



National Intellectual Disability Database

A N N U A L R E P O R T
of the National Intellectual Disability Database Committee

Fiona Mulvany

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ANNUAL REPORT 2000

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- *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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CHAIRMAN'S STATEMENT

It gives me great pleasure to introduce the third Annual Report from the Intellectual Disability Database. This report provides a profile of the population with intellectual disability as it was on 30th April, 2000 and sets out details of the level of services provided for this group. It also includes an assessment of need for services for the period 2001 to 2005. It 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 planning and delivering services.

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

With the publication of this report, The Intellectual Disability Database is also increasingly assisting in the monitoring, in a more transparent and effective manner, of the implementation of the major investment programme in the services which is currently in progress.

As in previous reports, I would like to take the opportunity to thank all those involved with the work of the Database. The ongoing enhancement of the range of information available to us will continue to ensure that the resources allocated to the services are targeted at the areas of most need. I would particularly like to acknowledge the contribution made by Ms. Fiona Mulvany 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 was established in 1995 to ensure that information is available to enable the Department of Health and Children, the health boards and the voluntary agencies in the Republic of Ireland to provide appropriate services designed to meet the changing needs of people with intellectual disability (mental handicap) and their families. The database is intended to provide a comprehensive and accurate information base for decision making in relation to the planning, funding, and management of services for people with an intellectual disability.

The database was established on the principle that minimum information with maximum accuracy was preferred, hence it incorporates only three basic elements of information: demographic details, current service provision, and future service requirements. The objective is to obtain this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service. Information as to causative diagnosis is specifically excluded as the database is not designed as a medical epidemiological tool. The data held in any individual record represent the information available for that person at a specified point in time only. The record is updated whenever there are changes in 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. This includes the implementation and maintenance of structures for the identification of individuals and the collection, review and updating of data. In practice, this responsibility is delegated to the Regional Database Co-ordinator. The initial step in the generation of the national dataset is the completion of a database form for each identified individual (Appendix A). Responsibility for providing this information to the health board lies primarily with the service providers, community care

personnel and school principals. The designated data providers supply this information to their health board and a regional database is compiled. Data from the regional databases enable more sophisticated service planning at health board level and promote effective co-ordination of local services. Regional Intellectual Disability Database Committees, consisting of the Regional Database Co-ordinator, the Regional Database Administrator and representatives from the health board and the voluntary services, monitor the operation of the regional database in each health board region.

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

DATA QUALITY

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

THIS REPORT

This is the third report of 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. The second report (Mulvany, 2000) was based on two datasets received from the health boards in December 1998 and April 1999, respectively. This third report is based on validated data sent to the Department of Health and Children in April 2000. 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 2000. 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 if they are 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 normally provided by the intellectual disability services. In April 2000, there were 142 people recorded as being of normal ability and 725 people in the borderline intellectual disability categories, an increase of 1 and a reduction of 36 respectively since 1999. The health boards are involved in an ongoing appraisal of such registrations on the database. The disability category described as 'not verified' has been included in the analyses as members of this group have an intellectual disability, but the level of disability has not been confirmed. Accordingly, the data presented include those with a mild, moderate, severe or profound intellectual disability, in addition to the 'not verified' category.

The information now available from the National Intellectual Disability Database provides a much better basis for decision making than was previously the case. Priorities can be set based on an objective evaluation of the needs of people with intellectual disability, and services that are sensitive to these needs can be delivered. The commitment of all services and agencies involved 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.

CHAPTER 2

PROFILE OF THE POPULATION

NATIONAL LEVEL

In April 2000 there were 26,760 people registered on the National Intellectual Disability Database, with a prevalence rate of 7.38/1000 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 2.99/1000, compared to 3.11/1000 in 1999, and the prevalence rate for moderate, severe and profound intellectual disability is 4.06/1000, unchanged since 1999.

	n	%	rate
Mild	10826	40.5	2.99
Moderate	9612	35.9	2.65
Severe	3996	14.9	1.10
Profound	1133	4.2	0.31
Not Verified	1193	4.5	0.33
Total	26760	100.0	7.38

Overall, the numbers registered on the National Intellectual Disability Database have decreased by 389 since 1999. This reduction in overall numbers and in the administrative prevalence of mild intellectual disability is attributed mainly to ongoing efforts to refine the database, including the recently introduced 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. The numbers of people with mild intellectual disability registered on the database reduced by 441 in the twelve-month period to April 2000.

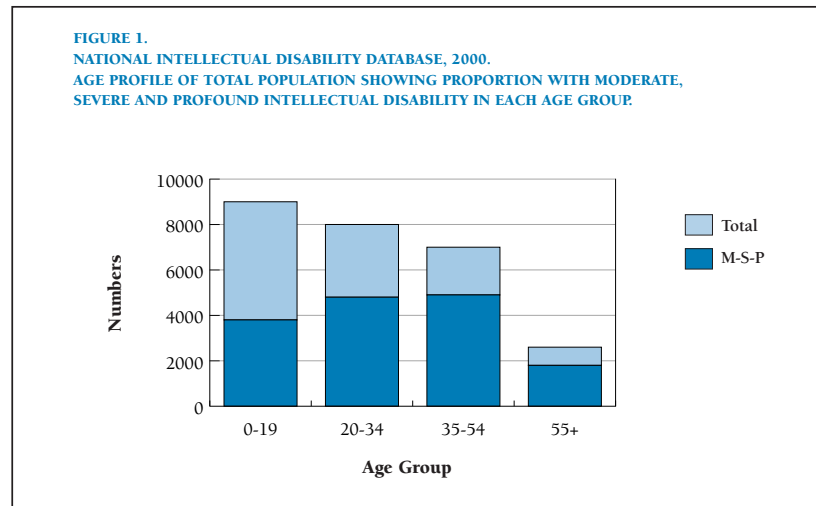
Table 2.2 summarises the age and gender distribution of this population by degree of disability. The data presented demonstrate falling prevalence rates in the 0-19 year age group at all levels

Age Group	NUMBERS												PREVALENCE RATES											
	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	266	204	470	92	43	135	72	58	130	25	13	38	7	10	17	462	328	790						
5-9	163	91	254	445	290	735	393	230	623	125	100	225	31	30	61	1157	741	1898						
10-14	34	23	57	1109	626	1735	518	320	838	173	107	280	40	23	63	1874	1099	2973						
15-19	26	24	50	1241	785	2026	591	417	1008	181	126	307	49	39	88	2088	1391	3479						
20-34	84	55	139	1814	1394	3208	1639	1388	3027	701	511	1212	221	192	413	4459	3540	7999						
35-54	75	64	139	1081	1087	2168	1469	1402	2871	788	667	1455	248	161	409	3661	3381	7042						
55 & over	38	46	84	396	423	819	514	601	1115	239	240	479	49	33	82	1236	1343	2579						
All ages	686	507	1193	6178	4648	10826	5196	4416	9612	2232	1764	3996	645	488	1133	14937	11823	26760						
0-4	2.07	1.68	1.88	0.71	0.35	0.54	0.56	0.48	0.52	0.19	0.11	0.15	0.05	0.08	0.07	3.59	2.70	3.16						
5-9	1.12	0.66	0.90	3.06	2.11	2.60	2.70	1.67	2.20	0.86	0.73	0.80	0.21	0.22	0.22	7.96	5.38	6.71						
10-14	0.20	0.14	0.17	6.63	3.94	5.32	3.09	2.02	2.57	1.03	0.67	0.86	0.24	0.14	0.19	11.20	6.92	9.12						
15-19	0.15	0.14	0.15	7.13	4.74	5.97	3.40	2.52	2.97	1.04	0.76	0.90	0.28	0.24	0.26	12.00	8.40	10.25						
20-34	0.21	0.14	0.17	4.47	3.42	3.94	4.03	3.41	3.72	1.73	1.26	1.49	0.54	0.47	0.51	10.98	8.70	9.83						
35-54	0.16	0.14	0.15	2.38	2.40	2.39	3.23	3.09	3.16	1.73	1.47	1.60	0.55	0.36	0.45	8.05	7.46	7.75						
55 & over	0.12	0.12	0.12	1.22	1.11	1.16	1.59	1.57	1.58	0.74	0.63	0.68	0.15	0.09	0.12	3.82	3.52	3.65						
All ages	0.38	0.28	0.33	3.43	2.55	2.99	2.89	2.42	2.65	1.24	0.97	1.10	0.36	0.27	0.31	8.30	6.48	7.38						

of intellectual disability since 1999 and stable, or slightly declining, prevalence rates in the 20-34 year age group. The data also demonstrate rising prevalence rates at all levels of intellectual disability in those aged 35 years and over.

