



National Intellectual Disability Database

A N N U A L R E P O R T

of the
National Intellectual Disability Database Committee

1998/1999

Fiona Mulvany

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- the Intellectual Disability Services Section and the Systems Unit in the Department of Health and Children,*
- the health boards, in particular the Regional Database Co-ordinators, the Database Administrators and the Regional Database Committees,*
- the Federation of Voluntary Bodies providing Services to People with a Mental Handicap,*
- the parents and families of people with intellectual disability and their representative bodies, and*
- all those in intellectual disability services throughout Ireland*

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It gives me great pleasure to introduce the second Annual Report from the database. The report provides a profile of the population with intellectual disability as it was on 30th April, 1999 and sets out details of the level of services provided to this group. It also includes an assessment of need for services for the five-year period 2000 to 2004 and a mid-term review of the progress made in relation to meeting the needs which were identified in the initial Assessment of Need 1997 - 2001. The report outlines the pattern of care required over the coming years in both residential and day care services and some of the issues which must be addressed in both the planning and delivering of services.

In 1999 the reporting date for the database was changed from December to April at the request of the service providers. As a result there was only a short period between the submission of the 1998 and that of the 1999 data. While in 1998 Assessment of Need data was released, there was no formal publication of the balance of the 1998 data, which is now included as an appendix to this report.

The Intellectual Disability Database adds a new dimension to the planning and development of services to persons with intellectual disability at local and regional levels. In parallel with this research it is gratifying to see the development of evaluation mechanisms and systems which will enable us to monitor not just the quantity but also the quality of the services.

I would like to take this opportunity to thank all those involved in the ongoing process of ensuring that the quality and accuracy of the information from the database is of the highest standard. The availability of this information has been a key factor in securing the very significant resources which are currently being invested in the services. I would particularly like to acknowledge the contribution made by Ms. Fiona Mulvany to the preparation of this report.

Brendan Ingoldsby

Chairman

National Intellectual Disability Database Committee.

THE NATIONAL INTELLECTUAL DISABILITY DATABASE**BACKGROUND**

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

The database was established on the principle that minimum information with maximum accuracy was preferred, hence it incorporates only three basic elements of information: demographic details, current service provision, and future service requirements. The objective is to obtain this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service. 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 a person's circumstances or during the Annual Review process in the spring of each year.

STRUCTURE

The relevant Programme Manager in each health board region is responsible for the administration of the database in the region, which 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. 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 the effective co-ordination of local services. Regional Intellectual Disability Database Committees monitor the operation of the regional database in each health board region. This committee consists of the Regional Database Co-ordinator, the Regional Database Administrator and representatives from the health board and the voluntary services. The key functions of the committee are:

- To review the operation of the regional database and ensure compliance with the National Intellectual Disability Database protocols,
- To agree arrangements for providing access to the regional database, and
- To advise the Regional Database Co-ordinator on operational issues.

Each April the health boards transfer their regional dataset, excluding personal details such as name and address, to the Department of Health and Children and the information from the health boards is then merged to form the National Intellectual Disability Database. The Health Research Board, on behalf of the Department of Health and Children, manages the national dataset.

The operational structure of the Intellectual Disability Database facilitates informed service planning at local, regional and national level. The information now available 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 has been significant in the development of the database and their continuing commitment and co-operation is crucial in ensuring the ongoing availability of accurate information.

DATA QUALITY

The HRB has developed a system of ongoing validation which aims to identify and correct gaps and inconsistencies in the data. A series of technical checks has been added to the National Intellectual Disability Database software which enables much of the routine validation to be carried out at health board level. In addition, the database guidelines and

protocols have been revised and refined in response to issues highlighted by the HRB, the health boards and service providers. This ensures greater standardisation of data collection.

During 1996 the Department of Health and Children initiated a Clinical Audit of people with moderate, severe or profound intellectual disability who had future service requirements. This evaluation sought to assess the accuracy of the data at that time and to document the difficulties encountered by health boards and service providers as they strive to collect accurate information. The final report on the Clinical Audit (Keane & Mulvany, 1999) was submitted to the National Intellectual Disability Database Committee in March 1999 and the executive summary of this report was circulated to the health boards. This report identifies key areas for improvement and the recommendations are currently being incorporated into the work of both the National Intellectual Disability Database Committee and the Regional Database Committees. These developments have resulted in very significant improvements in the quality of data since the first dataset was received in 1995. Efforts to ensure continued improvement of data quality are ongoing at local, regional and national levels.

THIS REPORT

This is the second official release of data from the National Intellectual Disability Database. The first report (National Intellectual Disability Database Committee, 1997), was based on data received from the health boards in September 1996. During 1997, in addition to the data going through an extensive process of validation, a national clinical audit of the database took place with the intention of improving the accuracy of the database information. In December 1998 data were received from the health boards for the purpose of compiling the Annual Report for that year. However, at this time the health boards and services requested a change in the reporting date for the National Intellectual Disability Database. As a result, from 1999 onwards, the reporting date for the database changed from December to April. Due to the 1998 and 1999 reporting periods being just four months apart and the data therefore being very similar, the 'assessment of need' information from the 1998 data was publicly released and a decision made to include comprehensive statistical information for that year in the 1999 Annual Report (see

Appendix B). Any comparison of figures between 1998 and 1999 should be interpreted in the context of the short time-span between both datasets.

The main body of this report is based on validated data sent to the Department of Health and Children in April 1999. The data presented can be interpreted as a national census of people with an intellectual disability in the Republic of Ireland, and the prevalence figures are representative of the point prevalence as at April 1999. Prevalence rates per thousand population are based on the 1996 Census of Population. 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 considered likely to require such a service within the next five years. Those in the normal ability and borderline intellectual disability categories have been excluded from analyses because services for this group are not usually provided by the intellectual disability services. In April 1999, there were 141 people recorded as being of normal ability and 761 people in the borderline intellectual disability categories, a reduction of 79 and 330 respectively since 1996. This reduction in numbers came about following a review of individuals in both of these categories and 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 this group is known to have an intellectual disability, but the level of disability has not been confirmed. Accordingly, the data presented include those with a mild, moderate, severe or profound intellectual disability, in addition to the 'not verified' category.

The 1996 Annual Report provided data on demographic characteristics and current service provision. The present report has been expanded to include the up-to-date global needs assessment for this population and a mid-term review of the Department of Health and Children report *Services to persons with a mental handicap/intellectual disability - An assessment of need 1997-2001* (Department of Health and Children, 1997).

PROFILE OF THE POPULATION

NATIONAL LEVEL

In April 1999 there were 27,149 people registered on the National Intellectual Disability Database, with a prevalence rate of 7.49/1000 total population. Table 2.1 summarises the numbers and prevalence rates at each level of intellectual disability. The administrative prevalence rate for mild intellectual disability is 3.11/1000 and the prevalence rate for moderate, severe and profound intellectual disability is 4.06/1000.

TABLE 2.1. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999. DEGREE OF INTELLECTUAL DISABILITY. NUMBERS, % AND PREVALENCE RATES PER 1,000.

	n	%	rate per 1,000
<i>Mild</i>	11267	41.5	3.11
<i>Moderate</i>	9631	35.5	2.66
<i>Severe</i>	3961	14.6	1.09
<i>Profound</i>	1121	4.1	0.31
<i>Not Verified</i>	1169	4.3	0.32
Total	27149	100.0	7.49

Overall, the number of individuals registered on the National Intellectual Disability Database has increased by 455 since 1996. However, there are 296 fewer records in the 1999 dataset compared to that received in 1998 and this reduction is mainly attributed to exercises which have been undertaken to refine the database, namely, the review of people registered on the database who are of normal and borderline ability and the practice of retaining on the National Intellectual Disability Database only those people with mild intellectual disability who are in receipt of, or in need of, intellectual disability services.

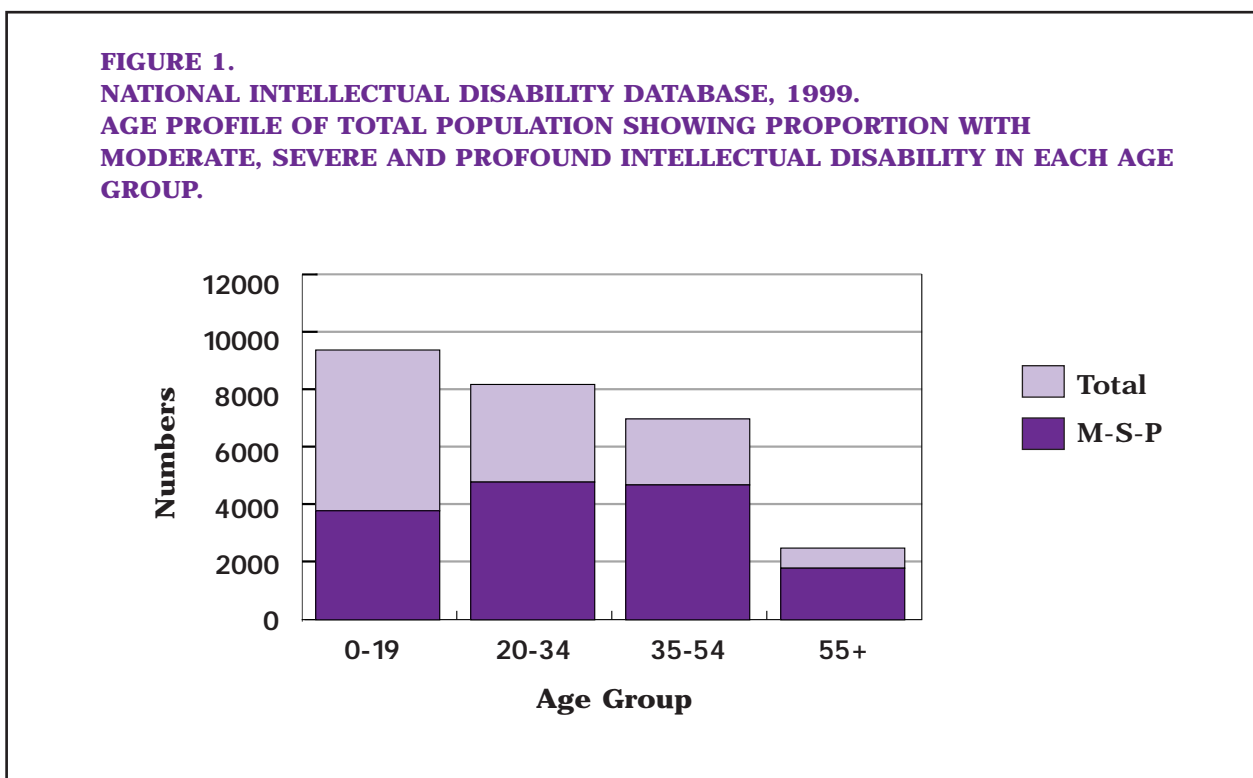
Table 2.2 summarises the age and gender distribution of this population by degree of disability.

**TABLE 2.2. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
AGE, GENDER AND DEGREE OF INTELLECTUAL DISABILITY.
NUMBERS AND PREVALENCE RATES PER 1,000.**

Age Group	Not Verified		Mild		Moderate		Severe		Profound		All Levels							
	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total						
0-4	279	200	479	120	73	193	95	81	176	36	21	57	10	13	23	540	388	928
5-9	152	89	241	485	284	769	407	245	652	136	111	247	34	28	62	1214	757	1971
10-14	30	17	47	1195	689	1884	524	331	855	170	113	283	42	28	70	1961	1178	3139
15-19	30	26	56	1325	803	2128	604	410	1014	176	134	310	53	37	90	2188	1410	3598
20-34	88	42	130	1867	1503	3370	1628	1396	3024	748	528	1276	220	197	417	4551	3666	8217
35-54	75	62	137	1081	1043	2124	1449	1381	2830	713	640	1353	230	155	385	3548	3281	6829
55 & over	36	43	79	383	416	799	504	576	1080	220	215	435	45	29	74	1188	1279	2467
All ages	690	479	1169	6456	4811	11267	5211	4420	9631	2199	1762	3961	634	487	1121	15190	11959	27149
Prevalence Rates																		
0-4	2.17	1.64	1.91	0.93	0.60	0.77	0.74	0.67	0.70	0.28	0.17	0.23	0.08	0.11	0.09	4.19	3.19	3.71
5-9	1.05	0.65	0.85	3.34	2.06	2.72	2.80	1.78	2.30	0.94	0.81	0.87	0.23	0.20	0.22	8.35	5.50	6.97
10-14	0.18	0.11	0.14	7.14	4.34	5.78	3.13	2.09	2.62	1.02	0.71	0.87	0.25	0.18	0.21	11.72	7.42	9.63
15-19	0.17	0.16	0.16	7.62	4.85	6.27	3.47	2.48	2.99	1.01	0.81	0.91	0.30	0.22	0.27	12.58	8.52	10.60
20-34	0.22	0.10	0.16	4.60	3.69	4.14	4.01	3.43	3.72	1.84	1.30	1.57	0.54	0.48	0.51	11.20	9.01	10.10
35-54	0.16	0.14	0.15	2.38	2.30	2.34	3.19	3.05	3.12	1.57	1.41	1.49	0.51	0.34	0.42	7.80	7.24	7.52
55 & over	0.11	0.11	0.11	1.18	1.09	1.13	1.56	1.51	1.53	0.68	0.56	0.62	0.14	0.08	0.10	3.67	3.35	3.50
All ages	0.38	0.26	0.32	3.59	2.63	3.11	2.89	2.42	2.66	1.22	0.97	1.09	0.35	0.27	0.31	8.44	6.55	7.49

The number of males at all levels of intellectual disability exceeds the number of females, with an overall male to female ratio of 1.27:1. This represents a prevalence rate of 8.44/1000 males and 6.55/1000 females.

Of the persons recorded on the National Intellectual Disability Database, 36% are aged 19 years and under, 30% are aged between 20 and 34 years, 25% are aged between 35 and 54 years, and 9% are 55 years of age and over. Figure 1 illustrates the number in each age group and the proportion with a moderate, severe or profound degree of intellectual disability.



The larger number with mild intellectual disability up to age 19 reflects the number of children in special education who receive support services from the intellectual disability sector, many of whom do not transfer to the intellectual disability services after school.

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 twenty-five years. The total number of those more severely affected has risen from 11,256 in 1974 to 14,713 in 1999

(an increase of 31%) and prevalence has risen from 3.80 per thousand to 4.06 per thousand over the same period. Of particular interest, from the point of view of service delivery, is the gradual increase of those in the categories of greatest severity, as illustrated in Table 2.3.

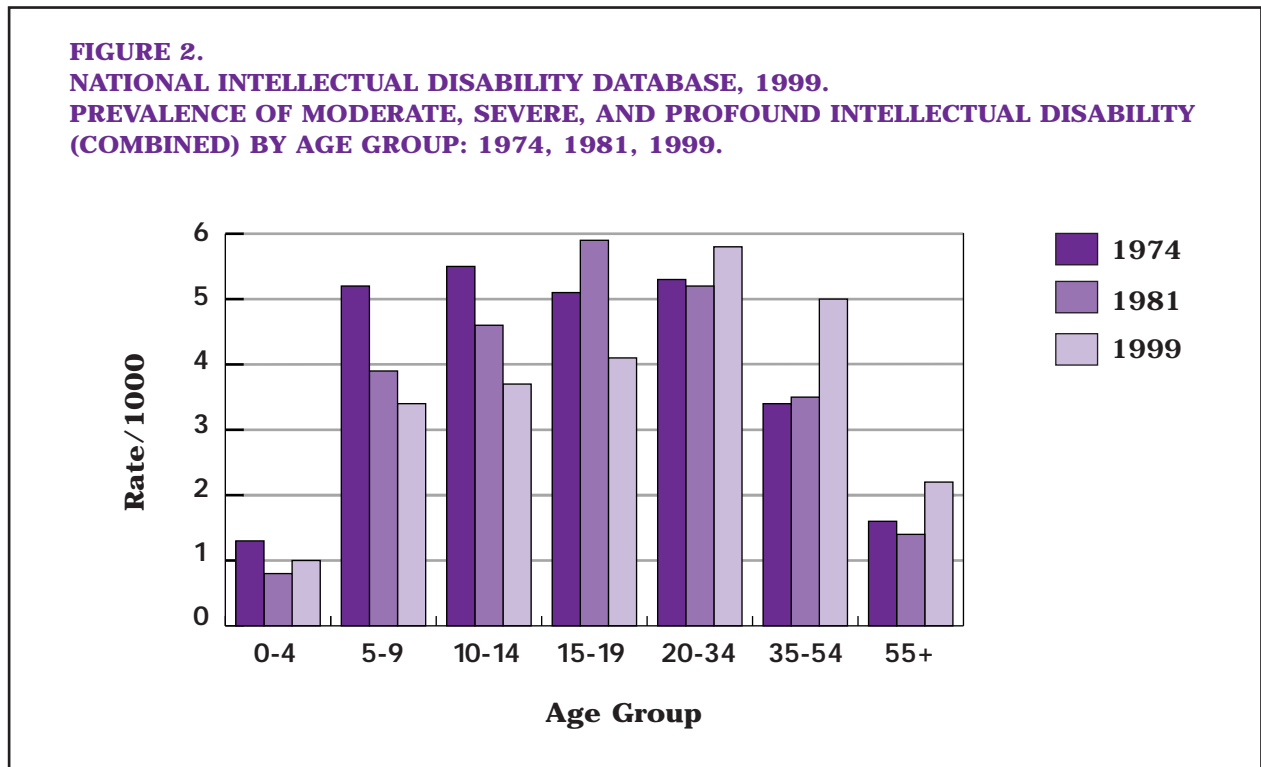
**TABLE 2.3. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
AGE, GENDER AND DEGREE OF INTELLECTUAL DISABILITY (MODERATE, SEVERE
AND PROFOUND COMBINED) - 1974, 1981, 1999.
NUMBERS AND PREVALENCE RATES PER 1,000.**

NUMBERS												
Age Group	Moderate			Severe			Profound			All Levels		
	1974	1981	1999	1974	1981	1999	1974	1981	1999	1974	1981	1999
0-4	189	214	176	143	92	57	99	26	23	431	332	256
5-9	809	955	652	617	330	247	224	99	62	1650	1384	961
10-14	752	1035	855	583	428	283	292	117	70	1627	1580	1208
15-19	698	1203	1014	445	508	310	241	154	90	1384	1865	1414
20-34	1498	2419	3024	1017	1129	1276	441	340	417	2956	3888	4717
35-54	1321	1559	2830	626	612	1353	201	97	385	2148	2268	4568
55 & over	669	715	1080	307	248	435	84	24	74	1060	987	1589
All ages	5936	8100	9631	3738	3347	3961	1582	857	1121	11256	12304	14713
PREVALENCE RATES												
0-4	0.60	0.62	0.70	0.45	0.27	0.23	0.31	0.07	0.09	1.36	0.97	1.02
5-9	2.55	2.73	2.30	1.95	0.94	0.87	0.71	0.28	0.22	5.20	3.95	3.40
10-14	2.52	3.08	2.62	1.95	1.27	0.87	0.98	0.35	0.21	5.45	4.70	3.70
15-19	2.61	3.79	2.99	1.66	1.60	0.91	0.90	0.48	0.27	5.17	5.88	4.16
20-34	2.78	3.33	3.72	1.88	1.56	1.57	0.82	0.47	0.51	5.48	5.35	5.80
35-54	2.13	2.43	3.12	1.01	0.95	1.49	0.32	0.15	0.42	3.46	3.53	5.03
55 & over	1.08	1.09	1.53	0.50	0.38	0.62	0.14	0.04	0.10	1.71	1.51	2.25
All ages	1.99	2.35	2.66	1.25	0.97	1.09	0.53	0.25	0.31	3.80	3.60	4.06

The graphical representation of the combined data for moderate, severe and profound intellectual disability shown in Figure 2 indicates a distinct changing age profile over the 25-year period, with fewer children and more adults currently availing of, or in need of, intellectual disability services. Figure 2 demonstrates a general trend towards falling prevalence rates of moderate, severe and profound intellectual disability in the younger age groups. However, the prevalence rate for the 0-4 age group clearly deviates from the pattern observed for the 5-9, 10-14, and 15-19 age groups. While these three age groupings show a distinct reduction in prevalence over the three data points, the prevalence rate observed in the 0-4 age group has increased slightly since 1981, from 0.97/1000 to 1.02/1000 in 1999. This may be due to better and earlier identification of intellectual disability among young children, but it may also reflect a real increase in prevalence. Certain demographic changes in the general population indicate that we should monitor this group closely. Firstly, the birth rate rose steadily between 1995 and 1998, primarily reflecting the fact that the high numbers born during the late 1960s and 1970s are now having children. The birth rate fell slightly in 1999 for the first time in four years (Central Statistics Office, 2000). Secondly, in recent years Ireland is experiencing the inward migration of returning Irish emigrants and increasing numbers of asylum seekers, many of whom already have young children or are of child-bearing age. In addition, and with particular implications for the intellectual disability services, the average maternal age has been increasing steadily from 28.3 years in 1978 to 29.6 years in 1998 (Department of Health and Children, 1999). Central Statistics Office figures show 50.8% of all births in 1994 were to mothers aged 30 and over. This percentage has been rising steadily since then and by 1999 had reached 53.8%. This trend is significant as older maternal age predisposes the offspring to increased risk of intellectual disability. Recent advancements in the field of neonatal care have increased the survival prospects of babies at risk of severe intellectual disability, for example, very low birthweight babies, and this could also result in an increase in prevalence. As a result, the prevalence rate among young children will need to be monitored closely.

