National Intellectual Disability Database Committee: annual report 2004 / Steve Barron, Fiona Mulvany.

National Intellectual Disability Database

Annual Report
of the National Intellectual
Disability Database Committee

2004

Steve Barron and Fiona Mulvany

ACKNOWLEDGEMENTS

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Chairman's Statement

It gives me great pleasure to introduce the seventh Annual Report from the Intellectual Disability Database. This report provides a profile of the population with intellectual disability as it was on 30 April 2004 and details the existing level of specialised health service provision for this group. It includes an assessment of need for specialised health services for the upcoming five-year period that outlines the pattern of care required in both residential and day care services for the years 2005 to 2009 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 noted in previous reports, this continues to be of particular importance as the population with intellectual disability is 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. Each health board receives a summary of the information for its region, including its full set of tables presented in this report. To facilitate service planning within the new health service structures due to come on stream in January 2005, this report examines the regional distribution of service provision and service need within the regional health areas of the Health Service Executive.

As in previous reports, I would like to take the opportunity to thank all those involved with the work of the database at both service provider and health board level. I would like to emphasise the importance of timely returns to both the regional databases and the national database. It is commendable that information in respect of 2004 is being published by the Health Research Board in 2004 ensuring that service planning for 2005 will be based on the most up to date information available.

The Government announced a comprehensive Disability Strategy in September 2004 including the Disability Bill 2004 and a commitment to a multi-annual Investment Programme for disability support services. The Disability Bill may have implications for the future criteria for inclusion in the database and the database will be a key determinant in deciding on the allocation of the multi-annual funding package, details of which are expected to be announced in December.

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 can be targeted at the areas of most need. I would particularly like to acknowledge the contribution made by Mr Steve Barron and Ms Fiona Mulvany to the preparation of this report.

Brendan Ingoldsby
Chairman
National Intellectual Disability Database Committee

Executive Summary

DEMOGRAPHIC PROFILE

There are 25,416 people registered on the National Intellectual Disability Database (NIDD) in 2004, representing a prevalence rate of 6.49 per 1,000 population. The administrative prevalence rate for mild intellectual disability is 2.30 per 1,000 and the prevalence rate for moderate, severe, and profound intellectual disability is 3.73 per 1,000. There are more males than females at all levels of intellectual disability, with an overall ratio of 1.28 to 1. The total number with moderate, severe, and profound intellectual disability has increased by 30% since the first Census of Mental Handicap in the Republic of Ireland was carried out in 1974. One of the factors contributing to this increase is the general population growth over the period. Since 1996 the increase in numbers is confined to those over 35 years of age. The proportion of people with moderate, severe, and profound intellectual disability aged 35 years and over has increased from 29% in 1974 to 38% in 1996, and to 46% in 2004. This reflects an increase in the lifespan of people with intellectual disability. 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 2004

The numbers registered on the NIDD in April 2004 are as follows:

- 23,843 people with intellectual disability in receipt of services, representing 94% of the total population registered on the NIDD.

- 357 people (1% of those registered) who are without services at present and are identified as requiring appropriate services in the period 2005-2009.

- 1,216 people (5%) who are not availing of services and have no identified requirement for services during the planning period 2005-2009. Most of this group (64%, 774 people) are in the mild or 'not verified' range of intellectual disability and their continued registration on the NIDD is being reviewed. However, the remaining 36% (442 people) of this group have a moderate, severe, or profound degree of intellectual disability and the need for continued monitoring of these individuals' circumstances is highlighted.

Of the 23,843 people in receipt of services in 2004:

- 8,093 are in receipt of full-time residential services which is broadly similar to 2003. The number of people with intellectual disability accommodated in psychiatric hospitals has decreased by 20 since 2003, to 474.

- 23,645 people are availing of at least one day programme. Of this group, 7,936 are in full-time residential placements and 4,415 are in receipt of residential support services such as respite care.

Sixty-two per cent of all children and adults (15,731 individuals) with intellectual disability live at home with parents, siblings, relatives, or foster parents. As the carers of adults begin to age beyond their caring capacity, formal supervised living arrangements will need to be established. Because people with intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years. These data highlight the importance of planning for such eventualities and avoiding crisis situations.

Since the first report from the NIDD in 1996, there has been significant growth in the level of provision of full-time residential services, residential support services, and day services, reflecting, in particular, the significant investment programme in the intellectual disability sector between 2000 and 2002. Key developments during the period 1996 to 2004 noted in this report include:

- a 45% growth in the number of people with intellectual disability living full-time in group homes within local communities;

- an increase in the provision of intensive residential placements designed to meet the needs of individuals with challenging behaviours, which has almost trebled from 107 places to 311 places;

- a 55% reduction in the number of people with intellectual disability accommodated in psychiatric hospitals;

- a continued expansion in the availability of residential support services, in particular planned or emergency centre-based respite services, which have grown by 357%;

- 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 2004 there are 2,210 people who are either without services or without a major element of service (either a full-time residential service, or a day service, or both) and require services, a decrease of 74, or 3%, since 2003. To meet the needs of these individuals the following will be required during the period 2005-2009 (though most service needs arise immediately):

- 1,893 full-time residential placements, an increase of 117, or 7%, since 2003 and the highest number since the database was established.

- 347 day programmes, a decrease of 199, or 36%, since 2003 and the lowest number since the database was established. This suggests that significant progress has been made in meeting the demand for day services.

- 1,763 residential support services, an increase of 126, or 8%, since 2003 and the highest number since the database was established.

- A group of 288 individuals living in psychiatric hospitals in 2004 has been identified as needing to transfer from these locations to more appropriate accommodation.

In 2004 a further 11,416 people are receiving services but require alternative, additional, or enhanced services within the next five years, an increase of 281, or 3%, since 2003. 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 children's to adult services, or from training to employment placements.

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. In particular, the number requiring full-time residential services has increased by 14% (260 places) over the past two years and is the highest recorded figure since formal reporting through the National Intellectual Disability Database was established.

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 Ireland to provide appropriate services designed to meet the changing needs of people with intellectual disability 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 pertaining 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 NIDD 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 identify 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 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. In addition 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. There are ongoing efforts to ensure continued improvement of data quality at local, regional, and national levels.

2004 ANNUAL REPORT

This is the seventh report of the National Intellectual Disability Database Committee. The report is based on validated data received from all eight regional databases in April 2004. Adherence to scheduled export dates ensures timely reporting of data by the HRB and enables accurate comparisons between regional datasets. Regional datasets will continue to exist under the new structures of the Health Service Executive with regional information to be maintained within the four new regional health areas. To facilitate service planning within the new health service structures due to come on stream in January 2005, this report examines the regional distribution of service provision and service need within the regional health areas of the Health Service Executive.

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[1]. In the 2004 dataset, there are 124 people recorded as being of average ability and 625 people in the borderline intellectual disability category, an increase of 9 and a reduction of 54 respectively since 2003. 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 the 'not verified' category in addition to those with a mild, moderate, severe, or profound intellectual disability.

[1] 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 2004 there are 25,416 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 2004 is 2.30/1000, compared to 2.38/1000 in 2003. This figure is not a true reflection of the prevalence of mild intellectual disability as only those with mild intellectual disability accessing or requiring intellectual disability services are included in the database. The prevalence rate for moderate, severe, and profound intellectual disability in 2004 is 3.73/1000, compared to 3.72/1000 in 2003.

Table 2.1. National Intellectual Disability Database, Ireland 2004.
Degree and prevalence of intellectual disability.

	n	%	rate per 1,000
Mild	9011	35.5	2.30
Moderate	9587	37.7	2.45
Severe	3968	15.6	1.01
Profound	1050	4.1	0.27
Not verified	1800	7.1	0.46
All levels	**25416**	**100.0**	**6.49**

Overall, the numbers registered on the NIDD have decreased by 141 (0.6%) since 2003 (Barron and Mulvany, 2004). During the review and update period prior to the 2004 export of data from the health boards to the national dataset, 1,352 people were removed from the database and the balance is accounted for by new registrations. The removed records consisted of 521 people who no longer required intellectual disability services (450 of whom were in the mild range of intellectual disability and 71 of whom were recorded as level of disability 'not verified'), 228 people who had died, 39 people who it was deemed would be more appropriately registered on the National Physical and Sensory Disability Database, 22 people who had emigrated, and 542 individuals where the reason for removal was 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 NIDD 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.

Table 2.2. National Intellectual Disability Database, Ireland 2004.
Age, gender and degree of intellectual disability.

Numbers

Age Group	Not verified			Mild			Moderate			Severe			Profound			All levels		
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
0-4	328	454	782	46	82	128	51	82	133	24	45	69	9	5	14	458	668	1126
5-9	100	218	318	261	434	695	250	390	640	114	161	275	30	30	60	755	1233	1988
10-14	35	40	75	454	804	1258	314	498	812	100	157	257	29	27	56	932	1526	2458
15-19	22	48	70	669	1064	1733	386	572	958	105	179	284	28	35	63	1210	1898	3108
20-34	79	91	170	1032	1330	2362	1267	1564	2831	444	676	1120	154	163	317	2976	3824	6800
35-54	108	112	220	1001	1096	2097	1457	1560	3017	675	810	1485	186	258	444	3427	3836	7263
55 & over	70	95	165	407	331	738	652	544	1196	249	229	478	34	62	96	1412	1261	2673
All ages	**742**	**1058**	**1800**	**3870**	**5141**	**9011**	**4377**	**5210**	**9587**	**1711**	**2257**	**3968**	**470**	**580**	**1050**	**11170**	**14246**	**25416**

Prevalence rates - numbers per 1,000 of the general population for each group

Age Group	Not verified			Mild			Moderate			Severe			Profound			All levels		
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
0-4	2.42	3.20	2.82	0.34	0.58	0.46	0.38	0.58	0.48	0.18	0.32	0.25	0.07	0.04	0.05	3.38	4.70	4.06
5-9	0.78	1.60	1.20	2.04	3.19	2.63	1.95	2.87	2.42	0.89	1.18	1.04	0.23	0.22	0.23	5.89	9.07	7.53
10-14	0.25	0.27	0.26	3.25	5.50	4.40	2.25	3.41	2.84	0.72	1.07	0.90	0.21	0.18	0.20	6.68	10.44	8.60
15-19	0.14	0.30	0.22	4.38	6.63	5.53	2.53	3.57	3.06	0.69	1.12	0.91	0.18	0.22	0.20	7.92	11.83	9.92
20-34	0.17	0.19	0.18	2.19	2.81	2.50	2.68	3.30	2.99	0.94	1.43	1.18	0.33	0.34	0.34	6.31	8.07	7.19
35-54	0.21	0.21	0.21	1.92	2.10	2.01	2.79	2.99	2.89	1.29	1.55	1.42	0.36	0.49	0.43	6.57	7.36	6.96
55 & over	0.17	0.26	0.21	0.97	0.90	0.94	1.55	1.48	1.52	0.59	0.62	0.61	0.08	0.17	0.12	3.35	3.44	3.39
All ages	**0.38**	**0.54**	**0.46**	**1.96**	**2.64**	**2.30**	**2.22**	**2.68**	**2.45**	**0.87**	**1.16**	**1.01**	**0.24**	**0.30**	**0.27**	**5.67**	**7.32**	**6.49**

Gender differences

As Table 2.2 indicates, the number of males at all levels of intellectual disability exceeds the number of females. The number of males exceeds the number of females at all age groups except the 55 years and over age group. The overall male to female ratio is 1.28:1. This represents a prevalence rate of 7.32/1000 males and 5.67/1000 females.

Age differences

Of the persons recorded on the NIDD, 34.2% (8,680) are aged 19 years and under, 26.8% (6,800) are aged between 20 and 34 years, 28.6% (7,263) are aged between 35 and 54 years, and 10.5% (2,673) 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 number of children in special education who receive support services from the intellectual disability sector, a proportion 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 who have an intellectual disability do not receive a definitive diagnosis of their level of intellectual disability in their earlier years.

Figure 1. National Intellectual Disability Database, Ireland 2004.
Age profile of total population, showing proportion at each level of intellectual disability in each age group.
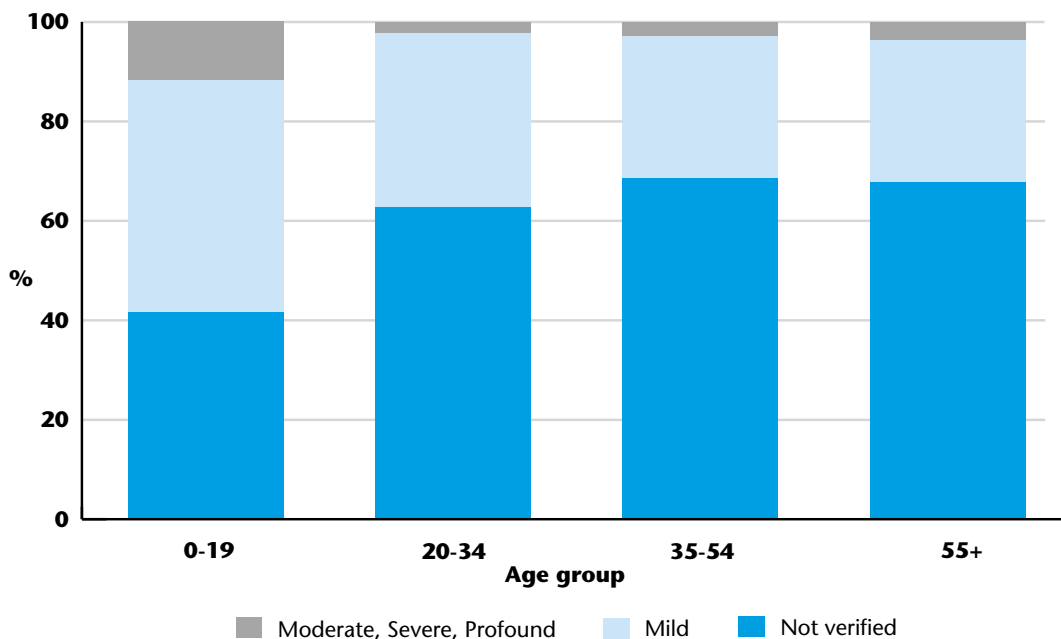
Trends over time

Recent trends

Prevalence rates for moderate, severe, and profound intellectual disability for 1996 and 2004 are compared in Table 2.3. The two years provide a good comparison as data from the NIDD is available for both years and a national census of the Irish population was taken in 1996 and 2002. Compared to the 1996 data (National Intellectual Disability Database Committee, 1997), the 2004 data in Table 2.3 demonstrate the following trends:

- A reduced prevalence rate for the 0-4 year age group. The decrease of 0.46/1000 in prevalence rate is associated with a 36.3% drop in numbers in this group registered on the database between 1996 and 2004. The prevalence rate for the 0-4 year age group, at 0.78/1000, 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 age range for maximum ascertainment of individuals with an intellectual disability, it is estimated that the number of children aged 0-4 years, as recorded on the database, may be underestimated by somewhere in the region of 878 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 situations where parents are reluctant to allow information about their young child to be recorded on the database.

- An overall increase in prevalence among the 5-9 year age group. This increase is observed despite a fall of 9.1% in numbers in this age group registered on the database between 1996 and 2004 and a decline in the general population in this age group during the corresponding census period.

- A slight increase in prevalence among the 10-14 year age group despite a fall of 16.4% in numbers in this age group registered on the database over the eight-year period.

- An overall decrease in prevalence among the 15-19 year age group between 1996 and 2004. A large decrease in prevalence is observed following the 1996 dataset but the rate has remained relatively constant since 1999.

- A downward trend in prevalence in the 20-34 year age group. The prevalence among 20-34 year olds has been falling consistently over the eight-year period. The 2003 dataset was the first in which this age group did not exhibit the highest prevalence of moderate, severe or profound intellectual disability and this is observed again in the 2004 dataset.

- An overall decrease in prevalence among the 35-54 year age group since 1996 but with an upward trend apparent since 2002. This upward trend has resulted in the 35-54 year age group exhibiting the highest prevalence of moderate, severe or profound intellectual disability of any age group in both 2003 and 2004. The significance of this upward trend is discussed later in this chapter.

- A slight increase in prevalence in the 55 and over age group. The number of people in this age group registered on the database has increased by 336 since 1996.

Table 2.3. National Intellectual Disability Database, Ireland 2004.
Age and degree of intellectual disability (moderate, severe and profound): 1974, 1981, 1996, 2004.