The number of males at all levels of intellectual disability exceeds the number of females, with an overall male to female ratio of 1.26:1. This represents a prevalence rate of 8.30/1000 males and 6.48/1000 females.

Of the persons recorded on the National Intellectual Disability Database, 34% are aged 19 years and under, 30% are aged between 20 and 34 years, 26% are aged between 35 and 54 years, and 10% are 55 years of age and over. Figure 1 illustrates the numbers in each age group and the proportion with a moderate, severe or profound degree of intellectual disability.



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

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-six years. The total number of those more severely affected has risen from 11,256 in 1974 to 14,741 in 2000 (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 that this increase in both numbers and prevalence is reflected in the adult population only, as illustrated in Table 2.3.

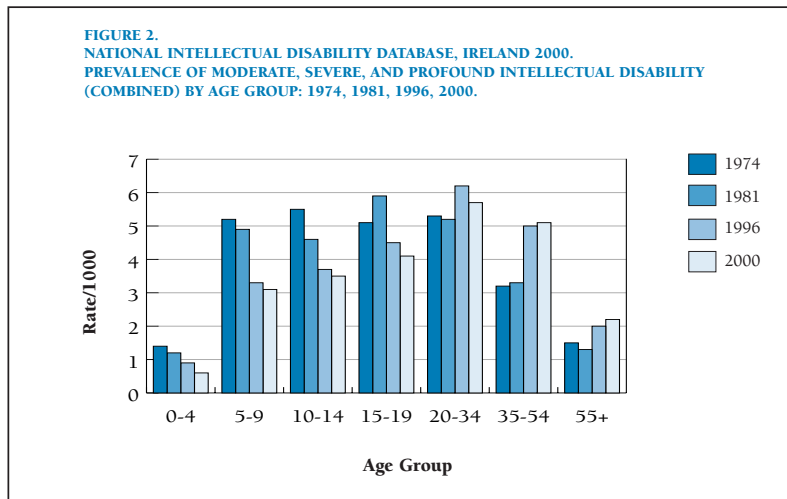
TABLE 2.3. NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
AGE AND DEGREE OF INTELLECTUAL DISABILITY (MODERATE, SEVERE AND PROFOUND) (COMBINED) - 1974, 1981, 2000.
NUMBERS AND PREVALENCE RATES PER 1,000.

NUMBERS												
Age Group	Moderate			Severe			Profound			All Levels		
	1974	1981	2000	1974	1981	2000	1974	1981	2000	1974	1981	2000
0-4	189	214	130	143	92	38	99	26	17	431	332	185
5-9	809	955	623	617	330	225	224	99	61	1650	1384	909
10-14	752	1035	838	583	428	280	292	117	63	1627	1580	1181
15-19	698	1203	1008	445	508	307	241	154	88	1384	1865	1403
20-34	1498	2419	3027	1017	1129	1212	441	340	413	2956	3888	4652
35-54	1321	1559	2871	626	612	1455	201	97	409	2148	2268	4735
55 & over	669	715	1115	307	248	479	84	24	82	1060	987	1676
All ages	5936	8100	9612	3738	3347	3996	1582	857	1133	11256	12304	14741
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	0.74
5-9	2.55	2.73	2.30	1.95	0.94	0.87	0.71	0.28	0.22	5.20	3.95	3.21
10-14	2.52	3.08	2.62	1.95	1.27	0.87	0.98	0.35	0.21	5.45	4.70	3.62
15-19	2.61	3.79	2.99	1.66	1.60	0.91	0.90	0.48	0.27	5.17	5.88	4.13
20-34	2.78	3.33	3.72	1.88	1.56	1.57	0.82	0.47	0.51	5.48	5.35	5.72
35-54	2.13	2.43	3.12	1.01	0.95	1.49	0.32	0.15	0.42	3.46	3.53	5.21
55 & over	1.08	1.09	1.53	0.50	0.38	0.62	0.14	0.04	0.10	1.71	1.51	2.38
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 twenty-six-year period, with fewer children and more adults currently availing of, or in need of, intellectual disability services. Figure 2 demonstrates an overall trend towards falling

prevalence rates of moderate, severe and profound intellectual disability in the younger age groups. The prevalence rate for the 0-4 age group, which had shown a slight increase over the 1981 rate in 1996, 1998, and 1999, is now lower than that reported in 1981. All four age groupings up to the age of 19 now show a distinct reduction in prevalence over the twenty-six-year period.

There is a population bulge, originating in the 1960s and lasting until the mid-1970s, currently moving through the intellectual disability services. The growth in numbers with intellectual disability during the 1960s and 1970s is attributed to a high birth rate and improved obstetric and paediatric care. Data from the previous Censuses of Mental Handicap allow us to monitor the progress of this group through the services. In 1974 there was a high prevalence rate in the 10-14 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 2000.



There is evidence of increased longevity in this population which has significant implications for service provision. By grouping people with moderate, severe and profound intellectual disability in the 35-54 and the 55-and-over age groups it can be seen that in 1974, 29% of this population, and in 1981, 27% of this population, were aged 35 years and over. By 1996, 38%

of persons with a moderate, severe or profound intellectual disability were aged 35 years and over, and in 2000 this age group accounts for 43% of the population.

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; and
- 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 2000 this has increased to 43%. 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 because of increased life expectancy,
 - the need for therapeutic support services for people who continue to live with their families to enable this caring arrangement to continue, and
 - an increased demand for more intensive services and for services designed specifically to meet the needs of older people with intellectual disability.

HEALTH BOARD LEVEL

Table 2.4 details the number of individuals included on each of the regional databases at April 2000. 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 2.5 summarises the number and proportion of people at each level of intellectual disability in each health board.

TABLE 2.4 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000. NUMBER OF PEOPLE INCLUDED ON EACH REGIONAL INTELLECTUAL DISABILITY DATABASE.

	n	%
Eastern Regional Health Authority	8420	31.5
Midland Health Board	1679	6.3
Mid-Western Health Board	2429	9.1
North-Eastern Health Board	2120	7.9
North-Western Health Board	1687	6.3
South-Eastern Health Board	3211	12.0
Southern Health board	3973	14.8
Western Health Board	3241	12.1
Total	26760	100.0

TABLE 2.5 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000. DEGREE OF INTELLECTUAL DISABILITY BY HEALTH BOARD AREA.