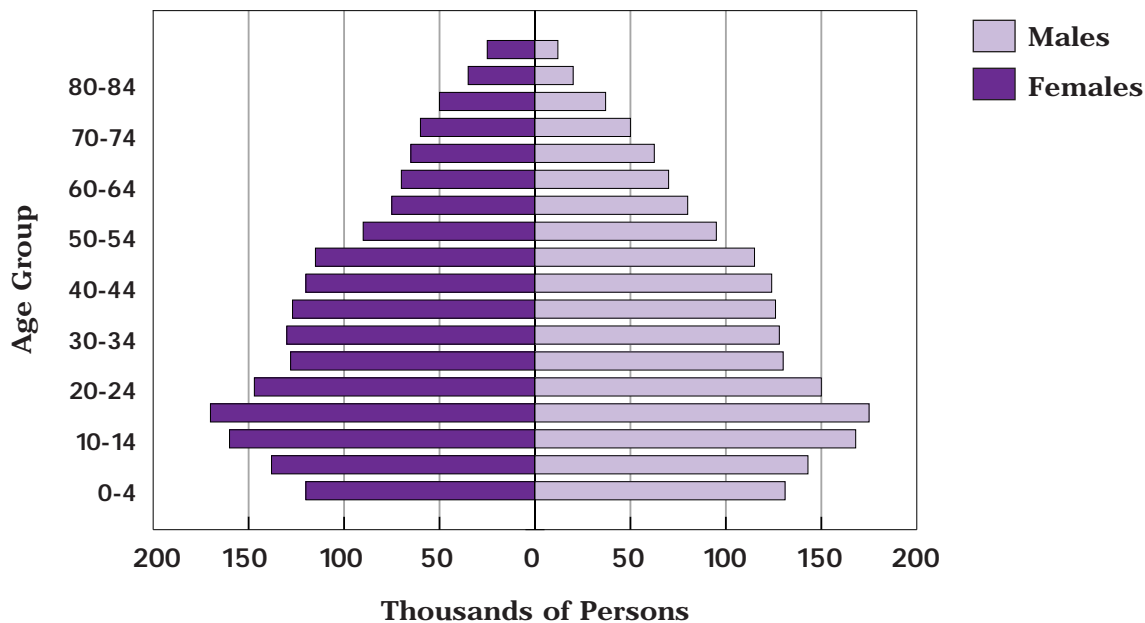
There is also evidence of increased longevity in this population. By grouping the 35-54 and the over-55 age groups, it can be seen that in 1974 29% of the population with moderate, severe or profound intellectual disability were aged 35 years and over. By 1996 38% of persons with a moderate, severe or profound intellectual disability were aged 35

years and over, and in 1999 this age group accounts for 42% of the population. This has implications for service provision, which are discussed briefly later in this chapter and in more detail in Chapter 4.



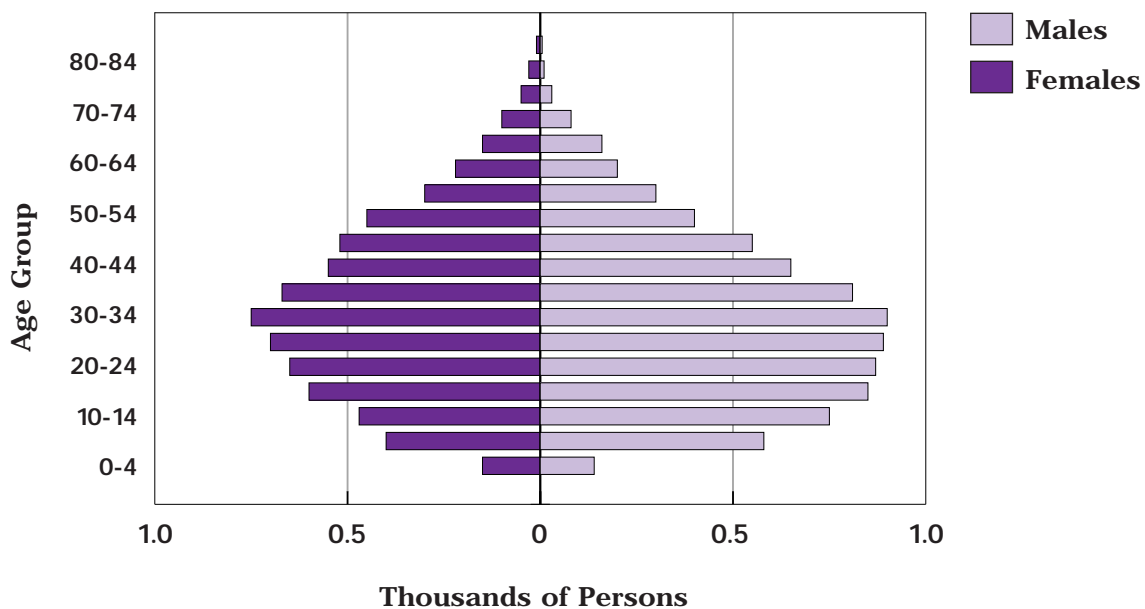
There is a population bulge originating in the 1960s and lasting until the mid-1970s currently moving through the intellectual disability services. The comparison of the population pyramids for the general population (Figure 3a) and for the population with intellectual disability (Figure 3b) clearly demonstrates the different age profiles in both populations. The general population pyramid shows continued expansion to age 20 and a gradual tapering thereafter across the life cycle. The intellectual disability population pyramid continues to expand up to age 35, with more pronounced tapering evident over the life cycle from that point onwards. The growth in numbers with intellectual disability during the 1960s and 1970s is attributed to a high birth rate and improved obstetric and paediatric care. Data from the previous Censuses of Mental Handicap allow us to monitor the progress of this group through the services. In 1974 there was a high prevalence rate in the 10-14 age group, which was observed as the peak prevalence rate in 1981 in the 15-19 age group and in the 20-34 age group in 1999.

**FIGURE 3A.
CENSUS OF POPULATION IRELAND 1996.
POPULATION PYRAMID - GENERAL POPULATION.**



SOURCE: CENTRAL STATISTICS OFFICE, CENSUS OF POPULATION 1996.

**FIGURE 3B.
NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
POPULATION PYRAMID - MODERATE, SEVERE AND PROFOUND
INTELLECTUAL DISABILITY COMBINED.**



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. The key features include:

- A decrease in current numbers of children in the more severe categories of intellectual disability, reflecting the decline in the birth rate during the 1980s and early 1990s and improved obstetric care. However, the benefits accruing from improved obstetric care in terms of the prevention of cases of severe intellectual disability are balanced to some extent by advancements in neonatal care which serve to increase the survival prospects of infants at risk, including very low birthweight babies. In addition, if the birth rate remains high and net immigration continues, as has been predicted, this downward trend may wane.
- An ageing population in the more severe range of disability. The older age group (35 years and over) accounted for 26% of the total population in the severe range in 1981; by 1999 this has increased to 42%. What we are witnessing is a cohort effect whereby a high incidence rate of intellectual disability in the 1960s is now reflected in the relatively large number of adults who have survived. This increase in numbers has resulted in:
 - an increased demand for residential services,
 - fewer places becoming free through death because of increased life expectancy,
 - demand for more intensive services and specific geriatric services to meet the needs of a population who will become increasingly dependent, and
 - the need for therapeutic support services for people who continue to live with their families to enable this caring arrangement to continue.

HEALTH BOARD LEVEL

Table 2.4 details the number of individuals included on each of the regional databases at April 1999. Each health board has responsibility for collecting the required information for all individuals who are in receipt of, or in need of, intellectual disability services within their health board region.

**TABLE 2.4 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
NUMBER OF PEOPLE INCLUDED ON EACH REGIONAL INTELLECTUAL
DISABILITY DATABASE.**

	n	%
Eastern	8699	32.0
Midland	1879	6.9
Mid-Western	2585	9.5
North-Eastern	2145	7.9
North-Western	1625	6.0
South-Eastern	3141	11.6
Southern	3854	14.2
Western	3221	11.9
Total	27149	100.0

Table 2.5 summarises the number and proportion of people at each level of intellectual disability in each health board region. The only significant change in the proportions at each level of disability since the 1996 report is in the mild range. At national level, 41.5% of all people with an intellectual disability are within the mild range, but regionally this proportion varies from 37.1% in the Eastern Health Board region to 47.0% in the Western Health Board region. In 1996, the Midland Health Board had the lowest proportion of people with mild intellectual disability at 34.6% and this proportion has increased to 46.1% in 1999. It appears that this increase is due to the re-classification of a number of people recorded in the 'not verified' category in 1996. At that time, 10.7% of all records on the Midland Health Board database had this designation but that proportion has been reduced to 2.6% in 1999.

**TABLE 2.5 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
DEGREE OF INTELLECTUAL DISABILITY BY HEALTH BOARD AREA.**

	Not Verified	Mild	Moderate	Severe	Profound	All Levels
	n %	n %	n %	n %	n %	n %
Eastern	574 6.6	3229 37.1	3268 37.6	1269 14.6	359 4.1	8699 100.0
Midland	49 2.6	866 46.1	698 37.1	222 11.8	44 2.3	1879 100.0
Mid-Western	25 1.0	1213 46.9	910 35.2	348 13.5	89 3.4	2585 100.0
North-Eastern	69 3.2	893 41.6	788 36.7	316 14.7	79 3.7	2145 100.0
North-Western	88 5.4	600 36.9	606 37.3	273 16.8	58 3.6	1625 100.0
South-Eastern	178 5.7	1330 42.3	1003 31.9	442 14.1	188 6.0	3141 100.0
Southern	115 3.0	1622 42.1	1287 33.4	591 15.3	239 6.2	3854 100.0
Western	71 2.2	1514 47.0	1071 33.3	500 15.5	65 2.0	3221 100.0
Total	1169 4.3	11267 41.5	9631 35.5	3961 14.6	1121 4.1	27149 100.0

The 1981 Census revealed considerable differences between health board areas in the prevalence rates of moderate, severe and profound intellectual disability. The data collection method used by the National Intellectual Disability Database does not seek information as to place of birth so it is not possible to compare prevalence in different areas for all age groups. However, for individuals 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, then the 0-19 years age groups are compared with some confidence (Table 2.6). There is some variation in prevalence rates between health board areas which is probably due to demographic factors such as higher migration from rural areas, later maternal age and large family size. A recent re-examination of the apparent high prevalence rates of moderate, severe

and profound intellectual disability in the Midland Health Board region concluded that the high rate was more likely to be the result of differences in ascertainment and classification rather than as a result of a high underlying prevalence rate of intellectual disability.

**TABLE 2.6 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
GEOGRAPHICAL DISTRIBUTION AND AGE (MODERATE, SEVERE AND PROFOUND
INTELLECTUAL DISABILITY COMBINED).
NUMBERS AND PREVALENCE RATES PER 1000.**

	Numbers				
	0-4 years	5-9 years	10-14 years	15-19 years	All ages
Eastern	70	288	396	446	1200
Midland	40	80	93	109	322
Mid-Western	28	90	96	119	333
North-Eastern	8	100	97	140	345
North-Western	6	47	81	77	211
South-Eastern	28	101	133	147	409
Southern	46	165	190	215	616
Western	30	90	122	161	403
Total	256	961	1208	1414	3839
	Rates				
Eastern	0.77	2.98	3.70	3.78	2.91
Midland	2.74	4.73	4.57	5.42	4.47
Mid-Western	1.29	3.63	3.27	3.89	3.13
North-Eastern	0.37	3.88	3.21	4.77	3.22
North-Western	0.41	2.71	4.02	3.86	2.93
South-Eastern	1.03	3.18	3.63	3.95	3.08
Southern	1.24	3.93	3.87	4.23	3.44
Western	1.29	3.23	3.66	4.82	3.42
Total	1.02	3.40	3.70	4.16	3.20

CHAPTER 3

CURRENT SERVICE PROVISION

NATIONAL LEVEL

There are 24,095 people with intellectual disability currently in receipt of services, which accounts for 89% of the total population registered on the National Intellectual Disability Database. A summary of the overall level of current service provision is provided in Table 3.1.

**TABLE 3.1 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
SUMMARY OF CURRENT SERVICE PROVISION.**

	n	%
<i>Receiving day services</i>	16041	59.1
<i>Receiving 5-day or 7-day residential services</i>	6956	25.6
<i>Residents in Psychiatric Hospitals</i>	854	3.1
<i>Receiving residential support services only</i>	244	0.9
<i>Receiving no service</i>	552	2.0
<i>No current service requirements</i>	2502	9.2
Total	27149	100.0

Note: 3348 day attenders and 161 full-time residents receive residential support services in addition to their principle service
7023 residents receive a day service in addition to their residential service

The 1999 data indicate that 552 people (2%) are without services and have service needs in the period 2000-2004, details of which are presented in Chapter 4. Two-thirds of this group (66%) are in the not verified and mild categories of intellectual disability. A further 2,502 (9%) have no identified requirement for services within this five-year period, of whom 68% are in the not verified and mild categories of intellectual disability. Of this group, 252 have their circumstances formally reviewed on an annual basis and 571 have contingency service plans identified on the database. The appropriateness of registering people with mild intellectual disability on the database is monitored on an on-going basis, as the primary function of the database is to record only people who are currently in receipt of intellectual disability services or who will require such services within a five-year period. Six out of ten people in each of the two categories outlined above have a mild intellectual disability and it is reasonable to assume that they genuinely do not require services at this time.

However, approximately one-third of both groups has either a moderate, severe or profound degree of intellectual disability. Each year, following the national export of data, the Health Research Board follows up on the individual circumstances of these people with the health boards. While these people may not wish to avail of services at this time, it is essential that their needs be monitored on a regular basis so that changing circumstances can be identified and responded to in a timely manner.

Comparing service provision in 1996 and 1999, there are an additional 1,291 people in receipt of intellectual disability services since the first data were reported in 1996. This figure includes 1,052 day attenders and 238 full-time residents over the three-year period.

Table 3.2 summarises current service provision in 1999 by degree of intellectual disability and age group.

There is a clear relationship between level of disability, age and utilisation of services. Day services tend to be accessed by younger individuals of higher ability, while residential services are utilised primarily by older people with moderate, severe and profound levels of intellectual disability. Of those availing of services on a day basis, 49% are in the mild range of intellectual disability and 51% are aged 18 years and under. The majority of full-time residents (78%) have a moderate, severe or profound degree of disability and 93% are aged 19 years and over. There are no residents under the age of 18 in psychiatric hospitals and 74% of the adult residents have a moderate, severe or profound degree of intellectual disability. Of those wait-listed for services within the period 2000-2004, 61% are in the mild range of disability and 84% are aged 19 years and over. The group which has no requirements for service at this moment in time is comprised mainly of adults with mild intellectual disability.

RESIDENTIAL CIRCUMSTANCES

Table 3.3 outlines the main residential circumstances of those included on the National Intellectual Disability Database in 1999. Almost two-thirds (63%) live in a home setting with parents, relatives, or foster parents. The remainder of the population live in full-time

**TABLE 3.2 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
SUMMARY OF CURRENT SERVICE PROVISION BY DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

	Not verified		Mild		Moderate, Severe and		All levels Profound					
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over				
Receiving day services	714	158	872	4317	3613	7930	3108	4131	7239	8139	7902	16041
Receiving 5 or 7 day residential services	11	30	41	92	1052	1144	365	5406	5771	468	6488	6956
Residents in Psychiatric Hospitals	0	11	11	0	215	215	0	628	628	0	854	854
Receiving residential support services only	0	8	8	10	154	164	4	68	72	14	230	244
Receiving no service	14	12	26	52	284	336	24	166	190	90	462	552
No current service requirements	66	145	211	120	1358	1478	57	756	813	243	2259	2502
Total	805	364	1169	4591	6676	11267	3558	11155	14713	8954	18195	27149

residential services (29%), mainly residential centres, community group homes, and psychiatric hospitals, or they live independently or semi-independently (3%). There are 16 people registered on the database who have no fixed abode, an increase of 10 since 1996. Information on the residential circumstances of 1,658 people registered on the database is insufficiently detailed. However, this is an improvement on the 1996 figure of 2,323 people. This group is being reviewed on an ongoing basis to improve the quality of data available. The availability of more detailed information on this group largely accounts for the identified increase in those living in home settings in the current dataset. In 1999, 16,692 people live in a home setting compared to 16,267 in 1996.