Numbers

Age Group	Moderate				Severe				Profound				All levels			
	1974	1981	1996	2004	1974	1981	1996	2004	1974	1981	1996	2004	1974	1981	1996	2004
0-4	189	214	226	133	143	92	83	69	99	26	30	14	431	332	339	216
5-9	809	955	736	640	617	330	260	275	224	99	77	60	1650	1384	1073	975
10-14	752	1035	948	812	583	428	305	257	292	117	93	56	1627	1580	1346	1125
15-19	698	1203	1072	958	445	508	378	284	241	154	132	63	1384	1865	1582	1305
20-34	1498	2419	2997	2831	1017	1129	1350	1120	441	340	460	317	2956	3888	4807	4268
35-54	1321	1559	2626	3017	626	612	1183	1485	201	97	343	444	2148	2268	4152	4946
55 & over	669	715	987	1196	307	248	394	478	84	24	53	96	1060	987	1434	1770
All ages	**5936**	**8100**	**9592**	**9587**	**3738**	**3347**	**3953**	**3968**	**1582**	**857**	**1188**	**1050**	**11256**	**12304**	**14733**	**14605**

Prevalence rates - numbers per 1,000 of the general population for each group

Age Group	Moderate				Severe				Profound				All levels			
	1974	1981	1996	2004	1974	1981	1996	2004	1974	1981	1996	2004	1974	1981	1996	2004
0-4	0.60	0.62	0.83	0.48	0.45	0.27	0.30	0.25	0.31	0.07	0.11	0.05	1.36	0.97	1.24	0.78
5-9	2.55	2.73	2.31	2.42	1.95	0.94	0.82	1.04	0.71	0.28	0.24	0.23	5.20	3.95	3.37	3.69
10-14	2.52	3.08	2.72	2.84	1.95	1.27	0.88	0.90	0.98	0.35	0.27	0.20	5.45	4.70	3.86	3.94
15-19	2.61	3.79	3.20	3.06	1.66	1.60	1.13	0.91	0.90	0.48	0.39	0.20	5.17	5.88	4.72	4.17
20-34	2.78	3.33	3.93	2.99	1.88	1.56	1.77	1.18	0.82	0.47	0.60	0.34	5.48	5.35	6.31	4.51
35-54	2.13	2.43	3.25	2.89	1.01	0.95	1.46	1.42	0.32	0.15	0.42	0.43	3.46	3.53	5.14	4.74
55 & over	1.08	1.09	1.45	1.52	0.50	0.38	0.58	0.61	0.14	0.04	0.08	0.12	1.71	1.51	2.11	2.25
All ages	**1.99**	**2.35**	**2.72**	**2.45**	**1.25**	**0.97**	**1.12**	**1.01**	**0.53**	**0.25**	**0.34**	**0.27**	**3.80**	**3.60**	**4.18**	**3.73**

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 30 years (Table 2.3).

The number of those more severely affected has increased by 29.8% (3,349 individuals) since 1974, which closely matches the general population increase over the 30-year period. The total number of those with a more severe disability is 14,605 in 2004, compared to 11,256 in 1974. The current prevalence rate of 3.73 per thousand is consistent with that reported in 1974 (3.80 per thousand). 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. With the exception of the 55 years and over age group in 2002, the two older age groups have shown a continued increase in numbers each year since 1996. The overall increase in numbers is influenced by a number of factors, including the general population increase in these age groups during the 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 30-year period, with fewer children and young adults and more older adults availing of, or in need of, intellectual disability services. There are fewer children and young people, aged 0-19 years, with moderate, severe, or profound intellectual disability now than in 1974, 1981, or 1996. This may reflect the decline in the birth rate in Ireland between 1980 and 1995, improved antenatal care, and the effectiveness of early intervention services but also raises questions regarding the under-registration of children. It is reasonable to assume that there are children with intellectual disability in mainstream education that do not have contact with specialised health services. Reluctance of parents to allow information about their children to be recorded on the database may also have an impact, particularly in the 0-4 year age group.

Cohort effect

There has been a significant increase in the number of adults currently availing of, or in need of, intellectual disability services. Closer examination suggests that the increase in the older age group almost certainly reflects a cohort effect, whereby a population bulge originating in the 1960s and lasting until the mid-1970s is moving through the services and now translating into large numbers of adults in the older age groups. This population bulge is attributable to a high birth rate in the 1960s and 1970s and improved obstetric and paediatric care over this period. 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 translated into the peak prevalence rate in 1981 in the 15-19 year age group. The peak prevalence rate in 1996 was observed in the 20-34 year age group and now, in 2004, the highest prevalence rate is seen in the 35-54 year age group. This is the second consecutive year of available data (1974, 1981, 1996, 1998 to 2004) in which the 35-54 year age group displays the highest prevalence rate and numbers of any age group with moderate, severe, and profound intellectual disability.

Figure 2. National Intellectual Disability Database, Ireland 2004.
Prevalence of moderate, severe, and profound intellectual disability (combined) by age group: 1974, 1981, 1996, 2004.
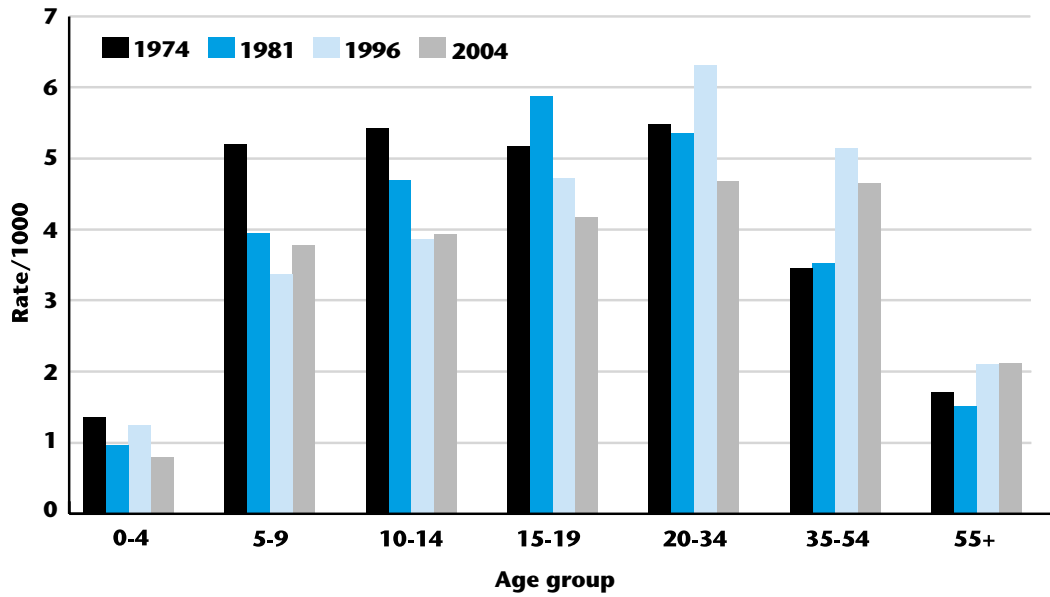
Figure 3. National Intellectual Disability Database, Ireland 2004.
Prevalence of moderate, severe, and profound intellectual disability (combined) by age group: 1974, 1981, 1996, 2004.
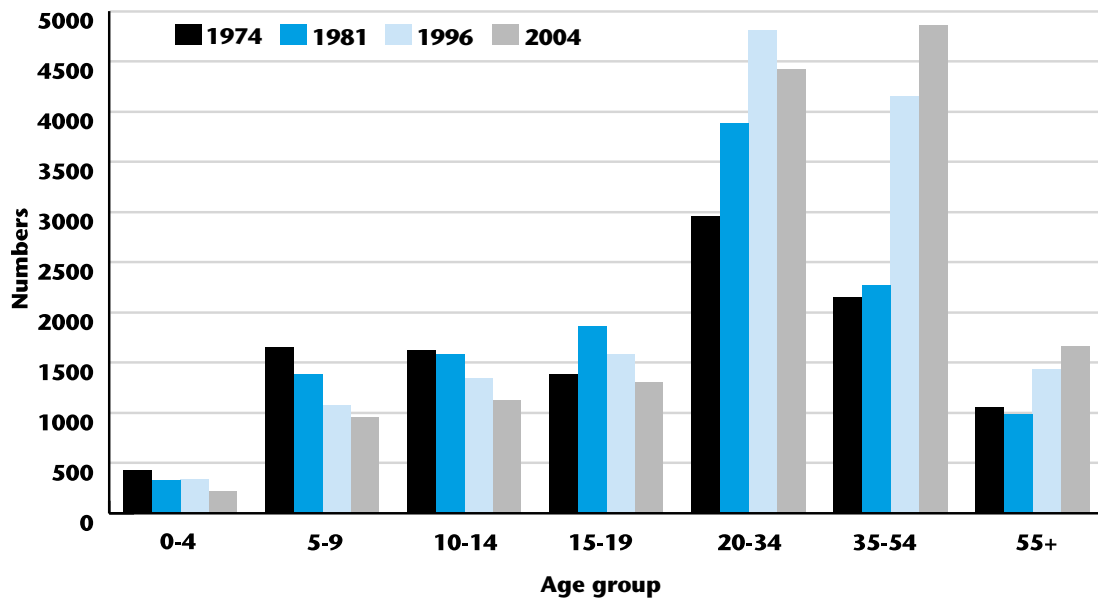
Ageing population

Figure 4 provides further evidence that the population of people with intellectual disability in Ireland is an ageing population. 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. By grouping people with a moderate, severe, or profound intellectual disability into two groups, people aged under 35 years and people aged 35 years and over, it can be seen that 28.5% of this population were aged 35 years and over in 1974, while 26.5% fell into this age category in 1981. A steady increase in the proportion aged 35 years and over has been observed in each dataset since 1996, from 37.9% in 1996 to 46.0% in the 2004 dataset. This increase between 1996 and 2004 represents 1,130 more people with a moderate, severe, or profound intellectual disability aged 35 years and over.

Figure 4. National Intellectual Disability Database, Ireland 2004.
Proportion of people with moderate, severe, and profound intellectual disability (combined) aged over 35 years: 1974, 1981, 1996, 1998-2004.
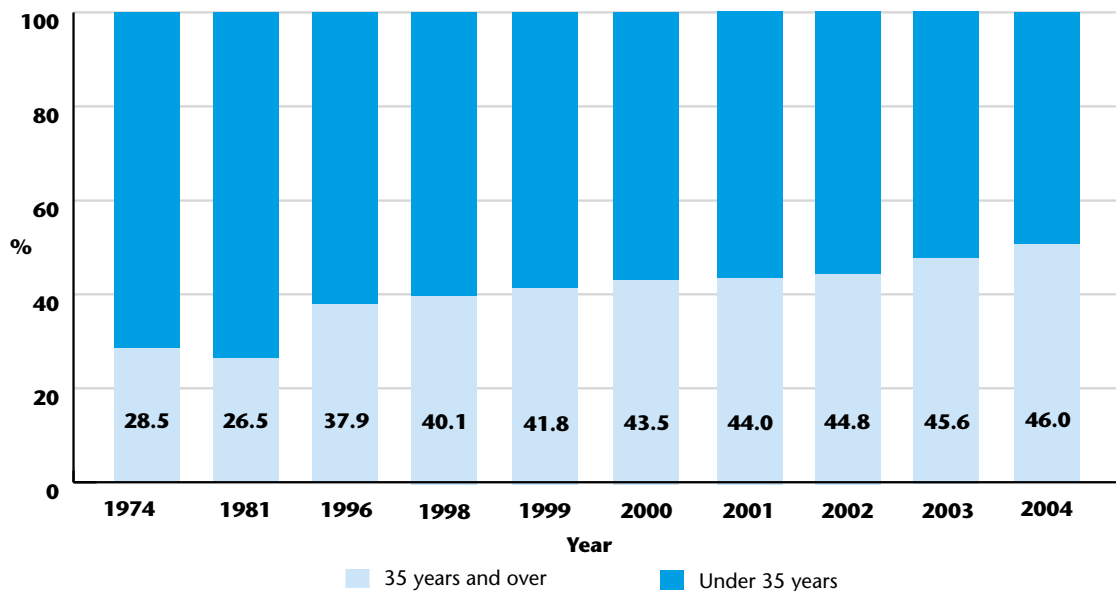
Impact of observed trends

As previous reports from the NIDD 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.

- As will be shown in Chapter 3, residential services are primarily used by adults with a more severe intellectual disability. As the number of individuals in this group increases, increased pressure will be experienced by residential services. This is reflected in the current waiting lists for full-time residential services.

- Improved life expectancy among adults with a more severe intellectual disability will place an increased demand on the health services and pose new challenges to health care professionals. Fewer places will become free over time, a higher degree of support within day and residential services will be required, and specific support services for older people will be needed.

- Chapter 3 indicates that the majority of adults with intellectual disability continue to live with their families. 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.

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 – this baby-boom generation, born in the 1960s and 1970s, will begin to reach age 55 in 2015, just eleven years away. Failure to anticipate the associated service needs often results in crisis situations for families and for service providers. The NIDD is an invaluable resource in providing a sound evidence base for service planning and delivery. Not only does it allow us to identify specific individual service requirements arising in the next five years, but the demographic information also allows us to look further into the future and anticipate the impact of changing demographic trends.

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 2004. 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 2.4a details the number individuals registered within each new regional health area of the Health Service Executive.

Table 2.4. National Intellectual Disability Database, Ireland 2004.
Number of people included on each Regional Intellectual Disability Database.

	n	%
Eastern Regional Health Authority	8438	33.2
Midland Health Board	1383	5.4
Mid-Western Health Board	2344	9.2
North-Eastern Health Board	2018	7.9
North-Western Health Board	1795	7.1
South-Eastern Health Board	3088	12.1
Southern Health Board	3661	14.4
Western Health Board	2689	10.6
Total	**25416**	**100.0**

Table 2.4a. National Intellectual Disability Database, Ireland 2004. Number of people registered within the regional health areas of the Health Service Executive.		
	n	**%**
Dublin/Mid-Leinster	6480	25.5
Southern	6749	26.6
Western	6828	26.9
Dublin/North-East	5359	21.1
Total	**25416**	**100.0**

Table 2.5 summarises the number and proportion of people at each level of intellectual disability in each health board area. Table 2.5a details the number and proportion of people at each level of intellectual disability within the new regional health areas of the Health Service Executive.

Table 2.5. National Intellectual Disability Database, Ireland 2004. Degree of intellectual disability by health board area.						
	Not verified	**Mild**	**Moderate**	**Severe**	**Profound**	**All levels**
	n **%**	**n** **%**	**n** **%**	**n** **%**	**n** **%**	**n** **%**
Eastern Regional Health Authority	780 9.2	2875 34.1	3227 38.2	1217 14.4	339 4.0	8438 100.0
Midland Health Board	79 5.7	392 28.3	649 46.9	220 15.9	43 3.1	1383 100.0
Mid-Western Health Board	133 5.7	881 37.6	884 37.7	359 15.3	87 3.7	2344 100.0
North-Eastern Health Board	133 6.6	729 36.1	757 37.5	321 15.9	78 3.9	2018 100.0
North-Western Health Board	194 10.8	639 35.6	630 35.1	283 15.8	49 2.7	1795 100.0
South-Eastern Health Board	184 6.0	1195 38.7	1070 34.7	465 15.1	174 5.6	3088 100.0
Southern Health Board	141 3.9	1301 35.5	1402 38.3	612 16.7	205 5.6	3661 100.0
Western Health Board	56 5.8	999 37.2	968 36.0	491 18.3	75 2.8	2689 100.0
Total	**1800** **7.1**	**9011** **35.5**	**9587** **37.7**	**3968** **15.6**	**1050** **4.1**	**25416** **100.0**

Table 2.5a. National Intellectual Disability Database, Ireland 2004. **Degree of intellectual disability by the regional health areas of the Health Service Executive**	Not verified	Mild	Moderate	Severe	Profound	All levels
	n %	n %	n %	n %	n %	n %
Dublin/Mid-Leinster	558 8.6	2243 34.6	2530 39.0	842 13.0	307 4.7	6480 100.0
Southern	325 4.8	2496 37.0	2472 36.6	1077 16.0	379 5.6	6749 100.0
Western	483 7.1	2519 36.9	2482 36.4	1133 16.6	211 3.1	6828 100.0
Dublin/North East	434 8.1	1753 32.7	2103 39.2	916 17.1	153 2.9	5359 100.0
Total	**1800 7.1**	**9011 35.5**	**9587 37.7**	**3968 15.6**	**1050 4.1**	**25416 100.0**

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 NIDD 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 Western Health Board and lowest in the North-Eastern Health Board. There is a general geographical pattern observable in this table, with the highest rates observed in the health boards in the west, south and midlands of the country and a lower prevalence observed in the north and east. These variations are most probably 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 2004.
**Prevalence rates for 0-19 year age groups by geographical region
(moderate, severe and profound intellectual disability combined).**

	0-4 years n rate	5-9 years n rate	10-14 years n rate	15-19 years n rate	0-19 years n rate
Eastern Regional Health Authority	46 0.48	281 3.17	345 3.66	428 4.00	1100 2.84
Midland Health Board	18 1.03	57 3.44	80 4.48	94 5.02	249 3.53
Mid-Western Health Board	17 0.71	74 3.19	114 4.59	122 4.37	327 3.27
North-Eastern Health Board	16 0.58	91 3.65	102 3.78	95 3.36	304 2.82
North-Western Health Board	5 0.31	54 3.37	66 3.71	84 4.54	209 3.06
South-Eastern Health Board	35 1.13	130 4.35	123 3.73	140 4.07	428 3.34
Southern Health Board	38 0.96	162 4.16	174 4.15	201 4.36	575 3.45
Western Health Board	41 1.61	125 4.86	120 4.14	141 4.40	427 3.80
All Regions **Rate**	**216** **0.78**	**974**[a] **3.69**	**1124**[a] **3.93**	**1305** **4.17**	**3619** **3.17**

[a] These totals differ from the corresponding age group totals in Table 2.3 as one individual in the 5-9 year age group and one individual in the 10-14 year age group have health board recorded as 'outside Ireland'.