	Not Verified	Mild	Moderate	Severe	Profound	All Levels
	n %	n %	n %	n %	n %	n %
Eastern Regional Health Authority	537 6.4	3038 36.1	3216 38.2	1263 15.0	366 4.3	8420 100.0
Midland Health Board	26 1.5	734 43.7	669 39.8	206 12.3	44 2.6	1679 100.0
Mid-Western Health Board	40 1.6	1065 43.8	898 37.0	340 14.0	86 3.5	2429 100.0
North-Eastern Health Board	74 3.5	864 40.8	789 37.2	314 14.8	79 3.7	2120 100.0
North-Western Health Board	123 7.3	624 37.0	617 36.6	261 15.5	62 3.7	1687 100.0
South-Eastern Health Board	199 6.2	1368 42.6	1008 31.4	450 14.0	186 5.8	3211 100.0
Southern Health Board	111 2.8	1656 41.7	1362 34.3	603 15.2	241 6.1	3973 100.0
Western Health Board	83 2.6	1477 45.6	1053 32.5	559 17.2	69 2.1	3241 100.0
Total	1193 4.5	10826 40.5	9612 35.9	3996 14.9	1133 4.2	26760 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, the 0-19 years age groups can be compared with some confidence (Table 2.6). There is some variation in prevalence rates between health board areas. The prevalence of moderate, severe and profound intellectual disability in the 0-19 age group is highest in the Midland Health Board and lowest in the Eastern Regional Health Authority. These variations are most likely due to demographic factors such as higher migration from rural areas, later maternal age and large family size, and may also be the result of differences in ascertainment and classification practices.

TABLE 2.6 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000. GEOGRAPHICAL DISTRIBUTION AND AGE (MODERATE, SEVERE AND PROFOUND INTELLECTUAL DISABILITY COMBINED). NUMBERS AND PREVALENCE RATES PER 1000.

	0-4 years	5-9 years	10-14 years	15-19 years	0-19 years
	n rate	n rate	n rate	n rate	n rate
Eastern Regional Health Authority	34 0.38	259 2.68	380 3.55	427 3.62	1100 2.67
Midland Health Board	30 2.05	68 4.02	90 4.42	101 5.02	289 4.01
Mid-Western Health Board	17 0.78	75 3.03	118 4.02	133 4.34	343 3.22
North-Eastern Health Board	3 0.14	95 3.68	100 3.31	128 4.36	326 3.05
North-Western Health Board	9 0.62	58 3.35	65 3.23	84 4.21	216 3.00
South-Eastern Health Board	15 0.55	117 3.69	114 3.11	148 3.97	394 2.97
Southern Health Board	32 0.87	150 3.57	189 3.85	219 4.31	590 3.30
Western Health Board	45 1.94	87 3.12	125 3.75	163 4.88	420 3.57
All Regions Rate	185 0.74	909 3.21	1181 3.62	1403 4.13	3678 3.07

CURRENT SERVICE PROVISION

NATIONAL LEVEL

There are 24,035 people with intellectual disability currently in receipt of services, which accounts for 89.8% of the total population registered on the National Intellectual Disability Database, compared to 88.7% in 1999. A summary of the overall level of current service provision is provided in Table 3.1.

TABLE 3.1 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000. SUMMARY OF CURRENT SERVICE PROVISION.

	n	%
<i>Receiving day services</i>	15861	59.3
<i>Receiving 5-day or 7-day residential services</i>	7102	26.5
<i>Residents in Psychiatric Hospitals</i>	806	3.0
<i>Receiving residential support services only</i>	266	1.0
<i>Receiving no service</i>	475	1.8
<i>No current service requirements</i>	2250	8.4
Total	26760	100.0

Note: 3555 day attenders and 178 full-time residents receive residential support services in addition to their principal service
7049 residents receive a day service in addition to their residential service

The 2000 data indicate that 475 people (1.8%) are without services and have service needs in the period 2001-2005, details of which are presented in Chapter 4. This represents a reduction of 14% in the numbers in this category since 1999. Of this group, 65% are in the not verified and mild categories of intellectual disability. A further 2250 people (8.4%) have no identified requirement for services within this five-year period, of whom 67% are in the not verified and mild categories of intellectual disability. Of this group, 746 have their circumstances formally reviewed on an annual basis and 490 of the group have contingency service plans identified on the database. The appropriateness of registering people with mild intellectual disability on the database is being monitored on an ongoing basis, as the primary function of the database is to register only people who are currently in receipt of intellectual disability services or who require such services within a five-year period. Almost six out of every ten people who are without services and have no identified service requirements in the next five years 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 the group without services at present and not identified as requiring services between 2001 and 2005 have either a moderate, severe or profound degree of intellectual disability (740 people). Of this group, 320 have their circumstances formally reviewed on an annual basis and 220 of the group have contingency service plans identified on the database. Each year, following the national export of data, the health boards are requested to follow-up on the individual circumstances of these people. 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 current service provision in 1999 and 2000, there are 60 fewer people in receipt of intellectual disability services. However, there was an overall reduction of 398 registrants on the database during this twelve-month period, comprising mainly people with mild intellectual disability. Consequently, while the overall numbers in receipt of services was reduced by 60, the proportion in receipt of services increased from 88.7% to 89.8%.

Table 3.2 summarises current service provision in 2000 by degree of intellectual disability and age group.

Since 1999, the numbers in receipt of full-time residential services has increased by 146, of whom 136 have a moderate, severe or profound level of intellectual disability. The numbers resident in psychiatric hospitals have declined by 48 during the same period. The numbers in receipt of day services have reduced by 180 overall during the twelve-month period but this reduction is confined to people with a mild intellectual disability. The numbers of people in day services in both the not verified and the moderate/severe/profound categories increased during the period.

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 or profound levels of intellectual disability. Of those availing of services on a day basis, 49% are in the mild range of intellectual disability and 49% are aged 18 years and under. The majority of full-time residents (83%) have a moderate, severe or profound degree of disability, and 94% are aged 19 years and over. There are no residents under the age of eighteen in psychiatric hospitals, and 73% of the adult

**TABLE 3.2 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000
SUMMARY OF CURRENT SERVICE PROVISION BY DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP**

	Not verified			Mild			Moderate, Severe and Profound			All levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Receiving day services	731	166	897	4099	3619	7718	2968	4278	7246	7798	8063	15861
Receiving 5 or 7 day residential services	12	38	50	81	1064	1145	321	5586	5907	414	6688	7102
Residents in Psychiatric Hospitals	0	12	12	0	206	206	0	588	588	0	806	806
Receiving residential support services only	0	8	8	10	156	166	5	87	92	15	251	266
Receiving no service	12	15	27	31	249	280	17	151	168	60	415	475
No current service requirements	59	140	199	97	1214	1311	49	691	740	205	2045	2250
Total	814	379	1193	4318	6508	10826	3360	11381	14741	8492	18268	26760

residents have a moderate, severe or profound degree of intellectual disability. Of those currently without services who are wait-listed for services within the period 2001-2005, 59% are in the mild range of disability and 87% are aged 19 years and over. The group which has no requirements for service at this moment in time comprises mainly 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 2000. Almost two-thirds (62%) live in a home setting with parents, relatives, or foster parents. The remainder of the population (30%) live in full-time residential services, mainly residential centres, community group homes, and psychiatric hospitals, or they live independently or semi-independently (3%). There are 10 people registered on the database who have no fixed abode, a decrease of 6 since 1999. There is insufficient information on the residential circumstances of 1,598 people registered on the database, a reduction of just 60 people since 1999. This group needs to be reviewed in detail as a matter of urgency to improve the overall quality of data available from the National Intellectual Disability Database.

There are 7,902 people in receipt of full-time residential services, an increase of 92 people since 1999. Within this group, 2,921 live in community group homes, 3,535 are in residential centres and 425 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, 131 individuals live in de-designated units and 84 reside in nursing homes. There are 806 people with intellectual disability currently accommodated in psychiatric hospitals, a reduction of 48 (5.6%) since 1999.

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 64% of those aged between 20 and 34 years, 36% of those aged 35-54 years and 22% 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 27% of 20-34 year olds, 51% of 35-54 year olds, and 63% of those aged 55 years and over.