There are 7,810 people in receipt of full-time residential services. Within this group, 2,835 live in community group homes, 3,539 are in residential centres and 365 are in special intensive placements either because they have profound or multiple disabilities or because they have special requirements due to challenging behaviour. In addition, 151 individuals live in de-designated units and 66 reside in nursing homes. 854 people with intellectual disability are currently accommodated in psychiatric hospitals, a reduction of 12% on the 1996 figure. The Department of Health and Children identifies the provision of alternative accommodation for people with intellectual disability currently accommodated in psychiatric hospitals as a priority. The needs of this group are addressed in Chapter 4.

There has been a 28% increase in the number of people living independently or semi-independently since 1996, which is concrete evidence of the philosophy underpinning services which is to enable people to develop to the maximum of their potential through a policy of care in the community. Further affirmation of this philosophy is observed in the 19% increase in the number of residential places available in community group homes, and a corresponding 8% reduction in the number of places in traditional-style residential centres, as people are re-located to more appropriate living situations. It should be noted that some of the reduction in numbers observed in traditional-style residential centres is accounted for by the establishment on the database of a new service code for de-designated units since the 1996 data were collected. Prior to the collection of the 1998 data, people resident in de-designated units were coded under the traditional-style settings.

**TABLE 3.3 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
MAIN RESIDENTIAL CIRCUMSTANCES.**

	n	%
Home Setting	16992	62.6
At home with both parents	12081	44.5
At home with one parent	3288	12.1
At home with sibling	972	3.6
At home with other relative	339	1.2
Lives with non-relative	49	0.2
Adoption	28	0.1
Foster care	235	0.9
Independent Setting	673	2.5
Lives independently	523	1.9
Living semi-independently	150	0.6
Community Group Homes	2835	10.4
5-day community group home	603	2.2
7-day (48-week) community group home	917	3.4
7-day (52-week) community group home	1315	4.8
Residential Centres	3539	13.1
5-day residential centre	204	0.8
7-day (48-week) residential centre	944	3.5
7-day (52-week) residential centre	2391	8.8
Other full-time services	1436	5.2
Nursing Home	66	0.2
De-designated Unit	151	0.6
Psychiatric hospital	854	3.1
Intensive placement (Challenging Behaviour)	148	0.5
Intensive placement (Profound or Multiple handicap)	217	0.8
No fixed abode	16	0.1
Insufficient Information	1658	6.1
Total	27149	100.0

^a De-designated units are defined as accommodation usually in the grounds of psychiatric hospitals which was formally designated under the Mental Treatment Act 1945.

Main residential circumstances by age and degree of intellectual disability

Table 3.4 provides an analysis of the type of main residential circumstances by degree of intellectual disability and age group.

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.

91% of all 0-19 year olds live in a home setting, declining to 63% of those aged between 20 and 34 years, 37% of those aged 34-54 years and 23% of those aged 55 years and over. Conversely, the proportion of people in the different age categories who are living in full-time residential services increases with age. 6% of all 0-19 years olds are in full-time residential placements compared to 28% of 20-34 year olds, 51% of 35-54 year olds and 62% of those aged 55 years and over.

There are also noticeable variations between level of ability and type of accommodation. Most people with a mild intellectual disability live in a home setting (75%) compared to 52% of those with a moderate, severe or profound intellectual disability. In the more severe categories of disability, the proportion of people in full-time residential services is increased. Only 12% of people with a mild intellectual disability have a full-time residential placement but this increases to 43% in the case of those with a moderate, severe or profound disability.

Where individuals are in full-time residential placements, the type of placement varies according to level of intellectual disability. Of those in the mild range of intellectual disability who are in full-time residential placements, 54% are in community group home, 24% are in residential centres and 22% are in other full-time residential placements. However, of those in full-time residential placements who have a moderate, severe or profound intellectual disability, 33% are in community group homes, 50% are in residential centres and 17% are in other full-time residential placements. The trend towards placing people in community group homes rather than in traditional-style residential centres extends to people in both the mild and more severe ranges of intellectual disability. In 1996, 49% of full-time residents with mild intellectual disability were living in community group homes compared to 54% in 1999 and 28% of full-time residents in the more severe range were living in community group homes compared to 33% in 1999.

**TABLE 3.4 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
MAIN RESIDENTIAL CIRCUMSTANCES, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

	Not verified					Mild					Moderate, Severe and Profound					All levels							
	0-19		20-34		55+	0-19		20-34		35-54	0-19		20-34		35-54	0-19		20-34		35-54	55+		Total
	Total	55+	Total	55+	Total	Total	55+	Total	55+	Total	Total	Total	55+	Total	55+	Total	Total	55+	Total	55+	Total	Total	
Residential Circumstances																							
Home Setting	748	76	68	28	920	4698	2433	1079	237	8447	3291	2634	1399	301	7625	8737	5143	2546	566	16992			
Independent Setting	1	11	12	7	31	2	176	247	102	527	0	14	69	32	115	3	201	328	141	673			
Community Group Home	2	4	2	2	10	71	198	314	151	734	119	720	1026	226	2091	192	922	1342	379	2835			
Residential Centre	11	4	5	7	27	33	96	115	88	332	259	960	1412	549	3180	303	1060	1532	644	3539			
Other full-time services	1	3	4	7	15	9	40	115	129	293	49	253	462	364	1128	59	296	581	500	1436			
No fixed abode	0	1	0	1	2	2	7	3	0	12	0	1	1	0	2	2	9	4	1	16			
Insufficient information	60	31	46	27	164	159	420	251	92	922	121	135	199	117	572	340	586	496	236	1658			
Total	823	130	137	79	1169	4974	3370	2124	799	11267	3839	4717	4568	1589	14713	9636	8217	6829	2467	27149			

At present, 23,064 people, representing 85% of the total population with an intellectual disability, avail of day services. This represents an increase of 1,105 people availing of day services since 1996. Of those availing of day services, 30% (7,023) are in full-time residential placements, the majority of whom are in the moderate, severe or profound range of intellectual disability (82%) and aged 19 years and over (93%). The remaining 70% (16,041) attend services on a daily basis, of whom 49% are in the mild range of intellectual disability and 51% are aged 18 years and under. The current data indicate that 787 full-time residents have no day activity programme and the needs of this group are addressed in Chapter 4.

Table 3.5 summarises the level of disability and age profiles of people availing of day services.

**TABLE 3.5. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
CATEGORY OF PERSONS AVAILING OF DAY SERVICES, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

	<i>Not Verified</i>			<i>Mild</i>			<i>Moderate, Severe and Profound</i>			<i>All Levels</i>		
	<i>18 and under</i>	<i>19 and over</i>	<i>All ages</i>	<i>18 and under</i>	<i>19 and over</i>	<i>All ages</i>	<i>18 and under</i>	<i>19 and over</i>	<i>All ages</i>	<i>18 and under</i>	<i>19 and over</i>	<i>All ages</i>
<i>Residents</i>	11	32	43	90	1144	1234	361	5385	5746	462	6561	7023
<i>Day Attenders</i>	714	158	872	4317	3613	7930	3108	4131	7239	8139	7902	16041
<i>Total</i>	725	190	915	4407	4757	9164	3469	9516	12985	8601	14463	23064

Of those availing of day services 37% are aged 18 years and under and 63% are 19 years and over. Four out of every ten people receiving day services have a mild intellectual disability while 56% have a moderate, severe or profound intellectual disability. The age profile of these groups is quite different. Only one in four of the population with moderate, severe or profound intellectual disability who are availing of day services is aged 18 years and under, whereas almost one in two with mild intellectual disability who are availing of day services are children. The higher number of children with mild intellectual disability

up to age 19 reflects the number of children in special education, many of whom do not transfer to the adult intellectual disability services after school-going age. However, the proportion of adults with mild intellectual disability who are accessing day services has increased from 47% in 1996 to 52% in 1999, representing an increased demand for specialised services for this group.

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

	Residents	Day Attenders	Total
Home Support	3	390	393
Early Services	3	498	501
Ordinary pre-school	0	165	165
Special pre-school for intellectual disability	8	541	549
Child Education and Development Centre	96	547	643
Ordinary School	1	844	845
Resource Teacher	2	198	200
Special Class - primary level	16	764	780
Special Class - secondary level	5	190	195
Special School	322	4332	4654
Generic vocational training	17	104	121
Special vocational training	343	1523	1866
Activation Centre	3107	1480	4587
Programme for the Elderly	211	75	286
Special high-support day service	366	66	432
Special intensive day service	125	28	153
Sheltered work centre-includes long term training schemes	1858	2740	4598
Sheltered employment centre	16	118	134
Multidisciplinary support service	2	70	72
Centre-based day respite service	0	1	1
Other day service	339	587	926
Enclave within open employment	43	13	56
Support employment	97	527	624
Open employment	22	164	186
Generic Day Services	21	59	80
Home Help	0	17	17
Total	7023	16041	23064

People who attend services on a day basis are availing mainly of educational, training and employment services, reflecting both the higher level of ability and younger age profile of people in these services. Those in full-time residential services are much more likely to avail of the caring services, such as activation programmes, specific programmes for the elderly and special high-support or intensive programmes.

In summary, the main areas of day service provision are as follows:

Special Education	25.3%
Sheltered Workshop/Employment	20.5%
Activation Centre	19.9%
Training	8.6%
Early Services/Pre-school	5.3%
Supported/Open Employment	3.8%
Mainstream Education	3.7%
Child Education and Development Centre (CEDC)	2.8%
High Support/Intensive Services	2.5%
Home Support Services	1.7%
Programme for the Elderly	1.2%
Other Day Services	4.8%

Main day services by age and degree of intellectual disability

Table 3.7 provides details of the principal day services by age group and degree of intellectual disability. There are 8,601 individuals aged 18 years and under currently accessing day services. The majority are availing of early intervention, pre-school, mainstream or special education services or are attending Child Education and Development Centres. Smaller numbers of children are availing of activation programmes or specialised high-support and intensive programmes. Just over half of children availing of day services have a mild degree of intellectual disability (51%), most of whom avail of services in the educational sector. Of the remaining group, 40% have a moderate, severe or profound intellectual disability and, while the majority of these are in the educational sector, some also avail of the more care-focused services such as child education and development centres.

There are 14,463 adults currently availing of day services. Of this group, 33% have a mild degree of intellectual disability and 66% are in the more severe range. Most adults with a mild degree of intellectual disability attend sheltered work centres or are in receipt of special vocational training. The adults with moderate, severe or profound intellectual disability are most likely to be in receipt of activation programmes, followed by sheltered work, special vocational training and high-support or intensive day programmes designed to address their special requirements.

For 393 people, 100 children and 293 adults, the principal day service being provided is Home Support, which can be as infrequent as once a month and is not considered to constitute a full day service. However, steps are being taken to address the needs of individuals who are considered to have an inadequate level of service and the impact of these measures is clearly demonstrated by a 44% reduction since 1996 in the number of people relying on Home Support for their main day service.

**TABLE 3.7 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
PRINCIPAL DAY SERVICE, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

	Not verified		Mild		Moderate, Severe and Profound		All levels					
	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over				
Home Support	32	12	44	38	94	132	30	187	217	100	293	393
Early Services	274	0	274	101	1	102	123	2	125	498	3	501
Ordinary pre-school	52	0	52	63	0	63	50	0	50	165	0	165
Special pre-school for intellectual disability	113	0	113	141	0	141	287	8	295	541	8	549
Child Education and Development Centre	37	0	37	6	1	7	512	87	599	555	88	643
Ordinary school	42	0	42	642	28	670	130	3	133	814	31	845
Resource Teacher	61	0	61	114	1	115	23	1	24	198	2	200
Special class - primary level	12	0	12	563	29	592	174	2	176	749	31	780
Special class - secondary level	0	0	0	109	50	159	29	7	36	138	57	195
Special School	40	1	41	2463	159	2622	1883	108	1991	4386	268	4654
Generic vocational training	0	2	2	10	83	93	0	26	26	10	111	121
Special vocational training	6	45	51	45	901	946	28	841	869	79	1787	1866
Activation Centre	1	42	43	4	459	463	61	4020	4081	66	4521	4587
Programme for the Elderly	0	6	6	0	68	68	0	212	212	0	286	286
Special high support day service	4	3	7	8	33	41	32	352	384	44	388	432
Special intensive day service	3	0	3	8	7	15	17	118	135	28	125	153
Sheltered work centre	1	34	35	10	1810	1820	15	2728	2743	26	4572	4598
Sheltered employment centre	0	1	1	3	103	106	1	26	27	4	130	134
Multidisciplinary support service	4	0	4	3	42	45	6	17	23	13	59	72
Centre-based day respite service	0	0	0	0	0	0	0	1	1	0	1	1
Other day service	41	37	78	68	276	344	61	443	504	170	756	926
Enclave within open employment	0	0	0	1	12	13	0	43	43	1	55	56
Support employment	0	7	7	4	393	397	4	216	220	8	616	624
Open employment	0	0	0	3	159	162	1	23	24	4	182	186
Generic Day Services	0	0	0	0	41	41	0	39	39	0	80	80
Home Help	2	0	2	0	7	7	2	6	8	4	13	17
Total	725	190	915	4407	4757	9164	3469	9516	12985	8601	14463	23064

OVERALL LEVEL OF CURRENT SERVICE PROVISION

The National Intellectual Disability Database permits the recording of two different types (main and secondary) of residential service and day service for each person on the database. The analyses of current service provision in Tables 3.8 and 3.9 are a combination of the main and secondary services under the day and residential programmes and are representative of the overall level of current service provision. The numbers presented in both of these tables, therefore, exceed the actual number of people with an intellectual disability in each of the service categories, as a number of people avail of two different types of service.

Table 3.8 details the overall number of residential services currently provided to this population. Of note in this table is the availability of a broad range of residential support services which assist people with an intellectual disability to continue living with their families or in their communities. Provision of such services has increased by 70% since 1996, with particularly significant increases in the number of people availing of planned or emergency respite care (up 135%), respite breaks with host families (up 88%) and regular part-time care (up 19%), as illustrated in Figure 4.

Table 3.9 gives the overall number of day services currently provided to people with intellectual disability. This table clearly demonstrates the wide availability of a variety of day services in 1999. Over the three years since 1996, there has been an increase in the number of people availing of mainstream education, employment, and early intervention services, as illustrated in Figure 5. There has been a 570% increase in the number of children recorded as having access to resource teachers, reflecting the Department of Education and Science's enhancement of supports available to children with special needs in 1998. There are now 61% more children attending mainstream pre-schools and the need for special classes at secondary level is increasing. There has been a 39% increase in such classes since 1996. In the area of employment, there has been a 278% increase in the number attending sheltered employment centres and there are growing numbers working in the community with a 134% increase observed in the number in supported employment and a 44% increase in those in open employment. This reflects the increased emphasis on the procurement of training and work experiences within the general employment field. There has also been a 227% increase in the number of children

receiving early intervention services, a priority area for development for the Department of Health and Children in recent years. These services take the form of parent support and guidance in meeting the baby's need for care and stimulation in ordinary parent-child interaction. There has been an increase of 16% in the number of high-support and intensive placements available. These specialist interventions are required, either on an ongoing or intermittent basis, by a number of people with intellectual disability who present with disturbed behaviour or have mental health needs.

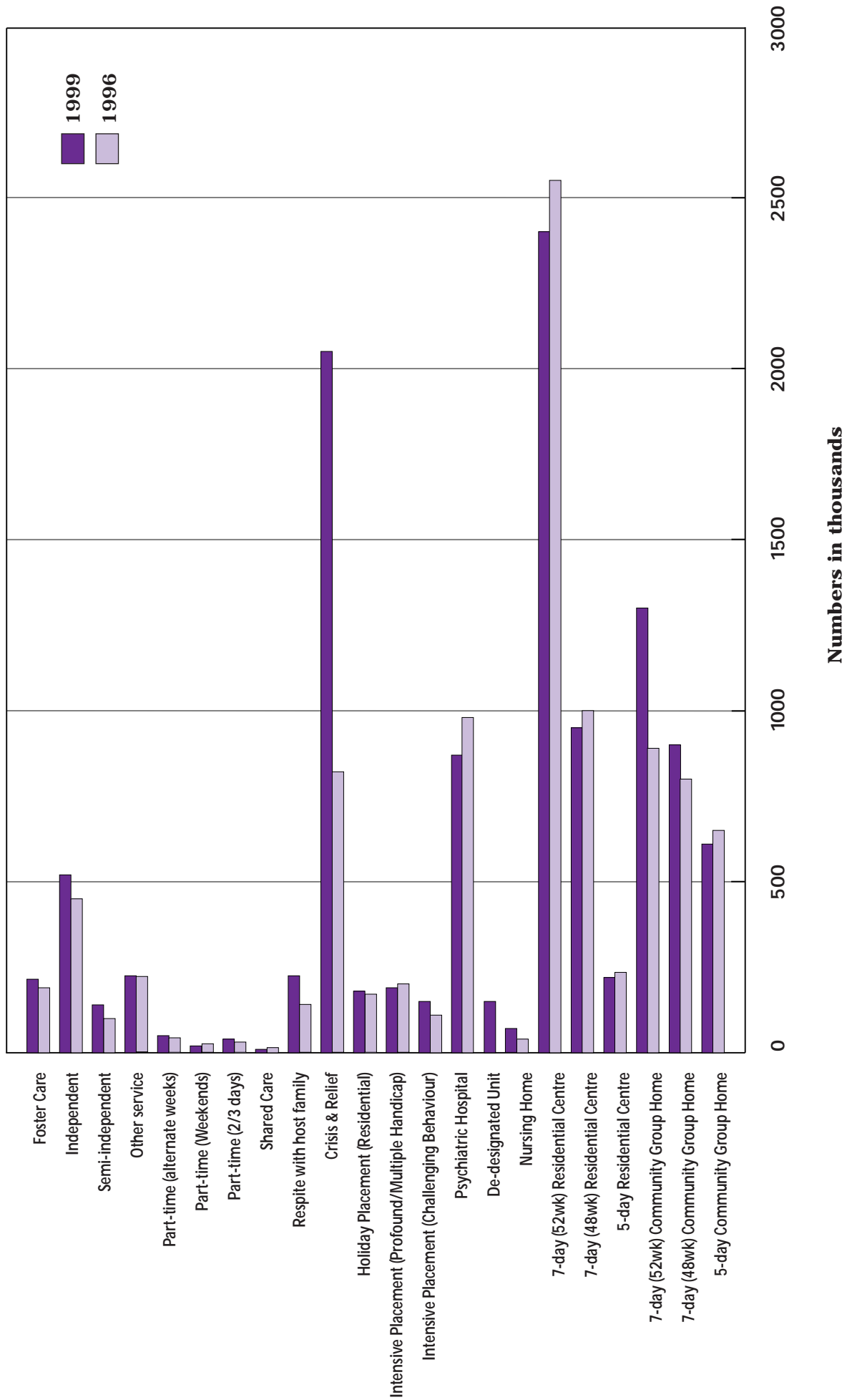
Over the past three years, a decreasing number of places has been observed in special classes, special schools, and child education and development centres. These decreases reflect the overall declining demand for such services which is attributed to the decrease in the number of children with intellectual disability over the past twenty years and the increased tendency for children to access mainstream education.