Chapter three

3. Service Provision in 2004

NATIONAL LEVEL

Summary of service provision

In 2004, 23,843 people with intellectual disability are receiving services, which accounts for 93.8% of the total population registered on the National Intellectual Disability Database, compared to a service provision level of 91.8% in 2003. A further 1,573 (6.2%) people are identified as not being in receipt of services, of whom 357 (1.4%) have expressed a need for services in the period 2005-2009. A summary of the overall level of service provision in 2004 is provided in Table 3.1.

Table 3.1. National Intellectual Disability Database, Ireland 2004. **Summary of service provision in 2004.**		
	n	**%**
Attending services on a day basis	15709	61.8
Receiving 5- or 7-day residential services	7619	30.0
Resident in a psychiatric hospital	474	1.9
Receiving residential support services only	41	0.2
Receiving no service	357	1.4
No identified service requirements	1216	4.8
Total	**25416**	**100.0**

Note:

4,415 day attenders and 483 full-time residents receive residential support services in addition to their principal service.

7,936 full-time residents receive a day service in addition to their full-time residential service.

Table 3.2 summarises service provision in 2004 by degree of intellectual disability and age group.

Without services

In 2004 there are 357 people (1.4%) without services and who have identified service needs in the period 2005-2009, details of which are presented in Chapter 4. Almost two-thirds of this group are in the 'not verified' (6.4%) and mild (54.1%) categories of intellectual disability and 39.5% have a moderate, severe, or profound level of intellectual disability. The majority (86.8%) are aged 19 and over.

A further 1,216 people (4.8% of total registrations) are also without services but have no identified requirement for services within the five-year period 2005-2009. Of this group of 1,216 people with no identified service requirements:

- 287 (23.6%) have their circumstances formally reviewed annually and 215 (17.7%) have contingency service plans identified on the database.

Table 3.2. National Intellectual Disability Database, Ireland 2004.
Summary of service provision in 2004 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
Attending services on a day basis	1150	305	1455	3385	3508	6893	3069	4292	7361	7604	8105	15709
Receiving 5- or 7-day residential services	15	126	141	60	1123	1183	225	6070	6295	300	7319	7619
Resident in a psychiatric hospital	0	4	4	0	123	123	0	347	347	0	474	474
Receiving residential support services only	12	1	13	1	8	9	5	14	19	18	23	41
Receiving no service	3	20	23	20	173	193	24	117	141	47	310	357
No service requirements in 2004	52	112	164	61	549	610	37	405	442	150	1066	1216
Total	**1232**	**568**	**1800**	**3527**	**5484**	**9011**	**3360**	**11245**	**14605**	**8119**	**17297**	**25416**

- 1,066 (87.7%) are aged 19 years or over.

- 774 (63.7%) have a mild or 'not verified' level of intellectual disability and it is not unreasonable to assume that they genuinely do not require services at this time. The appropriateness of registering people with mild intellectual disability who have no identified need for specialised health services on the database is being monitored on an ongoing basis.

- 442 (36.3%) have a moderate, severe, or profound degree of intellectual disability. Within this group, 153 have their circumstances formally reviewed annually and 119 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 that may not be tailored to the specific needs of the individual. The National Intellectual Disability Database Committee remains concerned about the circumstances of 37 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 2005-2009.

Availing of services

As mentioned in Chapter 2, there is a clear relationship between level of disability, age, and the type of service availed of. As is illustrated in Table 3.3, 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 a moderate, severe, or profound level of intellectual disability.

- Of the 15,709 individuals accessing services on a day basis in 2004, 6,893 (43.9%) have a mild level of intellectual disability and 7,604 (48.4%) are aged 18 years and under.

- There are 7,619 full-time residents in intellectual disability services in 2004, of whom 6,295 (82.6%) have a moderate, severe, or profound degree of disability, and 7,319 (96.1%) are aged 19 years and over. All 474 individuals with an intellectual disability residing in psychiatric hospitals are aged 19 years and over, and 347 (73.2%) have a moderate, severe, or profound degree of intellectual disability.

A further 41 individuals registered on the database in 2004 are availing of residential support services only.

Residential circumstances

Table 3.3 outlines the main residential circumstances of those registered on the NIDD in 2004. The majority of residential circumstances consists of

- 15,731 individuals (61.9%) living in a home setting with parents, relatives, or foster parents;

- 8,093 individuals (31.8%) living in full-time residential services, mainly in community group homes, residential centres, psychiatric hospitals, and intensive placements;

- 741 individuals (3.0%) living independently or semi-independently.

Table 3.3. National Intellectual Disability Database, Ireland 2004. **Main residential circumstances.**		
	n	**%**
Home setting	**15731**	**61.9**
At home with both parents	10752	42.3
At home with one parent	3560	14.0
At home with sibling	836	3.3
At home with other relative	267	1.1
Living with non-relative	44	0.2
Adoption	22	0.1
Foster care and boarding-out arrangements	250	1.0
Independent setting	**741**	**3.0**
Living independently	524	2.1
Living semi-independently	217	0.9
Community group homes	**3462**	**13.6**
5-day community group home	539	2.1
7-day (48-week) community group home	691	2.7
7-day (52-week) community group home	2232	8.8
Residential centres	**3444**	**13.6**
5-day residential centre	124	0.5
7-day (48-week) residential centre	569	2.2
7-day (52-week) residential centre	2751	10.8
Other full-time services	**1187**	**4.6**
Nursing home	106	0.4
Psychiatric hospital	474	1.9
Intensive placement (challenging behaviour)	311	1.2
Intensive placement (profound or multiple handicap)	233	0.9
Occupying a residential support place	32	0.1
Other full-time residential service	31	0.1
No fixed abode	**14**	**0.1**
Insufficient information	**837**	**3.3**
Total	**25416**	**100.0**

There are 8,093 people in receipt of full-time residential services in 2004 which is broadly similar to 2003. This is the first year of data that indicate that more full-time residents live in homes in the community (3,462) than in residential centres (3,444). The numbers of people accommodated in community group homes and residential centres have increased and decreased respectively since data collection commenced in 1996. This trend reflects a shift towards community integration in the provision of residential services to people with intellectual disabilities. In 2004, there are 474 people with intellectual disability residing full-time in psychiatric hospitals, a reduction of 20 (4.0%) since 2003.

The 2004 data indicate that 32 of the full-time residents are occupying residential support places on a full-time basis, thereby blocking these services from their intended use. There are 14 individuals registered on the database who have no fixed abode. There is insufficient information on the residential circumstances of 837 people (3.3%) registered on the database, a reduction of 340 people (28.9%) since 2003. Although much progress has been made over the last year, this group needs to be further reviewed as a matter of urgency to improve the overall quality of data available from the NIDD. All 837 records with insufficient information regarding main residential circumstance were returned by the Eastern Regional Health Authority.

Main residential circumstances: age group and degree of intellectual disability

Table 3.4 provides an overview 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.

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 – 94.5% of individuals aged 0-19 years live in a home setting, declining to 66.3% of those aged between 20-34 years, 35.5% of those aged 35-54 years, and 16.8% of those aged 55 years and over.

In contrast, the proportion of people in the different age categories who are living in full-time residential services increases with age – 4.2% of all 0-19-year-olds are in receipt of full-time residential services, compared to 28.7% of 20-34-year-olds, 53.8% of 35-54-year-olds, and 70.0% of those aged 55 years and over.

The data indicate that 25.3% of people with a moderate, severe, or profound intellectual disability aged 35 years and over 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.

Degree of intellectual disability

There are also noticeable variations between level of ability and type of residential situation. Of those people with a mild intellectual disability, 74.0% live in a home setting, compared to 51.9% of those with a moderate, severe, or profound intellectual disability. The proportion of people in full-time residential services is increased among the more severe categories of

disability. Only 14.5% of people with a mild intellectual disability live in full-time residential services but this increases to 45.5% 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. Full-time residents with a mild intellectual disability are most likely accommodated in community group homes while full-time residents with a moderate, severe or profound intellectual disability are most likely accommodated in residential centres.

- Of those in the mild range of intellectual disability who are in full-time residential services, 60.9% are in community group homes, 22.1% are in residential centres, and 17.0% are in other full-time residential services.

- Of those in full-time residential services who have a moderate, severe or profound intellectual disability, 39.6% are in community group homes, 46.3% are in residential centres and 14.1% are in other full-time residential services.

Day services

In 2004, 23,645 people, representing 93.0% of all those registered on the NIDD, are availing of day services. This represents an increase of 634 (2.8%) people availing of day services since 2003.

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.

Of the 23,645 individuals availing of day services, 33.6% (7,936) are also in full-time residential services, the majority of whom are in the moderate, severe, or profound range of intellectual disability (82.3%) or aged 19 years and over (96.3%). The remaining 66.4% (15,709) attend services on a day basis, of whom 43.9% are in the mild range of intellectual disability and 48.4% are aged 18 years and under.

The 2004 data indicate that 119 full-time residents have no day activity programme. The day service needs of this group, where identified, are documented in Chapter 4 of this report.

Details of the principal day services provided in 2004 both to residents and to those who attend services on a day basis can be seen in Table 3.6.

The top five day activities availed of by people with intellectual disability in 2004, and accounting for over 70% of day service provision, are: activation programmes, sheltered work, special schools, rehabilitative training, and multidisciplinary support services only (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. Those in full-time residential services are much more likely to avail of services such as activation programmes, sheltered work, multidisciplinary support services, specific programmes for older people, and special high-support programmes.

Table 3.4. National Intellectual Disability Database, Ireland 2004.

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	1199	130	113	43	1485	3680	1823	1014	155	6672	3320	2554	1450	250	7574	8199	4507	2577	448	15731
Independent setting	1	5	29	20	55	3	141	321	89	554	0	23	68	41	132	4	169	418	150	741
Community group home	7	7	13	7	34	48	184	362	202	796	99	677	1429	427	2632	154	868	1804	636	3462
Residential centre	2	4	29	49	84	16	54	103	115	288	129	689	1505	749	3072	147	747	1637	913	3444
Other full-time services	6	1	5	15	27	9	53	82	78	222	47	280	381	230	938	62	334	468	323	1187
No fixed abode	0	1	0	0	1	0	7	1	0	8	0	2	2	1	5	0	10	3	1	14
Insufficient information	30	22	31	31	114	58	100	214	99	471	26	43	111	72	252	114	165	356	202	837
Total	**1245**	**170**	**220**	**165**	**1800**	**3814**	**2362**	**2097**	**738**	**9011**	**3621**	**4268**	**4946**	**1770**	**14605**	**8680**	**6800**	**7263**	**2673**	**25416**

	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
Residents	14	128	142	60	1203	1263	224	6307	6531	298	7638	7936
Day attenders	1150	305	1455	3385	3508	6893	3069	4292	7361	7604	8105	15709
Total	1164	433	1597	3445	4711	8156	3293	10599	13892	7902	15743	23645

Table 3.5. National Intellectual Disability Database, Ireland 2004.
Residential status of people availing of day services by degree of intellectual disability and age group.

Main day services by age group and degree of intellectual disability

Table 3.7 provides details of the principal day services availed of in 2004, categorised by age group and degree of intellectual disability.

Age differences

Of those availing of day services in 2004 (23,645 individuals), 33.4% (7,902) are aged 18 years and under, and 66.6% (15,743) are aged 19 years and over (see Table 3.7).

In 2004 there are 7,902 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, attending both mainstream and specialised pre-school services, or are attending child education and development centres. A small number of 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 multidisciplinary support services only, high support or intensive services, or activation programmes.

There are 15,743 adults availing of day services in 2004. Most adults attend either activation centres (30.0%) or sheltered work centres (28.1%). The next largest groups are concentrated in the areas of rehabilitative training (9.7%), multidisciplinary support services only (8.9%), supported employment (6.1%), programmes for the older person (3.8%), and special high-support day services (3.1%).

Degree of intellectual disability

Of those receiving day services in 2004 (23,645 individuals), 34.5% (8,156) have a mild intellectual disability, 58.8% (13,892) have a moderate, severe, or profound intellectual disability, and 6.8% (1,597) have not yet had their degree of intellectual disability established (see Table 3.7).

The age profile of these groups is quite different. Less than one in four (23.7%) of the population with moderate, severe, or profound intellectual disability who are availing of day services is aged 18 years or under, whereas almost one in two (42.2%) of the population with mild intellectual disability who are availing of day services is aged 18 years or under. The higher number of children with mild intellectual disability in receipt of services reflects the number of children in special education, a proportion of whom do not transfer to the adult intellectual disability services upon leaving school.

	Residents	Day attenders	Total
Table 3.6. National Intellectual Disability Database, Ireland 2004. **Principal day service by category of persons availing of day services.**			
Home support	4	269	273
Home help	0	35	35
Early intervention team	5	441	446
Mainstream pre-school	0	239	239
Special pre-school for intellectual disability	0	585	585
Child education and development centre	45	285	330
Mainstream school	2	820	822
Resource/visiting teacher	2	307	309
Special class - primary level	9	540	549
Special class - secondary level	11	217	228
Special school	227	4145	4372
Rehabilitative training	272	1293	1565
Activation centre	2951	1782	4733
Programme for the older person	503	96	599
Special high-support day service	390	122	512
Special intensive day service	184	57	241
Sheltered work centre - includes long-term training schemes	1960	2476	4436
Sheltered employment centre	20	110	130
Multidisciplinary support services	964	502	1466
Centre-based day respite service	9	10	19
Day respite in the home	0	5	5
Other day service	148	188	336
Enclave within open employment	4	11	15
Supported employment	142	813	955
Open employment	26	113	139
Vocational training	33	217	250
Generic day services	25	31	56
Total	**7936**	**15709**	**23645**

Top five day activities All	%	Top five day activities Day attenders	%	Top five day activities Residents	%
Activation centre	20.0	Special school	26.4	Activation centre	37.2
Sheltered work centre	18.8	Sheltered work centre	15.8	Sheltered work centre	24.7
Special school	18.5	Activation centre	11.3	Multidisciplinary support services only	12.1
Rehabilitative training	6.6	Rehabilitative training	8.2	Programme for older people	6.3
Multidisciplinary support services only	6.2	Mainstream school	5.2	Special high-support service	4.9

Table 3.6a. National Intellectual Disability Database, Ireland 2004.
Top five day activities for people with intellectual disability.

Of the 7,902 children availing of day services in 2004:

- 43.6% (3,445) 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.

- 41.7% (3,239) 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.

- 14.7% (1,164) have not had their degree of intellectual disability verified as yet.

Of the 15,743 adults in receipt of day services in 2004:

- 29.9% (4,711) have a mild degree of intellectual disability, most of whom attend sheltered work centres (35.4%), are in receipt of rehabilitative training (13.7%), avail of activation programmes (13.0%), or are in supported employment (12.1%).

- 67.3% (10,599) are in the moderate, severe, or profound range and are most likely to be in receipt of activation programmes (37.9%), followed by sheltered work (25.2%), multidisciplinary support services only (10.0%), and rehabilitative training (8.1%).

- 2.8% (433) have not had their degree of intellectual disability established.

Overall level of service provision in 2004

Background

The NIDD permits the recording of two different types of residential service and three different types of day service 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, residential services and the main, secondary, and tertiary day programmes and are representative of the overall level of service provision. The total numbers presented in both tables 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 residential service and two or three different types of day service.

