older people (3%), and special high-support day services (3%).

### *DEGREE OF INTELLECTUAL DISABILITY*

Of those receiving day services in 2002, 36% have a mild intellectual disability, 59% have a moderate, severe or profound intellectual disability, and 5% have not yet had their degree of intellectual disability established.

The age profile of these groups is quite different. Only one in four (25%) of the population with moderate, severe and profound intellectual disability who are availing of day services is aged 18 years and under, whereas almost one in two (46%) of the population with mild intellectual disability who are availing of day services is aged 18 years and under. The higher number of children with mild intellectual disability in receipt of services reflects the number of children in special education, many of whom do not transfer to the adult intellectual disability services upon leaving school.

Of the children availing of day services in 2002, 46% have a mild degree of intellectual disability, most of whom avail of special education services, with smaller numbers in mainstream schools and pre-school services. Forty-two per cent of the children in receipt of day services have a moderate, severe or profound intellectual disability and, while most are receiving special education services, smaller numbers are in mainstream education or pre-school services and some also avail of more intensive services such as child education and development centres.

Of the 14,626 adults in receipt of day services in 2002, 30% have a mild degree of intellectual disability, 68% are in the moderate, severe, or profound range, and 2% have not had their degree of intellectual disability established. Most adults with a mild degree of intellectual disability who are registered on the database attend sheltered work centres (37%), are in supported employment (13%), are in receipt of special vocational training (13%), or avail of activation programmes (12%). The adults with moderate, severe or profound intellectual disability are most likely to be in receipt of activation programmes (43%), followed by sheltered work (27%), special vocational training (9%), multidisciplinary support services (4%), and high-support programmes (4%).

## OVERALL LEVEL OF SERVICE PROVISION IN 2002

### Background

The National Intellectual Disability Database permits the recording of two different types of residential service and day service (main and secondary) for each person on the database. The analyses of existing levels of service provision in Tables 3.8 and 3.9 are a combination of the main and secondary services under the day and residential programmes and are representative of the overall level of service provision.

The 2002 dataset is the sixth in a series that commenced in 1996, followed by 1998, 1999, 2000, and 2001. The first and fourth datasets, from 1996 (National Intellectual Disability Database Committee, 1997) and 2000 (Mulvany, 2001), have been selected for comparison with the 2002 data. The 1996 dataset is selected because it is the first in the series and the 2000 dataset is selected as a benchmark at the beginning of the significant investment programme in intellectual disability services over the period 2000-2002. The development within services over the three datasets is illustrated in Figures 5 and 6. If a particular service did not exist or was not captured by the National Intellectual Disability Database in 1996, growth rates are reported for the period 2000-2002 only.

The numbers presented in both the tables and graphs exceed the actual number of people with an intellectual disability in each of the service categories, as a number of people avail of two different types of service.

### Overall level of residential service provision in 2002

Table 3.8 details the overall number of residential services provided to this population in 2002.

In addition to the principal residential circumstances reported in Table 3.3, there exists a wide range of residential support services which are designed to assist people with intellectual disabilities to continue living with their families and in their communities. These residential supports range from holiday breaks with host families and service-based respite breaks, to the provision of regular, part-time care and supported living arrangements.

### Trends in residential service provision: 1996 to 2002

Figure 5 illustrates the growth in full-time residential services and residential support services during the period 1996-2002.

Key developments in the provision of full-time residential services in the period 1996-2002 include a 37% increase in the number of people with intellectual disability living in community group homes and a 165% increase in the number of intensive placements specially designed to cater for the needs of people with challenging behaviours, with 83 additional places being recorded between 2001 and 2002 alone. There has been a 47% reduction in the number of people with intellectual disability accommodated in psychiatric hospitals within the period 1996-2002, with 162 fewer people recorded between 2001 and 2002 alone.

Between 1996 and 2002 there has been tremendous growth in the number of residential support places available. In particular, the data show a 255% increase in the number of individuals availing of service-based respite services either as a planned or emergency intervention, with an additional 443 people recorded as being in receipt of planned or emergency respite services between 2001 and 2002, bringing the total number availing of respite services to 3,090.

Table 3.8. National Intellectual Disability Database, Ireland 2002.

**Overall level of residential service provision in 2002, degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
5-day community group home	0	6	6	33	116	149	30	395	425	63	517	580
7-day (48-week) community group home	0	1	1	9	134	143	21	560	581	30	695	725
7-day (52-week) community group home	2	14	16	17	487	504	49	1393	1442	68	1894	1962
5-day residential centre	2	0	2	1	7	8	27	103	130	30	110	140
7-day (48-week) residential centre	2	0	2	2	65	67	36	598	634	40	663	703
7-day (52-week) residential centre	1	9	10	7	197	204	71	2333	2404	79	2539	2618
Nursing home	0	7	7	0	16	16	0	31	31	0	54	54
Psychiatric hospital	0	8	8	0	137	137	0	370	370	0	515	515
Intensive placement												
Intensive placement (challenging behaviour)	1	0	1	4	32	36	15	232	247	20	264	284
Intensive placement (profound or multiple disability)	2	0	2	0	11	11	24	182	206	26	193	219
Other full-time residential place	0	5	5	5	32	37	3	154	157	8	191	199
Occupying a residential support place	0	0	0	2	17	19	16	68	84	18	85	103
Holiday residential placement	0	1	1	9	44	53	10	112	122	19	157	176
Crisis or planned respite	45	18	63	145	412	557	895	1575	2470	1085	2005	3090
Occasional respite with host family	4	0	4	11	8	19	68	60	128	83	68	151
Shared care or guardianship	0	0	0	2	1	3	1	3	4	3	4	7
Regular part-time care (2/3 days per week)	0	0	0	7	10	17	18	44	62	25	54	79
Regular part-time care (every weekend)	1	0	1	0	0	0	5	4	9	6	4	10
Regular part-time care (alternate weeks)	0	0	0	0	8	8	7	33	40	7	41	48
Other residential service	0	0	0	1	5	6	4	5	9	5	10	15
Foster care and boarding-out arrangements	10	3	13	88	44	132	54	34	88	152	81	233
Living semi-independently	0	8	8	0	130	130	0	57	57	0	195	195
Living independently	0	37	37	2	355	357	0	71	71	2	463	465

Figure 5. National Intellectual Disability Database, Ireland 2002.  
**Changes in overall level of residential service provision 1996, 2000, 2002.**

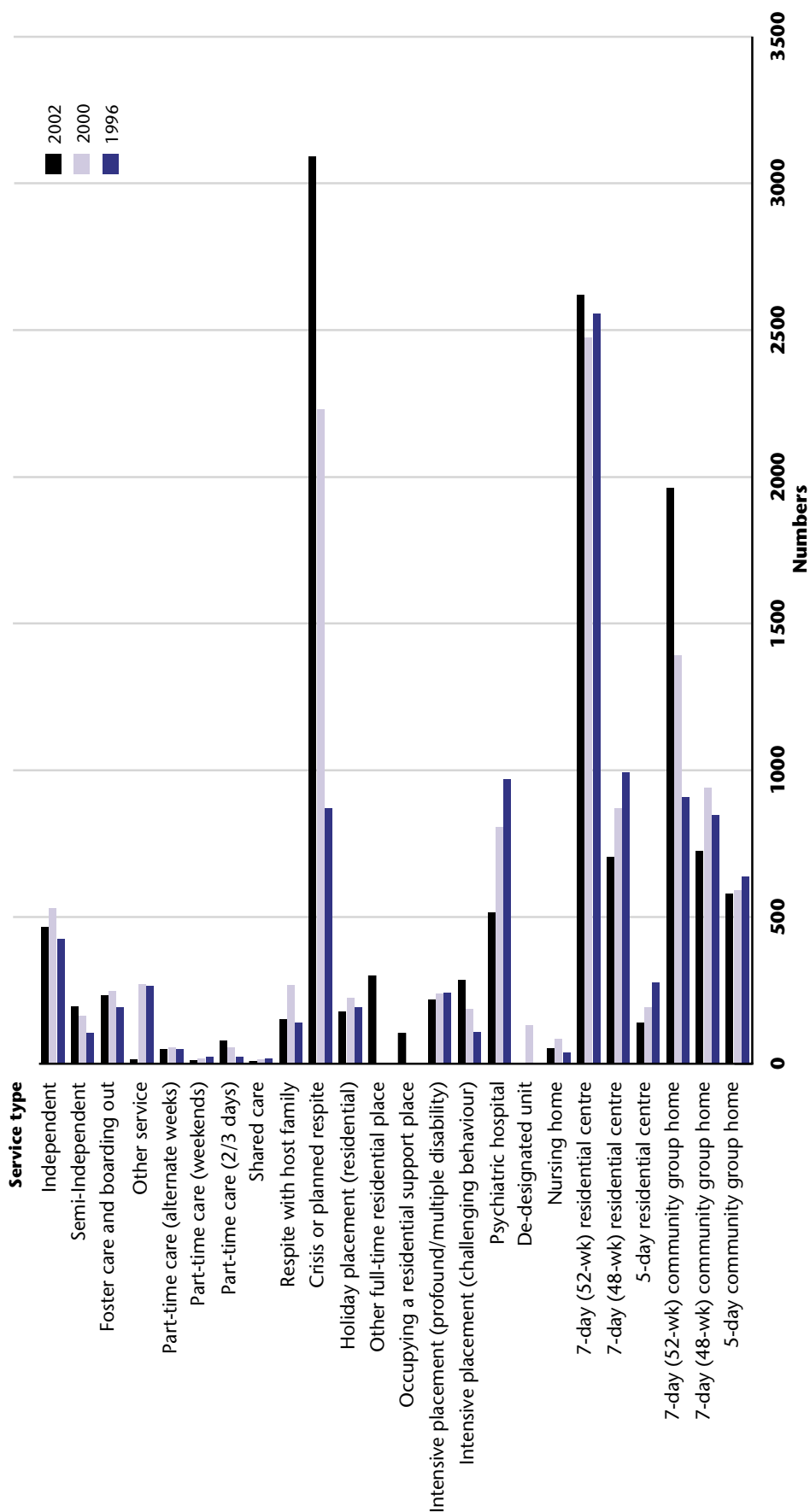
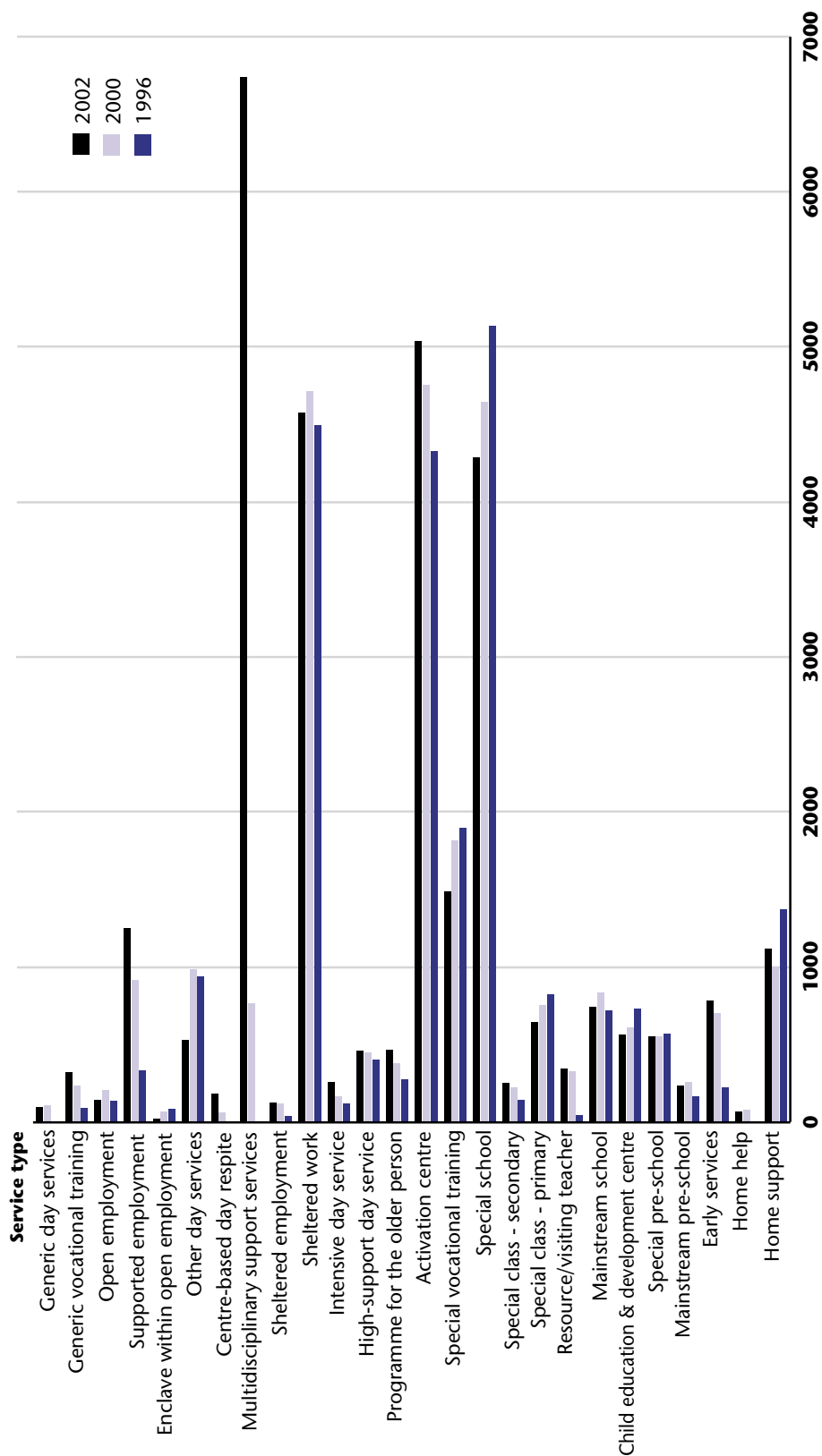