While the overall trend in service provision is predominantly in a positive direction, there also appears to have been a 19% fall in the number of home support services available. These services are designed to assist families in continuing to care for their family members at home. Any apparent reduction in such services gives cause for concern and the situation will be monitored closely.

**TABLE 3.8 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
OVERALL LEVEL OF CURRENT RESIDENTIAL SERVICE PROVISION, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

	Not Verified			Mild			Mod-Sev-Prof			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	4	5	47	116	163	35	400	435	83	520	603
7 day (48 week) community group home	0	2	2	7	193	200	21	694	715	28	889	917
7 day (52 week) community group home	0	3	3	9	362	371	41	900	941	50	1265	1315
5 day residential centre	2	0	2	5	25	30	48	124	172	55	149	204
7 day (48 week) residential centre	2	5	7	2	111	113	109	715	824	113	831	944
7 day (52 week) residential centre	5	13	18	16	173	189	67	2117	2184	88	2303	2391
Nursing Home	0	2	2	0	28	28	0	36	36	0	66	66
De-designated Unit	0	1	1	0	12	12	0	138	138	0	151	151
Psychiatric Hospital	0	11	11	0	215	215	0	628	628	0	854	854
Intensive Placement (Challenging Behaviour)	1	0	1	5	18	23	20	104	124	26	122	148
Intensive Placement (Profound or Multiple Handicap)	0	0	0	1	14	15	24	178	202	25	192	217
Holiday residential placement	0	1	1	8	32	40	39	121	160	47	154	201
Crisis and Relief Centre	26	6	32	51	209	260	689	1062	1751	766	1277	2043
Occasional respite with host family	2	0	2	22	11	33	138	87	225	162	98	260
Shared care or guardianship	0	0	0	2	1	3	5	4	9	7	5	12
Regular part-time care (2/3 days per week)	0	0	0	2	3	5	12	19	31	14	22	36
Regular part-time care (every weekend)	0	0	0	1	6	7	5	9	14	6	15	21
Regular part-time care (alternate weeks)	0	0	0	1	6	7	13	35	48	14	41	55
Other residential service	2	0	2	64	58	122	52	90	142	118	148	266
Lives semi-independently	0	8	8	0	99	99	0	43	43	0	150	150
Lives independently	1	22	23	0	431	431	0	73	73	1	526	527

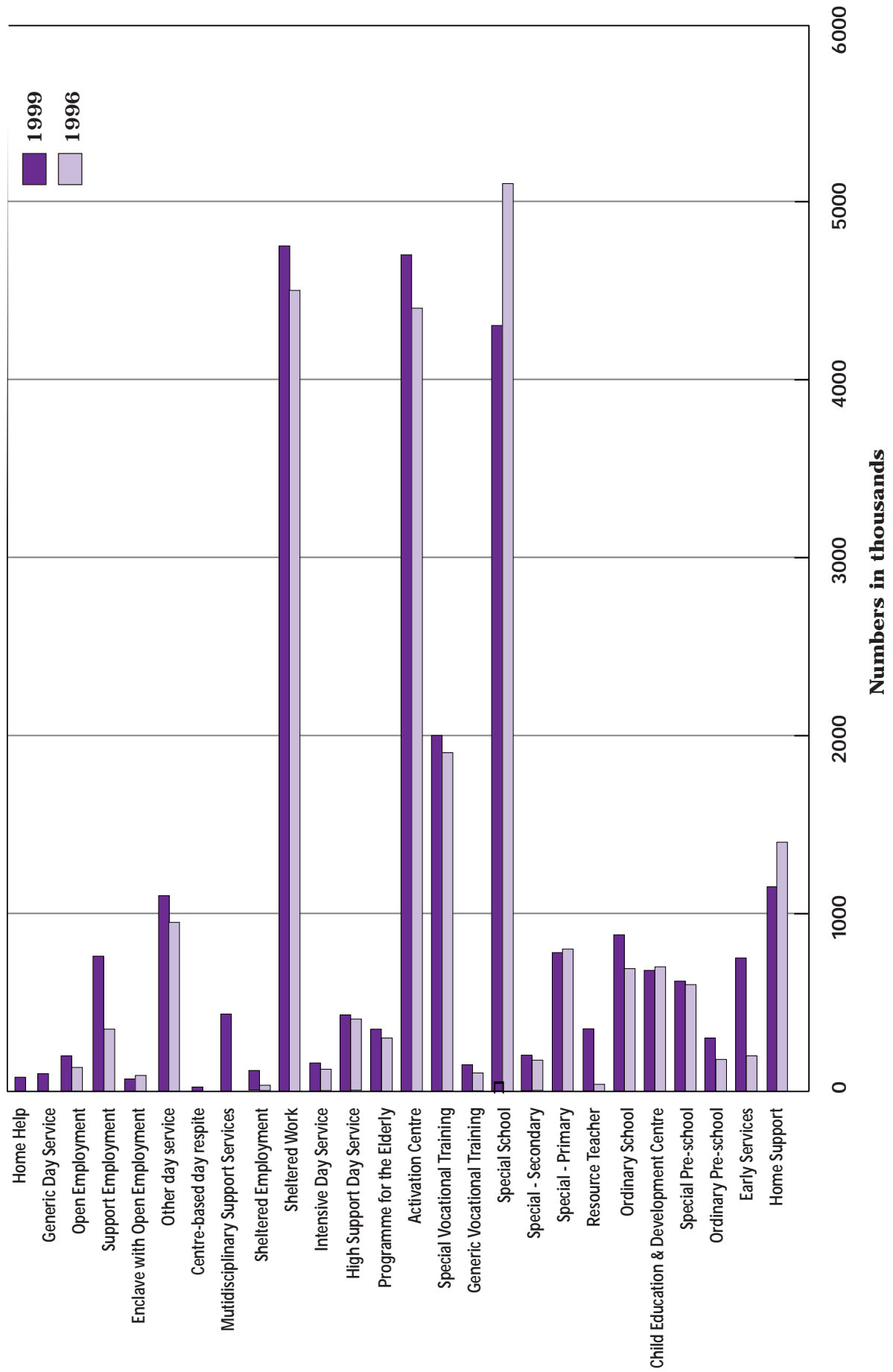
FIGURE 4.
NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
CHANGES IN LEVEL OF OVERALL CURRENT RESIDENTIAL SERVICE PROVISION 1996-1999.



**TABLE 3.9 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
OVERALL LEVEL OF CURRENT DAY SERVICE PROVISION, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

	Not Verified			Mild			Mod-Sev-Prof			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	56	14	70	150	176	326	326	391	717	532	581	1113
Early Services	362	0	362	155	1	156	212	2	214	729	3	732
Ordinary Pre-school	70	0	70	108	0	108	88	1	89	266	1	267
Special Pre-school	130	0	130	146	0	146	292	8	300	568	8	576
Child Education and Development Centre	37	0	37	6	2	8	541	90	631	584	92	676
Ordinary School	42	0	42	643	28	671	133	3	136	818	31	849
Resource Teacher	71	0	71	153	25	178	35	11	46	259	36	295
Special Class - Primary	12	0	12	569	34	603	176	11	187	757	45	802
Special Class - Secondary	0	0	0	109	51	160	29	7	36	138	58	196
Special School	42	1	43	2464	159	2623	1945	110	2055	4451	270	4721
Generic Vocational Training	0	2	2	12	86	98	0	32	32	12	120	132
Special Vocational Training	9	46	55	83	930	1013	46	867	913	138	1843	1981
Activation Centre	1	43	44	4	484	488	66	4065	4131	71	4592	4663
Programme for the Elderly	0	6	6	0	71	71	0	225	225	0	302	302
High Support Day Service	4	3	7	8	33	41	33	354	387	45	390	435
Intensive Day Service	3	0	3	8	7	15	20	124	144	31	131	162
Sheltered Work	1	34	35	11	1847	1858	15	2790	2805	27	4671	4698
Sheltered Employment	0	1	1	3	105	108	1	26	27	4	132	136
Multidisciplinary support service	21	0	21	207	88	295	85	44	129	313	132	445
Centre-based day respite service	0	0	0	0	3	3	7	21	28	7	24	31
Other Day Service	62	42	104	102	297	399	104	473	577	268	812	1080
Enclave within open employment	0	0	0	1	13	14	0	45	45	1	58	59
Supported Employment	0	7	7	4	452	456	4	304	308	8	763	771
Open Employment	0	0	0	3	163	166	1	25	26	4	188	192
Generic Day Services	1	0	1	0	42	42	0	41	41	1	83	84
Home Help	11	2	13	1	14	15	13	9	22	25	25	50

**FIGURE 5.
NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
CHANGES IN LEVEL OF OVERALL CURRENT DAY SERVICE PROVISION 1996-1999.**



HEALTH BOARD LEVEL

Table 3.10 provides details of the current level of service provision within each health board region. Nationally, 88.7% of the population of people with an intellectual disability are known to be in receipt of services at present, 2.0% are currently without any service whatsoever but are waitlisted for services in the five-year period 2000-2004 and 9.2% are without services at present and are not expected to require services within the next five years. Regionally, the highest level of service provision is in the South-Eastern Health Board where 99.3% of the population are currently receiving services. The Midland Health Board has the highest proportion of people who are currently without any service whatsoever and are awaiting services within the next five years (8.6%). Some health boards have considerable numbers of people registered on the database who are not currently availing of services and are not identified as requiring a service within the next five years. Ongoing review of such individuals is recommended in order to establish both their possible need for services and the appropriateness of their registration on the National Intellectual Disability Database

**TABLE 3.10 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
CURRENT SERVICE PROVISION BY HEALTH BOARD AREA.**

	Receiving day services	Receiving 5 or 7 day residential services	Residents in Psychiatric Hospitals	Receiving residential support services only	Receiving no service	No current service requirements	Total
	n %	n %	n %	n %	n %	n %	n %
Eastern	4589 52.8	2291 26.3	325 3.7	35 0.4	67 0.8	1392 16.0	8699 100.0
Midland	1115 59.3	454 24.2	25 1.3	31 1.6	162 8.6	92 4.9	1879 100.0
Mid-Western	1558 60.3	624 24.1	105 4.1	25 1.0	88 3.4	185 7.2	2585 100.0
North-Eastern	1378 64.2	449 20.9	24 1.1	27 1.3	79 3.7	188 8.8	2145 100.0
North-Western	835 51.4	585 36.0	1 0.1	19 1.2	63 3.9	122 7.5	1625 100.0
South-Eastern	2205 70.2	757 24.1	156 5.0	1 0.0	20 0.6	2 0.1	3141 100.0
Southern	2555 66.3	993 25.8	120 3.1	36 0.9	21 0.5	129 3.3	3854 100.0
Western	1806 56.1	803 24.9	98 3.0	70 2.2	52 1.6	392 12.2	3221 100.0
Total	16041 59.1	6956 25.6	854 3.1	244 0.9	552 2.0	2502 9.2	27149 100.0

CHAPTER 4

ASSESSMENT OF NEED 2000-2004

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

Unmet Need: describes people who are without any service whatsoever, or without a major element of service, and require a new service in the period 2000-2004.

Service Change: describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2000-2004 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.

UNMET NEED

MAJOR ELEMENT OF SERVICE

The data indicate that 2,493 people will require a major element of service, either a full-time residential service or a day service, in the five-year period 2000-2004. Of this group, 540 have no service and require full-time residential and/or day services; 1,564 receive a day service but require a residential service, 319 people receive a residential service but also require a day service and 70 people currently 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.

**TABLE 4.1 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
NUMBER OF PEOPLE REQUIRING A MAJOR ELEMENT OF SERVICE 2000-2004.**

	No current service	Receives minimal residential support only	Receives day only - requires residential	Receives residential only - requires day	Total
Not Verified	26	5	30	1	62
Mild	334	34	348	19	735
Mod-Sev-Prof	180	31	1186	299	1696
All levels	540^a	70^b	1564	319	2493

^a Of the 540, 75 require residential and day, 12 require residential only and 453 require day only.

^b Of the 70, 21 require residential and day, 5 require residential only and 44 require day only.

RESIDENTIAL SUPPORT SERVICES

The data indicate that 918 people are in need of residential support services only in the period 2000-2004. Table 4.2 provides a breakdown of this group by level of disability.

**TABLE 4.2 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
NUMBER OF PEOPLE REQUIRING RESIDENTIAL SUPPORT SERVICES ONLY 2000-2004.**

	No current service	Receives day only -requires residential support	Receives residential & day -requires residential support	Receives residential only - requires residential support	Total
Not Verified	0	24	0	0	24
Mild	2	315	43	1	361
Mod-Sev-Prof	10	469	54	0	533
All levels	12	808	97	1	918

NUMBER OF PLACES REQUIRED TO MEET NEED

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

Residential	1677
Day	912
Residential Support	948^a
<p>^a 29 of the group who have no current service and require a major element of service (i.e. day), will also need a residential support service. 1 of the group who currently has a day service and requires a residential service will also need a residential support service.</p> <p>Note: Approximately one-quarter of the residential support services are home-based services or independent living situations which are provided at considerably reduced costs.</p>	

YEAR IN WHICH SERVICE NEEDS ARISE

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

	2000	2001	2002	2003	2004	All years
Residential	1320	106	105	103	43	1677
Day	877	21	3	11	0	912
Residential Support	868	19	19	33	9	948

Details of the type of residential, day, and residential support services required by this group of people are set out in Tables 4.5 - 4.7.

The group that requires full-time residential services consists mainly of people in the moderate, severe and profound ranges of intellectual disability (75%) who require residential placements in community group homes. Much smaller proportions of the group in the more severe range of intellectual disability require residential accommodation on a campus setting (16%) and 11% need specialised high support or intensive placements because of their increased dependency (Table 4.5).

Demand for day services emanates almost exclusively from the adult population. There is a very small demand for children's services, suggesting that the level of service provision to children is satisfactory. The largest demand for day services comes from people who have no service whatsoever at the moment. Most of this group (63%) have a mild intellectual disability and their principal service requirements are in the training and employment fields. The other large group with day service needs are people who are in full-time residential services but do not have access to formal day programmes. Most of this group (94%) have a moderate, severe or profound intellectual disability and their needs are almost exclusively for the care-focused services, such as activation programmes, high-support and intensive placements, and programmes specifically designed for older people.

Residential support services are required mainly by people who live at home and attend services on a daily basis. The largest demand is for centre- and home-based respite services, (71% - 669 people). Two-thirds of the group requiring these services have a moderate, severe or profound intellectual disability. A further 18% of the demand is for independent and semi-independent living placements. It should be noted that not all of the need in this area requires the provision of residential places. Some of the demand is for access to 'host family' and 'share-a-break' schemes and to independent living situations.

Apart from existing waiting lists, emergency demand for residential places will arise among those currently living at home where family circumstances change suddenly, perhaps due to the death of a carer. This type of need, is by its very nature, unpredictable and is included on the database under the category 'contingency'. There are 3,187 people on the database who are not on the current waiting list for full-time residential services but are identified as being 'at risk' of requiring a full-time service should their circumstances change. The HRB proposes to conduct an evaluation of the 1999 and 2000 data to ascertain the proportion of contingency requirements that present for full-time residential services within a twelve-month period, thus allowing the cost of providing these services to be factored into annual budgets.

**TABLE 4.5 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
FUTURE FULL-TIME RESIDENTIAL SERVICE REQUIREMENTS OF INDIVIDUALS CURRENTLY RECEIVING NO RESIDENTIAL SERVICE.**

	No current 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				
5-day community group home	0	2	5	7	0	0	0	0	4	89	197	290	297
7-day (48-week) community group home	1	8	3	12	1	2	1	4	12	78	228	318	334
7-day (52-week) community group home	1	18	23	42	0	3	10	13	6	139	434	579	634
5-day residential centre	0	0	1	1	0	0	0	0	0	4	21	25	26
7-day (48-week) residential centre	0	0	4	4	0	1	2	3	1	8	48	57	64
7-day (52-week) residential centre	0	2	4	6	0	1	2	3	3	9	120	132	141
Nursing Home	0	1	5	6	0	0	1	1	1	2	1	4	11
Intensive placement (Challenging Behaviour)	1	1	4	6	0	0	1	1	3	14	68	85	92
Intensive placement (Profound or Multiple handicap)	0	0	3	3	0	0	1	1	0	5	69	74	78
All Services	3	32	52	87	1	7	18	26	30	348	1186	1564	1677

**TABLE 4.6 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
FUTURE DAY SERVICE REQUIREMENTS OF INDIVIDUALS CURRENTLY RECEIVING NO DAY SERVICE.**

	No current 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	
Home support	0	5	7	12	1	0	0	1	0	0	0	0	13
Early Services	3	0	0	3	0	0	0	0	0	0	0	0	3
Ordinary pre-school	3	2	0	5	0	0	0	0	0	0	0	0	5
Special pre-school	3	5	4	12	0	0	0	0	0	0	0	0	12
Child Education and Development Centre	1	0	3	4	0	0	1	1	0	0	0	0	5
Ordinary school	0	1	1	2	0	0	0	0	0	0	0	0	2
Resource Teacher	0	0	3	3	0	0	0	0	0	0	0	0	3
Special class - primary	1	1	0	2	0	0	0	0	0	0	0	0	2
Special class - secondary	0	1	0	1	0	0	0	0	0	0	0	0	1
Special School	2	4	1	7	0	0	1	1	0	0	0	0	8
Generic vocational training	0	10	1	11	0	1	0	1	0	1	0	1	13
Special vocational training	3	90	11	104	0	8	1	9	0	1	0	1	114
Activation Centre	2	28	65	95	0	4	10	14	1	3	107	111	220
Programme for the Elderly	1	7	18	26	0	8	2	10	0	10	83	93	129
Special high support day service	0	5	8	13	0	0	4	4	0	0	54	54	71
Special intensive day service	1	1	5	7	0	0	0	0	0	1	53	54	61
Sheltered work centre	0	50	28	78	2	3	4	9	0	0	2	2	89
Sheltered employment centre	1	9	6	16	1	3	0	4	0	1	0	1	21
Other day service	1	0	2	3	0	2	1	3	0	0	0	0	6
Enclave within open employment	0	4	0	4	0	0	0	0	0	0	0	0	4
Supported employment	3	86	5	94	0	3	1	4	0	1	0	1	99
Open employment	1	20	0	21	0	0	1	1	0	1	0	1	23
Generic Day Services	0	2	1	3	0	1	0	1	0	0	0	0	4
Home Help	0	0	2	2	0	1	1	2	0	0	0	0	4
All Services	26	331	171	528	4	34	27	65	1	19	299	319	912

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 2000-2004, and includes children currently in educational services who will require access to health-funded services in the period. Changes in current service provision relate to

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

The database indicates that 9,526 people who currently receive services will require a change in their current service provision in the period 2000-2004. Of this group 6,125 are day attenders (of whom 1,105 also avail of residential support services), 3,396 are full-time residents (of whom 3,381 also avail of day services and 111 avail of residential support services) and 5 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.