**TABLE 3.3 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
MAIN RESIDENTIAL CIRCUMSTANCES.**

	n	%
Home Setting	16563	61.9
At home with both parents	11680	43.6
At home with one parent	3317	12.4
At home with sibling	943	3.5
At home with other relative	316	1.2
Living with non-relative	42	0.2
Adoption	30	0.1
Foster care	235	0.9
Independent Setting	687	2.6
Lives independently	523	2.0
Living semi-independently	164	0.6
Community Group Homes	2921	10.9
5-day community group home	591	2.2
7-day (48-week) community group home	939	3.5
7-day (52-week) community group home	1391	5.2
Residential Centres	3535	13.2
5-day residential centre	191	0.7
7-day (48-week) residential centre	870	3.3
7-day (52-week) residential centre	2474	9.2
Other full-time services	1446	5.4
Nursing Home	84	0.3
De-designated Unit*	131	0.5
Psychiatric hospital	806	3.0
Intensive placement (Challenging Behaviour)	186	0.7
Intensive placement (Profound or Multiple Disability)	239	0.9
No fixed abode	10	0.0
Insufficient Information	1598	6.0
Total	26760	100.0

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

Of note in table 3.4 is the evidence that one-third of all people with intellectual disabilities aged 35 years and over continue to live with their families. As their caregivers age beyond their caregiving capacity, formal supervised living arrangements will need to be established. In addition, because people with intellectual disability are living longer, the likelihood of outliving their family caregivers has increased substantially in recent years. These data indicate the importance of planning for such eventualities and avoiding crisis situations.

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 (74%), compared to 51% of those with a moderate, severe or profound intellectual disability. In the more severe categories of disability, the proportion of people in full-time residential services is increased. Only 12% of people with a mild intellectual disability have a full-time residential placement but this increases to 44% 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, 55% are in community group homes, 23% 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, 49% are in residential centres and 17% are in other full-time residential placements.

DAY SERVICES

At present, 22,910 people, representing 85.6% of the total population with an intellectual disability, avail of day services. This represents a decrease of 154 people availing of day services since 1999 but, when this figure is interpreted in the context of the overall reduction in registrants on the database in the twelve-month period, it represents a proportional increase from 84.9% in 1999 to 85.6% in 2000. Of those availing of day services, 31% (7,049) 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 (94%). The remaining 69% (15,861) attend services on a daily basis, of whom 49% are in the mild range of intellectual disability and 49% are aged 18 years and under. The current data indicate that 859 full-time residents have no day activity programme and the identified day service needs of this group are addressed in Chapter 4.

	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
Residential Circumstances															
Home Setting	767	83	58	29	937	4390	2361	1060	230	8041	3182	2664	1437	302	7585
Independent Setting	0	9	15	9	33	3	160	259	101	523	0	13	83	35	131
Community Group Home	1	8	6	3	18	68	181	357	138	744	98	690	1116	255	2159
Residential Centre	9	4	5	6	24	20	72	111	108	311	239	907	1468	586	3200
Other full-time services	3	1	7	9	20	9	38	103	146	296	61	245	449	375	1130
No fixed abode	0	1	0	0	1	0	4	3	0	7	0	1	1	0	2
Insufficient information	51	33	48	28	160	141	392	275	96	904	98	132	181	123	534
Total	831	139	139	84	1193	4631	3208	2168	819	10826	3678	4652	4735	1676	14741
											9140	7999	7042	2579	26760

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

	Not Verified			Mild			Moderate, Severe and Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Residents	11	40	51	81	1134	1215	319	5464	5783	411	6638	7049
Day Attenders	731	166	897	4099	3619	7718	2968	4278	7246	7798	8063	15861
Total	742	206	948	4180	4753	8933	3287	9742	13029	8209	14701	22910

Of those availing of day services, 36% are aged 18 years and under, and 64% are 19 years and over. Almost four out of every ten people receiving day services have a mild intellectual disability while 57% 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 and profound intellectual disability who are availing of day services is aged 18 years or under, whereas almost one in two with mild intellectual disability who are availing of day services is a child. The higher number of children up to age 19 with mild intellectual disability reflects the number of children in special education, many of whom do not transfer to the adult intellectual disability services after school-going age.

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

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.

**TABLE 3.6 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
PRINCIPAL DAY SERVICE BY CATEGORY OF PERSONS AVAILING OF DAY SERVICES.**

	Residents	Day Attenders	Total
Home Support	1	296	297
Early Services	0	473	473
Ordinary pre-school	1	168	169
Special pre-school for intellectual disability	6	522	528
Child Education and Development Centre	92	485	577
Ordinary School	3	826	829
Resource Teacher	2	224	226
Special Class - primary level	16	722	738
Special Class - secondary level	12	209	221
Special School	308	4263	4571
Generic vocational training	22	185	207
Special vocational training centre	274	1450	1724
Activation Centre	3199	1482	4681
Programme for the Elderly	273	87	360
Special high-support day service	360	77	437
Special intensive day service	135	22	157
Sheltered work centre-includes long term training schemes	1861	2724	4585
Sheltered employment centre	14	99	113
Multidisciplinary support service	5	108	113
Centre-based day respite service	0	4	4
Other day service	245	565	810
Enclave within open employment	48	11	59
Supported employment	134	583	717
Open employment	21	176	197
Generic Day Services	17	80	97
Home Help	0	20	20
Total	7049	15861	22910

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

Special Education	24.1%
Sheltered Workshop/Employment	20.5%
Activation Centre	20.4%
Training	8.4%
Early Services/Pre-school	5.1%
Mainstream Education	4.6%
Supported/Open Employment	4.2%
High Support/Intensive Services	2.6%
Child Education and Development Centre (CEDC)	2.5%
Programme for the Elderly	1.6%
Home Support Services	1.3%
Other Day Services	4.6%

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 8,209 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, specialised high support or intensive programmes, home support and multidisciplinary services. Some children at the upper end of the age group have moved into training and employment placements. Just over half of the children availing of day services have a mild degree of intellectual disability, 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 more intensive services such as Child Education and Development Centres.

There are 14,701 adults currently availing of day services. Of this group, 32% have a mild degree of intellectual disability and 66% are in the more severe range. Most of the adults with a mild degree of intellectual disability who are registered on the database 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.

The principal day service being provided to 297 people (73 children and 224 adults) is a home support service, which can be as infrequent as once a month and is not considered to constitute a full day service. However, as indicated in the 1998/1999 Annual Report from the National Intellectual Disability Database, steps are being taken to address the needs of individuals who are considered to have an inadequate level of service. The impact of these measures is clearly demonstrated by the 24% reduction since 1999 in the numbers of people relying on Home Support Services for their main day service.

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 is 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. Since 1999, 256 more people are in receipt of residential support services, with the most notable increases in the number of people availing of planned or emergency respite care, centre-based holiday residential placements, regular part-time care, and semi-independent living, as illustrated in Figure 3.

The number of full-time residential placements increased by 92 in the period. Figure 3 demonstrates that the largest increases were in community-based group home placements, intensive placements for challenging behaviour and multiple disabilities and placements in

**TABLE 3.7 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
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	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	25	10	35	30	66	96	18	148	166	73	224	297
Early Services	282	0	282	91	0	91	99	1	100	472	1	473
Ordinary pre-school	55	0	55	70	1	71	42	1	43	167	2	169
Special pre-school for intellectual disability	148	0	148	134	0	134	242	4	246	524	4	528
Child Education and Development Centre	29	0	29	4	0	4	461	83	544	494	83	577
Ordinary school	31	1	32	607	44	651	143	3	146	781	48	829
Resource Teacher	62	0	62	128	4	132	28	4	32	218	8	226
Special class - primary level	13	0	13	502	29	531	188	6	194	703	35	738
Special class - secondary level	4	0	4	139	41	180	29	8	37	172	49	221
Special School	46	2	48	2342	147	2489	1901	133	2034	4289	282	4571
Generic vocational training	0	3	3	10	150	160	0	44	44	10	197	207
Special vocational training centre	3	55	58	15	831	846	5	815	820	23	1701	1724
Activation Centre	0	37	37	5	467	472	32	4140	4172	37	4644	4681
Programme for the Elderly	0	8	8	0	80	80	0	272	272	0	360	360
Special high support day service	4	3	7	7	26	33	32	365	397	43	394	437
Special intensive day service	1	3	4	8	6	14	9	130	139	18	139	157
Sheltered work centre	1	30	31	10	1745	1755	4	2795	2799	15	4570	4585
Sheltered employment centre	0	2	2	0	85	85	0	26	26	0	113	113
Multidisciplinary support service	8	1	9	5	59	64	4	36	40	17	96	113
Centre-based day respite service	0	1	1	0	0	0	0	3	3	0	4	4
Other day service	28	34	62	65	290	355	50	343	393	143	667	810
Enclave within open employment	0	0	0	0	16	16	0	43	43	0	59	59
Supported employment	0	12	12	4	442	446	0	239	239	4	713	717
Open employment	0	1	1	4	173	177	0	19	19	4	193	197
Generic Day Services	0	0	0	0	44	44	0	53	53	0	97	97
Home Help	2	3	5	0	7	7	0	8	8	2	18	20
Total	742	206	948	4180	4753	8933	3287	9742	13029	8209	14701	22910

nursing homes. There are 68 fewer people with intellectual disability resident in psychiatric hospitals and de-designated units than in 1999.