Table 3.7. National Intellectual Disability Database, Ireland 2004.
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	93	21	114	18	45	63	29	67	96	140	133	273
Home help	14	2	16	0	11	11	2	6	8	16	19	35
Early intervention team	371	0	371	30	0	30	45	0	45	446	0	446
Mainstream pre-school	134	0	134	65	0	65	40	0	40	239	0	239
Special pre-school for intellectual disability	245	0	245	122	0	122	218	0	218	585	0	585
Child education and development centre	11	0	11	3	0	3	274	42	316	288	42	330
Mainstream school	68	0	68	510	22	532	220	2	222	798	24	822
Resource/visiting teacher	59	0	59	183	11	194	55	1	56	297	12	309
Special class - primary level	34	1	35	255	68	323	186	5	191	475	74	549
Special class - secondary level	2	0	2	119	40	159	54	13	67	175	53	228
Special school	103	1	104	2039	115	2154	2071	43	2114	4213	159	4372
Rehabilitative training	1	35	36	19	645	664	11	854	865	31	1534	1565
Activation centre	0	89	89	1	614	615	10	4019	4029	11	4722	4733
Programme for the older person	0	26	26	0	80	80	0	493	493	0	599	599
Special high-support day service	2	5	7	7	31	38	16	451	467	25	487	512
Special intensive day service	2	2	4	4	15	19	8	210	218	14	227	241
Sheltered work centre	0	98	98	4	1666	1670	2	2666	2668	6	4430	4436
Sheltered employment centre	0	4	4	0	98	98	0	28	28	0	130	130
Multidisciplinary support services	15	75	90	26	269	295	22	1059	1081	63	1403	1466
Centre-based day respite service	3	0	3	1	5	6	0	10	10	4	15	19
Day respite in the home	2	2	4	0	0	0	0	1	1	2	3	5
Other day service	3	8	11	22	119	141	27	157	184	52	284	336
Enclave within open employment	0	0	0	0	6	6	0	9	9	0	15	15
Supported employment	0	37	37	2	572	574	0	344	344	2	953	955
Open employment	0	5	5	1	105	106	0	28	28	1	138	139
Vocational training	2	22	24	14	154	168	3	55	58	19	231	250
Generic day services	0	0	0	0	20	20	0	36	36	0	56	56
Total	**1164**	**433**	**1597**	**3445**	**4711**	**8156**	**3293**	**10599**	**13892**	**7902**	**15743**	**23645**

The 2004 dataset is the eighth in a series that commenced in 1996, and was continued in each of the six years from 1998 to 2003. The first and fourth datasets, from 1996 (National Intellectual Disability Database Committee, 1997) and 2000 (Mulvany, 2001), have been selected for comparison with the 2004 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 earlier datasets, growth rates are reported for the available years.

Overall level of residential service provision in 2004

Table 3.8 details the overall number of residential services provided to people with intellectual disability in 2004. 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 disability 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 2004

Figure 5 illustrates the growth in full-time residential services and residential support services during the period 1996-2004.

Key developments in the provision of full-time residential services in the period 1996-2004 include

- an increase of 44.7% (1,069) in the number of people with intellectual disability living in community group homes;

- an increase of 190.7% (204) in the number of intensive placements specially designed to cater for the needs of people with challenging behaviours;

- a reduction of 55.1% (496) in the number of people with intellectual disability accommodated in psychiatric hospitals during the period 1996 to 2004.

Between 1996 and 2004 there has been significant growth in the number of residential support places available. In particular, the data show

- an increase of 356.7% (3,107) in the number of individuals availing of centre-based respite services either as a planned or emergency intervention, bringing the total number availing of respite services to 3,978. The vast majority of respite services are planned. The 2004 data indicate that the overall ratio of planned respite nights to crisis respite nights is 19:1 (i.e. there are 19 times more planned respite nights reported than crisis respite nights). Planned respite is an important service as it assists people to continue living with their families and in their communities;

- an increase of 96.8% (91) in the number of people in receipt of regular part-time care;

- an increase of 106.7% (112) in the number of people being supported to live semi-independently.

Table 3.8. National Intellectual Disability Database, Ireland 2004.

Overall level of residential service provision in 2004, 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	1	3	4	19	121	140	20	375	395	40	499	539
7-day (48-week) community group home	1	3	4	5	130	135	23	529	552	29	662	691
7-day (52-week) community group home	5	21	26	16	505	521	41	1644	1685	62	2170	2232
5-day residential centre	0	1	1	1	9	10	21	92	113	22	102	124
7-day (48-week) residential centre	0	1	1	3	54	57	31	480	511	34	535	569
7-day (52-week) residential centre	2	80	82	9	212	221	53	2395	2448	64	2687	2751
Nursing home	0	14	14	1	22	23	1	68	69	2	104	106
Psychiatric hospital	0	4	4	0	123	123	0	347	347	0	474	474
Intensive placement (challenging behaviour)	2	0	2	2	42	44	7	258	265	11	300	311
Intensive placement (profound or multiple disability)	4	0	4	0	11	11	21	197	218	25	208	233
Other full-time residential place	0	1	1	3	13	16	2	12	14	5	26	31
Occupying a residential support place	0	2	2	1	4	5	5	20	25	6	26	32
Holiday residential placement	0	2	2	3	50	53	3	115	118	6	167	173
Crisis or planned respite	65	29	94	217	580	797	1096	1991	3087	1378	2600	3978
Occasional respite with host family	8	0	8	17	19	36	38	72	110	63	91	154
Overnight respite in the home	2	1	3	1	5	6	8	3	11	11	9	20
Shared care or guardianship	0	0	0	1	1	2	0	2	2	1	3	4
Regular part-time care (2/3 days per week)	0	0	0	2	11	13	32	60	92	34	71	105
Regular part-time care (every weekend)	0	0	0	2	1	3	3	12	15	5	13	18
Regular part-time care (alternate weeks)	0	0	0	1	5	6	7	49	56	8	54	62
Other residential service	0	0	0	2	3	5	3	5	8	5	8	13
Foster care and boarding-out arrangements	16	2	18	107	50	157	55	35	90	178	87	265
Living semi-independently	0	9	9	0	156	156	0	52	52	0	217	217
Living independently	0	46	46	1	401	402	0	80	80	1	527	528

Figure 5. National Intellectual Disability Database, Ireland 2004.
Changes in overall level of residential service provision 1996, 2000, 2004.
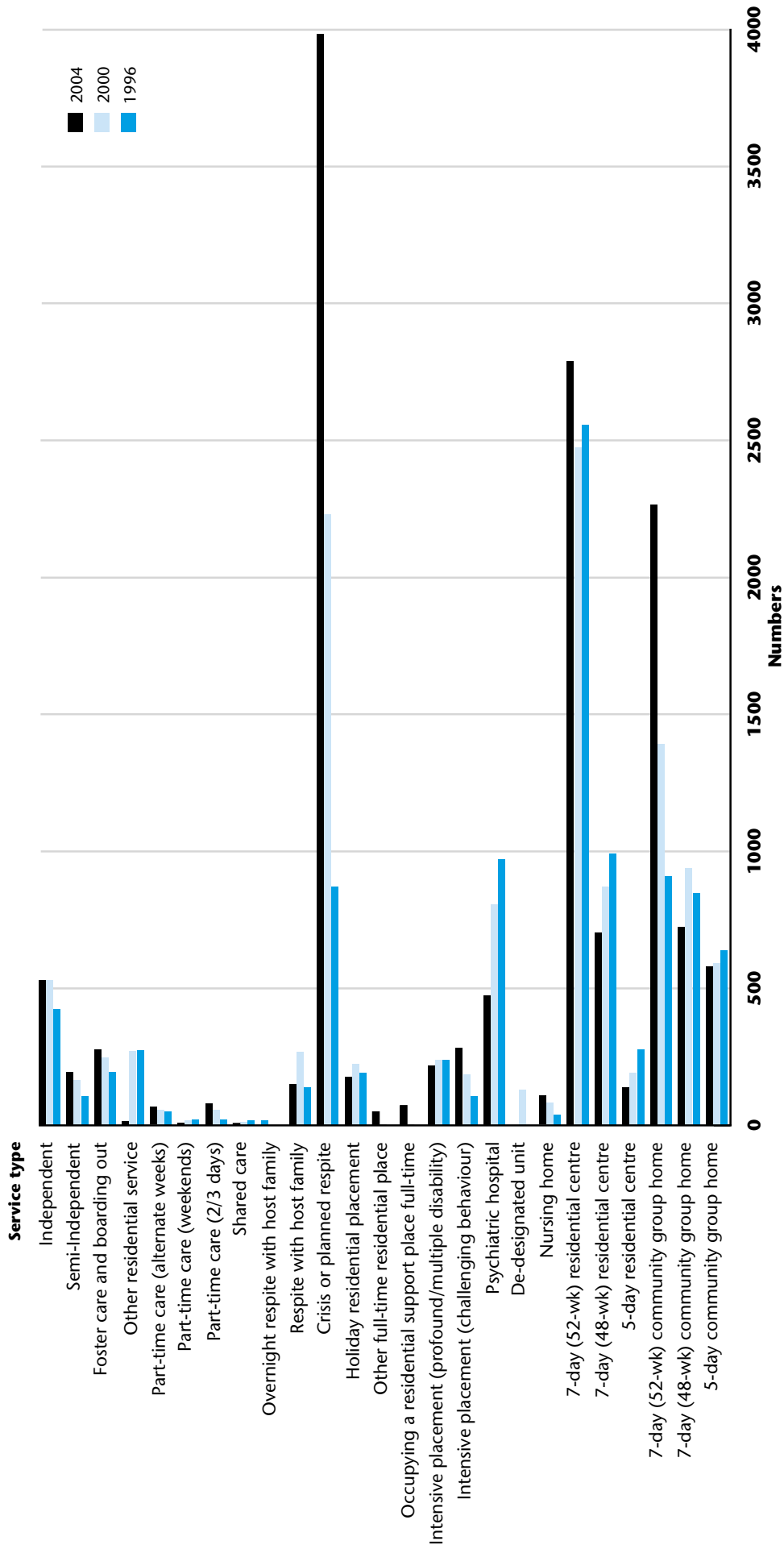
Overall level of day service provision in 2004

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 principal day service reported in Table 3.6; this includes services such as home support services, early services, educational services, centre-based and home-based day respite services, home help services, and multidisciplinary support services.

Trends in day service provision: 1996 to 2004

Figure 6 illustrates the growth in day services during the period 1996-2004.

Significant growth areas in day services during the eight-year period include:

- An increase of 391.5% (1,288 people) in the provision of supported employment. The 2004 data indicate that 1,617 people are in supported employment placements.

- Increases in both high-support and intensive day places. The number of high-support day places has increased by 32.3% (129 people) and the number of intensive day places has increased by 116.4% (135 people). The 2004 data indicate that 529 and 251 people attend high-support and intensive places respectively.

- An increase of 135.4% (375 people) in the number in receipt of day programmes specific to the older person. The number attending such services in 2004 is 652.

- An increase of 13.2% (573 people) in the number attending activation centres, bringing the total number to 4,899 in 2004.

- An increase in the number of young people attending mainstream pre-schools (116.3%, 193 individuals) and mainstream schools (19.7%, 141 individuals). In 2004, 359 individuals are attending mainstream pre-schools and 857 individuals are attending mainstream schools.

- An increase of 61.7% (87 individuals) in the number attending special classes at secondary level, to give a total attendance of 228 in 2004.

Significant reductions in day services during the eight-year period include:

- A decrease of 14.3% (734 individuals) attending special schools. Despite this reduction, special schools are the most commonly availed of day activity for young people, with 4,402 individuals attending in 2004.

- A decrease of 11.9% (225 people) in the number attending rehabilitative training, from 1,895 in 1996 to 1,670 in 2004.

- A decrease of 52.7% (385 individuals) in the number of young people attending child education and development centres. The number attending such centres is 346 in 2004.

- A decrease of 49.9% (468 people) in the number receiving day services described as 'other'. This reduction is attributable to the expansion of the range of day services captured on the database and a national emphasis on coding services within existing service codes where possible.

Table 3.9. National Intellectual Disability Database, Ireland 2004.

Overall level of day service provision in 2004, 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	187	45	232	236	158	394	602	437	1039	1025	640	1665
Home help	28	2	30	7	20	27	21	23	44	56	45	101
Early intervention team	892	0	892	275	0	275	400	0	400	1567	0	1567
Mainstream pre-school	165	0	165	115	0	115	79	0	79	359	0	359
Special pre-school	249	0	249	126	0	126	224	0	224	599	0	599
Child education and development centre	11	0	11	3	0	3	290	42	332	304	42	346
Mainstream school	69	0	69	524	23	547	239	2	241	832	25	857
Resource/visiting teacher	87	4	91	283	46	329	117	18	135	487	68	555
Special class - primary	37	1	38	258	68	326	189	5	194	484	74	558
Special class - secondary	2	0	2	119	40	159	54	13	67	175	53	228
Special school	103	1	104	2039	115	2154	2100	44	2144	4242	160	4402
Rehabilitative training	1	35	36	41	687	728	16	890	906	58	1612	1670
Activation centre	0	90	90	1	673	674	11	4124	4135	12	4887	4899
Programme for the older person	0	26	26	0	98	98	0	528	528	0	652	652
High-support day service	2	5	7	7	32	39	22	461	483	31	498	529
Intensive day service	2	2	4	5	16	21	8	218	226	15	236	251
Sheltered work	0	101	101	4	1774	1778	2	2761	2763	6	4636	4642
Sheltered employment	0	4	4	0	102	102	0	28	28	0	134	134
Multidisciplinary support services	169	243	412	1680	2570	4250	2501	8526	11027	4350	11339	15689
Centre-based day respite programme	17	2	19	41	46	87	176	130	306	234	178	412
Day respite in the home	6	3	9	2	2	4	4	8	12	12	13	25
Other day service	15	9	24	39	145	184	64	197	261	118	351	469
Enclave within open employment	0	0	0	0	9	9	0	13	13	0	22	22
Supported employment	0	38	38	3	892	895	0	684	684	3	1614	1617
Open employment	0	5	5	2	122	124	0	35	35	2	162	164
Vocational training	2	23	25	22	185	207	3	69	72	27	277	304
Generic day services	0	0	0	1	41	42	1	51	52	2	92	94

Figure 6. National Intellectual Disability Database, Ireland 2004.
Changes in overall level of day service provision 1996, 2000, 2004.
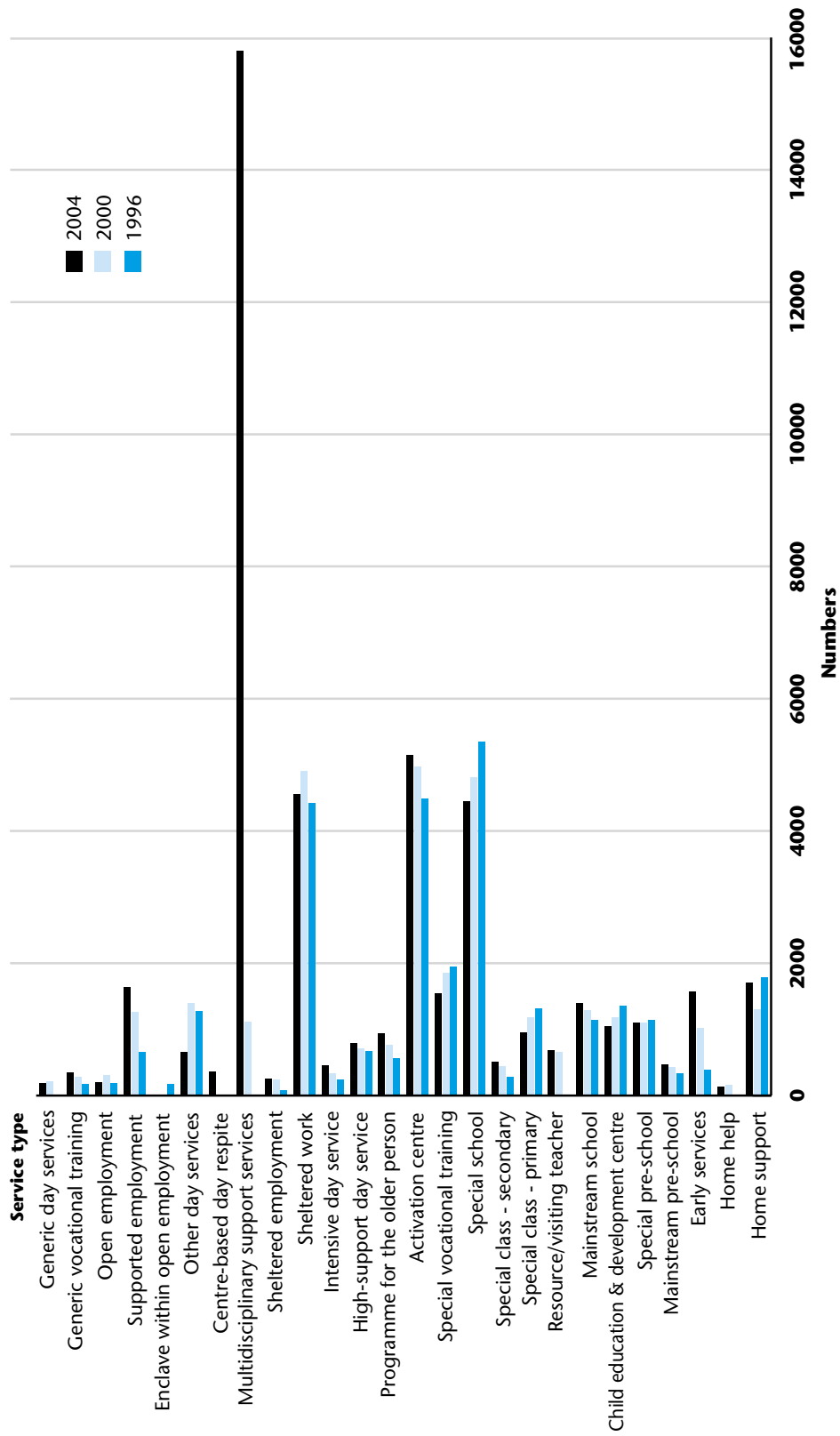
A noticeable trend during the 1996-2004 period is the increased number of people availing of mainstream services. Increases are observed in mainstream pre-schools, mainstream schools, resource teachers, and vocational training. Table 3.6a indicates that mainstream schools are the fifth most common day activity of day attenders in 2004. This is the first time that a mainstream service has appeared in this table. Although the numbers availing of mainstream services are proportionately low, the growth is in a positive direction and should be encouraged.