	Residential and day	Residential only	Day only	Day and residential support	Residential support only	All Service Changes
Not Verified	4	4	466	3	4	481
Mild	144	96	3403	31	33	3707
Mod-Sev-Prof	1116	547	3463	126	86	5338
All levels	1264	647	7332	160	123	9526

There are 1,615 people included in the data presented in the section on Unmet Need who are currently receiving one element of service, either day or residential, and require the second element. This entire group requires their existing element of service to be changed. However, to avoid double counting of individuals, their needs in relation to

service changes are not included in this section of the report. It is envisaged that when funding is made available for their unmet elements sufficient flexibility will be incorporated within this to allow their required service change to be implemented.

NUMBER OF PLACES REQUIRED TO ADDRESS SERVICE CHANGES

The number of places involved is summarised in Table 4.9. The number of places required exceeds the number of people requiring service changes as some people require to change both their residential and day services.

<i>Residential</i>	<i>1911</i>
<i>Day</i>	<i>8756</i>
Of which:	
Health Services	6069
Education Services	1531
Employment Services	1147
Other Generic Services	9
<i>Residential Support</i>	<i>283</i>

YEAR IN WHICH SERVICE CHANGES ARISE

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

	<i>2000</i>	<i>2001</i>	<i>2002</i>	<i>2003</i>	<i>2004</i>	<i>All years</i>
<i>Residential</i>	<i>1677</i>	<i>98</i>	<i>34</i>	<i>53</i>	<i>49</i>	<i>1911</i>
<i>Day</i>	<i>6700</i>	<i>915</i>	<i>506</i>	<i>486</i>	<i>149</i>	<i>8756</i>
Of which:						
Health Services	4594	636	343	384	112	6069
Education Services	1255	128	85	42	21	1531
Employment Services	846	149	78	58	16	1147
Other Generic Services	5	2	0	2	0	9
<i>Residential Support Service</i>	<i>266</i>	<i>7</i>	<i>6</i>	<i>2</i>	<i>2</i>	<i>283</i>

It is important to note that although 9,526 people require service changes, this does not translate into 9,526 new places. In most instances, these individuals will be vacating their existing placement when they receive their change of service. This will free up places for people on the 'service change' and the 'unmet need' waiting lists. 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 some level of funding is already committed to these individuals.

RESIDENTIAL SERVICE CHANGE

The database indicates that 1,911 individuals, currently in full-time residential services, will require an upgrading or change of accommodation within the next five years. A breakdown of these requirements is given in Table 4.11. For most of this group (1,514 people) a change of service is required. The largest group (832 people) need to transfer to or require alternative residential placements in the community, 504 individuals require intensive services for either challenging behaviour or profound or multiple handicap, 164 need to move into, or receive, alternative centre-based residential placements, 12 people need placements in nursing homes and 2 people are identified as needing admission to a psychiatric hospital. As can be seen, from the table, many of the changes involve moving from residential centres and de-designated units to community-based residences, or from 5-day services to 7-day services.

Furthermore, there is a group of 397 individuals who need an enhancement of their existing service. Most of these need increased supervision, and smaller proportions need to move to a different location or need to be upgraded from children's to adults' services. Some of the needs associated with the enhancement of existing services will be met through the funding which is made available to meet identified needs in existing services.

**TABLE 4.11 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
PATTERN OF MOVEMENT OF INDIVIDUALS FROM CURRENT RESIDENTIAL SERVICE TO FUTURE RESIDENTIAL SERVICE 2000-2004.**

Full-time residential service required in the period 2000-2004.											
	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	Int. placement (CB)	Int. placement (P/MH)	Total Current Services
Current full-time residential service:											
5-day Community Group Home	20	79	77	3	2	3	0	0	4	1	189
7-day (48-week) Community Group Home	0	34	78	0	3	3	3	0	3	2	126
7-day (52-week) Community Group Home	5	6	102	0	1	10	6	1	30	29	190
5-day Residential Centre	29	15	10	7	38	9	0	1	17	4	130
7-day (48-week) Residential Centre	9	118	58	1	77	47	1	0	36	15	362
7-day (52-week) Residential Centre	0	35	249	0	8	177	2	0	121	128	660
Nursing Home	0	0	7	0	0	0	1	0	0	1	9
De-designated Unit	0	1	39	0	0	21	0	0	35	12	108
Intensive placement (Challenging Behaviour)	0	4	5	0	0	0	0	0	21	1	31
Intensive placement (Profound/Multiple Handicap)	0	2	6	0	0	15	0	0	65	18	106
Total Services Required	63	294	631	11	129	225	13	2	332	211	1911

Within the next five years, 8,756 individuals will require a change, enhancement, or upgrading of their day service. Health-funded services are required in 69% of the changes, 18% involve educational services, and 13% involve employment services. A detailed breakdown of these services is provided in Table 4.12.

Health-funded services

CHILDREN'S SERVICES

Of the 6,069 service changes required within the health-funded services, those in respect of just 8% (476 individuals) are within the children's services.

Most of the changes required within the children's services are in the area of pre-school services (359 individuals) and most of the demand comes from children who are already receiving home support services and early services.

Changes or upgrades into Child Education and Development Centres (CEDC) are required by 111 children who are currently in early service, special pre-schools, special schools or in existing CEDC services.

Six children require early services.

ADULT SERVICES

There are 5,593 adults, currently receiving services funded from the health budget, who will require an upgrading or change of service within the next five years. Demand is focused on three main areas - sheltered work/employment, activation, and vocational training.

There are 1,560 individuals who need to move into sheltered work or sheltered employment settings, or to have their current services within these settings enhanced. Currently the majority of this group are in special schools (456), special vocational training (400), and activation centres (187). The remaining 380 people are in existing sheltered work placements, of whom 90 would be more appropriately placed in sheltered

employment and the remaining 290 need to have their existing sheltered work placement enhanced.

There are 1,370 individuals who need to move into activation programmes, or upgrading of such programmes. This group is mostly found in sheltered work centres (237), special schools (174), CEDCs (127), and special vocational training (89). 585 people need their existing activation programme enhanced, 83% of whom need increased supervision.

Transfers to vocational training programmes will be required by 1,231 people. Of this group, 1,059 require special vocational training and 172 require generic vocational training. The majority of this group is currently in special schools (975), special classes (43), mainstream classes (41), and sheltered work centres (42).

High-support or intensive services, will be required by 725 individuals. In the main, 355 of this group are currently in activation centres, 70 are in special schools, and 40 are in sheltered work centres. 161 are in existing high-support or intensive placements that need to be enhanced, of whom 149 are currently in high support placements but require a higher level of supervision within intensive placements.

The needs of older people with intellectual disability are reflected in the requirement for 514 specialised programmes for this group. At present 249 of this group are in activation programmes and 139 are in sheltered work centres.

EDUCATIONAL SERVICES

Alternative or enhanced educational services will be required by 1,531 children in the period 2000-2004. 148 children need to be placed in mainstream classes and they are currently receiving a mix of services including mainstream (50 children) and specialised (28 children) pre-school services, early services (23 children) and support from resource teachers (20 children).

The services of a resource teacher will be required by 206 children during the period. At the moment these children are mainly attending mainstream classes (117 children) and mainstream (14 children) and specialised (14 children) pre-schools.

Special classes at primary level are needed for 197 children. At present, this group is primarily availing of mainstream (18 children) and specialised (71 children) pre-school services, mainstream classes (18 children) and early services (14 children).

Special classes within second level schools are required for 536 children, who are mainly attending special classes at primary level (363 children), mainstream classes (124 children) or accessing a resource teacher (35 children) at present.

Places in special schools are required by 444 children. In the main, this group are in special pre-schools (183 children), in CEDCs (47), have access to a resource teacher (38), in mainstream pre-schools (37), in mainstream classes (32), receive early services (25) or attend special classes at primary level (23). Of this group, 43 children are currently in special schools but need their level of service to be upgraded and most of these children need increased supervision.

EMPLOYMENT SERVICES

These are 1,147 individuals who need to transfer to employment services during the period 2000-2004.

Supported employment placements are required for 864 individuals. At present, most of this group avail of special vocational training (310 individuals), sheltered work (306 individuals), attend special schools (101), are in activation programmes (58), or are in sheltered employment (38).

There are 225 people who require open employment. Currently, this group is mainly in special vocational training (126 people), sheltered work (31 people), special schools (28 people), and supported employment (15 people).

An additional 58 people would be more appropriately placed in an enclave within open employment. At the moment, most of this group attends special schools (21 people), sheltered work (12 people), special classes at secondary level (8 people), or special vocational training (9 people).

The pattern of movement in day services is not as clear-cut as the pattern of movement in residential services. People in full-time residential services who require alternative full-time placements will vacate their existing service when their new place becomes available. On the day service side, certain existing services, for example, early intervention services and home support services, will not necessarily be freed up when the new service is provided as these are on-going services that are generally required in addition to receiving other day services. Similarly, certain of the required services will not replace existing services, but rather will enhance the range of services being provided to that person.

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

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

The services involved include:

- Home Support Services
- Early Services
- Resource Teacher
- Home Help
- Multi-disciplinary support services for school-age children and adults
- Centre-based day respite service.

Table 4.12 maps the pattern of movement of individuals from their current day service to their future day services. The main day service is used as the current service indicator.

RESIDENTIAL SUPPORT SERVICE CHANGE

The database indicates that 283 individuals, currently receiving residential support services, will require an additional or alternative support service, or will require their existing support service to be upgraded during the period 2000-2004. An analysis of these enhancements is outlined in Table 4.13. The principal needs of this group include:

**TABLE 4.12 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
PATTERN OF MOVEMENT OF INDIVIDUALS FROM CURRENT DAY SERVICE TO FUTURE DAY SERVICE 2000-2004.**

	Day service required in the period 2000-2004																										
	HS	ES	OPS	SPS	CEDC	OS	RT	SCP	SCS	SS	GVT	SVT	AC	PE	SHS	SI	SWC	SEC	MS/OTH	E	SE	OE	GD	HH	DR	ALL	
Current Day Service:																											
Home support (HS)	11	0	20	33	3	7	0	3	0	6	0	4	19	6	1	3	19	0	0	0	0	2	0	0	0	0	137
Early Services (ES)	4	2	98	125	13	23	9	14	0	25	0	1	0	1	0	1	0	0	0	0	0	0	0	0	0	0	316
Ordinary pre-school (OPS)	0	0	4	6	1	50	14	18	0	37	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	130
Special pre-school (SPS)	13	3	10	25	48	28	14	71	0	183	0	1	2	0	0	1	0	0	0	0	0	0	0	0	0	0	399
Child Education and Development Centre (CEDC)	5	0	0	1	22	1	0	3	0	47	0	4	127	0	15	12	1	1	0	0	0	0	0	0	0	0	239
Ordinary school (OS)	11	0	0	1	0	11	117	70	124	32	17	24	2	0	0	0	3	3	1	2	2	7	0	0	0	0	427
Resource Teacher (RT)	7	0	8	0	1	20	35	7	35	38	2	4	0	0	0	0	0	0	2	1	0	2	0	0	0	0	162
Special class - primary (SCP)	3	0	0	0	2	3	8	7	363	23	11	21	7	0	1	3	17	1	5	6	0	1	1	0	0	0	483
Special class - secondary (SCS)	0	0	0	0	0	0	4	0	4	1	17	36	4	0	3	0	19	4	0	4	8	6	0	0	0	0	110
Special School (SS)	53	0	0	0	13	3	1	3	10	43	99	876	174	0	30	40	409	47	0	10	21	101	28	0	0	0	1961
Generic Vocational training (GVT)	0	0	0	0	0	0	0	0	0	0	2	5	2	0	0	0	6	9	0	0	2	14	6	0	0	0	46
Special Vocational training (SVT)	1	0	0	0	0	0	0	0	0	0	11	10	89	13	9	5	365	35	0	5	9	310	126	1	1	0	990
Activation Centre (AC)	7	0	0	1	0	0	2	0	0	0	3	16	585	249	116	239	168	19	0	3	0	58	11	4	0	3	1484
Programme for the Elderly (PE)	0	0	0	0	0	0	0	0	0	0	0	1	8	54	0	1	2	0	0	1	0	0	1	0	0	0	68
Special High Support Service (SHS)	0	0	0	0	1	0	1	0	0	5	0	0	20	5	12	149	1	0	0	0	0	0	0	0	0	0	194
Special Intensive Service (SI)	0	0	0	0	0	0	0	0	0	0	0	1	11	1	5	20	1	0	0	0	0	0	0	0	0	0	39
Sheltered Work Centre (SWC)	6	0	0	0	0	0	1	0	0	0	7	35	237	139	26	14	290	90	0	5	12	306	31	1	1	1	1202
Sheltered Employment Centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	3	2	0	0	0	1	0	0	0	0	38	1	0	0	0	45
Multi-disciplinary Supports (MS)	0	1	0	0	0	1	0	0	0	3	0	3	4	0	0	2	2	0	2	0	0	2	0	0	0	0	20
Other day service (OTH)	4	0	1	25	5	1	0	1	0	1	1	9	54	25	3	12	30	3	0	1	2	9	4	1	0	0	192
Enclave within open employment (E)	0	0	0	0	0	0	0	0	0	0	0	0	3	12	0	0	4	0	0	0	2	0	1	0	0	0	22
Supported employment (SE)	0	0	0	0	0	0	0	0	0	0	1	2	0	6	0	1	2	1	1	10	0	7	15	0	0	0	46
Open employment (OE)	0	0	0	0	0	0	0	0	0	0	0	2	2	1	0	0	5	1	0	2	0	1	1	0	0	0	15
Generic Day Service (GD)	0	0	0	0	0	0	0	0	0	0	0	1	16	1	0	0	0	0	0	0	0	0	0	0	1	0	19
Home Help (HH)	0	0	0	1	2	0	0	0	0	0	1	0	2	1	1	0	1	0	0	0	0	0	0	1	0	0	10
All Services	125	6	141	218	111	148	206	197	536	444	172	1059	1370	514	222	503	1346	214	11	50	58	864	225	9	3	4	8756

The abbreviations in the third row of the table refer to the programme descriptions outlined in column one. The abbreviation 'DR' refers to Centre-based day respite services.

**TABLE 4.13 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
RESIDENTIAL SUPPORT SERVICES REQUIRED BY PEOPLE CURRENTLY AVAILING OF RESIDENTIAL SUPPORT SERVICES.**

Current residential Support service	Residential Support Service required 2000-2004.											Total	
	Foster Care	Living Independently	Living semi-Independently	Holiday residential placement	Crisis & Relief Centre	Occasional respite care (Host family)	Shared care /guardianship	Regular part-time care (2/3 days per week)	Regular part-time care (every weekend)	Regular part-time care (alternate weeks)	Other residential service		
Foster Care	1	0	5	1	5	3	0	0	0	0	0	0	15
Living independently	0	2	12	1	7	0	1	0	0	0	0	0	25
Living Semi-independently	0	1	5	1	0	0	0	1	0	0	0	0	8
Holiday residential placement	0	0	0	2	4	10	0	0	0	0	0	0	16
Crisis & Relief Centre	1	0	3	4	101	19	1	9	4	11	2	2	155
Occasional respite care (host family)	0	0	0	8	21	7	0	3	1	4	1	1	45
Shared care /guardianship	0	0	0	0	1	0	0	0	0	0	0	0	1
Regular part-time care (2/3 days per week)	0	0	0	0	5	0	0	3	0	0	0	0	8
Regular part-time care (alternate weeks)	0	0	0	0	0	0	0	0	1	1	0	0	2
Other residential service	1	0	3	0	3	0	0	0	0	0	1	1	8
All Services	3	3	28	17	147	39	2	16	6	16	6	16	283

- more regular part-time care arrangements for people currently accessing crisis and relief services and respite breaks with host families
- more frequent centre-based respite breaks for people currently availing of this service
- more family-based respite breaks for people currently accessing centre-based respite
- increased supervision, in the form of semi-independent living placements, for people currently living independently.

As with certain types of day services, it is important to note that existing residential support services may be retained by the individual when the 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

There are 854 individuals, all aged 19 years and over, currently accommodated in psychiatric hospitals. Table 4.14 details the overall service requirements of this group by level of intellectual disability.

**TABLE 4.14 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
OVERALL SERVICE REQUIREMENTS OF PEOPLE WITH INTELLECTUAL DISABILITY CURRENTLY
RESIDENT IN PSYCHIATRIC HOSPITALS.**

	No Service requirements				Has service requirements				Total
	Not Verified	Mild	Mod-Sev-Prof	All Levels	Not Verified	Mild	Mod-Sev-Prof	All Levels	
Resident in Psychiatric Hospital - no day programme	0	22	64	86	4	52	216	272	358
Resident in Psychiatric Hospital - with day programme	0	61	159	220	7	79	189	275	495
Resident in Psychiatric Hospital - with day programme and Residential Support	0	1	0	1	0	0	0	0	1
All residents	0	84	223	307	11	131	405	547	854

For 307 individuals, their current day and residential programmes within the psychiatric services are deemed to be appropriate and they have no identified service needs in the period 2000-2004. 27% of this group have a mild intellectual disability and 73% have a moderate, severe or profound disability. However, within this group are 86 people who currently have no formal day programme (26% mild disability, 74% moderate, severe or profound disability). This level of service planning is not considered acceptable and review procedures will be put in place to examine the day service needs of this group and the overall service needs of people currently considered to be appropriately accommodated in psychiatric hospitals.

Of the remaining 547 people who require services, 54 will continue to reside within their psychiatric hospital setting but will require appropriate day services in the period 2000-2004. 19% of this group have a mild intellectual disability and 81% has a moderate, severe or profound intellectual disability. Of this group 16 have no day service at present and require activation programmes (11), special high support services (4), and a programme for older people (1). The remaining 38 are in receipt of day programmes that need to be enhanced or upgraded, as outlined in Table 4.15. Activation programmes are required by 26 individuals, 5 require specific programmes designed for older people, 4 require high-support services and of the remaining three, one requires home support (in addition to their current activation programme), one requires special vocational training and one requires a sheltered work placement. In addition 8 of this group will require residential support services within the period. Three need respite care, 2 need shared care, 1 requires a semi-independent living placement and the remaining two need other, unspecified, residential support services.