Table 3.9. National Intellectual Disability Database, Ireland 2002.

**Overall level of day service provision in 2002, degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Home support	90	14	104	93	131	224	361	427	788	544	572	1116
Home help	10	3	13	4	14	18	16	18	34	30	35	65
Early services	496	0	496	129	1	130	159	0	159	784	1	785
Mainstream pre-school	96	0	96	71	1	72	67	0	67	234	1	235
Special pre-school	181	0	181	116	0	116	250	3	253	547	3	550
Child education and development centre	32	0	32	32	2	34	432	66	498	496	68	564
Mainstream school	69	0	69	488	17	505	168	2	170	725	19	744
Resource/visiting teacher	81	4	85	158	17	175	63	18	81	302	39	341
Special class - primary	24	2	26	395	21	416	195	8	203	614	31	645
Special class - secondary	1	0	1	181	22	203	42	7	49	224	29	253
Special school	78	3	81	2041	119	2160	1958	88	2046	4077	210	4287
Special vocational training	0	31	31	45	582	627	32	795	827	77	1408	1485
Activation centre	1	59	60	3	572	575	27	4374	4401	31	5005	5036
Programme for the older person	0	18	0	0	99	99	0	350	350	0	467	467
High-support day service	4	2	6	6	27	33	26	391	417	36	420	456
Intensive day service	1	0	1	9	10	19	12	193	205	22	203	225
Sheltered work	0	84	84	8	1705	1713	4	2775	2779	12	4564	4576
Sheltered employment	0	3	3	0	89	89	0	30	30	0	122	122
Multidisciplinary support service	254	45	299	1049	838	1887	1156	3399	4555	2459	4282	6741
Centre-based day respite programme	2	2	4	27	15	42	59	76	135	88	93	181
Other day service	11	8	19	51	176	227	49	231	280	111	415	526
Enclave within open employment	0	0	0	0	12	12	0	10	10	0	22	22
Supported employment	0	18	18	1	733	734	0	497	497	1	1248	1249
Open employment	0	4	4	5	106	111	0	26	26	5	136	141
Generic vocational training	3	25	28	20	197	217	2	72	74	25	294	319
Generic day services	1	2	3	2	21	23	2	65	67	5	88	93

Figure 6. National Intellectual Disability Database, Ireland 2002.  
**Changes in overall level of day service provision 1996, 2000, 2002.**



### **Overall level of day service provision in 2002**

Table 3.9 provides details of the overall level of day service provision for people with intellectual disability. Of note in this table is the number of support services available to people with intellectual disability in addition to their substantive day service reported in Table 3.6; this includes services such as home support services, early services, resource/visiting teachers, centre-based day respite services, home help services, and multidisciplinary support services.

### **Trends in day service provision: 1996 and 2002**

Figure 6 illustrates the growth in day services during the period 1996-2002.

Since 1996 there has been an increase in the numbers of people availing of almost all adult day services. In some areas of service provision these increases are substantial, as Figure 6 illustrates. There has been a substantial increase of 920 (280%) in the number of people in supported employment. The number of people receiving either high-support or intensive day services has also increased over the period, with the level of provision of high-support services increasing by 14% and intensive services by 94%. Provision of specialised programmes designed for older people with intellectual disability has increased by 69%. The number availing of activation programmes has grown by 16% (710 places) during the period.

Reduced levels of adult service provision are observed in relation to enclaves within open employment, which have experienced a 74% decline but where numbers were always small in any case, and in special vocational training placements, which have declined by 22%. However there have been increases in the numbers availing of general vocational training opportunities (up from 87 to 319) and other employment opportunities.

Growth areas within children's services include the availability of resource/visiting teachers, with an additional 297 children availing of this service, and a continued growth in the number of young people attending special classes in second-level education. There have also been increases in the numbers of children in mainstream pre-schools and schools over the period 1996-2002, though numbers have declined in the period 2000-2002.

There is a decline in the numbers of children availing of certain special education services, including those in special classes at primary level, and those attending special schools. A reduction is also observed in the numbers of children attending Child Education and Development Centres. The reduction in numbers in these particular elements of service provision is attributed to the increased use of mainstream services described previously, and the overall reduction in the numbers of children with intellectual disability, as outlined in the second chapter of this report.

The 2002 dataset also demonstrates significant growth in the availability of support services which are delivered as part of a package of day services. Early services are being delivered to an additional 561 children since 1996, a growth rate of 250%, and growth is also recorded in centre-based day respite services. There has been phenomenal growth in the level of reporting of multidisciplinary support services for school-age children and adults. An additional 5,977 individuals are reported as being in receipt of these services since 2000, a 782% increase. An additional 5,128 individuals

are reported as being in receipt of this service since 2001.<sup>2</sup> The only area of support services showing a decline in numbers is the home support service, levels of which reduced by 19%.

### *RECENT INVESTMENT IN INTELLECTUAL DISABILITY SERVICES*

The growth in services documented in this section reflects the significant investment in the intellectual disability sector over the past few years. The availability of detailed information from the National Intellectual Disability Database has been a key factor in obtaining and allocating these additional resources and in monitoring their investment.

## Health Board Level

Table 3.10 provides details of the level of service provision in 2002 within each health board region.

Nationally, 90.6% of people with an intellectual disability registered on the National Intellectual Disability Database were in receipt of services. Regionally, the highest level of service provision was in the Western Health Board where 96.1% of the population registered on the database were receiving services. The lowest level of service provision was in the Eastern Regional Health Authority (ERHA) where 84.4% of the registered population with intellectual disability were in receipt of services.

Nationally, 31.8% of those registered on the National Intellectual Disability Database in 2002 were in receipt of a full-time residential service. Regionally, this proportion varied from 25.4% in the North-Eastern Health Board to 34.4% in the Western Health Board.

At national level, 58.6% of the database population were attending services on a daily basis and this proportion ranged from 50.9% in the Eastern Regional Health Authority to 67.6% in the North-Eastern Health Board.

Nationally, 1.8% were without services but were identified as requiring services in the five-year period 2003-2007. The North-Western Health Board had the highest proportion of people without any service and awaiting services within the next five years (5.4%). The Eastern Regional Health Authority had the lowest proportion, identifying just 0.5% of their population as being without services and requiring services between 2003 and 2007. Given that the Eastern Regional Health Authority also exhibits the lowest level of service provision it is likely that the numbers awaiting services in this region are under-reported.

There were considerable numbers of people registered on the database in 2002, 1,930 individuals or 7.6%, who were not availing of services and had no identified need for service within the five-year period 2003-2007. There are two likely explanations for this categorisation. Firstly, it is possible that some of this group are appropriately registered on the database but their service needs have not been adequately identified. However, it is also likely that a proportion of this group, who have a mild degree of intellectual disability, are inappropriately registered on the database, as they are not seeking to avail of specialised health services. The number of people so identified varies widely between health boards. The Eastern Regional Health Authority has the highest proportion of individuals in this category, at 15.2% of their registered population. The Western Health Board, which had the second highest level in this category in 2001 at 9.3% of all registrations, now has the lowest recorded proportion at 2.3%. The Western Health Board is to be commended for reviewing this group over the intervening period and removing from the database people who do not meet the criteria for registration.

<sup>2</sup> The method of identifying individuals in receipt of multidisciplinary support services was no different in 2002 than in previous years. However, for the first time the components of these services, e.g. speech and language therapy, physiotherapy, were listed on the data form and may have prompted people to record these therapeutic inputs, thereby resulting in the dramatic increase in the reporting of these services.



While efforts are being made to review and refine the database, the National Intellectual Disability Database Committee feels that the proportion of people with intellectual disability reported as being in receipt of services (90.6%) is still being kept artificially low because of the very high numbers of people described as having no identified service requirements in 2002 (1,930 individuals, of whom 66% are registered in the ERHA). A critical appraisal of these individuals is required to establish both their possible need for services and the appropriateness of their registration on the National Intellectual Disability Database. The National Intellectual Disability Database Committee urges the health boards involved to prioritise this work and so improve the overall quality of information held on the National Intellectual Disability Database.

Table 3.10. National Intellectual Disability Database, Ireland 2002.  
Service provision in 2002 by health board area.

	Receiving day services	Receiving 5- or 7-day residential services	Resident in a psychiatric hospital	Receiving residential support services only	Receiving no service	No service requirements in 2002	Total
	n	n	n	n	n	n	n
	%	%	%	%	%	%	%
Eastern Regional Health Authority	4274 50.9	2547 30.3	258 3.1	11 0.1	40 0.5	1274 15.2	8404 100.0
Midland Health Board	874 62.0	425 30.1	14 1.0	3 0.2	43 3.0	51 3.6	1410 100.0
Mid-Western Health Board	1422 59.7	758 31.8	22 0.9	4 0.2	58 2.4	119 5.0	2383 100.0
North-Eastern Health Board	1338 67.6	495 25.0	8 0.4	10 0.5	61 3.1	68 3.4	1980 100.0
North-Western Health Board	982 55.3	592 33.3	1 0.1	12 0.7	96 5.4	94 5.3	1777 100.0
South-Eastern Health Board	2042 64.4	812 25.6	103 3.2	3 0.1	98 3.1	112 3.5	3170 100.0
Southern Health Board	2390 63.5	1151 30.6	36 1.0	3 0.1	31 0.8	154 4.1	3765 100.0
Western Health Board	1579 61.7	807 31.5	73 2.9	1 0.0	41 1.6	58 2.3	2559 100.0
<b>All Boards</b>	<b>14901 58.6</b>	<b>7587 29.8</b>	<b>515 2.0</b>	<b>47 0.2</b>	<b>468 1.8</b>	<b>1930 7.6</b>	<b>25448 100.0</b>

# Chapter four

## 4. Assessment of Need 2003-2007

The National Intellectual Disability Database provides a needs assessment of people with intellectual disability. Three distinct categories of need are identified as follows:

**Unmet Need:** describes people who are without any service whatsoever, who are without a major element of service such as day or residential, or who are without residential support services, and require these services in the period 2003-2007.