The 2004 dataset also demonstrates significant growth in the provision of support services which are delivered as part of a package of day services.

• Increases can be seen in the numbers of individuals availing of home support, home help, resource/visiting teacher, and centre-based and home-based day respite.

• Multidisciplinary support services, including those delivered by early intervention teams, have shown very substantial increases in recent years. Individual therapeutic inputs (e.g. occupational therapy, speech and language therapy; see Appendix A, National Planning Form, for full details) were recorded for the first time in 2002 and this may have prompted data collectors to record these therapeutic inputs, thereby resulting in the dramatic increase in the reporting of these services in recent years. In 2004, there are 15,689 individuals reported as receiving one or more multidisciplinary support services and 1,567 children receiving these services from an early intervention team.

The large difference in numbers receiving multidisciplinary support services (including services delivered by early intervention teams) between Table 3.7 (principal day service provision) and Table 3.9 (overall day service provision) arises because early services and multidisciplinary support services are only recorded as a principal day service if they are the only day service that an individual receives. The majority of people who are in receipt of multidisciplinary support service or services from an early intervention team also receive another service as their principal day service. Table 3.7 reports those provided as the principal day service only, whereas Table 3.10 details the overall provision of therapeutic inputs.

• Overall, 17,256 individuals receive one or more multidisciplinary support service. The most commonly availed of multidisciplinary support services are social work (8,950 individuals), medical services (7,721 individuals), psychology (7,642 individuals), and psychiatry (5,973 individuals).

• The most commonly availed of service by adults are medical services (5,570 adults) and social work (5,448 adults).

• The most commonly availed of services by children are speech and language therapy (1,434 children aged six years and under and 2,515 children aged seven to eighteen years) and psychology (1,200 children aged six years and under and 2,425 children aged seven to eighteen years).

• Early intervention teams usually provide services to children aged six years and under and 85.3% (1,532 children) of this group receiving multidisciplinary support services have access to an early intervention team. There are also 34 children aged seven years and one child aged nine years who receive services from an early intervention team.

	6 and under			7-18			19 and over	Total
	Provided by an EIT	Not provided by an EIT	Total	Provided by an EIT	Not provided by an EIT	Total		
Table 3.10. National Intellectual Disability Database, Ireland 2004. **Overall provision of multidisciplinary support services by age and access to early intervention teams (EIT).**								
Community nursing	621	61	682	4	462	466	1138	2286
Medical services	795	119	914	9	1228	1237	5570	7721
Nutrition	150	38	188	2	313	315	1480	1893
Occupational therapy	728	103	831	13	1172	1185	1426	3442
Physiotherapy	1013	135	1148	16	1215	1231	1948	4327
Psychiatry	101	36	137	3	617	620	5216	5973
Psychology	1005	195	1200	24	2401	2425	4017	7642
Social work	956	160	1116	16	2370	2386	5448	8950
Speech & language therapy	1222	212	1434	28	2487	2515	738	4687
Other	427	93	520	4	468	472	1786	2778
Number of people	**1532**	**263**	**1795**	**35**	**4087**	**4122**	**11339**	**17256**

Note

Therapeutic inputs are only recorded if the individual has received, or will receive, at least four inputs of that service in a twelve-month period. The number of therapeutic inputs received exceeds the number of people as many people receive more than one input.

HEALTH BOARD LEVEL

Table 3.11 provides details of the level of service provision in 2004 within each health board region.

Nationally, 93.8% of people (23,843) with an intellectual disability registered on the NIDD are in receipt of services in 2004. Regionally, the highest level of service provision is in the Midland Health Board where 99.7% of the population registered on the database are receiving services. The lowest level of service provision is in the Eastern Regional Health Authority where 88.5% of the registered population with intellectual disability are in receipt of services.

Nationally, 31.8% (8,093) of those registered on the NIDD in 2004 are in receipt of a full-time residential service. Regionally, this proportion varies from 25.3% in the North-Eastern Health Board to 33.5% in the Eastern Regional Health Authority.

At national level, 61.8% (15,709) of the database population are attending services on a day basis and this proportion ranges from 54.7% in the Eastern Regional Health Authority to 72.3% in the North-Eastern Health Board.

	Attending services on a day basis	Receiving 5- or 7-day residential services	Resident in a psychiatric hospital	Receiving residential support services only	Receiving no service	No service requirements in 2004	Total
	n %	n %	n %	n %	n %	n %	n %
Eastern Regional Health Authority	4613 54.7	2577 30.5	252 3.0	22 0.3	57 0.7	917 10.9	8438 100.0
Midland Health Board	935 67.6	428 30.9	13 0.9	2 0.1	2 0.1	3 0.2	1383 100.0
Mid-Western Health Board	1423 60.7	758 32.3	24 1.0	4 0.2	56 2.4	79 3.4	2344 100.0
North-Eastern Health Board	1459 72.3	510 25.3	1 0.0	3 0.1	22 1.1	23 1.1	2018 100.0
North-Western Health Board	1085 60.4	592 33.0	1 0.1	3 0.2	100 5.6	14 0.8	1795 100.0
South-Eastern Health Board	2089 67.6	824 26.7	103 3.3	2 0.1	39 1.3	31 1.0	3088 100.0
Southern Health Board	2353 64.3	1129 30.8	28 0.8	3 0.1	38 1.0	110 3.0	3661 100.0
Western Health Board	1752 65.2	801 29.8	52 1.9	2 0.1	43 1.6	39 1.5	2689 100.0
All Boards	**15709 61.8**	**7619 30.0**	**474 1.9**	**41 0.2**	**357 1.4**	**1216 4.8**	**25416 100.0**

Nationally, 1.4% (357) of registrations are without services but are identified as requiring services in the five-year period 2005-2009. The North-Western Health Board has the highest proportion of people without any service and awaiting services within the next five years (5.6%) and there are two other health boards above the national average (the Mid-Western Health Board at 2.4% and the Western Health Board at 1.6%). The Eastern Regional Health Authority has the second-lowest proportion, identifying just 0.7% of their population as being without services and requiring services between 2005 and 2009. 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.

Although significantly reduced since 2003, there is a considerable number of people registered on the database in 2004 (1,216, or 4.8%) who are not availing of services and have no identified need for service within the five-year period 2005-2009. 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. Secondly, 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 10.9% (917 individuals) of the region's registered population. The Mid-Western Health Board has the second-highest level in this category, at 3.4% (79) of all the region's registrations. The Midland Health Board has the lowest recorded proportion of registrations with no service requirements, at 0.2% (3 individuals).

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 (93.8%) is still being kept artificially low because of the high numbers of people described as having no identified service requirements in 2004 (1,216 individuals, of whom 75.4% are registered in the Eastern Regional Health Authority). Although the number in this category has fallen from 1,737 over the past year, a critical appraisal of these individuals is required to establish both their possible need for services and the appropriateness of their registration on the NIDD. The NIDD Committee urges the health boards involved to prioritise this work and so improve the overall quality of information held on the database.

Table 3.11a provides details of the level of service provision in 2004 within each new regional health area of the Health Service Executive.

Table 3.11a. National Intellectual Disability Database, Ireland 2004.
Service provision in 2004 by health areas of the Health Service Executive.

	Attending services on a day basis	Receiving 5- or 7- day residential services	Resident in a psychiatric hospital	Receiving residential support services only	Receiving no service	No service requirements in 2004	Total
	n %	n %	n %	n %	n %	n %	n %
Dublin/Mid-Leinster	3741 57.7	2120 32.7	17 0.3	22 0.3	31 0.5	549 8.5	6480 100.0
Southern	4442 65.8	1953 28.9	131 1.9	5 0.1	77 1.1	141 2.1	6749 100.0
Western	4260 62.4	2151 31.5	77 1.1	9 0.1	199 2.9	132 1.9	6828 100.0
Dublin/North-Eastern	3266 60.9	1395 26.0	249 4.6	5 0.1	50 0.9	394 7.4	5359 100.0
All Areas	**15709 61.8**	**7619 30.0**	**474 1.9**	**41 0.2**	**357 1.4**	**1216 4.8**	**25416 100.0**

Chapter four

4. Assessment of Need 2005-2009

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 2005-2009.

Service Change: describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2005-2009, 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 2004 the NIDD facilitated the recording of two future residential services and two future day services for each individual. To avoid double-counting of individuals, only the first service identified is reported in the tables in this report 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 2004 indicate that 2,210 people will require major elements of service, either a full-time residential service or a day service, or both, in the five-year period 2005-2009 (Table 4.1), a decrease of 74 since 2003. Of this group of 2,210 people:

- 304 (13.8%) have no service and require full-time residential and/or day services,

- 1,852 (83.8%) receive a day service but require a residential service,

- 40 (1.8%) receive a residential service but also require a day service,

- 14 (0.6%) 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 304 people who are without services in 2004, 121 (39.8%) have a moderate, severe, or profound level of intellectual disability and 164 (53.9%) 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 (1,892 individuals), consists mainly (72.5%) of people in the moderate, severe, or profound ranges of intellectual disability.

Four hundred and twelve of the individuals who have an unmet need for a full-time residential service also require an additional future residential service, of whom 95.1% require a residential support service, in the period 2005-2009. Eighteen of the individuals who have an unmet need for a day service also require one additional future day service in the period 2005-2009.

Table 4.1. National Intellectual Disability Database, Ireland 2004. **Number of people requiring a major element of service 2005-2009.**					
	No service	**Receives minimal residential support only**	**Receives day only - requires residential**	**Receives residential only - requires day**	**Total**
Not verified	19	0	45	0	64
Mild	164	6	463	13	646
Moderate, severe & profound	121	8	1344	27	1500
All levels	**304**[a]	**14**[b]	**1852**	**40**	**2210**

[a] Of the 304, 28 require residential and day, 10 require residential only, and 266 require day only.
[b] Of the 14, 2 require residential and day, 1 require residential only, and 11 require day only.

Residential support services

The 2004 data indicate that 1,722 people are without residential support services and will require these services in the period 2005-2009, an increase of 125 (7.8%) since 2003 (Table 4.2). In excess of ninety-nine per cent of this group are already in receipt of a major element of service. Eight individuals who require residential support services are without services in 2004, of whom two have a moderate level of intellectual disability, five have a mild intellectual disability, and the remaining person's level of intellectual disability has not yet been verified.

One hundred and fifty-seven individuals who have an unmet need for a residential support service also require a second future residential service. More than two-thirds of these secondary future residential service requirements are also residential support services.

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 by health board area in Table 4.3. Table 4.3a shows the number of new places required to meet need 2005-2009 by the new regional health areas of the Health Service Executive.

Table 4.2. National Intellectual Disability Database, Ireland 2004. **Number of people requiring residential support services 2005-2009.**				
	No service	**Receives day only - requires residential support**	**Receives residential & day - requires residential support**	**Total**
Not verified	1	110	6	117
Mild	5	626	71	702
Moderate, severe & profound	2	765	136	903
All levels	**8**	**1501**	**213**	**1722**

Table 4.3. National Intellectual Disability Database, Ireland 2004. **Number of new places required to meet need 2005-2009 by health board area.**			
	Residential	**Day**	**Residential support**
Eastern Regional Health Authority	636	54	381
Midland Health Board	180	5	116
Mid-Western Health Board	111	60	164
North-Eastern Health Board	133	18	161
North-Western Health Board	120	106	180
South-Eastern Health Board	247	36	195
Southern Health Board	247	32	353
Western Health Board	219	36	213
Total	**1893**	**347**	**1763**[a]

[a] The total number of residential support places required is different to the figure in Table 4.2 (n=1,722) as 38 of the group who have no existing service and require a day service will also need a residential support service and 3 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 1,763.

Table 4.3a. National Intellectual Disability Database, Ireland 2004. Number of new places required to meet need 2005-2009 by regional health areas of the Health Service Executive.			
	Residential	**Day**	**Residential support**
Dublin/Mid-Leinster	486	45	394
Southern	494	68	548
Western	450	202	557
Dublin/North-Eastern	463	32	264
Total	**1893**	**347**	**1763[a]**

[a] The total number of residential support places required is different to the figure in Table 4.2 (n=1,722) as 38 of the group who have no existing service and require a day service will also need a residential support service and 3 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 1,763.

Following a slight downward trend during the years 2000 to 2002, the number of new residential places required has increased sharply (15.9% or 260 places) over the past two years. The current figure of 1,893 is the highest since the database was established. Data presented in Chapter 3 show that full-time residential services are primarily used by adults with a more severe disability and Chapter 2 noted that the numbers in this group are increasing due to a cohort of people born in the 1960s and mid-1970s currently moving through the services. This information would suggest that the number of new full-time residential places required is likely to increase over the coming years as those with a more severe disability advance in age. The number of new day places required has been falling steadily since 1996. The current figure of 347 is 689 less than that in 1996 and is the lowest since the database was established, suggesting that significant progress has been made in meeting the demand for day services. The demand for residential supports has increased steadily since 1998. The current figure of 1,763 represents an increase of 126 since 2003 and is the highest since national data collection began.

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 2004. Year in which service needs arise.						
	2005	**2006**	**2007**	**2008**	**2009**	**All years**
Residential	1675	113	56	37	12	**1893**
Day	338	9	0	0	0	**347**
Residential support	1664	52	16	15	16	**1763**

SUMMARY OF UNMET SERVICE REQUIREMENTS

Details of the types of services required by people who are without a major element of service or without residential support services in 2004 are set out in Tables 4.5 to 4.7.

Full-time residential services

Of the group that requires full-time residential services (1,893 individuals, see Table 4.5):

- 72.5% (1,373) consists of people in the moderate, severe, and profound ranges of intellectual disability. Of this sub-group, 82.4% (1,132) require residential placements in community group homes, 9.6% (132) require residential accommodation in a campus setting, and 7.2% (99) require specialised intensive placements because of their increased dependency.

- 25.0% (474) consists of people with mild intellectual disability. Of this sub-group 85.9% (407) require residential placements in community group homes, 7.2% (34) require residential accommodation in a campus setting, and 6.1% (29) require specialised intensive placements due to their increased dependency.

- 2.4% (46) have not had their level of intellectual disability verified.

Of those requiring full-time residential services, 98.0% already receive day services (1,852 individuals) or a residential support service (3 individuals).

Day services

As in previous years, demand for day services among those reported as not being in receipt of such services in 2004 is confined almost exclusively to adult services (Table 4.6). Of the 347 individuals who require day services, the largest demand comes from 294 people who have no service whatsoever at the moment. This figure has fallen from 333 in 2003. Of the 294 people with no service:

- The majority (54.4%, 160 individuals) have a mild intellectual disability and their principal service requirements are in the training and employment fields.

- 39.1% (115 individuals) fall into the moderate, severe, and profound range of intellectual disability and the principal service requirements are for rehabilitative training, activation programmes, sheltered work, and supported employment (Table 4.6).

A second group with day service needs consists of 40 people who are in full-time residential services but do not have access to formal day programmes. This figure has fallen from 196 in 2003, suggesting that significant progress has been made over the last year in the provision of day services to full-time residents who had no formal day programme. The remaining need in 2004 among this group consists mainly of activation programmes and programmes specific to the older person.

A third group with day service needs consists of 13 people who are accessing residential support services only and require a variety of day services.

Residential support services

Residential support services are required by 1,763 people (Table 4.7), most of whom live at home and are either in receipt of a day service (85.1%, 1,501 individuals) or have no day service (2.6%, 46 individuals). An additional 12.3% (216 individuals) 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, or profound intellectual disability account for 52.0% (917 individuals) of the demand for residential support services, while people with mild intellectual disability account for 41.1% (725 individuals). The remaining 6.9% (121 individuals) have not yet had their degree of intellectual disability verified.