**TABLE 4.15 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
DAY SERVICE REQUIREMENTS OF PEOPLE APPROPRIATELY ACCOMMODATED IN PSYCHIATRIC HOSPITALS.**

Services required:	Home support	Special vocational training	Activation Centre	Programme for the Elderly	Special high-support day service	Sheltered work centre	All services
Currently receiving:							
No day programme	0	0	11	1	4	0	16
Home support	0	0	1	0	0	0	1
Special vocational training	0	0	1	0	0	0	2
Activation Centre	1	1	4	0	1	1	8
Programme for the Elderly	0	0	3	0	0	0	3
Special high support day service	0	0	1	0	0	0	1
Other day service	0	0	15	5	3	0	23
All services	1	1	37	6	8	1	54

Of the population currently resident in psychiatric hospitals 493 need to transfer to the intellectual disability services. 25% of this group have a mild intellectual disability, 73% have a moderate, severe or profound intellectual disability and 2% have not had their level of disability verified. The majority (436 people) will require residential and day placements and 57 will require residential placements only. The day and residential services required by this group, and the year in which the service needs will arise, are outlined in Tables 4.16 and 4.17.

	Year in which residential service is required				
	2000	2001	2002	2004	2000-2004
5-day Community Group Home	1	0	0	0	1
7-day (48-week) Community Group Home	8	0	1	0	9
7-day (52-week) Community Group Home	150	0	0	0	150
7-day (48-week) Residential Centre	14	0	0	0	14
7-day (52-week) Residential Centre	114	1	0	1	116
Nursing Home	15	0	0	0	15
De-designated Unit	2	0	0	0	2
Intensive placement (Challenging Behaviour)	113	0	0	0	113
Intensive placement (Profound/Multiple Handicap)	49	0	0	0	49
Unspecified intellectual disability service	24	0	0	0	24
All residential services	490	1	1	1	493

Of the 493 people who need to transfer from psychiatric to intellectual disability services for their residential services, 32% will require community group home places, 33% will require intensive placements (70% of these need to be specially designed to cater for challenging behaviours), 26% need places in residential centres, 3% need to move into nursing homes and less than 1% need to be accommodated in de-designated units. A further 5% have an unspecified residential requirement within the intellectual disability services. Almost all of the need arises immediately.

**TABLE 4.17 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
DAY SERVICE REQUIREMENTS OF PEOPLE CURRENTLY RESIDENT IN PSYCHIATRIC HOSPITALS WHO
REQUIRE TO BE TRANSFERRED TO THE INTELLECTUAL DISABILITY SECTOR.**

	Year in which day service is required				
	2000	2001	2002	2004	2000-2004
Home support	4	0	0	0	4
Special vocational training	2	0	0	0	2
Activation Centre	328	1	1	1	331
Programme for the Elderly	9	0	0	0	9
Special high support day service	67	0	0	0	67
Special intensive day service	14	0	0	0	14
Sheltered work centre	9	0	0	0	9
All day services	433	1	1	1	436

Over three-quarters of the day service demand is for activation programmes (76%), 19% require high support or intensive day programmes, 2% require a programme for older people, 2% require sheltered work placements, 1% will need home support services and 0.5% need special vocational training. As with the demand for residential services, the vast majority of services are required immediately.

OVERALL SERVICE PROVISION TO PEOPLE WITH INTELLECTUAL DISABILITY AND THE CHANGING PATTERN OF CARE

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 forecasted. 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. When the latter group moves into new services their existing places will be freed up for occupation by others who are currently without services or who are inappropriately accommodated in psychiatric hospitals. The existing placements occupied by these individuals are secure until their new place becomes available. Such movement is part of the ongoing development of services and is tangible evidence of the ability of the database to match needs with service provision. Individuals who already avail of services

within either the intellectual disability or psychiatric services already have significant funding allocated to them and changes to their existing placements will incur only minimal costs.

PATTERN OF CARE REQUIRED IN FULL-TIME RESIDENTIAL SERVICES

As illustrated earlier in this chapter, demand for residential services over the next five years comes from three distinct groups:

- 1,677 individuals currently living at home who require full-time residential services for the first time,
- 493 individuals currently resident in psychiatric hospitals and with significant funding already allocated to their placement who require to transfer to the intellectual disability services, and
- 1,911 individuals currently in full-time residential services within the intellectual disability sector who require changes to their existing placement. When placed in their new services, this group will free up places for use by the previous two groups.

Table 4.18 outlines the pattern of full-time residential service provision that will be required in the period 2000-2004 to meet this demand. 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, 1,918 community-based placements will be required during the period. One consequence of this will be the availability of 426 campus-based residential placements even after the demand for campus-style accommodation has been met. It may be possible to use these places to begin to address the shortfall of 738 intensive residential placements which will occur. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

**TABLE 4.18 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
PATTERN OF FULL-TIME RESIDENTIAL SERVICE PROVISION REQUIRED 2000-2004.**

	New services required by people currently living at home	New services required by people transferring from psychiatric hospitals	Service changes required by people currently in full-time residential places	Places Vacated by people currently in full-time residential places	Shortfall (-)/ Excess (+) of places arising from demand
5-day Community Group Home	297	1	63	189	-172
7-day (48-week) Community Group Home	334	9	294	126	-511
7-day (52-week) Community Group Home	634	150	631	190	-1225
5-day Residential Centre	26	0	11	130	93
7-day (48-week) Residential Centre	64	14	129	362	155
7-day (52-week) Residential Centre	141	116	225	660	178
Nursing Home	11	15	13	9	-30
De-designated Unit	0	2	0	108	106
Psychiatric Hospital	0	0	2	0	-2
Intensive placement (Challenging Behaviour)	92	113	332	31	-506
Intensive placement (Profound/Multiple Handicap)	78	49	211	106	-232
Unspecified intellectual disability service	0	24	0	0	-24
Total	1677	493	1911	1911	-2170

PATTERN OF CARE REQUIRED IN DAY SERVICES

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

- 912 individuals currently without day services,
- 436 individuals currently resident in psychiatric hospitals who will require an appropriate day service when they transfer to the intellectual disability services,
- 54 individuals appropriately placed in psychiatric hospitals but requiring a day programme within that setting, and
- 8,756 individuals currently in day services within the intellectual disability sector who require changes to, or enhancements of, their existing placement. When placed in their new services, this group will free up places for use by the first two groups. Unlike the situation with full-time residential services, however, not all existing places will become available. As previously explained in this chapter, people who are currently accessing, or who require home support, early services, resource teachers, multi-disciplinary supports, day respite or home help services will not be freeing up existing services when their future needs are met.

Table 4.19 outlines the pattern of day service provision that will be required in the period 2000-2004 to meet demand. The data in the table have been adjusted to reflect the fact that not all existing services will be freed up. The table shows two distinct trends - a decrease in the number of young children requiring certain services and a huge demand for the full spectrum of adult services. Over the next five years there will be small reductions nationally in the number of children requiring special pre-school services, mainstream classes, and special classes at primary level. There will be a significant reduction in the number of children requiring special schools. However, there is a small demand within this group for mainstream pre-school services and early intervention services and a much larger demand for additional resource teachers and for the provision of special classes at secondary level.

Adult services will continue to experience considerable pressures across the whole spectrum of day services. There will be a shortfall of vocational training placements, both generic and specialised, and of employment opportunities. In the period 2000-2004, 139 generic vocational training places and 188 special vocational training places will be required. Over the next five years 918 supported employment placements and 233 open employment placements need to be developed to meet the demand that exists for those services. There will also be a shortfall of 252 sheltered work and 190 sheltered employment opportunities during this time. An additional 486 places in activation centres are needed, as are 590 programme placements designed specifically to meet the needs of the elderly. As with residential services, there is significant demand for high-support and intensive placements. Between 2000-2004, 175 high-support day placements and 539 intensive day placements will be required. These services involve a higher staff/client ratio and more specialist interventions to address needs arising from behavioural problems, multiple disabilities and the effects of ageing.

**TABLE 4.19 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
PATTERN OF DAY SERVICE PROVISION REQUIRED 2000-2004.**

	New services required by people currently 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 currently receiving day services	Places vacated by people currently receiving day services	Shortfall (-)/ Excess (+) of places arising from demand
Home support	13	4	1	125	0	-143
Early Services	3	0	0	6	0	-9
Ordinary pre-school	5	0	0	141	116	-30
Special pre-school	12	0	0	218	369	139
Child Education and Development Centre	5	0	0	111	234	118
Ordinary school	2	0	0	148	298	148
Resource Teacher	3	0	0	206	0	-209
Special class - primary	2	0	0	197	467	268
Special class - secondary	1	0	0	536	106	-431
Special School	8	0	0	444	1907	1455
Generic vocational training	13	0	0	172	46	-139
Special vocational training	114	2	1	1059	988	-188
Activation Centre	220	331	37	1370	1472	-486
Programme for the Elderly	129	9	6	514	68	-590
Special high support day service	71	67	8	222	193	-175
Special intensive day service	61	14	0	503	39	-539
Sheltered work centre	89	9	1	1346	1193	-252
Sheltered employment centre	21	0	0	214	45	-190
Multidisciplinary support services	0	0	0	11	0	-11
Centre-based day respite service	0	0	0	4	0	-4
Other day service	6	0	0	50	188	132
Enclave within open employment	4	0	0	58	22	-40
Supported employment	99	0	0	864	45	-918
Open employment	23	0	0	225	15	-233
Generic Day Services	4	0	0	9	18	5
Home Help	4	0	0	3	0	-7
All Services	912	436	54	8756	7829	-2329

ISSUES

The next chapter, which contains a mid-term review of the Department of Health's assessment of need for intellectual disability services in the period 1997 to 2001, documents the progress made in addressing the existing waiting lists for services up to April 1999. While the data presented within that review show that the needs of a proportion of individuals have been met, that data, taken together with the data presented in the current chapter, show that the overall waiting list situation did not greatly improve. Some progress was made during this period in addressing the shortfall of day places but the waiting list for full-time residential places continues to grow.

There are three clearly identifiable groups awaiting residential services:

1. People who are not presently receiving residential services and are seeking residential services outside their family home;
2. People in psychiatric hospitals waiting for placements within the intellectual disability services;
3. People needing an enhancement of their existing services mainly through increased supervision or by means of community-based accommodation.

The ongoing dilemma is to achieve a balance between providing more and better services to people already receiving services without denying access to services to a relatively large segment of this population who are currently without any service or are without an appropriate service.

Our experience of addressing service needs since the inception of the database indicates that it may be foolhardy to believe that addressing this identified need will solve all our problems. The 1999 data show that while more people than ever before are receiving intellectual disability services, the demand for such services is not decreasing. This is not a uniquely Irish experience. Recent experience in the US has shown that while residential

capacity increased by 27% between 1987 and 1996, the number of people requesting services increased by 38% (Lakin, 1998). A number of factors which contribute to the continued growth of waiting lists even as the number of people receiving services continues to increase are identified in this paper:

- Demographics are a key factor: Major challenges are encountered in attempting to meet service demands as the 'baby boom' generation moves through adulthood. Many of the parents of these individuals, who have cared for them at home, are no longer able to maintain the support role they have fulfilled for the past 30 or 40 years. We now have large numbers of adults in their late 20s and 30s, which is a prime age for requiring residential services.
- Another factor is the increased longevity of people with intellectual disability. In Chapter 2 it was demonstrated that, like everyone else, people in this population group are living longer. Improvements in survival at the older ages will mean that adults with intellectual disabilities today will use services for several more years than previous generations.
- In addition, demand for services has increased because services are becoming more person-focused and are more desirable both to individuals with intellectual disability and to their families.

There are therefore a number of uncontrollable factors that are making the challenge of responding to waiting lists greater. Lakin (1998), addressing the issue of tackling waiting lists for intellectual disability services in the United States, recommends a number of useful strategies:

- Having available good quality data which inform people about the situation.
- Having some minimum level of support guaranteed to all before some people receive more than the minimum.

- Identifying and designing possible solutions to reducing the use of higher-cost services that lack long-term cost-effectiveness since they do not contribute to people's independence and well-being. Resources saved through these efficiencies should be re-allocated to those without service and those with inadequate services. To do this, a mechanism to identify high-cost services is required, together with definitions of expected outcomes. The author acknowledges that it is hard to become efficient and even harder to defend efficiency efforts without good quality data.
- Dealing effectively with waiting lists requires planning. There is a need to develop plans and engender the commitment needed to reduce the number waiting for services. Such commitment begins with getting to know the people behind the waiting list statistics. Lists are by their nature impersonal and the people on them are too often voiceless and faceless to the people who are responsible for promoting their well-being.

Lakin concludes that responding to people who are waiting for services involves creating data sets that contain information that helps in the planning and prioritising of services. Such information systems must identify how many are waiting for services, what services they are waiting for, and when they need the service.

In the National Intellectual Disability Database we have such a service-planning tool, and in having national data available to enable us to plan a strategy to address the current waiting lists we would appear to be much further down the road than other countries. In order to address these needs effectively, however, it is essential that the database does not become static and that each person's information is regularly reviewed and updated to reflect changing circumstances.

Additional revenue and capital funding, amounting to £53m, was made available between 1997 and the end of 1999 for the development of services for persons with intellectual disability. The present Government has also committed itself to meeting the identified needs of this group within a defined time-frame of three years, starting with a major acceleration of investment, both capital and revenue, in 2000.

ASSESSMENT OF NEED 1997-2001: MID-TERM REVIEW

In April 1997, the Department of Health published *Services to persons with a mental handicap/intellectual disability. An assessment of need 1997-2001* based on the first release of data from the National Intellectual Disability Database. The data were received from the health boards in September 1996. The Government of the day committed itself to the development of services for people with intellectual disability based on these identified needs, at a cost of £63.5m over the lifetime of the plan. To this end, revenue funding of £10.75m was made available in the January 1998 budget and £18m was committed in the December 1998 budget for developments during 1999. The data on which this review is based were received from the health boards in April 1999. Progress reported in this chapter was achieved using the 1998 funding and the funding for the first quarter of 1999 only.

In 1997, three distinct categories of need were identified:

Unmet Need: described people who were without any service whatsoever, or without a major element of service, and required a new service in the period 1997-2001.

Service Change: described those who already had an intellectual disability service but required that service to be changed or upgraded during the period 1997-2001 and included children who required access to health-funded services in the period.

Persons with intellectual disability who are accommodated in psychiatric hospitals: included people who needed to transfer out of the psychiatric services within the five-year period 1997-2001. People who were resident in the psychiatric services but required an appropriate day service had their needs identified under the *unmet need* category.

An Assessment of Need 1997-2001 indicated that 2,359 people required a major element of service, either a full-time residential service or a day service, in the five-year period 1997-2001. Of this group, 604 had no service and required full-time residential and/or day services; 1,280 received a day service at that time but also required a residential service, 452 people received a full-time residential service but also required a day service and 23 people received residential support services only and required full-time residential and/or day services. Table 5.1 provides a breakdown of this group by level of intellectual disability.

**TABLE 5.1 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1996.
NUMBER OF PEOPLE REQUIRING A MAJOR ELEMENT OF SERVICE 1997-2001.**

Source: Services to persons with a mental/intellectual Disability. An assessment of need 1997-2001.

	No Current Service	Receives minimal residential support only	Receives day only -requires residential	Receives residential only -requires day	Total
Not Verified	105	0	13	6	124
Mild	229	6	224	62	521
Mod-Sev-Prof	270	17	1043	384	1714
All levels	604^a	23^b	1280	452	2359

^a Of the 604, 97 require residential and day, 39 require residential only and 468 require day only.

^b Of the 23, 19 require residential and day, 4 require residential only.

The database indicated that 1,439 residential places and 1,036 day places would be required within the period 1997-2001 to provide these people with services.

By April 1999, 2,085 of the original group of 2,359 were still registered on the database. The 274 individuals who were no longer registered on the database were removed for a variety of reasons. On review, some of the records were found to be duplicate records of which the duplicate entries were then deleted. In the case of other individuals, when reviewed it was found that their needs would be more appropriately met within services for people with physical and sensory disabilities, services for the elderly or within generic services. Relatively small numbers had emigrated and no longer had service requirements in this jurisdiction, and a number of people had died.

An Assessment of Need 1997-2001 stated that 1,439 residential places would be required to meet demand for full-time residential places in the period 1997-2001. The types of residential placements required were detailed in that report. This detail is presented in Table 5.2, together with a summary of the current status of these individuals.

Of the 1,439 individuals identified as requiring a full-time residential place in the five-year period 1997-2001, 143 have no record in the 1999 dataset, 1 person has a current record but insufficient information is recorded on which to assess their current situation, 48 received residential support services and no longer require a full-time residential place and 240 who were still without residential services in April 1999 had had their service requirements updated to indicate that they no longer required a full-time residential place. This left a balance of 1,007 people who were on the original waiting list for full-time residential services in the period 1997-2001.

Of this group of 1,007, 27% (269 people) had received a full-time residential place by April 1999. 119 of this group (44%) received the type of placement that they were waitlisted for and the remaining 150 (56%) received an alternative type of full-time placement.

People waitlisted for placement in residential centres were more likely to receive a full-time place than people waitlisted for placement in the community. Of those waitlisted for the various types of community group home placements 23% have received full-time services, while 39% of those waitlisted for the various types of residential centre placements received full-time services. People waitlisted for intensive placements for challenging behaviour were three times more likely to receive a full-time residential placement than those waitlisted for intensive placements for profound or multiple handicaps. However, it should be noted that only a small proportion of these individuals actually received either of the intensive placements for which they were waitlisted.

By April 1999, 73% (738 people) of the group who were waitlisted for full-time residential services between 1997 and 2001 had not received those services. Only 66 people from this group have access to residential support services and 672 have no residential services whatsoever.

**TABLE 5.2 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
PROFILE OF SERVICE PROVISION TO PEOPLE WHO REQUIRED FULL-TIME RESIDENTIAL SERVICES 1997-2001.**

	Service Status in 1999								Total
	No residential service - requires full-time service	Received residential service	Received other full-time service	Received residential support service(s) - requires full-time service	Received residential support service(s) - no requirements for full-time service	No residential service - no requirements for full-time service	No record in 1999 dataset	No details	
Service required 1997-2001:									
5-day CGH	128	19	7	2	7	71	22	0	256
7-day (48-week) CGH	148	16	26	8	6	65	33	1	303
7-day (52-week) CGH	249	47	47	22	17	64	44	0	490
5-day RC	12	1	4	0	0	8	3	0	28
7-day (48-week) RC	45	3	7	3	0	10	8	0	76
7-day (52-week) RC	51	29	47	30	18	9	24	0	208
Nursing Home	0	0	1	0	0	0	0	0	1
Psychiatric hospital	1	0	0	0	0	0	0	0	1
Intensive placement (CB)	19	3	9	0	0	9	5	0	45
Intensive placement (PMH)	19	1	2	1	0	4	4	0	31
All services	672	119	150	66	48	240	143	1	1439

Key: CGH = Community Group Home
 RC = Residential Centre
 Intensive placement (CB) : Intensive placement (Challenging Behaviour)
 Intensive placement (PMH) : Intensive placement (Profound or Multiple Handicap)

An Assessment of Need 1997-2001 stated that 1,036 day places would be required to meet demand for day services in the period 1997-2001. The types of day places required were detailed in that report. This detail is presented in Table 5.3, together with a summary of the current status of these individuals.