Table 3.9 provides details of the overall number of day services currently provided to people with intellectual disability. Since 1999 there has been an increase in the numbers of people availing of all day services with the exception of sheltered employment. In some areas of services provision these increases are substantial, as Figure 4 illustrates. Some of the largest proportional increases are observed in the areas of centre-based day respite services, multi-disciplinary support services, home help services, and generic day services. However, these increases are more than likely explained by the fact that these services have only been reported to the database over the past two years and, as would be expected, reporting of these services is more comprehensive in 2000 than it was in 1999. However, there are also substantial increases in the provision of generic vocational training (increased by 92% over the twelve-month period) and both supported and open employment opportunities (increased by 24% and 76% respectively over the period), reflecting the continued emphasis on the procurement of training and work experiences within the general employment field. The increased use of mainstream primary education facilities over the past decade is now reflected in increased use of similar facilities at secondary level. The numbers attending special classes in mainstream schools at secondary level increased by 63% between 1999 and 2000. The number of people accessing specialised services for the elderly in 2000 rose by 46%. The growing use of such services reflects the increasing numbers of older people with intellectual disability, as documented in Chapter 2.

The 1998/1999 Annual Report from the National Intellectual Disability Database identified a reduction in the overall number of home support services available to people with intellectual disabilities and their families since 1996. The numbers receiving home support services in 2000, while remaining lower than those recorded in 1996, have increased over the 1999 figures.

TABLE 3.8 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
OVERALL LEVEL OF CURRENT RESIDENTIAL SERVICE PROVISION, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.

	Not Verified			Mild			Moderate, Severe and Profound			All levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
5-day community group home	1	4	5	37	123	160	23	403	426	61	530	591
7-day (48 week) community group home	0	3	3	13	191	204	24	708	732	37	902	939
7-day (52 week) community group home	0	10	10	9	371	380	31	970	1001	40	1351	1391
5-day residential centre	2	0	2	2	20	22	34	133	167	38	153	191
7-day (48 week) residential centre	2	3	5	4	76	80	92	693	785	98	772	870
7-day (52 week) residential centre	5	12	17	12	197	209	67	2181	2248	84	2390	2474
Nursing Home	0	3	3	0	40	40	0	41	41	0	84	84
De-designated Unit	0	1	1	1	8	9	0	121	121	1	130	131
Psychiatric Hospital	0	12	12	0	206	206	0	588	588	0	806	806
Intensive Placement (Challenging Behaviour)	0	2	2	3	25	28	18	138	156	21	165	186
Intensive Placement (Profound or Multiple Disability)	2	0	2	0	13	13	32	192	224	34	205	239
Holiday residential placement	1	2	3	9	38	47	27	148	175	37	188	225
Crisis and Relief Centre	28	8	36	72	264	336	725	1133	1858	825	1405	2230
Occasional respite with host family	5	0	5	24	10	34	125	103	228	154	113	267
Shared care or guardianship	0	0	0	2	1	3	5	5	10	7	6	13
Regular part-time care (2/3 days per week)	0	0	0	5	7	12	18	25	43	23	32	55
Regular part-time care (every weekend)	0	0	0	0	3	3	5	10	15	5	13	18
Regular part-time care (alternate weeks)	0	0	0	2	6	8	7	41	48	9	47	56
Other residential service	1	2	3	58	67	125	43	99	142	102	168	270
Living semi-independently	0	8	8	1	108	109	0	47	47	1	163	164
Living independently	0	25	25	1	418	419	0	85	85	1	528	529

FIGURE 3.
NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
CHANGES IN LEVEL OF OVERALL CURRENT RESIDENTIAL SERVICE PROVISION 1999-2000.

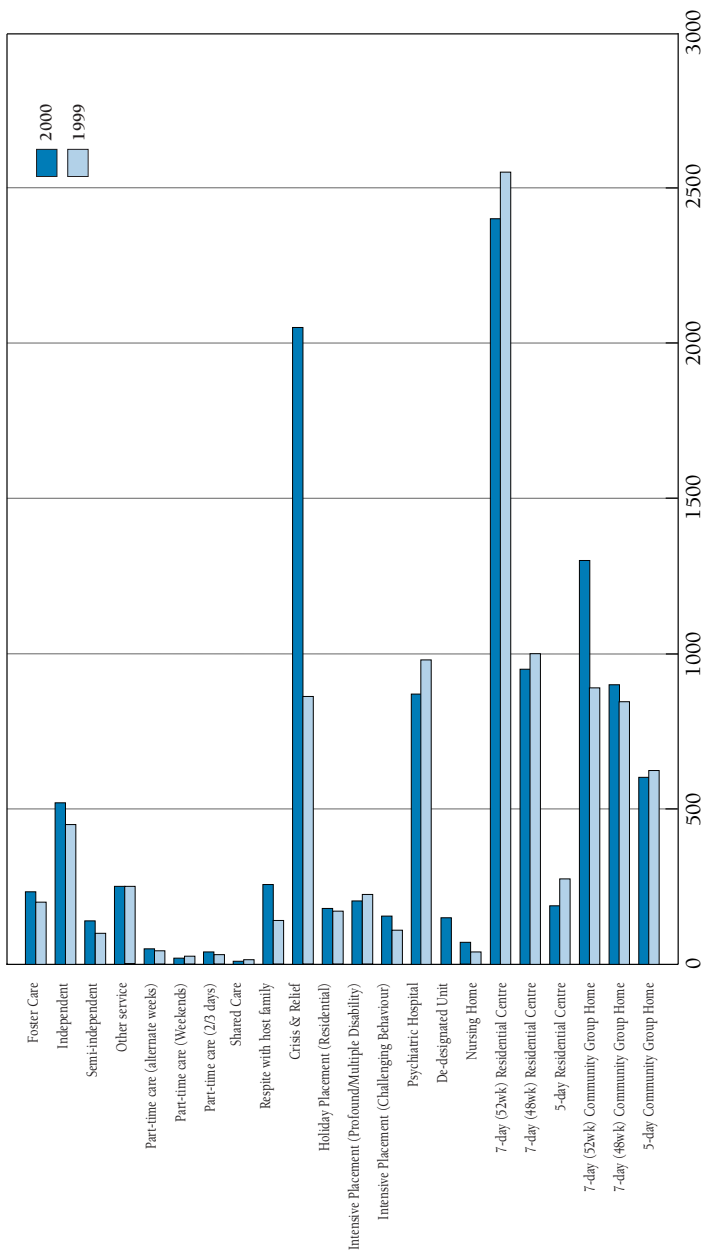
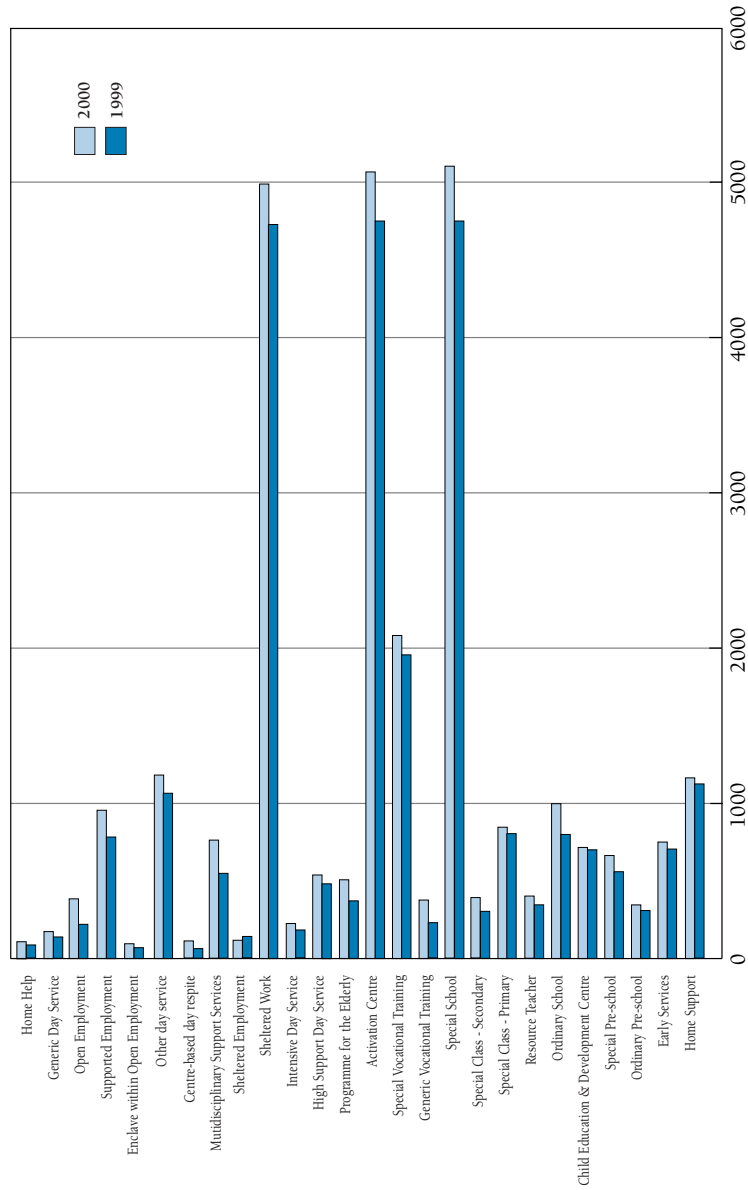