• Most of the demand is for centre-based respite services (56.9%, 1,004 individuals), semi-independent and independent living arrangements (20.6%, 364 individuals), holiday residential placements (9.8%, 172 individuals), and occasional respite care with a host family (5.6%, 98 individuals).

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 2005-2009, and includes children availing of educational services in 2004 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.

There are 2,127 people included in the data presented in the section on Unmet Need above (Tables 4.1 and 4.2) who are missing one element of service and require their existing element of service to be changed in some way.

• 1,045 people with an unmet need for a full-time residential place require a change in their day service.

• 14 people with an unmet need for a day service require a change in their full-time residential placement. Two people with an unmet need for a day service require a change in their residential support service.

• 1,066 people with an unmet need for a residential support service require a change in their day service.

Table 4.5. National Intellectual Disability Database, Ireland 2004.

Future full-time residential service requirements of individuals receiving no residential service in 2004.

	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	3	5	0	0	1	1	7	101	221	329	7	103	225	335
7-day (48-week) community group home	0	1	5	6	0	0	0	0	7	64	232	303	7	65	237	309
7-day (52-week) community group home	1	5	11	17	0	0	2	2	16	234	657	907	17	239	670	926
5-day residential centre	0	0	0	0	0	0	0	0	3	6	13	22	3	6	13	22
7-day (48-week) residential centre	0	0	0	0	0	0	0	0	0	5	35	40	0	5	35	40
7-day (52-week) residential centre	0	1	1	2	0	0	0	0	4	22	83	109	4	23	84	111
Nursing home	0	2	1	3	0	0	0	0	3	2	9	14	3	4	10	17
Intensive placement (challenging behaviour)	0	0	3	3	0	0	0	0	4	18	41	63	4	18	44	66
Intensive placement (profound or multiple disability)	0	0	2	2	0	0	0	0	1	11	53	65	1	11	55	67
All services	**1**	**11**	**26**	**38**	**0**	**0**	**3**	**3**	**45**	**463**	**1344**	**1852**	**46**	**474**	**1373**	**1893**

Table 4.6. National Intellectual Disability Database, Ireland 2004.
Future day service requirements of individuals receiving no day service in 2004.

	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	6	12	19	0	0	0	0	0	0	0	0	1	6	12	19
Home help	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Mainstream pre-school	0	2	1	3	0	0	0	0	0	0	0	0	0	2	1	3
Special pre-school	0	1	12	13	0	0	0	0	0	0	0	0	0	1	12	13
Child education and development centre	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Mainstream school	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Resource/visiting teacher	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	1
Special class - primary	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special class - secondary	0	3	0	3	0	0	0	0	0	0	0	0	0	3	0	3
Special school	1	0	0	1	0	1	1	2	0	0	0	0	1	1	1	3
Rehabilitative training	3	43	12	58	0	2	0	2	0	1	0	1	3	46	12	61
Activation centre	3	15	34	52	0	0	3	3	0	1	13	14	3	16	50	69
Programme for the older person	1	5	5	11	0	0	0	0	0	4	9	13	1	9	14	24
Special high-support day service	0	1	5	6	0	0	1	1	0	0	1	1	0	1	7	8
Special intensive day service	0	0	3	3	0	0	0	0	0	1	2	3	0	1	5	6
Sheltered work centre	1	22	20	43	0	2	1	3	0	3	1	4	1	27	22	50
Sheltered employment centre	1	6	0	7	0	0	0	0	0	0	0	0	1	6	0	7
Centre-based day respite service	0	0	0	0	0	0	0	0	0	0	1	1	0	0	1	1
Day respite in the home	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other day service	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Enclave within open employment	0	2	0	2	0	0	0	0	0	0	0	0	0	2	0	2
Supported employment	4	26	4	34	0	0	0	0	0	3	0	3	4	29	4	37
Open employment	2	9	2	13	0	0	0	0	0	0	0	0	2	9	2	13
Vocational training	1	18	3	22	0	1	1	2	0	0	0	0	1	19	4	24
Generic day services	1	0	1	2	0	0	0	0	0	0	0	0	1	0	1	2
All services	**19**	**160**	**115**	**294**	**0**	**6**	**7**	**13**	**0**	**13**	**27**	**40**	**19**	**179**	**149**	**347**

Table 4.7. National Intellectual Disability Database, Ireland 2004.

Future residential support service requirements of individuals receiving no residential support services in 2004.

	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	0	0	0	0	0	0	0	0	0	2	2	0	0	2	2
Living independently	1	3	0	4	3	46	4	53	0	1	0	1	0	7	1	8	4	57	5	66
Living semi-independently	2	10	4	16	17	161	33	211	0	1	0	1	1	45	24	70	20	217	61	298
Holiday residential placement	0	0	1	1	2	42	57	101	0	0	0	0	1	7	62	70	3	49	120	172
Crisis or planned respite	1	9	7	17	69	309	574	952	0	1	0	1	1	5	28	34	71	324	609	1004
Occasional respite care with host family	0	1	0	1	15	37	44	96	0	0	0	0	0	0	1	1	15	38	45	98
Overnight respite in the home	0	0	2	2	3	0	2	5	0	0	0	0	0	0	0	0	3	0	4	7
Shared care or guardianship	0	1	0	1	0	0	2	2	0	0	0	0	0	0	0	0	0	1	2	3
Regular part-time care (2/3 days per week)	0	0	0	0	0	14	11	25	0	0	0	0	0	0	0	0	0	14	11	25
Regular part-time care (every weekend)	0	0	0	0	1	2	5	8	0	0	0	0	0	1	0	1	1	3	5	9
Regular part-time care (alternate weeks)	0	0	0	0	0	2	3	5	0	0	0	0	0	1	0	1	0	3	3	6
Other residential service	1	1	2	4	0	13	30	43	0	0	0	0	3	5	18	26	4	19	50	73
All services	**5**	**25**	**16**	**46**	**110**	**626**	**765**	**1501**	**0**	**3**	**0**	**3**	**6**	**71**	**136**	**213**	**121**	**725**	**917**	**1763**

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.

Categories of service change requirements

Table 4.8 indicates that 11,416 people who are receiving services in 2004 will require a change to their existing service provision in the period 2005-2009, an increase of 281 (2.5%) since 2003. Of the 11,416 requiring a service change:

- 7,930 (69.5%) are day attenders (of whom 724 also avail of residential support services).

- 2,947 (25.8%) are full-time residents (of whom 2,170 also avail of day services).

- 539 (4.7%) 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 7,144 (62.6%) of the service changes.

- People in the mild range require 3,436 (30.1%) of the service changes.

- 836 (7.3%) 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 2004.
Category of service change required 2005-2009.

	Residential and day	Residential only	Day only	Day and residential support	Residential support only	Total requiring sevice changes
Not verified	22	22	756	23	13	836
Mild	217	111	2813	176	119	3436
Moderate, severe & profound	1931	644	3637	525	407	7144
All levels	**2170**	**777**	**7206**	**724**	**539**	**11416**

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. Day services are described under four headings: health, education, employment, and generic, and the programmes included under each heading are outlined in Appendix A.

Table 4.9. National Intellectual Disability Database, Ireland 2004. **Number of places requiring to be changed 2005-2009.**	
Residential	**2947**
Day	**10100**
Of which:	
Health services	7155
Education services	1071
Employment services	1507
Generic services	367
Residential support	**1263**

The number of places required exceeds the number of people requiring service changes because some people require changes in both their residential and day services. In addition, it is important to note that, although 11,416 people require service changes, this demand does not translate into 11,416 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 other 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.

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 data, most of the service changes are required immediately.

Table 4.10. National Intellectual Disability Database, Ireland 2004. **Year in which service changes are required**						
	2005	**2006**	**2007**	**2008**	**2009**	**All years**
Residential	2820	60	48	16	3	**2947**
Day	8718	624	412	282	64	**10100**
Of which:						
Health services	6158	421	310	225	41	7155
Education services	952	82	24	11	2	1071
Employment services	1394	73	31	7	2	1507
Generic services	214	48	47	39	19	367
Residential support	1225	20	7	8	3	**1263**

SUMMARY OF SERVICE CHANGE REQUIREMENTS

Details of the types of service change 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

Table 4.11 indicates that 2,947 individuals in full-time residential services in 2004 will require an upgrading or change of accommodation within the next five years.

For most of this group (75.4%, 2,221 individuals) a change of service is required.

- Residential placements in the community are required by 950 individuals (32.2%).

- Intensive services for either challenging behaviour or profound or multiple disability are required by 676 individuals (22.9%).

- Centre-based placements are required by 118 individuals (4.0%).

- Nursing home placements are required by 43 individuals (1.5%).

- One person has been identified as requiring admission to a psychiatric hospital.

- Four hundred and two individuals need their existing service upgraded to include care at weekends and holiday times, and 31 people require less care and could return to their families at weekends and holiday times.

Furthermore, there is a group of 726 (24.6%) individuals who need an enhancement of their existing service (shaded area of Table 4.11). Over two-thirds of this group need increased support. 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.

Two hundred individuals of the 2,947 who require an upgrading or change of accommodation also require an additional future residential service, over two-thirds of which are residential support services.

Day Service Change

Within the next five years, 10,100 individuals will require a change, enhancement, or upgrading of their day service (Table 4.12)
.
- Health-funded services are required in 70.8% (7,155 individuals) of the changes or enhancements.

- Employment services are required in 14.9% (1,507 individuals) of the changes or enhancements.

- Educational services are required in 10.6% (1,071 individuals) of the changes or enhancements.

- Generic services are required in 3.6% (367 individuals) of the chances or enhancements.

Table 4.11. National Intellectual Disability Database, Ireland 2004.

Pattern of movement of individuals from existing residential service to future residential service 2005-2009.

Full-time residential service in 2004	Full-time residential service required in the period 2005-2009										Total services 2004
	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	Psychiatric Hospital	Intensive placement (CB)	Intensive placement (P/M D)	
5-day community group home (CGH)	25	87	123	0	2	3	0	0	7	5	252
7-day (48-week) community group home	1	80	115	1	9	14	0	0	10	9	239
7-day (52-week) community group home	5	18	376	1	1	26	25	0	49	49	550
5-day residential centre (RC)	8	16	26	2	11	15	0	0	9	2	89
7-day (48-week) residential centre	3	87	79	1	63	51	3	0	37	12	336
7-day (52-week) residential centre	3	19	626	0	6	110	12	0	238	201	1215
Nursing home	0	0	22	0	0	0	1	0	2	4	29
Intensive placement (challenging behaviour) (CB)	0	4	37	3	1	35	2	1	29	6	118
Intensive placement (profound/multiple disability) (P/M D)	0	1	3	0	0	20	0	0	27	40	91
Occupying a residential support place	0	2	11	0	0	0	0	0	2	4	19
Other full-time residential place	0	0	3	0	0	2	1	0	2	1	9
Total services required	**45**	**314**	**1421**	**8**	**93**	**276**	**44**	**1**	**412**	**333**	**2947**

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

The shaded areas of the table represent existing services that require alteration or enhancement

Day service groupings are reported under health, employment, educational, and generic services as set out in Appendix A.

Health services

Of the 7,155 service changes required within health-funded services, 5,340 (74.6%) are requirements for an alternative or additional service and 1,815 (25.4%) are requirements for an enhancement of the person's existing service (Table 4.12).

The majority of the demand for alternative or additional health-funded services occurs within the more care-focused services.

• 992 individuals require high-support or intensive placements, the majority of whom currently attend activation programmes (426 individuals), or receive multidisciplinary support services as their only day service (254 individuals).

• 967 individuals require activation programmes, the majority of whom currently receive multidisciplinary support services as their only day service (306 individuals), attend special schools (231 individuals), or attend sheltered work (172 individuals).

• 718 individuals require services specific to older people, the majority of whom currently attend activation programmes (311 individuals) or sheltered work (242 individuals).

A large part of the demand for alternative or additional health-funded services also comes from

• 979 individuals who require rehabilitative training, the majority of whom currently attend special schools (768 individuals), and

• 729 individuals who require a sheltered work centre, the majority of whom currently attend rehabilitative training (283 individuals), attend special schools (206 individuals), or attend activation programmes (127 individuals).

The above data on current services and demand for future services highlight the progression of individuals through the services from special schools to rehabilitative training and on to sheltered work. The demand in the employment services section below shows that the demand for supported employment places comes mainly from people who currently attend sheltered work.

Demand for alternative or additional health-funded services specifically for children (pre-school services, child education and development centres, and centre-based day respite services) account for only 569 of the 5,340 (10.7%) of the alternative or additional health-funded services required. The main demand is for mainstream and specialised pre-school services.

There are also 1,815 individuals who need to have their existing health-funded service enhanced (shaded area of Table 4.12). Most of these people are attending activation (830 individuals, 45.7%) or attending sheltered work (529 individuals, 29.1%). The main enhancements required are an increased level of support (70.6%) and an increased level of service provision from part-time to full-time (19.2%).

Employment services

Of the 1,507 service changes required within employment services, 1,443 (95.8%) are requirements for an alternative placement and 64 (4.2%) are requirements for an enhancement of the person's existing placement (Table 4.12).

Most demand for alternative employment opportunities comes from 1,294 individuals who require supported employment, the majority of whom currently attend sheltered work (562 individuals) or rehabilitative training (349 individuals).

There are 64 individuals who require their existing employment placement to be enhanced (shaded area of Table 4.12). Sixty-three of these avail of supported employment and almost two-thirds need their placement to be increased from part-time to full-time.

Educational services

Of the 1,071 service changes required within educational services, 910 (85.0%) are requirements for an alternative service and 161 (15.0%) are requirements for an enhancement of the child's existing service (Table 4.12).

Most of the demand for alternative educational services comes from three groups:

- 331 children who require special classes, particularly at secondary level. The majority of those requiring special classes at secondary level (258 children) currently attend special classes at primary level (204 children).

- 257 children who require a special school placement, the majority of whom currently attend special pre-schools (134 children).

- 252 children who require a mainstream school placement, the majority of whom currently attend a mainstream (110 children) or specialised (82 children) pre-school.

There are 161 children who require their existing educational placement to be enhanced (shaded area of Table 4.12), the majority of whom currently attend special schools (92 children). Over half the enhancements identified require the child's existing service at primary level to be carried through to secondary level. There is also a significant demand for increased support within existing educational placements.

Generic services

Of the 367 service changes required within generic services, 363 (98.9%) are requirements for an alternative service and 4 (1.1%) are requirements for an enhancement of the person's existing service (Table 4.12).

Most demand for alternative generic services comes from 331 individuals who require vocational training, the majority of whom currently attend special schools (215 individuals).

Three individuals attending vocational training and one individual availing of generic day services require their existing generic service to be enhanced (shaded area of Table 4.12).

Table 4.12. National Intellectual Disability Database, Ireland 2004.

Pattern of movement of individuals from existing day service to future day service 2005-2009.