**Service Change:** describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2003-2007, and includes children who will require access to health-funded services in the period.

**Persons with intellectual disability who are accommodated in psychiatric hospitals:** includes people who need to transfer out of the psychiatric services within the next five years and people who are resident in the psychiatric services but require an appropriate day service within the same time period.

In 2002 the National Intellectual Disability Database facilitated the recording of two future residential services and three future day services for each individual. To avoid double-counting of individuals, only the first service identified is reported in the tables but the level of additional need of these individuals is noted in the relevant sections of the text.

### Unmet Need

#### *FULL-TIME RESIDENTIAL AND DAY SERVICES*

The data returned in 2002 indicate that 2,262 people will require major elements of service, either a full-time residential service or a day service, or both, in the five-year period 2003-2007, a reduction of 178, or 7%, since 2001. Of this group, 457 have no service and require full-time residential and/or day services; 1,566 receive a day service but require a residential service; 216 people receive a residential service but also require a day service; and 23 people receive residential support services only, and require full-time residential and/or day services. Table 4.1 provides a breakdown of this group by level of intellectual disability. Of the group who were without services in 2002, 37% have a moderate, severe or profound level of intellectual disability and 52% have a mild level of intellectual disability. The group which receives one major element of service, day or residential, but which needs the other element, consists mainly of people in the moderate, severe or profound ranges of intellectual disability.

Two hundred and ninety-one individuals who have an unmet need for a full-time residential service also require an additional future residential service, of whom 98% require a residential support service in the period 2003-2007. Seventy-four individuals who have an unmet need for a day service also require one additional future day service and four individuals require two additional future day services in the period 2003-2007.

Table 4.1. National Intellectual Disability Database, Ireland 2002.  
Number of people requiring a major element of service 2003-2007.

	No service	Receives minimal residential support only	Receives day only - requires residential	Receives residential only - requires day	Total
Not verified	49	3	34	0	86
Mild	238	10	395	21	664
Moderate, severe & profound	170	10	1137	195	1512
<b>All levels</b>	<b>457<sup>a</sup></b>	<b>23<sup>b</sup></b>	<b>1566</b>	<b>216</b>	<b>2262</b>

<sup>a</sup> Of the 457, 44 require residential and day, 12 require residential only, and 401 require day only.

<sup>b</sup> Of the 23, 9 require residential and day, 2 require residential only, and 12 require day only.

### RESIDENTIAL SUPPORT SERVICES

The 2002 data indicate that 1,411 people are without residential support services and will require these services in the period 2003-2007, an increase of 304 since 2001 (Table 4.2). Ninety-nine per cent of this group are already in receipt of a major element of service. Eleven individuals who require residential support services were without services in 2002, of whom five have a moderate, severe, or profound level of intellectual disability.

Sixty-one individuals who have an unmet need for a residential support service also require an additional future residential service, of whom 74% require another residential support service.

Table 4.2. National Intellectual Disability Database, Ireland 2002.  
Number of people requiring residential support services 2003-2007.

	No service	Receives day only - requires residential support	Receives residential & day - requires residential support	Total
Not verified	0	108	4	112
Mild	6	488	53	547
Moderate, severe & profound	5	669	78	752
<b>All levels</b>	<b>11</b>	<b>1265</b>	<b>134</b>	<b>1411</b>

## NUMBER OF PLACES REQUIRED TO MEET NEED

The number of additional residential, day, and residential support places required over the next five years to provide these people with services is identified in Table 4.3.

Table 4.3. National Intellectual Disability Database, Ireland 2002.  
**Number of new places required to meet need 2003-2007.**

Residential	1633
Day	682
Residential Support	1446 <sup>a</sup>
<sup>a</sup> The total number of residential support places required is different to the figure in Table 4.2 (n=1,411) as 33 of the group who have no existing service and require a day service will also need a residential support service and 2 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 1,446.	

## YEAR IN WHICH SERVICES ARE REQUIRED

Table 4.4 identifies the year in which the service needs arise. Most of the service needs are immediate, reflecting the backlog of people awaiting services over the past number of years.

Table 4.4. National Intellectual Disability Database, Ireland 2002.  
**Year in which service needs arise.**

	2003	2004	2005	2006	2007	All years
Residential	1305	105	122	68	33	1633
Day	655	15	8	4	0	682
Residential support	1289	74	44	33	6	1446

## Summary of Unmet Service Requirements

Details of the types of services required by people who were without a major element of service or without residential support services in 2002 are set out in Tables 4.5 to 4.7.

### FULL-TIME RESIDENTIAL SERVICES

Of the group that requires full-time residential services, 72% consists of people in the moderate, severe and profound ranges of intellectual disability, 26% consists of people with mild intellectual disability and 2% have not had their level of intellectual disability verified. Most of the sub-group with moderate, severe and profound intellectual disabilities require residential placements in community group homes (80%), 11% require residential accommodation in a campus setting, and 8% need specialised intensive placements because of their increased dependency. Within the sub-group with mild intellectual disability, 88% require community-based placements, 6% require placements in traditional-style residential centres, and 5% require intensive placements. Approximately 1% of both sub-groups require nursing home placements. Of those requiring full-time residential services, 96% already receive day services (Table 4.5).

## DAY SERVICES

Demand for day services among those reported as not being in receipt of day services in 2002 is confined almost exclusively to adult services. The largest demand for day services comes from 445 people who have no service whatsoever at the moment (compared to 488 in 2001). Most of this group (52%) have a mild intellectual disability and their principal service requirements are in the training and employment fields. The remainder of the group fall mainly into the moderate, severe and profound range of intellectual disability (37%) and the principal service requirements are for activation programmes, sheltered work, multidisciplinary support services, special vocational training, home support services and programmes specifically designed for older people. (Table 4.6).

The other large group with day service needs consists of 216 people who are in full-time residential services but do not have access to formal day programmes (compared to 336 in 2001). Most of this group (90%) have a moderate, severe or profound intellectual disability and their needs are almost exclusively for care-focused services such as activation programmes, high-support and intensive placements, programmes specifically designed for older people, and multidisciplinary support services.

A smaller group of 21 people are accessing residential support services only, and require a wide range of day services, compared to 52 people in 2001. Of this group 43% are in the mild range of intellectual disability and 48% have a moderate, severe, or profound intellectual disability.

## RESIDENTIAL SUPPORT SERVICES

Residential support services are required by 1,446 people, most of whom live at home and either attend services on a daily basis (87%) or have no day service (3%). An additional 9% are full-time residents and need a residential support service either to enhance, or as an alternative to, their existing services. People with moderate, severe and profound intellectual disabilities account for 53% of the demand for residential support services, while people with mild intellectual disability account for 39%. Most of the demand is for centre- and home-based respite services (70%). Semi-independent living arrangements are planned for 15% of this group (211 people), of whom 25% are living in full-time residential placements. Independent living arrangements are planned for 5% of this group (69 people), of whom 19% are living in full-time residential placements. Holiday residential placements are required by 6% (Table 4.7).

## Service Change

The term **service change** describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2003-2007, and includes children availing of educational services in 2002 who will require access to health-funded services in the period. Changes in service provision relate to

- upgrading of existing residential places from 5-day to 7-day,
- changes in type of residential accommodation being provided, such as from residential centres to community-based residential services,
- provision of more intensive care and specialist interventions, and
- changes to existing day services, for example from education to training or from training to employment.

Table 4.5. National Intellectual Disability Database, Ireland 2002.  
**Future full-time residential service requirements of individuals receiving no residential service in 2002.**

	No service - requires residential service				Receives residential support only - requires residential service				Receives day service - requires residential service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
5-day community group home	0	2	5	7	0	1	1	2	4	107	200	311	4	110	206	320
7-day (48-week) community group home	2	1	7	10	0	2	0	2	6	60	211	277	8	63	218	289
7-day (52-week) community group home	1	9	11	21	1	3	3	7	16	181	509	706	18	193	523	734
5-day residential centre	0	0	1	1	0	0	0	0	0	6	7	13	0	6	8	14
7-day (48-week) residential centre	0	0	4	4	0	0	0	0	0	5	42	47	0	5	46	51
7-day (52-week) residential centre	0	3	4	7	0	0	0	0	2	10	68	80	2	13	72	87
Nursing home	0	1	1	2	0	0	0	0	2	4	6	12	2	5	7	14
Intensive placement (challenging behaviour)	0	1	2	3	0	0	0	0	2	15	53	70	2	16	55	73
Intensive placement (profound or multiple disability)	0	0	1	1	0	0	0	0	2	7	41	50	2	7	42	51
<b>All services</b>	<b>3</b>	<b>17</b>	<b>36</b>	<b>56</b>	<b>1</b>	<b>6</b>	<b>4</b>	<b>11</b>	<b>34</b>	<b>395</b>	<b>1137</b>	<b>1566</b>	<b>38</b>	<b>418</b>	<b>1177</b>	<b>1633</b>

Table 4.6. National Intellectual Disability Database, Ireland 2002.  
**Future day service requirements of individuals receiving no day service in 2002.**

	No service - requires day service				Receives residential support only - requires day service				Receives residential service only - requires day service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Home support	1	3	12	16	0	0	1	1	0	0	0	0	1	3	13	17
Home help	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Early services	8	0	3	11	0	0	0	0	0	0	0	0	8	0	3	11
Mainstream pre-school	2	0	1	3	0	0	0	0	0	0	0	0	2	0	1	3
Special pre-school	1	2	4	7	0	0	0	0	0	0	0	0	1	2	4	7
Child education and development centre	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Mainstream school	0	1	1	2	0	0	0	0	0	0	0	0	0	1	1	2
Resource/visiting teacher	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special class - primary	2	0	2	4	0	0	0	0	0	0	0	0	2	0	2	4
Special class - secondary	0	3	0	3	0	0	0	0	0	0	0	0	0	3	0	3
Special school	1	2	2	5	0	0	0	0	0	0	4	4	1	2	6	9
Special vocational training	4	57	13	74	0	2	0	2	0	1	0	1	4	60	13	77
Activation centre	10	20	48	78	0	1	4	5	0	5	68	73	10	26	120	156
Programme for the older person	3	7	11	21	1	1	1	3	0	7	59	66	4	15	71	90
Special high-support day service	0	2	6	8	0	0	1	1	0	0	25	25	0	2	32	34
Special intensive day service	0	1	2	3	0	0	1	1	0	1	17	18	0	2	20	22
Sheltered work centre	1	36	31	68	0	2	0	2	0	2	2	4	1	40	33	74
Sheltered employment centre	1	14	1	16	0	0	0	0	0	0	0	0	1	14	1	16
Multidisciplinary support services	3	7	16	26	0	1	0	1	0	0	18	18	3	8	34	45
Centre-based day respite service	0	0	0	0	0	0	1	1	0	0	0	0	0	0	1	1
Other day service	0	1	1	2	0	0	0	0	0	0	0	0	0	1	1	2
Enclave within open employment	0	4	0	4	0	0	0	0	0	1	0	1	0	5	0	5
Supported employment	4	40	4	48	0	1	1	2	0	3	2	5	4	44	7	55
Open employment	5	16	2	23	0	0	0	0	0	0	0	0	5	16	2	23
Generic vocational training	2	15	2	19	1	1	0	2	0	1	0	1	3	17	2	22
Generic day services	0	1	3	4	0	0	0	0	0	0	0	0	0	1	3	4
<b>All services</b>	<b>48</b>	<b>232</b>	<b>165</b>	<b>445</b>	<b>2</b>	<b>9</b>	<b>10</b>	<b>21</b>	<b>0</b>	<b>21</b>	<b>195</b>	<b>216</b>	<b>50</b>	<b>262</b>	<b>370</b>	<b>682</b>



Table 4.7. National Intellectual Disability Database, Ireland 2002.  
**Future residential support service requirements of individuals receiving no residential support services in 2002.**