TABLE 3.9 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
OVERALL LEVEL OF CURRENT DAY SERVICE PROVISION, DEGREE OF INTELLECTUAL DISABILITY AND AGE GROUP.

	Not Verified			Mild			Moderate, Severe and Profound			All Levels		
	18 and under		All ages	18 and under		All ages	18 and under		All ages	18 and under		All ages
	19 and over			19 and over			19 and over			19 and over		
Home Support	75	14	89	121	147	268	376	417	793	572	578	1150
Early Services	406	0	406	164	1	165	198	1	199	768	2	770
Ordinary Pre-school	93	0	93	125	1	126	87	1	88	305	2	307
Special Pre-school	184	0	184	172	0	172	286	5	291	642	5	647
Child Education and Development Centre	37	0	37	6	2	8	535	101	636	578	103	681
Ordinary School	63	1	64	711	67	778	162	3	165	936	71	1007
Resource Teacher	75	3	78	178	31	209	44	16	60	297	50	347
Special Class - Primary	18	0	18	558	44	602	210	14	224	786	58	844
Special Class - Secondary	4	0	4	174	92	266	30	19	49	208	111	319
Special School	53	2	55	2502	338	2840	2033	179	2212	4588	519	5107
Generic Vocational Training	0	4	4	11	176	187	0	63	63	11	243	254
Special Vocational Training	5	71	76	37	1062	1099	14	869	883	56	2002	2058
Activation Centre	0	50	50	9	590	599	41	4386	4427	50	5026	5076
Programme for the Elderly	0	9	9	0	99	99	0	333	333	0	441	441
High Support Day Service	4	3	7	7	30	37	37	385	422	48	418	466
Intensive Day Service	7	6	13	8	10	18	10	144	154	25	160	185
Sheltered Work	2	39	41	11	1950	1961	5	2989	2994	18	4978	4996
Sheltered Employment	0	2	2	1	93	94	0	26	26	1	121	122
Multidisciplinary support service	29	2	31	267	209	476	186	111	297	482	322	804
Centre-based day respite programme	7	1	8	3	3	6	21	25	46	31	29	60
Other Day Service	56	45	101	138	461	599	135	432	567	329	938	1267
Enclave within open employment	0	0	0	0	18	18	0	47	47	0	63	65
Supported Employment	1	12	13	4	563	567	0	376	376	5	951	956
Open Employment	0	4	4	41	266	307	1	26	27	42	296	338
Generic Day Services	0	1	1	1	49	50	1	57	58	2	107	109
Home Help	13	5	18	5	14	19	32	12	44	50	31	81

FIGURE 4.
NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
CHANGES IN LEVEL OF OVERALL CURRENT DAY SERVICE PROVISION 1999-2000.



HEALTH BOARD LEVEL

Table 3.10 provides details of the current level of service provision within each health board region. Nationally, 89.8% of the population of people with an intellectual disability are known to be in receipt of services at present, 1.8% are currently without any service whatsoever but are wait-listed for services in the five-year period 2001-2005, and 8.4% are without services at present but are not identified as requiring services within the next five years.

Regionally, the highest level of service provision is in the South-Eastern Health Board where 99.0% of the population are currently receiving services. The lowest level of service provision is in the Eastern Regional Health Authority, where 83.7% of the registered population with intellectual disability are in receipt of services. Nationally, 29.6% of the database population receives a full-time residential service. Regionally, this proportion varies from 24.2% in the North-Eastern Health Board to 35.1% in the North-Western Health Board. At national level, 59.3% of the database population attend services on a daily basis and this proportion ranges from 51.5% in the Eastern Regional Health Authority to 70.5% in the South-Eastern Health Board.

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 (9.8%). The Eastern Regional Health Authority and the Southern Health Board have the lowest proportions wait-listed for services: both identify 0.4% of their population as being without services and requiring services between 2001 and 2005.

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. The Eastern Regional Health Authority has the highest proportion of individuals in this category at 15.9% of their registered population, and the South-Eastern Health Board has the lowest proportion at 0.3%. A critical appraisal of such individuals is required to establish both their possible need for services and the appropriateness of their registration on the National Intellectual Disability Database.

	Receiving day services	Receiving 5 or 7 day residential services	Resident in Psychiatric Hospitals	Receiving residential support services only	Receiving no service	No current service requirements	Total
	n %	n %	n %	n %	n %	n %	n %
Eastern Regional Health Authority	4338 51.5	2370 28.1	298 3.5	40 0.5	37 0.4	1337 15.9	8420 100.0
Midland Health Board	958 57.1	420 25.0	24 1.4	26 1.5	164 9.8	87 5.2	1679 100.0
Mid-Western Health Board	1577 64.9	623 25.6	106 4.4	15 0.6	46 1.9	62 2.6	2429 100.0
North-Eastern Health Board	1369 64.6	489 23.1	24 1.1	29 1.4	77 3.6	132 6.2	2120 100.0
North-Western Health Board	894 53.0	591 35.0	1 0.1	20 1.2	70 4.1	111 6.6	1687 100.0
South-Eastern Health Board	2263 70.5	773 24.1	143 4.5	1 0.0	21 0.7	10 0.3	3211 100.0
Southern Health Board	2610 65.7	1022 25.7	118 3.0	64 1.6	15 0.4	144 3.6	3973 100.0
Western Health Board	1852 57.1	814 25.1	92 2.8	71 2.2	45 1.4	367 11.3	3241 100.0
All Boards	15861 59.3	7102 26.5	806 3.0	266 1.0	475 1.8	2250 8.4	26760 100.0

CHAPTER 4

ASSESSMENT OF NEED 2001-2005

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 2001-2005.