Day service in 2004	Day service required in the period 2005-2009																									
	HS	HH	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	RHT	AC	POP	SHS	SI	SWC	SEC	CDR	DRH	OTH	E	SE	OE	VT	GD	All
Home support (HS)	12	0	44	36	4	4	1	0	0	5	2	6	2	0	1	6	0	1	0	0	0	6	0	1	0	131
Home help (HH)	2	0	8	7	0	0	0	0	0	0	0	3	0	0	0	1	0	0	0	1	0	0	0	0	2	24
Early intervention team[a]	14	1	134	96	4	20	0	3	0	12	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	285
Mainstream pre-school (MPS)	0	0	13	5	0	110	3	13	1	18	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	164
Special pre-school (SPS)	17	0	28	40	26	82	7	33	0	134	0	0	0	0	0	0	0	5	0	1	0	0	0	0	1	374
Child education & development centre (CEDC)	7	0	1	2	13	1	0	0	0	5	2	86	0	7	5	0	0	1	1	0	0	0	1	0	0	132
Mainstream school (MS)	31	1	0	0	0	21	31	17	33	31	17	0	0	0	0	1	1	35	0	0	0	11	1	13	0	244
Resource/visiting teacher (RT)	5	0	19	2	0	9	39	1	13	18	5	0	0	0	0	1	1	0	0	0	0	4	0	25	0	142
Special class – primary (SCP)	18	0	0	0	1	10	17	6	204	17	12	2	0	1	1	3	0	3	0	2	0	0	0	2	0	299
Special class – secondary (SCS)	1	1	0	0	0	1	1	0	3	1	29	14	0	1	1	7	0	5	0	0	0	7	0	23	0	95
Special school (SS)	112	1	2	1	11	8	4	4	6	92	768	231	0	48	20	206	31	53	0	5	4	47	30	215	0	1899
Rehabilitative training (RHT)	2	0	0	0	0	0	0	0	0	0	45	61	10	12	5	283	10	0	0	2	0	349	18	20	0	817
Activation centre (AC)	25	3	0	0	0	0	0	0	0	0	42	830	311	183	243	127	8	6	0	1	3	162	1	5	1	1951
Programme for the older person (POP)	0	1	0	0	0	0	0	0	0	0	1	9	221	3	47	7	0	0	0	0	0	0	0	0	3	292
Special high-support service (SHS)	1	0	0	0	0	0	0	1	0	2	23	43	11	73	94	8	0	0	0	1	0	2	0	1	0	260
Special intensive service (SI)	1	1	0	0	0	0	0	0	0	1	3	5	0	6	35	0	0	0	0	0	0	1	0	0	0	53
Sheltered work centre (SWC)	8	0	0	0	0	0	0	0	0	0	40	172	242	24	23	529	24	14	0	3	10	562	12	9	10	1682
Sheltered employment centre (SEC)	0	0	0	0	0	0	1	0	0	0	0	0	3	0	0	5	1	0	0	0	2	14	0	1	0	27
Multidisciplinary support services[a]	12	0	1	4	3	4	4	1	1	10	18	306	109	107	147	32	3	0	0	3	1	40	10	8	1	825
Centre-based day respite service (CDR)	0	0	1	0	0	1	1	0	0	0	0	0	4	2	1	0	0	0	0	0	0	1	0	0	0	11
Day respite in the home (DRH)	0	0	1	1	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	3
Other day service (OTH)	0	1	0	1	1	2	0	0	0	3	7	15	13	5	2	7	1	0	0	3	0	11	0	1	0	73
Enclave with open employment (E)	1	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	2
Supported employment (SE)	4	0	0	0	0	0	0	0	0	0	3	6	12	3	0	6	7	0	0	2	1	63	17	4	14	142
Open employment (OE)	0	1	0	0	0	0	0	0	0	0	1	1	0	0	0	2	1	0	0	0	0	9	1	3	0	19
Vocational training (VT)	0	0	0	0	1	0	0	0	0	0	6	3	1	0	0	23	2	0	0	1	0	64	38	3	0	142
Generic day service (GD)	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	4	1	0	0	0	0	4	0	0	1	12
All services	273	11	252	195	64	273	109	79	261	349	1024	1797	939	475	625	1258	91	124	2	25	21	1357	129	334	33	10100

[a] Multidisciplinary support services, including those delivered by early intervention teams, have been excluded from future service requirements and are documented in the Multidisciplinary Support Services section below.

The abbreviations in the third row of the table headings refer to the programme descriptions outlined in column one.
The shaded areas of the table represent existing services that require alteration or enhancement.

Pattern of movement within day services

The pattern of movement in day services is not as clear-cut as that 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 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 certain day services are reported and interpreted on the assumption that

(a)   where the service already exists, it will be retained by the individual, even when their new service comes on stream, or

(b)   where the service is new to the individual, it will not replace existing services.

The services involved include:

•   Home support services

•   Early intervention team

•   Resource/visiting teacher

•   Home help

•   Multidisciplinary support services

•   Centre-based day respite service

•   Day respite in the home

Table 4.12 maps the pattern of movement of individuals from their existing day service to their future day service. The main day service and the first future day service recorded on the NIDD is used to indicate the existing and future day services.

Future multidisciplinary support services, including those to be delivered by early intervention teams, are only recorded as a first future day service if these support services are the only future day service required. To avoid under-reporting the demand for these services, they are excluded from both the unmet need and service change sections above and they are reported separately below in Table 4.13. A 'requirement' refers to a new type of therapeutic input that the individual does not currently receive and an 'enhancement' refers to a change in the delivery of a therapeutic input that the individual currently receives (e.g. an increase in the provision of the service or a change in service provider). Data from Table 3.10 are also included in Table 4.13 to compare current service provision with the demand for future services.

Multidisciplinary support services

As Table 4.13 shows, 17,256 people are currently in receipt of multidisciplinary support services (including services delivered by early intervention teams), 3,697 of whom have no further requirements for such services. There are 15,689 individuals with a requirement for multidisciplinary support services whose needs involve either a requirement for a new type of service (4,892 individuals), an enhancement of an existing type of service (3,267 individuals) or both (7,530 individuals). Of this 15,689 with future multidisciplinary support service needs, 2,317 do not receive any multidisciplinary support services at the moment. Ninety-nine per cent of the demand is immediate.

- Despite high levels of current provision, there is substantial demand for new services and enhanced services of all the therapeutic inputs and, in particular, psychology, social work, and speech and language therapy. For example, 7,642 individuals currently receive a psychology service, 4,343 of whom need an enhancement of their service, and a further 5,553 individuals who do not receive a psychology service require one.

- The data suggest that there is a significant shortfall of occupational therapy and nutrition services as these are the only therapeutic inputs where the demand for new services exceeds current service provision. For example, 3,442 individuals are currently in receipt of occupational therapy, 2,093 of whom need an enhancement of their service, and a further 4,424 individuals who are not in receipt of occupational therapy require it.

Residential support service change

The database indicates that 1,263 individuals receiving residential support services will require an additional or alternative residential support service, or will require their existing support service to be upgraded during the period 2005-2009 (Table 4.14). Additional or alternative support services are required by 414 individuals (32.8%), and 849 individuals (67.2%) require their existing service to be upgraded (shaded area of Table 4.14).

The principal residential support service changes or enhancements include:

- more frequent centre-based crisis or planned respite breaks for people already availing of this service. Of these 824 individuals, 733 currently receive planned respite and require an enhanced service, 10 received crisis respite and require their support to be planned, and 46 are in receipt of both planned and crisis respite and require increased planned respite. It is unknown what type of respite 35 people currently receive.

- more regular part-time care arrangements for people already accessing crisis or planned respite services (109 people).

- occasional holiday residential placements and occasional respite care with a host family for people currently availing of crisis or planned respite (92 people).

- opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (61 people).

Table 4.13. National Intellectual Disability Database, Ireland 2004.
Current and future multidisciplinary support services by age and access to early intervention teams (EIT).

	Currently receiving service					Enhancement of service required 2005-2009 by people currently receiving this input					New service required 2005-2009 by people not currently receiving this input				
	6 and under		7-18	19 and over	Total	6 and under		7-18	19 and over	Total	6 and under		7-18	19 and over	Total
	EIT	Not EIT				EIT	Not EIT				EIT	Not EIT			
Community nursing	621	61	466	1138	2286	297	51	225	412	985	34	14	223	637	908
Medical services	795	119	1237	5570	7721	292	90	450	2309	3141	133	32	270	683	1118
Nutrition	150	38	315	1480	1893	59	23	134	543	759	177	61	429	2499	3166
Occupational therapy	728	103	1185	1426	3442	394	130	712	857	2093	344	86	919	3075	4424
Physiotherapy	1013	135	1231	1948	4327	450	123	612	1151	2336	100	33	396	1571	2100
Psychiatry	101	36	620	5216	5973	48	28	247	2669	2992	58	18	250	848	1174
Psychology	1005	195	2425	4017	7642	492	179	1312	2360	4343	250	61	1234	4008	5553
Social work	956	160	2386	5448	8950	430	166	1217	2948	4761	112	32	664	2613	3421
Speech & language therapy	1222	212	2515	738	4687	719	238	1529	444	2930	190	58	978	2763	3989
Other	427	93	472	1786	2778	49	19	153	870	1091	142	49	444	1346	1981
Number of people	**1532**	**263**	**4122**	**11339**	**17256**	**928**	**308**	**2652**	**6909**	**10797a**	**698**	**209**	**2736**	**8779**	**12422a**

a 'Enhancement of service required' refers to a change in the delivery of a therapeutic input that the individual currently receives. 'New service required' refers to a new type of therapeutic input that the individual does not currently receive. There are 7,530 individuals whose multidisciplinary support service change involves both a requirement and an enhancement. Therefore, the actual number of people represented in this table as requiring enhanced and/or additional services is 12,422 + 10,797 - 7,530 = 15,689.

Therapeutic inputs are only recorded if the individual has received, or will receive, at least four inputs of that service in a twelve-month period. The number of therapeutic inputs received or required exceeds the number of people as many people receive or require more than one input.

Table 4.14. National Intellectual Disability Database, Ireland 2004.
Additional residential support services required by people availing of residential support services in 2004.

Residential support service in 2004	Residential support service required 2005-2009												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)	Overnight respite in the home	Other residential service	
Foster care and boarding-out	1	1	5	4	10	0	0	2	0	0	0	1	24
Living semi-independently	0	12	15	4	3	1	0	0	0	0	2	0	37
Holiday residential placement	0	1	2	0	13	0	0	0	0	5	0	0	21
Crisis or planned respite	2	10	61	60	824	32	6	62	12	35	2	0	1106
Occasional respite care (host family)	0	1	1	1	25	6	1	0	0	1	0	0	36
Shared care or guardianship	0	0	0	0	2	0	0	0	0	0	0	0	2
Regular part-time care (2/3 days per week)	0	1	1	0	6	1	0	2	2	3	0	0	16
Regular part-time care (every weekend)	0	1	0	0	0	0	0	0	1	1	0	0	3
Regular part-time care (alternate weeks)	0	0	0	1	2	1	0	0	1	0	0	0	5
Overnight respite in the home	0	0	0	0	6	1	0	0	0	0	0	3	10
Other residential service	0	0	1	0	1	0	0	0	0	1	0	0	3
All services	**3**	**27**	**86**	**70**	**892**	**42**	**7**	**66**	**16**	**46**	**4**	**4**	**1263**

The shaded areas of the table represent existing services that require alteration or enhancement.

One hundred and eighty-one individuals of the 1,263 who are receiving residential support services and require that service to be changed also require an additional future residential service. Almost two-thirds of these additional future residential services are residential support services.

As with certain types of day service, 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.

PERSONS WITH INTELLECTUAL DISABILITY WHO ARE ACCOMMODATED IN PSYCHIATRIC HOSPITALS

The data from the NIDD for 2004 identify 474 individuals with intellectual disability, all aged 20 years or over, accommodated in psychiatric hospitals. Table 4.15 details the overall service requirement status of this group by level of intellectual disability.

Table 4.15. National Intellectual Disability Database, Ireland 2004.
Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2004.

	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	5	21	26	1	8	39	48	74
Resident in a psychiatric hospital - with day programme	1	34	97	132	2	74	189	265	397
Resident in a psychiatric hospital - with residential support service	0	0	1	1	0	0	0	0	1
Resident in a psychiatric hospital - with residential support service and day programme	0	0	0	0	0	2	0	2	2
All residents	**1**	**39**	**119**	**159**	**3**	**84**	**228**	**315**	**474**

Of this group, 315 (66.5%) individuals have service requirements in the period 2005-2009, of whom:

- 286 have an appropriate alternative residential facility identified for them and two require residential support services to assist them to live semi-independently in the community;

- 24 have identified day service requirements (two of whom also require a residential support service and one of whom also requires increased support within a psychiatric hospital);

- three require increased support within a psychiatric hospital.

Twenty-seven of the 315 individuals who require services will continue to reside within the psychiatric hospital.

- Twenty-four of these will require day services in the period 2005-2009. Almost half of this group, 11 individuals, have a mild intellectual disability and the remaining 13 individuals have a more severe intellectual disability. At present, four of this group have no day service, two of whom require an activation programme, one requires rehabilitative training, and one requires a programme for the older person. The remaining 20 people are in receipt of day programmes and require alternative day programmes (18 people) or require their existing service to be enhanced or upgraded (2 people), as outlined in Table 4.16. Nine of the 18 individuals who have an identified need for an alternative service require specific programmes designed for older people. Eleven of the 24 individuals also have multidisciplinary support services requirements.

- Three people require increased support within a psychiatric hospital.

Table 4.16. National Intellectual Disability Database, Ireland 2004.
Day service requirements of people appropriately accommodated in psychiatric hospitals.

	Services required					
Day service in 2004	Rehabilitative training	Activation centre	Programme for the older person	Special high support day service	Supported employment	All services
No day programme	1	2	1	0	0	4
Rehabilitative training	0	0	0	0	2	2
Activation centre	0	2	0	0	0	2
Special high support day service	0	1	0	0	0	1
Multidisciplinary support services only	0	0	7	2	0	9
Other day programme	0	4	2	0	0	6
All services	**1**	**9**	**10**	**2**	**2**	**24**

Of the 315 residents in psychiatric hospitals who require services (see Table 4.15), 286 people need to transfer to specific intellectual disability services and two people require support services to assist them to live semi-independently in the community. Of the group of 286 individuals who need to transfer to specific intellectual disability services, almost three-quarters (211 individuals) have a moderate, severe, or profound intellectual disability and just over a quarter (72 individuals) have a mild intellectual disability. Three people have not had their level of disability verified. Residential and day service requirements are identified for 121 individuals, while 165 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 4.17 and 4.18.

Table 4.17. National Intellectual Disability Database, Ireland 2004.
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		
	2005	2008	2005-2009
7-day (48-week) community group home	1	0	1
7-day (52-week) community group home	77	1	78
7-day (48-week) residential centre	2	0	2
7-day (52-week) residential centre	113	0	113
Nursing home	2	0	2
Intensive placement (challenging behaviour)	64	0	64
Intensive placement (profound/multiple disability)	25	0	25
Unspecified intellectual disability service	1	0	1
All residential services	**285**	**1**	**286**

Of the 286 people who need to transfer from psychiatric to intellectual disability services for provision of their residential services, 40.2% (115 individuals) will require places in residential centres, 31.1% (89 individuals) will require intensive placements, and 27.6% (79 individuals) will require community group home places. Two individuals need to move to nursing homes. One individual is recorded as requiring a transfer to an intellectual disability service but the type of service is unspecified. Almost all of the need arises immediately (Table 4.17).

Of this same group of 286 people, 121 will also require an appropriate day service. The greatest demand is for high-support or intensive day programmes (49.6%), activation programmes (32.2%), and programmes for older people (9.9%). All day services are required immediately (Table 4.18).

The 2004 data suggest that the current day and residential programmes for 159 people with intellectual disability within the psychiatric services are appropriate and these people have no identified service needs in the period 2005-2009 (Table 4.15). Almost three-quarters of this group have a moderate, severe, or profound intellectual disability, almost a quarter have a mild disability and one individual's level of disability is not verified. Within this group are 26 people who have no formal day programme. The day service needs of this group need to be reviewed.

Table 4.18. National Intellectual Disability Database, Ireland 2004.
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
	2005
Rehabilitative training	1
Activation centre	39
Programme for the older person	12
Special high-support day service	49
Special intensive day service	11
Sheltered work centre	3
Sheltered employment centre	1
Generic day services	2
Centre-based day respite service	1
Other day service	2
All day services	**121**

Note:
67 of the 121 also have multidisciplinary support services requirements..

OVERALL SERVICE PROVISION TO PEOPLE WITH INTELLECTUAL DISABILITY AND THE PATTERN OF CARE REQUIRED IN THE PERIOD 2005-2009

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.

Pattern of care required in full-time residential services

As is indicated in Table 4.19, demand for full-time residential services in the period 2005-2009 will come from three distinct groups already identified in this chapter:

- 1,893 individuals living at home who require full-time residential services for the first time,

- 286 individuals resident in psychiatric hospitals who require to transfer to the intellectual disability services, and

- 2,947 individuals in full-time residential services within the intellectual disability sector who require changes to their existing placement. Of this group, 2,221 require alternative services and 726 require their existing service to be enhanced. Not all of the group who require service enhancements will move to new placements. For example, 504 out of the 726 individuals (69.4%) 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 involves a move to a new placement, the freed-up place may be available to others who are identified as requiring this service.

Table 4.19 outlines the pattern of full-time residential service provision that will be required in the period 2005-2009 to meet this demand. A total of 2,198 residential places will be required – an increase of 97 since 2003.

- 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, 2,388 community-based placements will be required during the period, a substantial increase of 261 since 2003.

- There will also be a shortfall of 758 intensive residential placements, a decrease of 46 since 2003. 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

As can be seen from Table 4.20, demand for day services over the next five years comes from four distinct groups:

- 347 individuals who are without day services,

- 121 individuals resident in psychiatric hospitals who will require an appropriate day service when they transfer to intellectual disability services,

- 24 individuals appropriately placed in psychiatric hospitals but requiring a day programme within that setting, and

- 10,100 individuals in existing day services within the intellectual disability sector who require changes to, or enhancements of, their existing placement. Of this group 8,056 require alternative or additional services and 2,044 require their existing service to be enhanced. The majority (7,155) of these service changes are within the health sector. Many of the changes are required to address transitional needs such as moving from child to adult services or moving from training into employment. Not all of the group who require service enhancements will move to new placements. Again, as is seen with the requirement for enhancement of residential placements, 1,354 out of the 2,044 identified individuals (66.2%) 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 involves 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

Table 4.19. National Intellectual Disability Database, Ireland 2004.
Pattern of full-time residential service provision required 2005-2009.