	No service - requires residential support				Receives day service - requires residential support				Receives residential service - requires residential support				Receives residential and day services - requires residential support				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Foster care and boarding-out	0	0	0	0	0	2	0	2	0	0	0	0	0	1	0	3	0	3	0	3
Living independently	2	3	0	5	5	38	7	50	0	1	0	1	0	12	1	54	7	54	8	69
Living semi-independently	1	5	1	7	8	114	29	151	0	1	0	1	2	33	17	153	11	153	47	211
Holiday residential placement	0	0	3	3	0	24	34	58	0	0	0	0	1	1	20	22	1	25	57	83
Crisis or planned respite	1	6	16	23	76	255	502	833	0	1	0	1	0	3	26	29	77	265	544	886
Occasional respite care																				
with host family	1	0	1	2	15	44	64	123	0	0	0	0	0	0	6	6	16	44	71	131
Shared care or guardianship	0	1	0	1	0	1	2	3	0	0	0	0	0	1	1	2	0	3	3	6
Regular part-time care																				
(2/3 days per week)	0	0	1	1	2	6	17	25	0	0	0	0	0	0	2	2	2	6	20	28
Regular part-time care																				
(every weekend)	0	0	0	0	0	2	2	4	0	0	0	0	0	0	1	1	0	2	3	5
Regular part-time care																				
(alternate weeks)	0	0	0	0	1	1	9	11	0	0	0	0	0	0	1	1	1	1	10	12
Other residential service	0	1	1	2	1	1	3	5	0	0	0	0	1	1	3	5	2	3	7	12
<b>All services</b>	<b>5</b>	<b>16</b>	<b>23</b>	<b>44</b>	<b>108</b>	<b>488</b>	<b>669</b>	<b>1265</b>	<b>0</b>	<b>3</b>	<b>0</b>	<b>3</b>	<b>4</b>	<b>52</b>	<b>78</b>	<b>134</b>	<b>117</b>	<b>559</b>	<b>770</b>	<b>1446</b>

## CATEGORIES OF SERVICE CHANGE REQUIREMENTS

The database indicates that 12,516 people who were receiving services in 2002 will require a change in their existing service provision in the period 2003-2007, an increase of 2,334 since 2001. Of this group, 9,841 are day attenders (of whom 731 also avail of residential support services); 2,454 are full-time residents (of whom 1,994 also avail of day services); and 221 receive residential support services only. A breakdown of the category of service change required by level of intellectual disability is provided in Table 4.8. People in the moderate, severe and profound ranges of intellectual disability account for 64% of the service changes, people in the mild range account for 31%, and 5% of the service changes are required by people whose level of intellectual disability has not been verified.

Table 4.8. National Intellectual Disability Database, Ireland 2002.  
**Category of service change required 2003-2007.**

	<b>Residential and day</b>	<b>Residential only</b>	<b>Day only</b>	<b>Day and residential support</b>	<b>Residential support only</b>	<b>All service changes</b>
Not verified	6	1	644	31	4	686
Mild	243	80	3366	150	36	3875
Moderate, severe & profound	1745	379	5100	550	181	7955
<b>All levels</b>	<b>1994</b>	<b>460</b>	<b>9110</b>	<b>731</b>	<b>221</b>	<b>12516</b>

There are 2,149 people included in the data presented in the section on Unmet Need above who are missing one major element of service and require their existing element of service to be changed in some way. However, to avoid double-counting of individuals, their needs in relation to service changes are not included in this section of the report. It is envisaged that, when funding is made available for their unmet elements, sufficient flexibility will be incorporated within this to allow their required service change to be implemented.

## NUMBER OF PLACES REQUIRED TO ADDRESS SERVICE CHANGES

The number of places involved in addressing the required service changes is summarised in Table 4.9. Services are described under four headings: health, education, employment, and generic, and the programmes included under each heading are outlined in Appendix A.

The number of places required exceeds the number of people requiring service changes as some people require changes in both their residential and day services. In addition, it is important to note that although 12,516 people require service changes, this demand does not translate into 12,516 new places. In most instances, these individuals will be vacating their existing placement when they receive their change of service. This will free up places for people requiring a 'service change' and those with 'unmet needs'. For example, when young adults move into sheltered work from training, their training place is freed up for the young adults leaving school. It is also important to note that this entire group gets some level of service at present so a certain level of funding is already committed to these individuals.

Table 4.9. National Intellectual Disability Database, Ireland 2002.

**Number of places requiring to be changed 2003-2007**

<b>Residential</b>	<b>2454</b>
<b>Day</b>	<b>11835</b>
Of which:	
Health services	8875
Education services	1309
Employment services	1405
Generic services	246
<b>Residential support</b>	<b>952</b>

### *YEAR IN WHICH SERVICE CHANGES ARE REQUIRED*

Table 4.10 identifies the year in which the service changes are required. Again, as with the unmet need, most of the service changes are required immediately.

Table 4.10. National Intellectual Disability Database, Ireland 2002.

**Year in which service changes are required**

	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>All years</b>
<b>Residential</b>	2217	122	71	31	13	<b>2454</b>
<b>Day</b>	10276	790	421	233	133	<b>11835</b>
Of which:						
Health services	7798	497	303	185	92	8875
Education services	1093	138	48	24	6	1309
Employment services	1219	123	45	13	5	1405
Generic services	166	32	25	11	12	246
<b>Residential support</b>	904	11	21	14	2	<b>952</b>

## Summary of Service Change Requirements

Details of the types of service changes required by people who need alternative or enhanced full-time residential, day, and residential support services are set out in Tables 4.11 to 4.13.

### *RESIDENTIAL SERVICE CHANGE*

The database indicates that 2,454 individuals, in full-time residential services in 2002, will require an upgrading or change of accommodation within the next five years (Table 4.11).

Table 4.11. National Intellectual Disability Database, Ireland 2002.

**Pattern of movement of individuals from existing residential service to future residential service 2003-2007.**

	Full-time residential service required in the period 2003-2007									
	5-day CGH	7-day (48-wk) CGH	7-day (52-wk) CGH	5-day RC	7-day (48-wk) RC	7-day (52-wk) RC	Nursing Home	Intensive placement (CB)	Intensive placement (P/M D)	Total Services 2002
Full-time residential service in 2002	33	81	124	1	2	4	2	8	1	256
	2	35	75	1	2	15	0	6	2	138
	5	12	291	1	5	21	23	40	32	430
	12	9	11	7	19	10	0	12	6	86
	6	96	97	1	57	50	2	20	7	336
	0	19	476	1	8	103	12	174	165	958
	0	0	13	0	1	1	0	0	3	18
	1	3	28	1	1	5	1	32	4	76
	0	1	2	0	0	18	0	28	32	81
	9	7	30	1	3	9	0	2	6	67
0	0	2	0	0	2	1	3	0	8	
Total services required	68	263	1149	14	98	238	41	325	258	2454

The abbreviations in the third row of the table refer to the placement descriptions outlined in column one.

The shaded area of the table represents existing services that require alteration or enhancement.

For most of this group (1,864 people) a change of service is required. Residential placements in the community are required by 822 individuals, 519 individuals require intensive services for either challenging behaviour or profound or multiple disability, 94 people require centre-based placements, and 41 people need placements in nursing homes. Three hundred and fifty-nine individuals need their service upgraded to include care at weekends and holiday times and 29 people require less care and could return to their families at weekends and holiday times.

Furthermore, there is a group of 590 individuals who need an enhancement of their existing service (shaded area of Table 4.11). Over two-thirds of this group need increased support, and among the other enhancements required are transfers to a location closer to the family home or transfers to age-appropriate services. Some of the needs associated with the enhancement of existing services will be met through the funding which is made available to meet identified needs in existing services. One hundred and seventeen individuals in this category require an additional future residential service, of whom 84% require a residential support service.

### *DAY SERVICE CHANGE*

Within the next five years, 11,835 individuals will require a change, enhancement, or upgrading of their day service (Table 4.12). Health-funded services are required in 75% of the changes, 12% involve employment services, 11% involve educational services, and 2% involve generic services. Within this category there are 3,116 individuals who also require one additional future day service and 278 individuals who require two additional future day services.

### **Health-funded services**

#### *CHILDREN'S SERVICES*

Of the 8,875 service changes required within the health-funded services, those in respect of just 5% (484 individuals) are specifically identifiable as children's services (early services, pre-school services, child education and development centres and centre-based day respite services) (Table 4.12).

Four hundred and twenty-five children require alternative or additional day services. Most of the demand is for mainstream and specialised pre-school services (320 children) and the majority of these children (76%) are receiving early services. The balance of the demand is for centre-based day respite services (43 children), placements in child education and development centres (59 children), and early services (three children). Most of the children requiring these placements are attending special pre-school services.

There are 59 children who need to have their existing day service enhanced (shaded area of Table 4.12). These children are in receipt of early services, or are attending mainstream pre-schools, specialised pre-schools, or child education and development centres. Most of these children require their existing service more frequently, need a higher level of support within their existing service, or need to receive their service closer to their family home.

#### *ADULT SERVICES*

There are 8,391 placements primarily designed for adults and funded from the health budget which will require upgrading or change within the next five years (Table 4.12).

There are 6,409 individuals who require alternative or additional day services between 2003 and 2007. Special vocational training programmes are required by 984 individuals, the majority of whom (81%) are attending special schools. Sheltered work placements are required by 730 individuals, most of whom are attending special schools (30%) or are in receipt of special vocational training (37%). Within the more care-focused services, demand is mainly for activation programmes (872 people), high-support or intensive placements (770 people) and programmes designed specifically to address the needs of older people with intellectual disability (753 people). Demand for activation programmes stems from four main groups: those who are attending special schools (28%), in sheltered work centres (22%), attending child education and development centres (14%), and receiving multidisciplinary support services (11%). Individuals who are receiving activation programmes require the majority of the high-support and intensive placements (59%). Programmes to meet the needs of older people with intellectual disability are required primarily by individuals in activation programmes (57%) or attending sheltered work centres (26%).

There are 1,982 individuals who need to have their existing day service enhanced (shaded area of Table 4.12). Most of this group are receiving activation programmes (55%) or are attending sheltered work centres (24%). Of the 1,982 who require enhanced day services, the majority require either increased support (69%), an increased level of service provision (14%), or need to avail of their services closer to the family home (4%).

### **Educational services**

Alternative or enhanced educational services will be required by 1,309 children in the period 2003-2007 (Table 4.12).

There are 1,062 children who require alternative or additional educational services. Most of the demand is for special classes at secondary level (349 children) or for special school placements (318 children). Of the group who require special classes at secondary level, most are in special classes at primary level (77%). Of those requiring places in special schools, most are in special pre-schools (53%). The remaining services required by the overall group of 1,062 children include mainstream school placements (required by 182 children – the majority of whom are in mainstream pre-schools and special pre-schools at present), special classes at primary level (required by 122 children – the majority of whom are in special pre-schools and mainstream schools), and resource/visiting teachers (required by 91 children – the majority of whom are in mainstream schools).

Two hundred and forty-seven children need their existing educational placement to be enhanced in the period 2003-2007 (shaded area of Table 4.12). These needs arise among children attending special schools (184 children), availing of the services of a resource/visiting teacher (32 children), attending mainstream schools (25 children), and in special classes at primary level (five children) and secondary level (one child). Most (62%) are identified as requiring their existing services which are delivered at primary school level to be carried through to secondary level. There is also a demand for increased support within existing educational placements (30%).