Service Change: describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2001-2005 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 2,500 people will require major elements of service, either a full-time residential service or a day service, or both, in the five-year period 2001-2005. Of this group, 462 have no service and require full-time residential and/or day services; 1,621 receive a day service but require a residential service, 342 people receive a residential service but also require a day service and 75 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.

Residential Support Services

The data indicate that 991 people are in need of residential support services only in the period 2001-2005. Table 4.2 provides a breakdown of this group by level of disability.

	No current service	Receives minimal residential support only	Receives day only - requires residential	Receives residential only - requires day	Total
Not Verified	27	6	26	3	62
Mild	279	38	340	26	683
Mod-Sev-Prof	156	31	1255	313	1755
All levels	462^a	75^b	1621	342	2500

^a Of this total, 52 require residential and day, 12 require residential only and 398 require day only.

^b Of this total, 20 require residential and day, 6 require residential only and 49 require day only.

	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	38	1	0	39
Mild	1	373	38	1	413
Mod-Sev-Prof	12	479	48	0	539
All levels	13	890	87	1	991

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	1711
Day	861
Residential Support	1014^a

^a 22 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 residential service and requires a day service will also need a residential support service.

YEAR IN WHICH SERVICE NEEDS ARISE

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

	2001	2002	2003	2004	2005	All years
Residential	1373	120	126	42	50	1711
Day	539	310	4	6	2	861
Residential Support	913	52	27	13	9	1014

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

Of the group that requires full-time residential services, 76% consists of people in the moderate, severe and profound ranges of intellectual disability and 22% consists of people with mild intellectual disability. Most of the sub-group with moderate, severe and profound intellectual disabilities (72%) require residential placements in community group homes, 17% require residential accommodation in a campus setting and 11% need specialised intensive placements because of their increased dependency. Within the sub-group with mild intellectual disability, 87% require community-based placements, 8% require placements in traditional-style residential centres and 5% require intensive placements (Table 4.5).

Demand for day services is confined almost exclusively to adult services. The largest demand for day services comes from people who have no service whatsoever at the moment. Most of this group (61%) have a mild intellectual disability and their principal service requirements are in the training and employment fields. The remainder of the group mainly fall into the moderate, severe and profound range of intellectual disability and require activation programmes, sheltered work and programmes specifically designed for older people. The other large group with day service needs are people who are in full-time residential services but do

**TABLE 4.5 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
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	3	2	5	0	0	0	0	4	94	191	289	294
7-day (48-week) community group home	1	4	4	9	1	2	0	3	7	69	257	333	345
7-day (52-week) community group home	2	11	18	31	0	7	10	17	5	132	460	597	645
5-day residential centre	0	0	1	1	0	0	0	0	0	3	17	20	21
7-day (48-week) residential centre	0	0	3	3	0	1	1	2	2	8	50	60	65
7-day (52-week) residential centre	0	2	2	4	0	1	1	2	5	14	147	166	172
Nursing Home	0	1	4	5	0	0	1	1	1	2	0	3	9
Intensive placement (Challenging Behaviour)	1	1	3	5	0	0	0	0	2	11	75	88	93
Intensive placement (Profound or Multiple Disability)	0	0	1	1	0	0	1	1	0	7	58	65	67
All Services	4	22	38	64	1	11	14	26	26	340	1255	1621	1711

**TABLE 4.6 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
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	2	7	9	1	0	0	1	0	0	0	0	10
Early Services	4	0	0	4	0	0	0	0	0	0	0	0	4
Ordinary pre-school	3	0	0	4	0	0	0	0	0	0	0	0	4
Special pre-school	3	1	3	7	0	0	0	0	1	0	0	1	8
Child Education and Development Centre	0	0	3	3	0	1	1	2	0	0	0	0	5
Resource Teacher	0	1	2	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	0	5	0	5	0	0	0	0	0	0	0	0	5
Generic vocational training	0	8	2	10	0	2	0	2	0	1	0	1	13
Special vocational training	3	58	12	73	0	7	3	10	0	0	0	0	83
Activation Centre	2	19	50	71	1	3	11	15	2	6	108	116	202
Programme for the Elderly	0	9	19	28	0	5	3	8	0	13	86	99	135
Special high support day service	0	1	4	5	0	0	3	3	0	0	54	54	62
Special intensive day service	1	1	4	6	0	1	1	2	0	1	61	62	70
Sheltered work centre	2	43	25	70	2	7	4	13	0	4	3	7	90
Sheltered employment centre	0	16	4	20	1	3	0	4	0	1	0	1	25
Multidisciplinary support services	1	1	0	2	0	0	0	0	0	0	0	0	2
Other day service	0	1	3	4	0	2	0	2	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	87	5	95	0	3	1	4	0	0	1	1	100
Open employment	2	17	1	20	0	1	0	1	0	0	0	0	21
Generic Day Services	0	0	1	1	0	1	0	1	0	0	0	0	2
Home Help	0	0	3	3	0	1	0	1	0	0	0	0	4
All Services	26	276	148	450	5	37	27	69	3	26	313	342	861

**TABLE 4.7 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
FUTURE RESIDENTIAL SUPPORT SERVICE REQUIREMENTS OF INDIVIDUALS CURRENTLY RECEIVING NO RESIDENTIAL SUPPORT SERVICES.**

	No Current service - requires residential support			Receives day service - requires residential support			Receives residential service - requires residential support			Receives residential and day service - requires residential support			Overall need			
	NV	MILD	MSP ALL	NV	MILD	MSP ALL	NV	MILD	MSP ALL	NV	MILD	MSP ALL				
Foster Care	0	0	0	0	2	1	3	0	0	0	0	0	1	1	4	
Living Independently	1	1	3	2	32	4	38	0	0	0	0	2	1	3	44	
Living semi-independently	1	3	1	5	1	66	13	80	0	2	0	2	28	20	136	
Holiday residential placement	0	0	4	4	1	20	25	46	0	0	0	0	3	12	65	
Crisis and Relief Centre	1	6	15	22	26	160	307	493	0	0	0	0	2	8	525	
Occasional respite care with host family	0	0	1	1	7	78	103	188	0	0	0	0	0	3	192	
Shared care or guardianship	0	0	0	0	0	1	0	1	0	0	0	0	1	1	3	
Regular part-time care (2/3 days per week)	0	0	0	0	1	5	5	11	0	0	0	0	1	0	12	
Regular part-time care (every weekend)	0	0	0	0	0	2	3	5	0	0	0	0	0	1	6	
Regular part-time care (alternate weeks)	0	0	0	0	0	6	16	22	0	0	0	0	0	0	22	
Other residential service	0	0	0	0	0	1	2	3	0	0	0	0	1	1	5	
All Services	3	10	22	35	38	373	479	890	0	2	0	2	1	38	48	1014

not have access to formal day programmes. Most of this group (92%) 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. People with moderate, severe and profound intellectual disabilities account for 54% of the demand for residential support services while people with mild intellectual disability account for 42%. Most of the demand (71%) is for centre- and home-based respite services. A further 18% require independent and semi-independent living placements.