	New services required by people living at home	New services required by people transferring from psychiatric hospitals	Service changes required by people in existing full-time residential places	Places vacated by people in full-time residential places	Shortfall (-)/ Excess of places arising from demand
5-day community group home	335	0	45	252	-128
7-day (48-week) community group home	309	1	314	239	-385
7-day (52-week) community group home	926	78	1421	550	-1875
5-day residential centre	22	0	8	89	59
7-day (48-week) residential centre	40	2	93	336	201
7-day (52-week) residential centre	111	113	276	1215	715
Nursing home	17	2	44	29	-34
Psychiatric hospital	0	0	1	0	-1
Intensive placement (challenging behaviour)	66	64	412	118	-424
Intensive placement (profound or multiple disability)	67	25	333	91	-334
Other/unspecified intellectual disability service	0	1	0	9	8
Designated residential support placement	0	0	0	[19a]	0
Total	**1893**	**286**	**2947**	**2928**	**-2198**

[a] 19 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.

accessing, or who require, home support, early services, resource/visiting teachers, multidisciplinary supports, centre- and home-based day respite or home help services will not be freeing up existing services when their future needs are met.

Table 4.20 outlines the pattern of day service provision that will be required in the period 2005-2009 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 1,913 day places will be required – a decrease of 17 places on the corresponding 2003 figure. The table shows two distinct trends consistent with previous years – a decrease in the numbers of young children requiring certain services and a huge demand for the full spectrum of adult services. The data indicate that over the next five years there will be

- Small reductions nationally in the number of children requiring special pre-school services, 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, special classes at secondary level, and resource/visiting teachers. This demand may be greater than the data indicate due to the possible under-estimation of young children on the database mentioned in Chapter 2.

- A shortfall of training and employment opportunities. In the period 2005-2009, 270 rehabilitative training placements and 216 vocational training placements need to be developed to meet the demand that exists for those services. There will be a shortfall of 1,254 supported employment opportunities and 123 placements in open employment during this time.

- The ageing population with intellectual disability discussed in Chapter 2 is resulting in increased demand for specific programmes for the older person and there will be a shortfall of 693 such places over the next five years.

- As with residential services, there is significant demand for high-support and intensive day placements. Over the next five years, 274 high-support day placements and 589 intensive day placements will be required. These services involve a higher staff to client ratio and more specialist interventions to address needs arising 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 2004 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 a growing number of older people with intellectual disability moving through the services at present. In the medium term, it is expected that the increased demand for intellectual disability services will continue.

Table 4.20. National Intellectual Disability Database, Ireland 2004.
Pattern of day service provision required 2005-2009.

	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	19	0	0	273	0	-292
Home help	0	0	0	11	0	-11
Mainstream pre-school	3	0	0	252	164	-91
Special pre-school	13	0	0	195	374	166
Child education and development centre	1	0	0	64	132	67
Mainstream school	0	0	0	273	244	-29
Resource/visiting teacher	1	0	0	109	0	-110
Special class - primary	0	0	0	79	299	220
Special class - secondary	3	0	0	261	95	-169
Special school	3	0	0	349	1899	1547
Rehabilitative training	61	1	1	1024	817	-270
Activation centre	69	39	9	1797	1951	37
Programme for the older person	24	12	10	939	292	-693
Special high-support day service	8	49	2	475	260	-274
Special intensive day service	6	11	0	625	53	-589
Sheltered work centre	50	3	0	1258	1682	371
Sheltered employment centre	7	1	0	91	27	-72
Centre-based day respite service	1	1	0	124	0	-126
Day respite in the home	0	0	0	2	0	-2
Other day service	0	2	0	25	73	46
Enclave within open employment	2	0	0	21	2	-21
Supported employment	37	0	2	1357	142	-1254
Open employment	13	0	0	129	19	-123
Vocational training	24	0	0	334	142	-216
Generic day services	2	2	0	33	12	-25
All Services	**347**	**121**	**24**	**10100**	**8679**	**-1913**

References

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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 and Barron S (2003) Annual Report of the National Intellectual Disability Database Committee 2002. 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. All 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

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. **P**ersonal **I**dentification **N**umber **(PIN)** |__|__|__|__|__|__|

16. Sex |__| 1=male 2=female
17. Degree of intellectual disability |__| 0=not verified 1=average range 2=borderline 3=mild 4=moderate 5=severe 6=profound
18. Year of last psychological assessment |__|__|__|__|
19. Does this individual have physical and/or sensory disability needs? |__| 1=yes 2=no
20. If yes, indicate type of physical and/or sensory disability |__|

NEXT OF KIN DETAILS

	(A)		(B)	
Next of Kin name	30a		30b	
Next of Kin address	31a		31b	
Next of Kin address	32a		32b	
Next of Kin address	33a		33b	
Next of Kin address	34a		34b	
Next of Kin address (County)	35a	|__|__|	35b	|__|__|
Next of Kin telephone number	36a		36b	
Relationship of next of Kin	37a		37b	

DAY SERVICES

40. Agency providing main day service (Appendix A) |__|__|__|__|__|__|
41. Type of main day service (Appendix B) |__|__|
42. Current level of main day service support   0.   1.   2.   3.   4.   5.
43. Main day service: number of days received each week   [0.0-7.0] |__|.|__|

44. Agency providing secondary day service (Appendix A) |__|__|__|__|__|__|
45. Type of secondary day service (Appendix B) |__|__|
46. Current level of secondary day service support   0.   1.   2.   3.   4.   5.
47. Secondary day service: number of days received each week   [0.0-7.0] |__|.|__|

48. Agency providing third day service (Appendix A) |__|__|__|__|__|__|
49. Type of third day service (Appendix B) |__|__|
50. Current level of third day service support   0.   1.   2.   3.   4.   5.
51. Third day service: number of days received each week   [0.0-7.0] |__|.|__|

MULTIDISCIPLINARY SUPPORT SERVICES

52.   If multidisciplinary support services are received, please indicate type(s):

		Agency
O	Community Nursing	|__|__|__|__|__|__|
O	Nutritionist	|__|__|__|__|__|__|
O	Medical Services	|__|__|__|__|__|__|
O	Occupational Therapy	|__|__|__|__|__|__|
O	Physiotherapy	|__|__|__|__|__|__|
O	Psychiatry	|__|__|__|__|__|__|
O	Psychology	|__|__|__|__|__|__|
O	Social Work	|__|__|__|__|__|__|
O	Speech & Language Therapy	|__|__|__|__|__|__|
O	Other Multidisciplinary support service **Specify**	|__|__|__|__|__|__|

For children aged six and under:
53.   Are these supports provided by an early intervention team? |__| 1=yes   2=no   3=not applicable

RESIDENTIAL SERVICES

54. Agency providing main residential service (Appendix A) |__|__|__|__|__|__|
55. Type of main residential circumstances (Appendix B) |__|__|__|
56. Current level of main residential service support   A.   B.   C.   D.   Z.

57. Agency providing secondary residential service (Appendix A) |__|__|__|__|__|__|
58. Type of secondary residential circumstances (Appendix B) |__|__|__|
59. Current level of secondary residential service support   A.   B.   C.   D.   Z.
60. If Planned Respite or Crisis Respite is the secondary residential service, indicate number of nights availed of in the past 12 months: Total |__|__|__| Planned |__|__|__| Crisis |__|__|__|

61. Health Board responsible for funding current services |__|__|

FUTURE SERVICE REQUIREMENTS

REQUIRED DAY SERVICES

70. Type of day service required (1) (Appendix B) |__|__|

71. Level of support required in day service (1)   0.   1.   2.   3.   4.   5.

72. Year in which day service (1) is required |__|__|__|__|

73. Primary reason for duplication on current day service and future day service (1) |__|__|

74. Type of day service required (2) (Appendix B) |__|__|

75. Level of support required in day service (2)   0.   1.   2.   3.   4.   5.

76. Year in which day service (2) is required |__|__|__|__|

77. Primary reason for duplication on current day service and future day service (2) |__|__|

MULTIDISCIPLINARY SUPPORT SERVICES

78. If multidisciplinary support services are required, please indicate type(s):

Rq	En		Duplication Reason
O	O	Community Nursing	|__|__|
O	O	Nutritionist	|__|__|
O	O	Medical Services	|__|__|
O	O	Occupational Therapy	|__|__|
O	O	Physiotherapy	|__|__|
O	O	Psychiatry	|__|__|
O	O	Psychology	|__|__|
O	O	Social Work	|__|__|
O	O	Speech & Language Therapy	|__|__|
O	O	Other Multidisciplinary support service Specify _____	

79. Year in which multidisciplinary support services are required |__|__|__|__|

For children aged six and under:

80. Will these supports be provided by an early intervention team? |__| 1=yes   2=no   3=not applicable

CONTINGENCY DAY SERVICES

81. Type of day service required - contingency plan |__|__|

82. Level of (contingency plan) day support required   0.   1.   2.   3.   4.   5.

83. Primary reason for duplication on current/contingency day service |__|__|

84. Primary reason for duplication on future day service (1) or (2) and contingency day service |__|__|

DAY SUPPORT LEVEL CODES	**RESIDENTIAL SUPPORT LEVEL CODES**
Coding for variables 42, 46, 50, 71, 75 & 82	Coding for variables 56, 59, 86, 90 & 94

0: NOT APPLICABLE		A: MINIMUM	(no sleep-in)
1: MINIMUM	(staff to client ratio is 1 to 10+)	B: LOW	(staff on duty most of the time plus sleep-in)
2: LOW	(between 1 to 6 and 1 to 9)	C: MODERATE	(two staff on duty plus sleep-in)
3: MODERATE	(between 1 to 4 and 1 to 5)	D: HIGH	(two staff on duty plus on-duty night staff)
4: HIGH	(between 1 to 2 and 1 to 3)	Z: NOT APPLICABLE	
5: INTENSIVE	(1 to 1 or above)		

FUTURE SERVICE REQUIREMENTS contd.

RESIDENTIAL SERVICES

85. Type of residential service required (1) (Appendix B) |__|__|__|
86. Level of support required in residential service (1)   A.   B.   C.   D.   Z.
87. Year in which residential service (1) is required |__|__|__|__|
88. Primary reason for duplication on current residential service and future residential service (1) |__|__|

89. Type of residential service required (2) (Appendix B) |__|__|__|
90. Level of support required in residential service (2)   A.   B.   C.   D.   Z.
91. Year in which residential service (2) is required |__|__|__|__|
92. Primary reason for duplication on current residential service and future residential service (2) |__|__|

CONTINGENCY RESIDENTIAL SERVICES

93. Type of residential service required - contingency plan |__|__|__|
94. Level of (contingency plan) residential support required   A.   B.   C.   D.   Z.
95. Primary reason for duplication on current/contingency residential service |__|__|
96. Primary reason for duplication on future residential service (1) or (2) and contingency
     residential service |__|__|

97. Health Board responsible for funding future services |__|__|

ADDITIONAL INFORMATION

100. Date of completion/review |__|__|-|__|__|-|__|__|__|__|
101. Person responsible for update of 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 HB |__|__| to CCA |__|__| to Agency |__|__|__|__|__|__|
                                           to National Physical & Sensory Disability Database |__|

      If deleted (3) please indicate: O   Emigrated   O   Parents' request
                                        O   Service no longer required   O   Client's request
                                        O   Other reason   O   Duplication between health boards
                                                                         O   Duplication within health board

106. Date of Removal |__|__|-|__|__|-|__|__|__|__|

NATIONAL PERFORMANCE INDICATOR (NPI)
To be completed for all people in fulltime residential services (codes 115 to 172)

200. **NPI (1):** 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. Vocational training (e.g. F.A.S., VEC, CERT, N.T.D.I.)
13. Rehabilitative 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
32. Day respite in the home

> **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 weekends/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 weekends/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
181. Overnight respite in the home

DAY SERVICE GROUPINGS

Health

Home support
Home help
Early services
Mainstream pre-school
Special pre-school
Child education and development centre
Rehabilitative 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
Day respite in the home
Other day service

Education

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

Employment

Enclave within open employment
Supported employment
Open employment

Generic

Vocational training
Generic day services

Appendix
B

Table B.1. National Intellectual Disability Database, Ireland 2004.
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
Home setting	1199	130	113	43	1485	3680	1823	1014	155	6672	3320	2554	1450	250	7574	8199	4507	2577	448	15731
At home with both parents	1016	98	41	1	1156	2782	1340	395	12	4529	2676	1896	486	9	5067	6474	3334	922	22	10752
At home with one parent	163	29	47	8	247	722	397	399	26	1544	562	576	600	31	1769	1447	1002	1046	65	3560
At home with sibling	0	1	20	25	46	7	16	155	81	259	5	38	314	174	531	12	55	489	280	836
At home with other relative	4	2	4	7	17	50	24	46	30	150	15	19	34	32	100	69	45	84	69	267
Living with non-relative	0	0	0	1	1	2	12	11	1	26	3	3	9	2	17	5	15	20	4	44
Adoption	1	0	0	0	1	9	5	0	0	14	4	2	1	0	7	14	7	1	0	22
Foster care and boarding-out arrangements	15	0	1	1	17	108	29	8	5	150	55	20	6	2	83	178	49	15	8	250
Independent/Semi-independent setting	1	5	29	20	55	3	141	321	89	554	0	23	68	41	132	4	169	418	150	741
Living independently	1	4	23	18	46	3	94	232	69	398	0	14	38	28	80	4	112	293	115	524
Living semi-independently	0	1	6	2	9	0	47	89	20	156	0	9	30	13	52	0	57	125	35	217
Community group home	7	7	13	7	34	48	184	362	202	796	99	677	1429	427	2632	154	868	1804	636	3462
5-day community group home	1	3	0	0	4	20	59	49	12	140	20	167	200	8	395	41	229	249	20	539
7-day (48-week) community group home	1	1	1	1	4	5	35	68	27	135	27	145	347	33	552	33	181	416	61	691
7-day (52-week) community group home	5	3	12	6	26	23	90	245	163	521	52	365	882	386	1685	80	458	1139	555	2232
Residential centres	2	4	29	49	84	16	54	103	115	288	129	689	1505	749	3072	147	747	1637	913	3444
5-day residential centre	0	1	0	0	1	1	7	2	0	10	22	53	37	1	113	23	61	39	1	124
7-day (48-week) residential centre	0	0	1	0	1	3	17	27	10	57	36	165	249	61	511	39	182	277	71	569
7-day (52-week) residential centre	2	3	28	49	82	12	30	74	105	221	71	471	1219	687	2448	85	504	1321	841	2751
Other full-time services	6	1	5	15	27	9	53	82	78	222	47	280	381	230	938	62	334	468	323	1187
Nursing home	0	0	2	12	14	1	2	5	15	23	1	3	28	37	69	2	5	35	64	106
Psychiatric hospital	0	1	2	1	4	0	20	47	56	123	0	37	155	155	347	0	58	204	212	474
Intensive placement (challenging behaviour)	2	0	0	0	2	4	24	15	1	44	15	136	105	9	265	21	160	120	10	311
Intensive placement (profound or multiple handicap)	4	0	0	0	4	0	2	6	3	11	24	90	84	20	218	28	92	90	23	233
Fulltime resident in 'other' residential service	0	0	0	1	1	3	4	6	3	16	2	1	4	7	14	5	5	10	11	31
Fulltime resident in residential support place	0	0	1	1	2	1	1	3	0	5	5	13	5	2	25	6	14	9	3	32
No fixed abode	0	1	0	0	1	0	7	1	0	8	0	2	2	1	5	0	10	3	1	14
Insufficient information	30	22	31	31	114	58	100	214	99	471	26	43	111	72	252	114	165	356	202	837
Total	1245	170	220	165	1800	3814	2362	2097	738	9011	3621	4268	4946	1770	14605	8680	6800	7263	2673	25416

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, subject to the following provision:

   a. 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.

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. 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.

5. 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.

6. Completed forms should be returned to:

   The Chairman, National Intellectual Disability Database Committee
   Intellectual Disability Services
   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	
Telephone Number	
Email address	
Name of agency/academic institution (where applicable)	
Date requested	
Details of the type of analysis required	
Reason for request - please be as specific as possible in describing why the information is required and how the data will be used - general explanations such as, 'research purposes' should not be used (continue on separate page if necessary)	

Declaration of confidentiality:

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: _____

Office Use Only:

Date request received	
Received by	HRB ☐ DoHC ☐
Date considered by NIDDC	
Decision of 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.

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Mulvany F and Barron S (2003) Annual Report of the National Intellectual Disability Database Committee 2002. Dublin: Health Research Board.

Barron S and Mulvany F (2004) Annual Report of the National Intellectual Disability Database Committee 2003. Dublin: Health Research Board.