Day service in 2002		Day service required in the period 2003-2007																								All	
	HS	HH	ES	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	SVT	AC	POP	SHS	SI	SWC	SEC	MSS	DR	OTH	E	SE	OE	GVT	GD	
Home support (HS)	8	0	0	6	9	3	0	2	1	0	7	2	10	3	0	0	1	0	17	0	1	0	3	0	0	0	73
Home help (HH)	1	0	0	0	1	0	0	0	0	0	0	0	4	0	0	0	0	0	0	0	0	0	0	0	0	1	9
Early services (ES)	2	0	10	110	133	8	35	7	7	0	17	0	0	0	0	0	0	0	26	0	1	0	0	0	0	0	356
Mainstream pre-school (MPS)	1	0	0	2	3	0	63	3	17	0	24	0	0	0	0	0	0	0	7	0	0	0	0	0	0	0	120
Special pre-school (SPS)	6	1	2	21	22	27	59	14	58	0	170	0	0	0	0	0	0	0	23	3	0	0	0	0	0	0	406
Child education & development centre (CEDC)	7	0	0	1	1	25	0	0	2	0	14	2	119	1	7	9	14	1	53	0	0	1	2	0	0	0	259
Mainstream school (MS)	8	0	0	0	2	0	25	49	30	55	27	24	1	0	0	1	4	1	148	10	2	0	7	1	9	0	404
Resource/visiting teacher (RT)	4	0	0	9	3	6	17	32	2	18	28	4	0	0	0	0	0	0	53	0	0	0	6	0	13	0	195
Special class – primary (SCP)	7	0	0	0	0	2	4	8	5	270	22	13	6	0	2	1	6	0	34	3	1	0	1	0	5	0	390
Special class – secondary (SCS)	0	1	0	0	0	0	0	0	0	1	1	32	13	0	1	0	5	2	11	2	1	0	7	0	24	0	101
Special school (SS)	65	1	0	0	0	0	6	2	3	6	184	797	243	1	32	26	216	21	265	25	3	10	63	44	131	0	2147
Special vocational training (SVT)	0	0	0	0	0	0	0	0	0	0	0	41	68	14	8	5	273	8	71	0	1	1	355	28	12	2	887
Activation centre (AC)	19	1	0	0	1	1	0	1	0	0	2	39	1098	430	167	291	131	11	538	6	1	1	104	1	3	6	2852
Programme for the older person (POP)	1	0	0	0	0	0	0	0	0	0	0	0	7	126	1	4	6	0	60	0	0	0	0	0	0	2	207
Special high-support service (SHS)	0	0	0	0	0	2	0	0	2	0	1	0	44	15	63	67	3	1	53	0	1	0	2	1	1	1	257
Special intensive service (SI)	0	0	0	0	0	0	0	1	0	0	1	4	7	0	34	1	0	26	0	0	0	0	0	0	0	0	74
Sheltered work centre (SWC)	7	0	0	0	0	0	0	1	0	0	0	22	189	199	23	26	476	32	502	20	3	11	485	12	9	12	2029
Sheltered employment centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	1	1	1	0	0	0	11	0	0	0	16
Multidisciplinary support services (MSS)	3	0	1	13	5	3	2	1	0	2	2	11	98	57	30	55	17	2	134	1	1	1	28	1	6	0	472
Centre-based day respite service (DR)	0	0	0	0	0	0	0	1	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	3
Other day service (OTH)	4	0	0	0	0	1	0	0	0	0	2	16	25	14	4	4	12	0	9	0	1	0	11	1	3	0	107
Enclave with open employment (E)	0	0	0	0	0	0	0	0	0	0	0	0	2	3	0	0	0	0	4	0	0	0	1	0	0	0	10
Supported employment (SE)	1	0	0	0	0	0	0	0	0	0	0	6	6	12	1	0	11	6	96	0	2	1	74	15	1	0	232
Open employment (OE)	0	2	0	0	0	0	0	0	0	0	0	2	1	0	0	0	7	2	8	0	0	0	8	0	1	0	31
Generic vocational training (GVT)	0	0	0	0	0	0	0	0	0	0	0	7	15	1	0	0	20	5	11	0	0	0	62	40	3	0	164
Generic day service (GD)	0	0	0	1	1	0	0	0	0	0	0	3	12	1	5	0	0	1	4	0	0	0	5	0	0	1	34
All services	144	6	13	163	181	84	207	123	127	350	502	1025	1970	879	344	523	1206	94	2154	70	19	26	1235	144	221	25	11835

The shaded area of the table represents existing services that require alteration or enhancement.

### **Employment services**

There are 1,405 individuals who will require access to new or enhanced employment opportunities during the period 2003-2007 (Table 4.12).

A total of 1,331 of this group will require new employment opportunities. Supported employment placements are required for 1,161 individuals. In the main, these individuals avail of sheltered work (42%), special vocational training (31%), or activation programmes (9%). There are 144 people who require open employment and at present they are mainly in special schools (31%), special vocational training (19%), supported employment (10%), and sheltered work centres (8%). The remainder of the group requiring new employment opportunities (26 people) require placements in enclaves within open employment. At the moment, most of this group attend sheltered work centres (42%) and special schools (38%).

There are 74 individuals who need to have their existing employment placement enhanced (shaded area of Table 4.12). All of this group are in supported employment and most of the required changes relate to decreased support levels (37%), increased support levels (26%) or an increased level of service provision (34%).

### **Generic services**

There is a relatively small group of 246 individuals who require access to generic day services during the period 2003-2007 or who need to have their existing placement within the generic services enhanced (Table 4.12).

Of this group, 242 require new placements within the generic services. A total of 218 individuals require generic vocational training opportunities and 24 require access to other, unspecified generic day services. Of the group requiring generic vocational training, most are in special schools (60%) and special classes at secondary level (11%). Of the group requiring access to other unspecified generic day services, most are in sheltered work centres (50%) and activation programmes (25%).

Three individuals who are in receipt of generic vocational training and one person receiving an unspecified generic day service require their existing service to be enhanced or altered in the period 2003-2007 (shaded area of Table 4.12). Three of these four people need changes to their existing level of support and one needs a more frequent service.

The pattern of movement in day services is not as clear-cut as the pattern of movement in residential services. People in full-time residential services who require alternative full-time placements will vacate their existing services when their new places become available. However, certain existing day services, for example, early services and home support services, will not necessarily be freed up when a new service is provided as these are ongoing services that are generally required in addition to other day services. Similarly, certain of the required services will not replace existing services, but rather will enhance the range of services being provided to an individual.

The data in relation to day services are reported and interpreted on the assumption that certain services

- (a) where the service already exists, will be retained by the individual, even when their new service comes on stream, or
- (b) where the service is new to the individual, will not replace existing services.



The services involved include:

- Home support services
- Early services
- Resource/visiting teacher
- Home help
- Multidisciplinary support services for school-age children and adults
- Centre-based day respite service.

Table 4.12 maps the pattern of movement of individuals from their existing day service to their future day service. The main day service recorded on the National Intellectual Disability Database is used to indicate the existing day service.

### *RESIDENTIAL SUPPORT SERVICE CHANGE*

The database indicates that 952 individuals receiving residential support services will require an additional or alternative support service, or will require their existing support service to be upgraded during the period 2003-2007 (Table 4.13). Additional or alternative support services are required by 255 individuals, and 697 individuals require their existing service to be upgraded (shaded area of Table 4.13).

The principal needs of this group include

- more frequent centre-based respite breaks for people already availing of this service (574 people),
- more regular part-time care arrangements for people already accessing crisis or planned respite services and respite breaks with host families (97 people),
- more centre-based respite breaks for people availing of family-based respite breaks (19 people),
- more family-based respite breaks for people accessing centre-based respite and residential placements during holiday times (32 people),
- opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (19 people).

Eighty-four individuals in this category require an additional future residential service, of whom 61% require a residential support service.

As with certain types of day services, it is important to note that existing residential support services may be retained by the individual when their new service becomes available, with the result that existing services may not be freed up for use by people who are without such services at present.

Table 4.13. National Intellectual Disability Database, Ireland 2002.

**Additional residential support services required by people availing of residential support services in 2002.**

	<b>Residential support service required 2003-2007</b>											Total
	Foster care and boarding-out	Living independently	Living semi-independently	Holiday residential placement	Crisis or planned respite	Occasional respite care (host family)	Shared care /guardianship	Regular part-time care (2/3 days per week)	Regular part-time care (every weekend)	Regular part-time care (alternate weeks)	Other residential service	
<b>Residential support service in 2002</b>												
Foster care and boarding-out	0	0	3	3	11	1	0	0	0	0	0	18
Living semi-independently	0	7	14	1	1	0	0	1	0	0	2	26
Holiday residential placement	0	0	2	3	7	1	0	0	0	1	0	14
Crisis or planned respite	1	4	17	5	672	31	3	67	9	17	12	838
Occasional respite care (host family)	0	0	0	3	19	4	0	2	1	1	0	30
Regular part-time care (2/3 days per week)	0	1	1	1	1	1	0	4	0	7	0	16
Regular part-time care (every weekend)	0	0	0	0	2	1	0	0	0	0	0	3
Regular part-time care (alternate weeks)	0	0	1	0	2	0	0	1	0	0	0	4
Other residential service	0	0	0	0	2	0	0	0	1	0	0	3
<b>All services</b>	<b>1</b>	<b>12</b>	<b>38</b>	<b>16</b>	<b>717</b>	<b>39</b>	<b>3</b>	<b>75</b>	<b>11</b>	<b>26</b>	<b>14</b>	<b>952</b>

The shaded area of the table represents existing services that require alteration or enhancement.

## Persons with Intellectual Disability who are Accommodated in Psychiatric Hospitals

The data from the National Intellectual Disability Database for 2002 identify 515 individuals with intellectual disability, all aged 19 years and over, accommodated in psychiatric hospitals. Table 4.14 details the overall service requirement status of this group by level of intellectual disability.

Table 4.14. National Intellectual Disability Database, Ireland 2002. Overall service requirements of people with intellectual disability resident psychiatric hospitals in 2002.									
	No service requirements				Has service requirements				
	Not Verified	Mild	Moderate, severe & profound	All levels	Not Verified	Mild	Moderate, severe & profound	All levels	Total
Resident in a psychiatric hospital - no day programme	0	16	41	57	3	36	168	207	264
Resident in a psychiatric hospital - with day programme	1	25	37	63	4	60	124	188	251
<b>All residents</b>	<b>1</b>	<b>41</b>	<b>78</b>	<b>120</b>	<b>7</b>	<b>96</b>	<b>292</b>	<b>395</b>	<b>515</b>

Of this group, 395 (77%) have service requirements in the period 2003-2007, of whom 380 have an appropriate alternative residential facility identified for them, 12 have identified day service requirements and three are identified as requiring residential support services only. One hundred and twenty individuals have no alternative residential or day service needs identified for them in the 2002 dataset even though the 2001 health strategy *Quality and Fairness: A Health System for You* acknowledged the inappropriateness of psychiatric hospital accommodation for people with intellectual disability and made a commitment to transfer those resident in psychiatric hospitals to appropriate accommodation no later than 2006.

As already stated, the 2002 data suggest that the day and residential programmes for 120 people with intellectual disability within the psychiatric services are appropriate and these people have no identified service needs in the period 2003-2007. Thirty-four per cent of this group have a mild intellectual disability and 65% have a moderate, severe or profound disability. Within this group are 57 people who have no formal day programme. The day service needs of this group, and the overall service needs of people considered, according to their database record, to be appropriately accommodated in psychiatric hospitals, need to be reviewed.

Of the remaining 395 people who require services, 12 will continue to reside within their psychiatric hospital setting but will require day services in the period 2003-2007. Fifty-eight per cent of this group have a mild intellectual disability and 42% have a moderate, severe or profound intellectual disability. At present, five of this group have no day service and require

activation programmes (two people), a programme for older people (two people) and one person requires special vocational training. The remaining seven people are in receipt of day programmes that need to be enhanced or upgraded, as outlined in Table 4.15. Three individuals require specific programmes designed for older people, two individuals require activation programmes, one individual requires special vocational training and another requires multidisciplinary support services.

In addition, three people are identified as requiring residential support services within the period 2003-2007 but it is not clear if the intention is for these people to live outside the psychiatric hospital with these support services or if they are to remain within the psychiatric hospital. One person needs respite care, one needs shared care and one needs an unspecified residential support service.