Of the 1,036 individuals identified as requiring a day service in the five-year period 1997-2001, 149 have no record in the 1999 dataset and 76 who were still without a day service in April 1999 had had their service requirements updated to indicate that they no longer required a day service. This left a balance of 811 people who were on the original waiting list for day services in the period 1997-2001.

Of this group of 811, 50% (402 people) had received a day placement by April 1999. 128 of this group (32%) received the type of placement that they were waitlisted for and the remaining 274 (68%) received an alternative type of day placement.

Of the group of children who were identified as requiring early childhood and educational services, 85% received day services during the first fifteen months of the plan.

By April 1999, 48% of the 484 people who required more care-focused services during the lifetime of the plan had received day services

Of the 233 individuals who required training and employment opportunities, 95 (41%) had received day services by April 1999.

Of the group who were originally identified as requiring day services between 1997 and 2001 and who continue to be waitlisted for day services, 50% (409 people) had not received those services by April 1999.

**TABLE 5.3 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
PROFILE OF SERVICE PROVISION TO PEOPLE WHO REQUIRED DAY SERVICES 1997-2001.**

	Service Status in 1999						Total
	No day service - requires day service	Received required day service	Received other day service	No day service - no requirements for day service	No Record in 1999 dataset		
Service required 1997-2001	5	0	4	3	5	17	
Home support	0	0	1	0	0	1	
Early Services	5	2	7	0	1	15	
Ordinary pre-school	6	13	20	0	12	51	
Special pre-school	0	1	11	0	2	14	
Child Education and Development Centre	1	1	0	0	0	2	
Ordinary school	0	0	9	0	3	12	
Special class - primary	0	0	1	0	1	2	
Special class - secondary	0	1	2	0	2	5	
Special School	1	0	3	3	5	12	
Generic vocational training	28	7	13	10	15	73	
Special vocational training	142	72	63	23	27	327	
Activation Centre	36	13	18	3	18	88	
Programme for the Elderly	53	1	22	4	3	83	
Special high-support day service	23	4	37	0	5	69	
Special intensive day service	35	11	41	22	32	141	
Sheltered work centre	11	0	3	4	2	20	
Sheltered employment centre	0	0	4	1	0	5	
Other day service	1	0	1	0	0	2	
Enclave within open employment	59	2	9	3	10	83	
Supported employment	3	0	5	0	6	14	
Open employment	409	128	274	76	149	1036	
All services							

An Assessment of Need 1997-2001 indicated that 7,722 people who were in receipt of services in 1996 would require a change in their service provision between 1997 and 2001. Changes in both their day and residential services were required by 621 people, 751 people needed to change their residential service only, and 6,350 people needed to change their day service only. In total, 1,372 residential service changes and 6,971 day service changes would be required over the lifetime of the plan to ensure that everybody currently receiving intellectual disability services was in receipt of appropriate services.

RESIDENTIAL

There were 1,372 individuals in full-time residential services who were identified as requiring an upgrade or change of accommodation in the period 1997-2001. Table 5.4 summarises progress in this area up to April 1999.

Of the total group of 1,372 people requiring residential service change, 70 have no record in the 1999 dataset and 236 have had their database records updated to indicate that they have no identified need for changes to their residential service. This left a balance of 1066 people requiring residential service changes in the period 1997-2001.

By April 1999 13% (140 people) of this group received the service that was identified for them and 18% (189 people) received an alternative service. In the 1999 dataset 22 people from the first group and 105 people from the second group have had new service changes identified.

Eighteen people who were in full-time residential services are now living in a home setting with family members (15 people) or living in independent or semi-independent settings (3 people). Four of the group who are living at home require full-time residential services and their requirements are included in the 'unmet residential service' section of Chapter 4. One person, also living at home, requires residential support services while another needs a change in the existing residential support service.

Of the group who required to change or upgrade their residential service 67% (719 people) are still identified on the database as requiring these changes.

**TABLE 5.4 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
CURRENT SERVICE STATUS OF PEOPLE IN FULL-TIME RESIDENTIAL SERVICES IN 1996 WHO REQUIRED RESIDENTIAL SERVICE CHANGES 1997-2001.**

	Service Status in 1999							Total
	Received required residential service	Received other full-time service	Still in existing service - requires full-time service	Still in existing service - no longer requires full-time service	Living independently /semi-independently	Home setting	No record in 1999 dataset	
Full-time Residential Service required 1997-2001:								
5-day CGH	11	6	29	7	1	1	1	56
7-day (48-week) CGH	29	47	137	54	0	10	10	287
7-day (52-week) CGH	70	64	262	136	1	1	26	560
5-day RC	1	1	0	0	0	0	0	2
7-day (48-week) RC	3	8	41	5	0	0	5	62
7-day (52-week) RC	7	11	30	12	1	1	10	72
Nursing Home	0	0	2	1	0	0	0	3
Intensive placement (CB)	18	36	152	11	0	2	14	233
Intensive placement (PMH)	1	16	66	10	0	0	4	97
All Services	140	189	719	236	3	15	70	1372

Key: CGH = Community Group Home
 RC = Residential Centre
 Intensive placement (CB) : Intensive placement (Challenging Behaviour)
 Intensive placement (PMH) : Intensive placement (Profound or Multiple Handicap)

There were 6,971 individuals in receipt of day services who were identified as requiring an alternative day service in the period 1997-2001. Table 5.5 summarises progress in this area up to April 1999.

Of the total group of 6,971, 1,217 (17%) have no record in the 1999 dataset. An additional 282 individuals (4%) are now without service, of whom 219 have service requirements identified in the 'unmet day service' section of Chapter 4 and the remaining 63 have no day service requirements. A further 289 individuals who are currently availing of day services have had their database records updated to indicate that they no longer require to change this service. This left a balance of 5,183 people requiring day service changes in the period 1997-2001.

By April 1999 1,227 people (24%) have received the actual day service that they required and 1,288 (25%) have received an alternative day service. In the 1999 dataset 530 people from the first group and 666 people from the second group have new day service changes identified. Such recurrences in day service requirements are a common feature of day service planning as requirements change regularly over the individual's life cycle.

There are 2,668 people (51%) still awaiting their original alternative day service.

**TABLE 5.5 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
CURRENT SERVICE STATUS OF PEOPLE IN DAY SERVICES IN 1996 WHO REQUIRED DAY SERVICE CHANGES 1997-2001.**

Day service required 1997-2001	Service Status							Total
	Received required service	Received other service	Still in existing service - requires day service	Still in existing service - no longer requires day service	Without day service - requires day service ^a	Without day service - no longer requires day service	No record in 1999 dataset	
Home support	8	24	17	2	0	0	14	65
Ordinary pre-school	15	44	21	1	2	0	20	103
Special pre-school	61	67	24	1	0	0	29	182
Child Education and Development Centre	39	21	15	3	0	0	20	98
Generic Vocational training	4	41	56	3	3	6	60	173
Generic Vocational training	281	141	392	10	63	20	188	1095
Activation Centre	176	128	305	47	41	1	56	754
Programme for the Aged	24	25	149	24	28	2	24	276
Special high support day service	10	19	94	14	8	0	11	156
Special intensive day service	4	25	229	36	5	2	13	314
Sheltered work centre	223	301	496	47	23	16	237	1343
Sheltered employment centre	0	37	130	27	5	1	50	250
Other day service	0	2	10	3	0	0	5	20
Ordinary school	23	17	9	0	0	0	24	73
Resource Teacher	28	35	54	4	0	0	21	142
Special class - primary	26	60	37	2	0	0	56	181
Special class - secondary	61	54	263	14	2	2	110	506
Special school	136	63	51	10	0	1	90	351
Enclave within open employment	0	16	13	0	2	1	8	40
Supported employment	99	138	242	37	27	10	100	653
Open employment	9	30	61	4	10	1	81	196
All services	1227	1288	2668	289	219	63	1217	6971

^a The needs of this group are included in the 'unmet need for day service' figures presented in Chapter 4.

An Assessment of Need 1997-2001 identified 310 people with intellectual disability who were inappropriately accommodated within psychiatric hospitals and required to transfer to the intellectual disability services in the period 1997-2001. The types of residential placements required were detailed in that report. This detail is presented in Table 5.6, together with a summary of the current status of these individuals.

By April 1999, 30 of this group were no longer registered on the database and 9 had their database records updated to indicate that they no longer required to move from the psychiatric services into the intellectual disability services.

Of the remaining 271 people, 43 (16%) had moved to the intellectual disability services. Of this group, 24 received the type of placement that they were waitlisted for and the remaining 19 people received an alternative placement.

By April 1999, 84% (228 people) of the group who were resident in psychiatric hospitals and were waitlisted to transfer to the intellectual disability services had not made this move. However, by early 2002 over 200 people from this group will have moved to new facilities which are currently being constructed or are at an advanced stage of planning and design.

Note:

The remaining needs of all three groups identified in this chapter:

1. Those with unmet need for services,
2. Those requiring service change, and
3. Those with intellectual disability in psychiatric hospitals who require to transfer to the intellectual disability services

have been included in the updated assessment of need which is documented in Chapter 4 of this report.

**TABLE 5.6 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1999.
CURRENT SERVICE STATUS OF PEOPLE IN PSYCHIATRIC HOSPITALS IN 1996 WHO REQUIRED TO TRANSFER TO
INTELLECTUAL DISABILITY SERVICES 1997-2001.**

	Resident in psychiatric hospital- requires to transfer to intellectual disability services	Received required intellectual disability service	Received other service	Resident in psychiatric hospital - no longer requires to transfer to intellectual disability services	No record in 1999 dataset	Total
Service required 1997-2001:						
5-day CGH	1	0	1	0	0	2
7-day (48-week) CGH	5	0	1	1	0	7
7-day (52-week) CGH	132	21	2	1	7	163
7-day (48-week) RC	5	0	0	1	6	12
7-day (52-week) RC	27	3	11	2	12	55
Intensive placement (CB)	52	0	4	4	3	63
Intensive placement (PMH)	6	0	0	0	2	8
All services	228	24	19	9	30	310

Key: CGH = Community Group Home
 RC = Residential Centre
 Intensive placement (CB) : Intensive placement (Challenging Behaviour)
 Intensive placement (PMH) : Intensive placement (Profound or Multiple Handicap)

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Requests for additional information

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

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

APPENDIX A

NATIONAL INTELLECTUAL DISABILITY DATABASE - NATIONAL PLANNING DATA FORM

PERSONAL DETAILS

- | | |
|--|---|
| <p>1. Surname</p> <p>201. Previous Surname</p> <p>3. Address</p> <p>4. Address</p> <p>5. Address</p> <p>6. Address</p> <p>7. Address (County) _ _ </p> <p>8. Date of Birth _ _ - _ _ - _ _ _ _ </p> <p>8A. Year of birth (where DOB is unknown) _ _ _ _ </p> <p>9. Health Board Region _ </p> <p>10. Community Care Area _ _ </p> <p>11. Sub-area (DED) within the Health Board Region _ _ _ </p> <p>12. Planning area within the Health Board _ _ </p> <p>13. Personal identification number _ _ _ _ _ _ </p> <p>14. Sex 1=male 2=female _ </p> <p>15. Degree of intellectual disability _ 0=not verified 1=normal range 2=borderline 3=mild 4=moderate 5=severe 6=profound</p> | <p>2. First Name</p> <p>202. Next of Kin name</p> <p>203. Next of Kin address</p> <p>204. Next of Kin address.....</p> <p>205. Next of Kin address.....</p> <p>206. Next of Kin address</p> <p>207. Next of kin address (County) _ _ </p> <p>208. Next of kin telephone number</p> <p>209. Relationship of next of kin</p> |
|--|---|

CURRENT SERVICE PROVISION

20. Agency providing main day service (Appendix A) |_|_|_|_|_|_|
21. Type of main day service (Appendix B) |_|_|
22. Current level of main day service supervision 0. 1. 2. 3. 4.
- 23A. Agency providing secondary day service (Appendix A) |_|_|_|_|_|_|
23. Type of secondary day service (Appendix B) |_|_|
24. Agency providing main residential service (Appendix A) |_|_|_|_|_|_|
25. Type of main residential circumstances (Appendix B) |_|_|_|
26. Current level of main residential service supervision A. B. C. D. Z.
- 27A. Agency providing secondary residential service (Appendix A) |_|_|_|_|_|_|
27. Type of secondary residential circumstances (Appendix B) |_|_|_|
28. Current level of secondary residential service supervision A. B. C. D. Z.

Coding for variables 22, 31 & 34

- Level 0: Not applicable
 Level 1: Staff to client=1 to 10+
 Level 2: Between 1 to 6 & 1 to 9
 Level 3: Between 1 to 2 & 1 to 5
 Level 4: 1 to 1 or above

Coding for variables 26, 28, 41 & 44

- Level A: Minimum - no sleep-in
 Level B: Staff on duty most of the time plus sleep-in
 Level C: Two staff on duty plus sleep-in
 Level D: Two staff on duty plus on-duty night staff
 Level Z: Not applicable

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32. Year in which this day service is required |_|_|_|_|
33. Day service required - contingency plan |_|_|
34. Level of (contingency plan) day supervision required 0. 1. 2. 3. 4.
40. Residential service required (Appendix B) |_|_|_| 40A. Reason for duplication on current/future res. service |_|
41. Level of residential supervision required A. B. C. D. Z.
42. Year in which this residential service is required |_|_|_|_|
43. Residential service required - contingency plan |_|_|_|
44. Level of (contingency plan) residential supervision required A. B. C. D. Z.

Additional Information

100. Date of Completion |_|_|-|_|_|-|_|_|_|_|
101. Reason for Removal |_| 102. Date of Removal |_|_|-|_|_|-|_|_|_|_|

The shaded information in the Personal Details section is removed from all records before they are sent to the Department of Health and Children.

APPENDIX B

National Intellectual Disability Database

Statistical Report 1998

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**TABLE 1. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
DEGREE OF INTELLECTUAL DISABILITY. NUMBERS, % AND PREVALENCE RATES PER 1,000.**

	n	%	rate per 1000
Mild	11541	42.0	3.18
Moderate	9708	35.4	2.68
Severe	3975	14.5	1.10
Profound	1131	4.1	0.31
Not Verified	1090	4.0	0.30
Total	27445	100.0	7.57

**TABLE 2. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
AGE, GENDER AND DEGREE OF INTELLECTUAL DISABILITY
NUMBERS AND PREVALENCE RATES PER 1,000.**

Age Group	NUMBERS																	
	Not Verified			Mild			Moderate			Severe			Profound			All Levels		
	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total
0-4	298	204	502	131	100	231	123	68	191	38	26	64	8	14	22	598	412	1010
5-9	112	73	185	566	319	885	411	277	688	150	118	268	32	26	58	1271	813	2084
10-14	26	16	42	1302	714	2016	540	355	895	180	110	290	52	34	86	2100	1229	3329
15-19	29	21	50	1280	830	2110	606	455	1061	203	136	339	57	39	96	2175	1481	3656
20-34	70	37	107	1891	1537	3428	1661	1422	3083	753	547	1300	228	205	433	4603	3748	8351
35-54	71	55	126	1039	1044	2083	1416	1364	2780	674	620	1294	227	145	372	3427	3228	6655
55 & over	35	43	78	380	408	788	467	543	1010	213	207	420	35	29	64	1130	1230	2360
All ages	641	449	1090	6589	4952	11541	5224	4484	9708	2211	1764	3975	639	492	1131	15304	12141	27445
RATES																		
0-4	2.31	1.68	2.00	1.02	0.82	0.92	0.96	0.56	0.76	0.30	0.21	0.26	0.06	0.12	0.09	4.65	3.39	4.03
5-9	0.77	0.53	0.65	3.89	2.32	3.13	2.83	2.01	2.43	1.03	0.86	0.95	0.22	0.19	0.20	8.75	5.91	7.37
10-14	0.16	0.10	0.13	7.78	4.50	6.18	3.23	2.24	2.74	1.08	0.69	0.89	0.31	0.21	0.26	12.55	7.74	10.21
15-19	0.17	0.13	0.15	7.36	5.01	6.21	3.48	2.75	3.12	1.17	0.82	1.00	0.33	0.24	0.28	12.50	8.94	10.77
20-34	0.17	0.09	0.13	4.65	3.78	4.21	4.09	3.49	3.79	1.85	1.34	1.60	0.56	0.50	0.53	11.33	9.21	10.27
35-54	0.16	0.12	0.14	2.28	2.30	2.29	3.11	3.01	3.06	1.48	1.37	1.42	0.50	0.32	0.41	7.53	7.12	7.33
55 & over	0.11	0.11	0.11	1.17	1.07	1.12	1.44	1.42	1.43	0.66	0.54	0.60	0.11	0.08	0.09	3.49	3.22	3.34
All ages	0.36	0.25	0.30	3.66	2.71	3.18	2.90	2.46	2.68	1.23	0.97	1.10	0.35	0.27	0.31	8.50	6.65	7.57

**TABLE 3. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
AGE, GENDER AND DEGREE OF INTELLECTUAL DISABILITY - 1974, 1981, 1998.
NUMBERS AND PREVALENCE RATES PER 1,000.**

Age Group	NUMBERS											
	Moderate			Severe			Profound			All Levels		
	1974	1981	1998	1974	1981	1998	1974	1981	1998	1974	1981	1998
0-4	189	214	191	143	92	64	99	26	22	431	332	277
5-9	809	955	688	617	330	268	224	99	58	1650	1384	1014
10-14	752	1035	895	583	428	290	292	117	86	1627	1580	1271
15-19	698	1203	1061	445	508	339	241	154	96	1384	1865	1496
20-34	1498	2419	3083	1017	1129	1300	441	340	433	2956	3888	4816
35-54	1321	1559	2780	626	612	1294	201	97	372	2148	2268	4446
55 & over	669	715	1010	307	248	420	84	24	64	1060	987	1494
All ages	5936	8100	9708	3738	3347	3975	1582	857	1131	11256	12304	14814
	RATES											
0-4	0.60	0.62	0.76	0.45	0.27	0.26	0.31	0.07	0.09	1.36	0.97	1.11
5-9	2.55	2.73	2.43	1.95	0.94	0.95	0.71	0.28	0.20	5.20	3.95	3.58
10-14	2.52	3.08	2.74	1.95	1.27	0.89	0.98	0.35	0.26	5.45	4.70	3.90
15-19	2.61	3.79	3.12	1.66	1.60	1.00	0.90	0.48	0.28	5.17	5.88	4.41
20-34	2.78	3.33	3.79	1.88	1.56	1.60	0.82	0.47	0.53	5.48	5.35	5.92
35-54	2.13	2.43	3.06	1.01	0.95	1.42	0.32	0.15	0.41	3.46	3.53	4.90
55 & over	1.08	1.09	1.43	0.50	0.38	0.60	0.14	0.04	0.09	1.71	1.51	2.12
All ages	1.99	2.35	2.68	1.25	0.97	1.10	0.53	0.25	0.31	3.80	3.60	4.09