Table 4.15. National Intellectual Disability Database, Ireland 2002.  
**Day service requirements of people appropriately accommodated in psychiatric hospitals.**

<b>Day service in 2002</b>	<b>Services required</b>				
	Special vocational training	Activation centre	Programme for the older person	Multidisciplinary support services	All services
No day programme	1	2	2	0	5
Sheltered work centre	1	0	0	1	2
Other day programme	0	2	3	0	5
<b>All services</b>	<b>2</b>	<b>4</b>	<b>5</b>	<b>1</b>	<b>12</b>

Finally, of the 395 residents in psychiatric hospitals who require services, 380 people need to transfer to specific intellectual disability services. Twenty-three per cent of this group have a mild intellectual disability, 75% have a moderate, severe or profound intellectual disability and 2% have not had their level of disability verified. Residential and day service requirements are identified for 146 individuals, while 234 require only an alternative residential placement. The day and residential services required by this group, and the year in which the service needs will arise, are outlined in Tables 4.16 and 4.17. None of this group is reported to have service needs in addition to those identified in the tables.

Of the 380 people who need to transfer from psychiatric to intellectual disability services for their residential services, 38% will require intensive placements, 23% will require community group home places, 35% need places in residential centres, and 3% need to move into nursing homes. Almost all of the need arises immediately (Table 4.16).

Of this same group of 380 people, 146 will also require an appropriate day service. The greatest demand is for high-support or intensive day programmes (46%), activation programmes (38%), a programme for older people (8%), sheltered work placements (3%), sheltered employment placements (2%), special vocational training (2%), one person needs multidisciplinary support services and one person requires an unspecified intellectual disability service. All day services are required immediately (Table 4.17).

Table 4.16. National Intellectual Disability Database, Ireland 2002.

**Residential service requirements of people resident in psychiatric hospitals who require to be transferred to the intellectual disability sector.**

	Year in which residential service is required			
	2003	2004	2005	2003-2007
7-day (48-week) community group home	3	0	0	3
7-day (52-week) community group home	86	0	0	86
7-day (48-week) residential centre	8	0	0	8
7-day (52-week) residential centre	123	1	1	125
Nursing home	13	0	0	13
Intensive placement (challenging behaviour)	94	0	0	94
Intensive placement (profound/multiple disability)	51	0	0	51
<b>All residential services</b>	<b>378</b>	<b>1</b>	<b>1</b>	<b>380</b>

Table 4.17. National Intellectual Disability Database, Ireland 2002.

**Day service requirements of people resident in psychiatric hospitals who require to be transferred to the intellectual disability sector.**

	Year in which day service is required
	2003
Special vocational training	3
Activation centre	55
Programme for the older person	12
Special high-support day service	53
Special intensive day service	14
Sheltered work centre	4
Sheltered employment centre	3
Other day programme	1
Multidisciplinary support services	1
<b>All day services</b>	<b>146</b>

## Overall Service Provision to People with Intellectual Disability and the Pattern of Care Required in the Period 2003-2007

The data presented in this chapter in relation to unmet need for services and demand for service changes need to be considered together to enable the future pattern of care to be forecast. The database indicates that there are large numbers of people who require day or residential services, or both, for the first time and also that there are significant numbers who require changes to, or enhancements of, their existing placements. Not all service changes will require the individual to move to a new placement as many require enhancements such as

increased support which can be made available in their existing placement. Where the enhancement involves a move to a new placement, the freed-up place may become available to others who have an identified need for such a placement. The existing placements occupied by these individuals are secure until their new places become available. Such movement is part of the ongoing development of services and is tangible evidence of the ability of the database to match needs with service provision. Individuals who already avail of services within either intellectual disability or psychiatric services have significant funding allocated to them and changes to their existing placements will incur only minimal costs.

### *PATTERN OF CARE REQUIRED IN FULL-TIME RESIDENTIAL SERVICES*

Demand for full-time residential services in the period 2003-2007 will come from three distinct groups already identified in this chapter:

- 1,633 individuals living at home who require full-time residential services for the first time,
- 380 individuals resident in psychiatric hospitals who require to transfer to the intellectual disability services, and
- 2,454 individuals in full-time residential services within the intellectual disability sector who require changes to their existing placement. Of this group, 1,864 require alternative services and 590 require their existing service to be enhanced. Not all of the group who require service enhancements will move to new placements. For example, 399 out of the 590 individuals (68%) require increased support in their existing placements. However, they have been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading their services. Where the change does involve a move to a new placement, the freed-up place may be available to others who are identified as requiring this service.

Table 4.18 outlines the pattern of full-time residential service provision that will be required in the period 2003-2007 to meet this demand. A total of 2,013 residential places will be required – a reduction of 84 since 2000. As expected, there is significant demand for community-based placements both from people who will be coming into residential services for the first time and from people in existing residential placements. In total, 2,088 community-based placements will be required during the period, an increase of 216 since 2001. There will also be a shortfall of 695 intensive residential placements. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

### *PATTERN OF CARE REQUIRED IN DAY SERVICES*

Demand for day services over the next five years comes from four distinct groups:

- 682 individuals without day services,
- 146 individuals resident in psychiatric hospitals who will require an appropriate day service when they transfer to the intellectual disability services,
- 12 individuals appropriately placed in psychiatric hospitals but requiring a day programme within that setting, and

Table 4.18. National Intellectual Disability Database, Ireland 2002.  
**Pattern of full-time residential service provision required 2003-2007.**

	<b>New services required by people living at home</b>	<b>New services required by people transferring from psychiatric hospitals</b>	<b>Service changes required by people in existing full-time residential places</b>	<b>Places vacated by people in full-time residential places</b>	<b>Shortfall (-)/ Excess (+) of places arising from demand</b>
5-day community group home	320	0	68	256	-132
7-day (48-week) community group home	289	3	263	138	-417
7-day (52-week) community group home	734	86	1149	430	-1539
5-day residential centre	14	0	14	86	58
7-day (48-week) residential centre	51	8	98	336	179
7-day (52-week) residential centre	87	125	238	958	508
Nursing home	14	13	41	18	-50
Intensive placement (challenging behaviour)	73	94	325	76	-416
Intensive placement (profound or multiple disability)	51	51	258	81	-279
Other/unspecified intellectual disability service	0	0	0	8	8
Designated residential support placement	0	0	0	[67 <sup>a</sup> ]	0
<b>Total</b>	<b>1633</b>	<b>380</b>	<b>2454</b>	<b>2387</b>	<b>-2013</b>

<sup>a</sup> 67 designated residential support places being blocked by full-time residents will be freed up but they have not been deducted from the total number of full-time residential places required as they should not be made available for full-time use.

- 11,835 individuals in existing day services within the intellectual disability sector who require changes to, or enhancements of, their existing placement. Of this group 9,464 require alternative or additional services and 2,366 require their existing service to be enhanced. Many of the changes are required to address transitional needs such as moving from child to adult services and moving from training into employment. Not all of the group who require service enhancements will move to new placements. Again, as was seen with the requirement for enhancement of residential placements, 1,478 out of the 2,366 identified individuals (63%) require increased support in their existing placements. However, the entire group has been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading their services. Where the change does involve a move to a new placement, the freed-up place may be available to others who are identified as requiring this service. However, unlike the situation with full-time residential services, not all existing places will become available. As previously explained in this chapter, people who are accessing, or who require home support, early services, resource/visiting teachers, multidisciplinary supports, day respite or home help services will not be freeing up existing services when their future needs are met.

Table 4.19 outlines the pattern of day service provision that will be required in the period 2003-2007 to meet demand. The data in the table have been adjusted to reflect the fact that not all existing services will be freed up. A total of 1,948 day places will be required – an increase of 239 since 2001. The table shows two distinct trends – a decrease in the numbers of young children requiring certain services and a huge demand for the full spectrum of adult services. Over the next five years there will be small reductions nationally in the number of children requiring special pre-school services, mainstream classes and special classes at primary level and placements in child education and development centres. There will be a significant reduction in the number of children requiring special schools. However, there is a small demand within this group for mainstream pre-school services and early services, and a larger demand for additional resource/visiting teachers and for the provision of special classes at secondary level.

Adult services will continue to experience considerable pressure across the whole spectrum of day services. There will be a shortfall of vocational training placements, both generic and specialised, and of employment opportunities. In the period 2003-2007, 79 generic vocational training places and 220 special vocational training places will be required. Over the next five years, 1,058 supported employment placements and 136 open employment placements need to be developed to meet the demand that exists for those services. There will also be a shortfall of 97 sheltered employment opportunities and 21 placements in enclaves within open employment during this time.

An additional 779 programme placements designed specifically to meet the needs of older people with intellectual disability are needed. An additional 2,201 people will require multidisciplinary support services but, as already highlighted in the discussion of existing service provision, this is believed to reflect only an increase in the reporting of these needs. Home support services are required by an additional 161 people, centre-based day respite placements by an additional 71 people, and home help services by an additional six people during the period. As with residential services, there is significant demand for high-support and intensive placements, though the demand is less than in 2001. Between 2003 and 2007, 174 high-support day placements and 485 intensive day placements will be required. These services involve a higher staff to client ratio and more specialist interventions to address needs arising



Table 4.19. National Intellectual Disability Database, Ireland 2002.  
**Pattern of day service provision required 2003-2007.**

	New services required by people without day services	New services required by people transferring from psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Shortfall (-)/ Excess (+) of places arising from demand
Home support	17	0	0	144	0	-161
Home help	0	0	0	6	0	-6
Early services	11	0	0	13	0	-24
Mainstream pre-school	3	0	0	163	120	-46
Special pre-school	7	0	0	181	406	218
Child education and development centre	0	0	0	84	259	175
Mainstream school	2	0	0	207	404	195
Resource/visiting teacher	0	0	0	123	0	-123
Special class - primary	4	0	0	127	390	259
Special class - secondary	3	0	0	350	101	-252
Special school	9	0	0	502	2147	1636
Special vocational training	77	3	2	1025	887	-220
Activation centre	156	55	4	1970	2852	667
Programme for the older person	90	12	5	879	207	-779
Special high-support day service	34	53	0	344	257	-174
Special intensive day service	22	14	0	523	74	-485
Sheltered work centre	74	4	0	1206	2029	745
Sheltered employment centre	16	3	0	94	16	-97
Multidisciplinary support services	45	1	1	2154	0	-2201
Centre-based day respite service	1	0	0	70	0	-71
Other day service	2	1	0	19	107	85
Enclave within open employment	5	0	0	26	10	-21
Supported employment	55	0	0	1235	232	-1058
Open employment	23	0	0	144	31	-136
Generic vocational training	22	0	0	221	164	-79
Generic day services	4	0	0	25	34	5
<b>All Services</b>	<b>682</b>	<b>146</b>	<b>12</b>	<b>11835</b>	<b>10727</b>	<b>-1948</b>

from behavioural problems, multiple disabilities and the effects of ageing. The data indicate that demands for activation programmes and sheltered work placements are likely to be met as other identified service needs are met and existing services are consequently freed up.

## Continued Demand for Services

The 2002 dataset, in line with data in recent years, indicates significant ongoing demand for new intellectual disability services and a growing requirement to enhance existing services. This need is presenting against a background of significant investment in intellectual disability services in the period 2000-2002. While the data in recent years highlight the corresponding growth in services, demographic factors are contributing to long waiting lists for services, most notably for full-time residential services. In particular, there is a large adult population and there are significantly more older people with intellectual disability than previously, and these features are contributing to an ongoing demand for services.

# References

Central Statistics Office (2003) *Census 2002. Principal Demographic Results*. Dublin: Stationery Office.

Department of Health and Children (2001) *Quality and Fairness: A Health System for You*. Dublin: Stationery Office.

Mulcahy M (1976) *Census of the mentally handicapped in the Republic of Ireland 1974. Non-Residential*. Dublin: Medico-Social Research Board.

Mulcahy M and Ennis B (1976) *Census of the mentally handicapped in the Republic of Ireland 1974. Residential*. Dublin: Medico-Social Research Board.

Mulcahy M and Reynolds A (1984) *Census of mental handicap in the Republic of Ireland 1981*. Dublin: Medico-Social Research Board.