**TABLE 4. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
GEOGRAPHICAL DISTRIBUTION AND AGE (MODERATE, SEVERE AND PROFOUND
INTELLECTUAL DISABILITY COMBINED). NUMBERS AND PREVALENCE RATES PER 1000.**

	<i>0-4 years</i>	<i>5-9 years</i>	<i>10-14 years</i>	<i>15-19 years</i>	<i>All ages</i>
	<i>n</i> <i>rate</i>	<i>n</i> <i>rate</i>	<i>n</i> <i>rate</i>	<i>n</i> <i>rate</i>	<i>n</i> <i>rate</i>
<i>Eastern</i>	71 0.78	299 3.10	405 3.78	455 3.86	1230 2.98
<i>Midland</i>	35 2.39	87 5.14	88 4.32	111 5.52	321 4.46
<i>Mid-Western</i>	34 1.57	102 4.12	116 3.95	151 4.93	403 3.78
<i>North-Eastern</i>	19 0.88	107 4.15	102 3.38	154 5.24	382 3.57
<i>North-Western</i>	13 0.90	52 3.00	88 4.37	75 3.76	228 3.17
<i>South-Eastern</i>	45 1.65	110 3.47	137 3.74	156 4.19	448 3.37
<i>Southern</i>	29 0.78	162 3.86	209 4.26	228 4.48	628 3.51
<i>Western</i>	31 1.34	95 3.41	126 3.78	166 4.97	418 3.55
<i>All Regions</i>	277	1014	1271	1496	4058
<i>Rate</i>	1.11	3.58	3.90	4.41	3.38

**TABLE 5. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
SUMMARY OF CURRENT SERVICE PROVISION.**

	n	%
<i>Receiving day services</i>	16180	59.0
<i>Receiving 5 or 7 day residential services</i>	6906	25.2
<i>Residents in Psychiatric Hospitals</i>	874	3.2
<i>Receiving residential support services only</i>	270	1.0
<i>Receiving no service</i>	617	2.2
<i>No current service requirements</i>	2598	9.5
<i>Total</i>	27445	100.0

	Not verified		Mild		Moderate, Severe and Profound		All levels			
	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over		
Receiving day services	639	138	4588	3551	8139	4037	7264	8454	7726	16180
Receiving 5 or 7 day residential services	10	23	98	1029	1127	408	5338	516	6390	6906
Residents in Psychiatric Hospitals	0	12	0	226	226	0	636	0	874	874
Receiving residential support services only	0	4	14	170	184	6	76	20	250	270
Receiving no service	31	11	65	291	356	39	180	135	482	617
No current service requirements	84	138	144	1365	1509	69	798	297	2301	2598
Total	764	326	4909	6632	11541	3749	11065	9422	18023	27445

**TABLE 6. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
SUMMARY OF CURRENT SERVICE PROVISION BY DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

**TABLE 7. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
MAIN RESIDENTIAL CIRCUMSTANCES.**

	n	%
Home Setting	17210	62.7
At home with both parents	12284	44.8
At home with one parent	3285	12.0
At home with sibling	966	3.5
At home with other relative	360	1.3
Lives with non-relative	58	0.2
Adoption	30	0.1
Foster care	227	0.8
Independent Setting	665	2.4
Lives independently	523	1.9
Living semi-independently	142	0.5
Community Group Homes	2751	9.9
5 day community group home	614	2.2
7 day community group home	918	3.3
7 day (52 week) community group home	1219	4.4
Residential Centres	3640	13.2
5 day residential centre	220	0.8
7 day centre	942	3.4
7 day (52 week) residential centre	2478	9.0
Other full-time services	1389	5.0
Nursing Home	67	0.2
De-designated Unit	77	0.3
Psychiatric hospital	874	3.2
Intensive placement (Challenging Behaviour)	140	0.5
Intensive placement (Profound or Multiple handicap)	231	0.8
Residential Support Placement	63	0.1
Other Residential Service	320	1.2
No Fixed Abode	14	.1
Insufficient Information	1393	5.1
Total	27445	100.0

**TABLE 8. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
MAIN RESIDENTIAL CIRCUMSTANCES, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

	Not verified				Mild				Moderate, Severe and 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	
Residential Circumstances																					
Home Setting	692	63	62	29	846	4892	2456	1057	245	8650	3431	2636	1366	281	7714	9015	5155	2485	555	17210	
Independent Setting	0	6	9	6	21	6	170	250	97	523	0	16	74	31	121	6	192	333	134	665	
Community Group Home	2	3	3	2	10	61	202	316	139	718	118	747	955	203	2023	181	959	1274	344	2751	
Residential Centre	8	1	4	8	21	42	93	118	85	338	313	1007	1415	546	3281	363	1101	1537	639	3640	
Intensive placements	0	0	0	0	0	8	15	8	6	37	59	176	86	13	334	67	191	94	19	371	
Nursing Home	0	0	0	1	1	0	0	6	21	27	0	2	8	29	39	0	2	14	51	67	
De-Designated Unit	0	0	0	1	1	0	1	2	4	7	0	18	34	17	69	0	19	36	22	77	
Psychiatric Hospital	0	4	3	5	12	0	29	94	103	226	0	65	312	259	636	0	98	409	367	874	
Residential Support Placement	0	0	0	0	0	1	3	2	2	8	20	24	11	0	55	21	27	13	2	63	
Other Residential Service	4	0	1	0	5	111	36	9	6	162	65	12	27	49	153	180	48	37	55	320	
No fixed abode	0	1	0	1	2	1	6	3	0	10	1	0	1	0	2	2	7	4	1	14	
Insufficient Information	73	29	44	25	171	120	417	218	80	835	51	113	157	66	387	244	559	419	171	1393	
Total	779	107	126	78	1090	5242	3428	2083	788	11541	4058	4816	4446	1494	14814	10079	8351	6655	2360	27445	

**TABLE 9. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
CATEGORY OF PERSONS AVAILING OF DAY SERVICES, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

	Not verified		Mild		Moderate, Severe and Profound		All levels		
	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over	
Residents*	10	26	98	1128	399	5371	507	6525	7032
Day Attenders	639	138	4588	3551	3227	4037	8454	7726	16180
Total	649	164	4686	4679	3626	9408	8961	14251	23212

* Receive a full-time residential service

**TABLE 10. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
PRINCIPAL DAY SERVICE BY CATEGORY OF PERSONS AVAILING OF DAY SERVICES.**

	Residents	Day Attenders	Total
Home Support	3	436	439
Home Help	0	17	17
Early Services	4	491	495
Ordinary Pre-School	0	147	147
Special Pre-school for intellectual disability	8	534	542
Child Education and Development Centre	106	571	677
Ordinary School	1	867	868
Resource Teacher	2	88	90
Special Class - Primary Level	17	821	838
Special Class - Secondary Level	8	199	207
Special School	326	4426	4752
Generic vocational training	18	90	108
Special vocational training	324	1585	1909
Activation Centre	3039	1504	4543
Programme for the Elderly	236	74	310
Special high support day service	356	60	416
Special intensive day service	133	25	158
Sheltered work centre	1881	2865	4746
Sheltered employment centre	18	92	110
Other day services	384	622	1006
Generic Day Services	21	50	71
Enclave within open employment	45	16	61
Supported employment	80	437	517
Open employment	22	163	185
Total	7032	16180	23212

**TABLE 11. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
PRINCIPAL DAY SERVICES, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.**

Type of Day Service	Not verified		Mild		Moderate, Severe and Profound		All levels	
	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over
Home Support	38	15	45	105	38	198	121	318
Home Help	2	0	0	9	2	4	4	13
Early Services	298	0	79	1	116	1	493	2
Ordinary Pre-school	41	0	55	00	51	0	147	0
Special pre-school	109	0	139	0	286	8	534	8
Child Education and Development Centre	28	0	7	5	566	74	601	76
Ordinary school	33	0	676	26	132	1	841	27
Resource Teacher	0	0	74	1	14	1	88	2
Special class - primary level	12	0	636	16	173	1	821	17
Special class - secondary level	0	0	129	41	27	10	156	51
Special School	36	0	2588	113	1932	83	4556	196
Generic vocational training	0	4	8	60	1	35	9	99
Special vocational training	1	27	72	966	40	803	113	1796
Activation Centre	1	30	14	468	79	3951	94	4449
Programme for the Elderly	0	7	0	71	0	232	0	310
Special high support day services	5	3	7	21	42	338	54	362
Special intensive day services	2	0	12	13	21	110	35	123
Sheltered work centre	2	33	23	1886	22	2780	47	4699
Sheltered employment centre	0	1	3	78	2	26	5	105
Other day service	39	38	100	271	80	478	219	787
Generic Day Service	0	0	0	37	0	34	0	71
Enclave within open employment	0	0	1	15	0	45	1	60
Supported employment	2	6	8	326	1	174	11	506
Open employment	0	0	10	153	1	21	11	174
Total day services	649	164	4686	4679	3626	9408	8961	23212

TABLE 12. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.

OVERALL LEVEL OF CURRENT RESIDENTIAL SERVICE PROVISION, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.

Type of Residential Service	Not Verified			Mild			Mod-Sev-Prof			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	2	3	5	38	125	163	36	410	446	76	538	614
7 day community group home	0	2	2	8	196	204	18	694	712	26	892	918
7 day (52 week) community group home	0	3	3	9	342	351	38	827	865	47	1172	1219
5 day residential centre	1	0	1	14	18	32	60	127	187	75	145	220
7 day residential centre	1	0	1	2	111	113	120	708	828	123	819	942
7 day (52 week) residential centre	6	13	19	19	174	193	84	2182	2266	109	2369	2478
Nursing Home	0	1	1	0	27	27	0	39	39	0	67	67
De-designated Unit	0	1	1	0	7	7	0	69	69	0	77	77
Psychiatric Hospital	0	12	12	0	226	226	0	636	636	0	874	874
Intensive Placement (Challenging Behaviour)	0	0	0	7	16	23	17	100	117	24	116	140
Intensive Placement (Profound/Multiple Disability)	0	0	0	1	13	14	35	182	217	36	195	231
Holiday residential placement	0	2	2	11	34	45	42	133	175	53	169	222
Crisis and Relief Centre	25	3	28	46	179	225	684	946	1630	755	1128	1883
Occasional respite with host family	3	0	3	19	8	27	123	80	203	145	88	233
Shared care or guardianship	0	0	0	2	1	3	3	4	7	5	5	10
Regular part-time care (2/3 days per week)	1	0	1	0	3	3	10	8	18	11	11	22
Regular part-time care (every weekend)	0	0	0	0	4	4	3	9	12	3	13	16
Regular part-time care (alternate weeks)	0	1	1	1	4	5	13	28	41	14	33	47
Other residential service	4	2	6	98	69	167	70	97	167	172	168	340
Lives semi-independently	0	4	4	0	88	88	0	50	50	0	142	142
Lives Independently	0	17	17	2	437	439	0	72	72	2	526	528

**TABLE 14. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
NUMBER OF PEOPLE INCLUDED ON EACH REGIONAL
INTELLECTUAL DISABILITY DATABASE.**

	n	%
Eastern Health Board	8582	31.3
Midland Health Board	1832	6.7
Mid-Western Health Board	2584	9.4
North-Eastern Health Board	2215	8.1
North-Western Health Board	1798	6.6
South-Eastern Health Board	3137	11.4
Southern Health Board	4034	14.7
Western Health Board	3263	11.9
All Health Boards	27445	100.0

**TABLE 15. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
DEGREE OF INTELLECTUAL DISABILITY BY HEALTH BOARD AREA.**

	Not Verified	Mild	Moderate	Severe	Profound	All Levels
	n %	n %	n %	n %	n %	n %
Eastern Health Board	542 6.3	3178 37.0	3251 37.9	1258 14.7	353 4.1	8582 100.0
Midland Health Board	22 1.2	858 46.8	682 37.2	226 12.3	44 2.4	1832 100.0
Mid-Western Health Board	18 0.7	1225 47.4	902 34.9	347 13.4	92 3.6	2584 100.0
North-Eastern Health Board	73 3.3	948 42.8	795 35.9	319 14.4	80 3.6	2215 100.0
North-Western Health Board	66 3.7	754 41.9	645 35.9	279 15.5	54 3.0	1798 100.0
South-Eastern Health Board	174 5.5	1324 42.2	1011 32.2	438 14.0	190 6.1	3137 100.0
Southern Health Board	114 2.8	1715 42.5	1353 33.5	602 14.9	250 6.2	4034 100.0
Western Health Board	81 2.5	1539 47.2	1069 32.8	506 15.5	68 2.1	3263 100.0
All Boards	1090 4.0	11541 42.1	9708 35.4	3975 14.5	1131 4.1	27445 100.0

**TABLE 16. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
CURRENT SERVICE PROVISION BY HEALTH BOARD AREA.**

	Receiving day services		Receiving 5 or 7 day residential services		Residents in Psychiatric Hospitals		Receiving residential services only		Receiving no service requirements		Total			
	n	%	n	%	n	%	n	%	n	%	n	%		
Eastern Health Board	4435	51.7	2252	26.2	322	3.8	39	0.5	110	1.3	1424	16.6	8582	100.0
Midland Health Board	1092	59.6	430	23.5	31	1.7	30	1.6	163	8.9	86	4.7	1832	100.0
Mid-Western Health Board	1636	63.3	615	23.8	106	4.1	22	0.9	49	1.9	156	6.0	2584	100.0
North-Eastern Health Board	1446	65.3	449	20.3	25	1.1	26	1.2	81	3.7	188	8.5	2215	100.0
North-Western Health Board	861	47.9	596	33.1	5	0.3	42	2.3	95	5.3	199	11.1	1798	100.0
South-Eastern Health Board	2193	69.9	763	24.3	157	5.0	1	0.0	22	0.7	1	0.0	3137	100.0
Southern Health Board	2703	67.0	1012	25.1	123	3.0	36	0.9	31	0.8	129	3.2	4034	100.0
Western Health Board	1814	55.6	789	24.2	105	3.2	74	2.3	66	2.0	415	12.7	3263	100.0
All Boards	16180	59.0	6906	25.2	874	3.2	270	1.0	617	2.2	2598	9.5	27445	100.0

TABLE 17. (ASSESSMENT OF NEED) NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998. NUMBER OF PEOPLE NEEDING A NEW SERVICE 1999-2003														
	No current service		Receives minimal residential support only		Receives day-requires residential		Receives day-requires residential support		Receives residential-requires day		Receives residential & day - requires residential support		Total	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Not Verified	42		2		30		15		3		0		92	
Mild	356		35		333		288		24		50		1086	
Mod-Sev-Prof	219		31		1181		440		274		57		2202	
All Levels	617*		68**		1544		743		301***		107		3380	

* Of the 617, 90 require residential and day; 466 require day only, 33 require day and residential support services, 15 require residential only, 13 require residential support services only.

** Of the 68, 18 require residential and day; 44 require day only, 6 require residential only.

*** Of the 301, 2 require a residential support service in addition to the day service.

TABLE 18. (ASSESSMENT OF NEED) NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998. NUMBER OF PLACES REQUIRED TO MEET IDENTIFIED NEED, 1999-2003.	
Residential Places	1673
Day Places	952
Residential Support Places	898

TABLE 19. (ASSESSMENT OF NEED) NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998. YEAR IN WHICH SERVICE NEEDS ARISE.							
	1999	2000	2001	2002	2003	Year not specified	All years
Residential	1171	192	105	99	106	0	1673
Day	872	37	17	4	17	5	952
Residential Support	770	44	21	22	38	3	898

**TABLE 20. (ASSESSMENT OF NEED) NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
SERVICE CHANGES REQUIRED 1999-2003.**

Service Change - Residential and Day		1258
Day Service -	Health	1203
	Education	4
	Employment	51
Service Change - Residential Only		925
Service Change - Day Only		8688
Day Service -	Health	5858
	Education	1575
	Employment	1255
Service Change - Day and Residential Support		139
Day Service -	Health	110
	Education	18
	Employment	11
Service Change - Residential Support Only		121
Number of People Requiring Service Changes		11131*

* 1,501 of this group also appear in the 'Unmet Need' data. They need changes to their existing service as well as needing 'missing' elements of service.

**TABLE 21. (ASSESSMENT OF NEED) NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
SUMMARY OF SERVICE CHANGES REQUIRED 1999-2003.**

Residential		2183
Day		10085
	Health	7171
	Education	1597
	Employment (Enclave/Supported/Open)	1317
Residential Supports		260

	1999	2000	2001	2002	2003	Year not specified	All years
Residential	1787	207	87	38	58	6	2183
Day	7075	1230	810	465	459	46	10085
Health	4977	843	607	341	370	33	7171
Education	1166	237	94	58	32	10	1597
Employment (Enclave/Supported/Open)	932	150	109	66	57	3	1317
Residential Support	235	11	5	5	3	1	260

Residential and Day change	459
Residential change only	56
Remain in psychiatric services, require day change	35*

* 7 of this group also need a residential support service.

There are 874 people with an intellectual disability currently accommodated in psychiatric hospitals. Of this group, 515 have been classified as being inappropriately accommodated and require to be transferred to the intellectual disability services, while 359 are appropriately placed. 35 of the group who are appropriately placed within the psychiatric services need a new or enhanced day programme and seven of this group also need additional residential support services. Of the 515 who are classified as being inappropriately accommodated and require to be transferred to the intellectual disability services, 459 require both day and residential services and 56 require a residential service only.

**TABLE 24. (ASSESSMENT OF NEED) NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 1998.
YEAR IN WHICH SERVICE CHANGES ARISE.**

	1999	2000	2001	2002	2003	Year not specified	All years
Residential and Day change	434	22	1	1	1	0	459
Residential change only	53	3	0	0	0	0	56
Remain in psychiatric services, require day change	30	1	0	1	0	3	35

APPENDIX C

Requesting information from the National Intellectual Disability Database

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

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

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

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

Requesting information from Regional Intellectual Disability Databases

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

National Intellectual Disability Database
Request for Information Form

Name of Applicant: _____

Address: _____

Name of agency/academic institution (where applicable) : _____

Date requested: _____

Details of the type of analysis required:

How will data be used:

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

(Continue on separate page if necessary)

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

Signature of Applicant: _____ Date: _____

Date Request Considered: _____

Decision of National Intellectual Disability Database Committee (NIDDC):

Any conditions which are to be applied to the request:

Signed on behalf of NIDDC: _____

Date: _____