Mulvany F (2001) *Annual Report of the National Intellectual Disability Database Committee 2000*. Dublin: Health Research Board.

Mulvany F (2003) *Annual Report of the National Intellectual Disability Database Committee 2001*. Dublin: Health Research Board.

National Intellectual Disability Database Committee (1997) *Annual Report 1996*. Dublin: Health Research Board.

## Requests for additional statistical information

Further statistical information pertaining to specific health board regions may be requested from the Regional Database Co-ordinator in the relevant health board.

Additional statistical information from the national dataset may be requested from the National Intellectual Disability Database Committee, using copies of the request form contained in Appendix C. Any queries about accessing data from the National Intellectual Disability Database should be addressed to the Disability Databases Division, Health Research Board.

# Appendix A

# INTELLECTUAL DISABILITY DATABASE

## NATIONAL PLANNING DATA FORM 2002

### PERSONAL DETAILS

1. Surname .....
2. First Name .....
3. Previous Surname .....
4. Address .....
5. Address .....
6. Address .....
7. Address .....
8. Address (County) .....
9. Date of Birth .....
10. Year of birth (where DOB is unknown) .....
11. Health Board Region .....
12. Community Care Area .....
13. Sub-area (DED) within Health Board Region .....
14. Planning area within Health Board .....
15. Personal Identification Number .....
16. Sex 1=male 2=female .....
17. Degree of intellectual disability 0=not verified 1=normal range 2=borderline 3=mild 4=moderate 5=severe 6=profound

#### Next of Kin - (A)

- 18a. Next of Kin name .....
- 19a. Next of Kin address .....
- 20a. Next of Kin address .....
- 21a. Next of Kin address .....
- 22a. Next of Kin address .....
- 23a. Next of kin address (County) .....
- 24a. Next of kin telephone number .....
- 25a. Relationship of next of kin .....

#### Next of Kin - (B)

- 18b. Next of Kin name .....
- 19b. Next of Kin address .....
- 20b. Next of Kin address .....
- 21b. Next of Kin address .....
- 22b. Next of Kin address .....
- 23b. Next of kin address (County) .....
- 24b. Next of kin telephone number .....
- 25b. Relationship of next of kin .....

### CURRENT SERVICE PROVISION

30. Agency providing main day service (Appendix A) .....
31. Type of main day service (Appendix B) .....
32. Current level of main day service supervision 0. 1. 2. 3. 4. 5.
33. Main day service: number of days received each week [1-5] .....
34. If multidisciplinary support services are received, please indicate type(s): .....
 

<input type="checkbox"/> Community Nursing <input type="checkbox"/> Nutritionist <input type="checkbox"/> Medical services <input type="checkbox"/> Occupational Therapy <input type="checkbox"/> Physiotherapy	<input type="checkbox"/> Psychiatry <input type="checkbox"/> Psychology <input type="checkbox"/> Social Work <input type="checkbox"/> Speech & Language Therapy <input type="checkbox"/> Other multidisciplinary service specify: .....
---	--
35. Agency providing secondary day service (Appendix A) .....
36. Type of secondary day service (Appendix B) .....
37. Current level of secondary day service supervision 0. 1. 2. 3. 4. 5.
38. Secondary day service: number of days received each week [1-5] .....
39. If multidisciplinary support services are received, please indicate type(s): .....
 

<input type="checkbox"/> Community Nursing <input type="checkbox"/> Nutritionist <input type="checkbox"/> Medical services <input type="checkbox"/> Occupational Therapy <input type="checkbox"/> Physiotherapy	<input type="checkbox"/> Psychiatry <input type="checkbox"/> Psychology <input type="checkbox"/> Social Work <input type="checkbox"/> Speech & Language Therapy <input type="checkbox"/> Other multidisciplinary service specify: .....
---	--
40. Agency providing main residential service (Appendix A) .....
41. Type of main residential circumstances (Appendix B) .....
42. Current level of main residential service supervision A. B. C. D. Z.
43. Agency providing secondary residential service (Appendix A) .....
44. Type of secondary residential circumstances (Appendix B) .....
45. Current level of secondary residential service supervision A. B. C. D. Z.
46. If Crisis or Planned Respite is the secondary residential service, indicate number of nights availed of in the past 12 months: .....
47. Health Board responsible for funding current services .....

#### DAY SUPERVISION LEVEL CODES

Coding for variables 32, 37, 51, 56, 61, & 66

- Level 0: NOT APPLICABLE  
 Level 1: MINIMUM - Staff to client=1 to 10+  
 Level 2: LOW - Between 1 to 6 & 1 to 9  
 Level 3: MODERATE - Between 1 to 4 & 1 to 5  
 Level 4: HIGH - Between 1 to 2 & 1 to 3  
 Level 5: INTENSIVE - 1 to 1 or above

#### RESIDENTIAL SUPERVISION LEVEL CODES

Coding for variables 42, 43, 71, 76 & 81

- Level A: MINIMUM - no sleep-in  
 Level B: LOW - Staff on duty most of the time plus sleep-in  
 Level C: MODERATE - Two staff on duty plus sleep-in  
 Level D: HIGH - Two staff on duty plus on-duty night staff  
 Level Z: NOT APPLICABLE

The shaded information in the Personal Details and Additional Information sections is removed from all records before they are sent to the Department of Health and Children and the Health Research Board.

## FUTURE SERVICE REQUIREMENTS

Rq: Required E: Enhanced

50. Type of day service required (1) (Appendix B) ☐ ☐ ☐ ☐
51. Level of supervision required in day service (1) 0. 1. 2. 3. 4. 5.
52. If multidisciplinary support services are required, please indicate type(s): \_\_\_\_\_
53. Year in which day service (1) is required ☐ ☐ ☐ ☐
54. Reason for duplication on current day service and future day service (1) ☐ ☐
55. Type of day service required (2) (Appendix B) ☐ ☐ ☐ ☐
56. Level of supervision required in day service (2) 0. 1. 2. 3. 4. 5.
57. If multidisciplinary support services are required, please indicate type(s): \_\_\_\_\_
58. Year in which day service (2) is required ☐ ☐ ☐ ☐
59. Reason for duplication on current day service and future day service (2) ☐ ☐
60. Type of day service required (3) (Appendix B) ☐ ☐ ☐ ☐
61. Level of supervision required in day service (3) 0. 1. 2. 3. 4. 5.
62. If multidisciplinary support services are required, please indicate type(s): \_\_\_\_\_
63. Year in which day service (3) is required ☐ ☐ ☐ ☐
64. Reason for duplication on current day service and future day service (3) ☐ ☐
65. Type of day service required - contingency plan ☐ ☐ ☐ ☐
66. Level of (contingency plan) day supervision required 0. 1. 2. 3. 4. 5.
67. Reason for duplication on current/contingency day service ☐ ☐
68. Reason for duplication on future day service (1), (2) or (3) and contingency day service ☐ ☐
70. Type of residential service required (1) (Appendix B) ☐ ☐ ☐ ☐
71. Level of supervision required in residential service (1) A. B. C. D. Z.
72. Year in which residential service (1) is required ☐ ☐ ☐ ☐
73. If Planned Respite is the required residential service, estimate the average number of nights required in a 12 month period: ☐ ☐ ☐ ☐
74. Reason for duplication on current residential service and future residential service (1) ☐ ☐
75. Type of residential service required (2) (Appendix B) ☐ ☐ ☐ ☐
76. Level of supervision required in residential service (2) A. B. C. D. Z.
77. Year in which residential service (2) is required ☐ ☐ ☐ ☐
78. If Planned Respite is the required residential service, estimate the average number of nights required in a 12 month period: ☐ ☐ ☐ ☐
79. Reason for duplication on current residential service and future residential service (2) ☐ ☐
80. Type of residential service required - contingency plan ☐ ☐ ☐ ☐
81. Level of (contingency plan) residential supervision required A. B. C. D. Z.
82. Reason for duplication on current/contingency residential service ☐ ☐
83. Reason for duplication on future residential service (1) or (2) and contingency residential service ☐ ☐
84. Health Board responsible for funding future services ☐ ☐ ☐ ☐

Rq	E	Rq	E
<input type="checkbox"/>	Community Nursing	<input type="checkbox"/>	Psychiatry
<input type="checkbox"/>	Nutritionist	<input type="checkbox"/>	Psychology
<input type="checkbox"/>	Medical services	<input type="checkbox"/>	Social Work
<input type="checkbox"/>	Occupational Therapy	<input type="checkbox"/>	Speech & Language Therapy
<input type="checkbox"/>	Physiotherapy	<input type="checkbox"/>	Other multidisciplinary service
			specify: _____

Rq	E	Rq	E
<input type="checkbox"/>	Community Nursing	<input type="checkbox"/>	Psychiatry
<input type="checkbox"/>	Nutritionist	<input type="checkbox"/>	Psychology
<input type="checkbox"/>	Medical services	<input type="checkbox"/>	Social Work
<input type="checkbox"/>	Occupational Therapy	<input type="checkbox"/>	Speech & Language Therapy
<input type="checkbox"/>	Physiotherapy	<input type="checkbox"/>	Other multidisciplinary service
			specify: _____

Rq	E	Rq	E
<input type="checkbox"/>	Community Nursing	<input type="checkbox"/>	Psychiatry
<input type="checkbox"/>	Nutritionist	<input type="checkbox"/>	Psychology
<input type="checkbox"/>	Medical services	<input type="checkbox"/>	Social Work
<input type="checkbox"/>	Occupational Therapy	<input type="checkbox"/>	Speech & Language Therapy
<input type="checkbox"/>	Physiotherapy	<input type="checkbox"/>	Other multidisciplinary service
			specify: _____

## ADDITIONAL INFORMATION

100. Date of completion/review ☐ ☐ ☐ ☐ ☐ ☐
101. Person responsible for update of database form ☐ ☐ ☐ ☐
102. Unit/Centre of person responsible ☐ ☐ ☐ ☐
103. Agency returning record to Health Board database ☐ ☐ ☐ ☐
104. Date consent received ☐ ☐ ☐ ☐ ☐ ☐
105. Reason for removal ☐
- If transferred (1): please indicate: to Health Board ☐ to CCA ☐ to Agency ☐ ☐ ☐ ☐
- to National Physical and Sensory Disability Database ☐
- If deleted (3): please indicate: Emigrated ☐ Parent's request ☐ Client's request ☐
- Duplication within Health Board ☐ Duplication between 2 or more Health Boards ☐
- Service no longer required ☐ Other reason ☐
106. Date of Removal ☐ ☐ ☐ ☐ ☐ ☐

## NATIONAL PERFORMANCE INDICATORS 2002 – To be completed for all people in fulltime residential services (codes 115-172):

200. National Performance Indicator 2002 (1): Has this person received the Hepatitis B vaccination ☐ 1=yes 2=no 3=declined
201. Year of vaccine administration ☐ ☐ ☐ ☐
202. National Performance Indicator 2002 (2): Does this person have a written Person-Centred Plan ☐ 1=yes 2=no



## Programme Codes and Descriptions

### DAY PROGRAMME

- 00. Not applicable
- 01. No day service
- 02. Home support
- 05. Mainstream pre-school
- 06. Special pre-school for intellectual disability
- 07. Mainstream school
- 08. Special class - primary level
- 09. Special class - secondary level
- 10. Special school
- 11. Child education and development centre (Programme for children with severe or profound intellectual disability)
- 12. Generic vocational training (e.g. F.A.S., VEC, CERT, N.T.D.I.)
- 13. Special vocational training centre - such as short-term training
- 14. Activation centre/adult day centre
- 15. Programme for the older person
- 16. Special high-support day service (e.g. relating to challenging behaviour) less than 1:1 staff ratio
- 17. Special intensive day service (e.g. relating to challenging behaviour) 1:1 staff ratio contact or greater
- 18. Sheltered work centre - may include long-term training schemes
- 19. Sheltered employment centre (receives pay and pays PRSI)
- 20. Enclave within open employment
- 21. Supported employment
- 22. Open employment
- 23. Other day programme
- 24. Resource teacher/Visiting teacher
- 25. Early Services
- 26. Generic day services
- 27. Home help
- 28. Annual review
- 29. Multidisciplinary support services for school age children or adults
- 30. Full-time resident with no formal day programme
- 31. Centre-based day respite service

#### Values 18-22

Distinguish between 'employment' which has real wages appropriate to the work done and 'work' for which real wages are not paid

### RESIDENTIAL CIRCUMSTANCES

- 101. At home, with both parents
- 102. At home, with one parent
- 103. At home with sibling
- 104. At home with relative
- 105. Lives with non-relative (e.g. neighbour or family friend)
- 106. Adoption
- 107. Foster care (includes 'boarding-out' arrangements)
- 108. Living independently
- 109. Living semi-independently - maximum 2 hours supervision daily
- 110. Vagrant or homeless
- 115. 5-day community group home - goes home for holidays
- 120. 7-day x 48-week community group home - goes home for holidays
- 125. 7-day x 52-week community group home
- 130. 5-day village-type/residential centre - goes home for holidays
- 140. 7-day x 48-week village-type/residential centre - goes home for holidays
- 145. 7-day x 52-week village-type/residential centre
- 146. Nursing home
- 170. Psychiatric hospital
- 171. Other intensive placement with special requirements due to challenging behaviour
- 172. Other intensive placement with special requirements due to profound or multiple handicap
- 173. Holiday residential placement
- 174. Crisis or planned respite
- 175. Occasional respite care with a host family in a scheme such as Home Sharing or Share-a-Break
- 176. Shared care or guardianship (usually 5 or 7 days per week)
- 177. Regular part-time care - 2-3 days per week
- 178. Regular part-time care - every weekend
- 179. Regular part-time care - alternate weeks
- 180. Other residential service

## *DAY SERVICE GROUPINGS*

### **HEALTH**

- Home support
- Home help
- Early services
- Mainstream pre-school
- Special pre-school
- Child education and development centre
- Special vocational training
- Activation centre
- Programme for the older person
- Special high support day service
- Special intensive day service
- Sheltered work centre
- Sheltered employment centre
- Multidisciplinary support services
- Centre-based day respite service
- Other day service

### **EDUCATION**

- Mainstream school
- Resource/visiting teacher
- Special class - primary
- Special class - secondary
- Special school

### **EMPLOYMENT**

- Enclave within open employment
- Supported employment
- pen employment

### **GENERIC**

- Generic vocational training
- Generic day services





# Appendix B

Table B.1. National Intellectual Disability Database, Ireland 2002.

**Details of main residential circumstances, degree of intellectual disability and age group.**

Residential circumstances	Not verified					Mild					Moderate-Severe-Profound					All Levels				
	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages
<b>Home Setting</b>	<b>972</b>	<b>114</b>	<b>106</b>	<b>30</b>	<b>1222</b>	<b>3864</b>	<b>1944</b>	<b>916</b>	<b>140</b>	<b>6864</b>	<b>3205</b>	<b>2502</b>	<b>1393</b>	<b>262</b>	<b>7362</b>	<b>8041</b>	<b>4560</b>	<b>2415</b>	<b>432</b>	<b>15448</b>
At home with both parents	836	82	30	3	951	3098	1422	363	15	4898	2636	1858	445	18	4957	6570	3362	838	36	10806
At home with one parent	118	28	45	4	195	618	420	345	19	1402	478	552	569	40	1639	1214	1000	959	63	3236
At home with sibling	1	0	22	17	40	5	35	145	69	254	11	44	320	165	540	17	79	487	251	834
At home with other relative	6	2	8	4	20	43	28	42	34	147	17	19	44	34	114	66	49	94	72	281
Living with non-relative	1	0	0	2	3	2	4	14	1	21	2	6	8	1	17	5	10	22	4	41
Adoption	0	0	0	0	0	11	4	0	0	15	7	5	1	0	13	18	9	1	0	28
Foster care and boarding-out arrangements	10	2	1	0	13	87	31	7	2	127	54	18	6	4	82	151	51	14	6	222
<b>Independent/Semi-independent Setting</b>	<b>0</b>	<b>9</b>	<b>22</b>	<b>14</b>	<b>45</b>	<b>3</b>	<b>131</b>	<b>264</b>	<b>84</b>	<b>482</b>	<b>0</b>	<b>21</b>	<b>75</b>	<b>32</b>	<b>128</b>	<b>3</b>	<b>161</b>	<b>361</b>	<b>130</b>	<b>655</b>
Living independently	0	9	15	13	37	3	90	197	62	352	0	8	44	19	71	3	107	256	94	460
Living semi-independently	0	0	7	1	8	0	41	67	22	130	0	13	31	13	57	0	54	105	36	195
<b>Community Group Home</b>	<b>3</b>	<b>2</b>	<b>12</b>	<b>6</b>	<b>23</b>	<b>65</b>	<b>189</b>	<b>374</b>	<b>168</b>	<b>796</b>	<b>122</b>	<b>692</b>	<b>1300</b>	<b>334</b>	<b>2448</b>	<b>190</b>	<b>883</b>	<b>1686</b>	<b>508</b>	<b>3267</b>
5-day community group home	1	1	4	0	6	35	59	50	5	149	34	201	183	7	425	70	261	237	12	580
7-day (48-week) community group home	0	0	1	0	1	10	40	70	23	143	27	176	338	40	581	37	216	409	63	725
7-day (52-week) community group home	2	1	7	6	16	20	90	254	140	504	61	315	779	287	1442	83	406	1040	433	1962
<b>Residential Centres</b>	<b>5</b>	<b>3</b>	<b>4</b>	<b>2</b>	<b>14</b>	<b>11</b>	<b>47</b>	<b>106</b>	<b>115</b>	<b>279</b>	<b>167</b>	<b>800</b>	<b>1524</b>	<b>677</b>	<b>3168</b>	<b>183</b>	<b>850</b>	<b>1634</b>	<b>794</b>	<b>3461</b>
5-day residential centre	2	0	0	0	2	1	3	4	0	8	32	58	36	4	130	35	61	40	4	140
7-day (48-week) residential centre	2	0	0	0	2	2	18	33	14	67	47	215	311	61	634	51	233	344	75	703
7-day (52-week) residential centre	1	3	4	2	10	8	26	69	101	204	88	527	1177	612	2404	97	556	1250	715	2618
<b>Other full-time services</b>	<b>3</b>	<b>3</b>	<b>8</b>	<b>9</b>	<b>23</b>	<b>11</b>	<b>55</b>	<b>88</b>	<b>102</b>	<b>256</b>	<b>71</b>	<b>304</b>	<b>428</b>	<b>292</b>	<b>1095</b>	<b>85</b>	<b>362</b>	<b>524</b>	<b>403</b>	<b>1374</b>
Nursing home	0	0	4	3	7	0	2	5	9	16	0	1	14	16	31	0	3	23	28	54
Psychiatric hospital	0	1	3	4	8	0	14	51	72	137	0	33	175	162	370	0	48	229	238	515
Intensive placement (challenging behaviour)	1	0	0	0	1	4	16	14	2	36	20	136	86	5	247	25	152	100	7	284
Intensive placement (profound or multiple handicap)	2	0	0	0	2	0	2	5	4	11	30	93	70	13	206	32	95	75	17	219
Fulltime resident in 'other' residential service	0	2	1	2	5	5	10	8	14	37	3	2	63	89	157	8	14	72	105	199
Fulltime resident in residential support place	0	0	0	0	0	2	11	5	1	19	18	39	20	7	84	20	50	25	8	103
No fixed abode	0	1	0	0	1	0	6	2	0	8	0	1	2	0	3	0	8	4	0	12
<b>Insufficient information</b>	<b>44</b>	<b>34</b>	<b>44</b>	<b>29</b>	<b>151</b>	<b>66</b>	<b>289</b>	<b>280</b>	<b>92</b>	<b>727</b>	<b>42</b>	<b>103</b>	<b>139</b>	<b>69</b>	<b>353</b>	<b>152</b>	<b>426</b>	<b>463</b>	<b>190</b>	<b>1231</b>
<b>Total</b>	<b>1027</b>	<b>166</b>	<b>196</b>	<b>90</b>	<b>1479</b>	<b>4020</b>	<b>2661</b>	<b>2030</b>	<b>701</b>	<b>9412</b>	<b>3607</b>	<b>4423</b>	<b>4861</b>	<b>1666</b>	<b>14557</b>	<b>8654</b>	<b>7250</b>	<b>7087</b>	<b>2457</b>	<b>25448</b>

# Appendix C

## REQUESTING INFORMATION FROM THE NATIONAL INTELLECTUAL DISABILITY DATABASE

1. Requests for information from the national dataset should be made to the National Intellectual Disability Database Committee using the official **Request Form**.
2. Any individual requiring information from the National Intellectual Disability Database is required to make a written submission to this Committee outlining the information required, the reason the information is required and the manner in which the information will be used.
3. On receiving a request for information, the chairperson of the National Intellectual Disability Database Committee will discuss the request with the other members of the committee at the earliest possible opportunity. The committee will satisfy itself:
  - (a) that the use of the National Intellectual Disability Database is a valid one in view of the proposed use or research project; and
  - (b) that there is no doubt concerning violation of client confidentiality.

If satisfied on these two points, the committee will authorise the release of the requested information from the National Intellectual Disability Database to assist the person in that particular research project or application.

4. Requests for information concerning the National Intellectual Disability Database will be subject to the following provision:

A student of a professional discipline seeking information from the National Intellectual Disability Database will be requested to ask their professional supervisor to make the application on their behalf.
5. The committee will make decisions regarding authorisation of requests on the basis of a consensus. If one member feels they cannot agree to the request, the chairperson will contact the applicant to try and resolve the issue by, for instance, requesting further information or reassurance regarding the methodology of the study or the proposed use of data.
6. When the committee authorises a request, the chairperson will state in writing the precise information to be made available and to whom it is being made available, and will give a copy of this statement to the individual(s) who has responsibility for accessing the information from the National Intellectual Disability Database.
7. Information will be made available in the form of paper reports only.
8. Completed forms should be returned to:

**The Chairman  
National Intellectual Disability Database Committee  
Intellectual Disability Services Section  
Department of Health and Children  
Hawkins House  
Dublin 2**

### **Requesting information from Regional Intellectual Disability Databases**

People requiring information pertaining to a specific Health Board region should request the information from the relevant Regional Database Co-ordinator.

**National Intellectual Disability Database  
Request for Information Form**

Name of Applicant: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Name of agency/academic institution (*where applicable*): \_\_\_\_\_

Date requested: \_\_\_\_\_

Details of the type of analysis required:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How will data be used:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Reason for request - please be as specific as possible, general explanations such as, 'research purposes' should not be used:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

(Continue on separate page if necessary)

***If I am given access to this data, I undertake to ensure the security of all information supplied to me. I undertake to maintain the confidentiality of all information in relation to clients. I will not make any such information available, in any form, to any unauthorised person or in any form that could lead to identification of any person or persons. I have read these guidelines and understand the conditions that are specified.***

Signature of Applicant: \_\_\_\_\_ Date: \_\_\_\_\_

\_\_\_\_\_  
Date Request Considered: \_\_\_\_\_

Decision of National Intellectual Disability Database Committee (NIDDC):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Any conditions which are to be applied to the request:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Signed on behalf of NIDDC:** \_\_\_\_\_

**Date:** \_\_\_\_\_





# Appendix D



## Disability Databases Division Publications

National Intellectual Disability Database Committee (1997) *Annual Report 1996*. Dublin: Health Research Board.

Mulvany F (2000) *Annual Report of the National Intellectual Disability Database Committee 1998/1999*. Dublin: Health Research Board.

Mulvany F (2001) *Annual Report of the National Intellectual Disability Database Committee 2000*. Dublin: Health Research Board.

Mulvany F (2003) *Annual Report of the National Intellectual Disability Database Committee 2001*. Dublin: Health Research Board.