SERVICE CHANGE

The term *service change* describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2001-2005, 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 centres 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 9,678 people who currently receive services will require a change in their current service provision in the period 2001-2005. Of this group, 6,083 are day attenders (of whom 1,195 also avail of residential support services), 3,591 are full-time residents (of whom 3,557 also avail of day services and 112 avail of residential support services) and 4 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	5	2	453	6	1	467
Mild	172	96	3281	39	44	3632
Mod-Sev-Prof	1249	551	3500	171	108	5579
All levels	1426	649	7234	216	153	9678

There are 1,685 people included in the data presented in the previous 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 in addressing the required service changes is summarised in Table 4.9. The number of places required exceeds the number of people requiring services changes as some people require to change both their residential and day services.

Residential	2075
Day	8876
Of which:	
Health Services	6042
Education Services	1480
Employment Services	1182
Other Generic Services	172
Residential Support	369

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.

	2001	2002	2003	2004	2005	All years
Residential	1815	57	74	110	19	2075
Day	6999	776	623	346	132	8876
Of which:						
Health Services	4774	472	427	259	110	6042
Education Services	1191	154	75	48	12	1480
Employment Services	933	130	83	28	8	1182
Other Generic Services	101	20	38	11	2	172
Residential Support	353	10	2	3	1	369

It is important to note that although 9,678 people require service changes, this does not translate into 9,678 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 2,075 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 (1,534 people) a change of service is required. The largest group (536 individuals) requires intensive services for either challenging behaviour or profound or multiple disability, 520 people would be more appropriately accommodated in residential placements in the community, 82 people require centre-based placements, 25 people need

**TABLE 4.11 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
PATTERN OF MOVEMENT OF INDIVIDUALS FROM CURRENT RESIDENTIAL SERVICE TO FUTURE RESIDENTIAL SERVICE 2001-2005.**

	Full-time residential service required in the period 2001-2005.											Total Current Services
	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 (CGB)	Int. placement (P/M/D)		
Current full-time residential service:												
5-day Community Group Home	15	80	86	4	5	3	0	0	4	1	198	
7-day (48-week) Community Group Home	1	55	77	1	5	7	1	0	7	1	155	
7-day (52-week) Community Group Home	5	4	120	0	4	10	7	0	39	30	219	
5-day Residential Centre	27	13	9	8	39	11	0	1	14	6	128	
7-day (48-week) Residential Centre	8	106	35	2	79	53	0	0	37	11	331	
7-day (52-week) Residential Centre	0	38	224	2	10	199	5	0	164	130	772	
Nursing Home	0	0	10	0	1	0	0	0	0	3	14	
De-designated Unit	1	1	31	0	0	26	10	0	18	6	93	
Intensive placement (Challenging Behaviour)	0	4	6	0	1	0	2	0	34	4	51	
Intensive placement (Profound/Multiple Disability)	0	2	5	0	1	14	0	0	61	31	114	
Total Services Required	57	303	603	17	145	323	25	1	378	223	2075	

placements in nursing homes and 1 person is identified as needing admission to a psychiatric hospital. There are 346 individuals who need their service upgraded to include care at weekends and holiday times and 24 people require less care and could return to their families at weekends and holiday times.

Furthermore, there is a group of 541 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 closer to their family home or need to transfer 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.

DAY SERVICE CHANGE

Within the next five years, 8,876 individuals will require a change, enhancement, or upgrading of their day service. Health-funded services are required in 68% of the changes, 17% involve educational services, 13% involve employment services, and 2% involve generic services. A detailed breakdown of these service requirements is provided in Table 4.12.

Health funded services

CHILDRENS SERVICES

Of the 6,042 service changes required within the health-funded services, those in respect of just 7% (433 individuals) are specifically identifiable as children's services.

379 children require alternative or additional day services. Most of the demand is for mainstream and specialised pre-school services (295 children) and the majority of these children are currently in receipt of early services. The balance of the demand is for placements in child education and development centres (83 children), and most of the children requiring these placements are currently receiving early services, special pre-school services or are attending special schools.

There are 54 children who need to have their existing day service enhanced. These children are currently receiving early services, or are attending mainstream pre-schools, specialised pre-schools, or child education and development centres. Most of these children need an increased

amount of service, a higher level of supervision within that service or to receive their service closer to their family home.

ADULT SERVICES

There are 5,609 adults currently receiving services funded from the health budget who will require an upgrading or change of service within the next five years.

There are 4,387 individuals who require alternative or additional day services between 2001 and 2005. Special vocational training programmes are required by 1,061 individuals, the majority of whom (83%) are currently attending special schools. Sheltered work placements are required by 938 individuals, most of whom are currently attending special schools (38%) or are in receipt of special vocational training (36%). Within the more care-focused services, demand is mainly for activation programmes (788 people), high-support or intensive placements (743 people) and programmes designed specifically to address the needs of older people with intellectual disability (474 people). Demand for activation programmes stems from three main groups, those currently attending special schools (29%), in sheltered work centres (26%) or attending child education and development centres (15%). Individuals who are currently receiving activation programmes require the majority of the high-support and intensive placements (62%). Programmes to meet the needs of older people with intellectual disability are required primarily by individuals currently in activation programmes (56%) or attending sheltered work centres (26%).

There are 1,222 individuals who need to have their existing day service enhanced. Most of this group are currently receiving activation programmes (60%) or attending sheltered work centres (25%). Of the 1,222 who require enhanced day services, the majority (64%) require increased supervision, and smaller proportions need an increased amount of service (10%) or to receive their service closer to home (9%).

Educational services

Alternative or enhanced educational services will be required by 1,480 children in the period 2001-2005.

1,277 children require alternative or additional educational services. Most of the demand is for special classes at secondary level (38%) or for special school placements (28%). Of the group

requiring special classes at secondary level, most are currently in special classes at primary level (68%) or in mainstream classes (24%). Of those requiring places in special schools, most are currently in special pre-schools (48%) with smaller proportions in mainstream pre-schools, mainstream and special classes at primary level, accessing the services of resource teachers or attending child education and development centres. The remaining services required by the overall group of 1,277 children include special classes at primary level (13% - the majority of whom are currently in special pre-schools and mainstream classes), resource teachers (11% - the majority of whom are currently in mainstream classes) and mainstream school placements (10% - the majority of whom are in mainstream pre-schools and special pre-schools at present).

203 children need their current educational placement to be enhanced in the period 2001-2005. These needs arise among children currently attending special schools (122 children), availing of the services of a resource teacher (47 children), attending mainstream classes (24 children), and in special classes at primary level (8 children) and secondary level (2 children). Most (46%) are identified as requiring their existing services which are delivered at primary school level to be carried through to secondary level. There is also a demand for increased supervision within existing school placements (23%).

Employment services

There are 1,182 individuals who will require access to new or enhanced employment opportunities during the period 2001-2005.

A total of 1,155 of this group will require new employment opportunities. Supported employment placements are required for 932 individuals (81%). These individuals currently avail of sheltered work (336 individuals), special vocational training (332 individuals), or attend special schools (102 individuals). There are 185 people who require open employment and at present they are mainly in special vocational training (90 people), special schools (45 people), and supported employment (24 people). The remainder of the group requiring new employment opportunities (38 people) requires placements in enclaves within open employment. At the moment, most of this group attend special schools (18 people), sheltered work centres (7 people), or special vocational training (7 people).

There are 27 individuals who need to have their existing employment placement enhanced. Of

this group, 23 are in supported employment, 3 are in open employment and one is in an enclave within open employment and most of the enhancements identified relate to increased supervision within these placements.

Generic services

There is a much smaller group of 172 individuals who require access to generic day services during the period 2001-2005 or who need to have their existing placement within the generic services enhanced.

Of this group, 170 require new placements within the generic services. A total of 158 individuals require generic vocational training opportunities and 12 require access to other, unspecified, generic day services. Of the group requiring generic vocational training, most are currently in special schools (85 individuals), special classes at secondary level (14 individuals), or are receiving special vocational training (18 individuals). Of the group requiring access to other unspecified generic day services, the largest sub-group is currently in activation programmes (5 individuals).

Two individuals currently in receipt of generic vocational training require their existing service to be enhanced in the period 2001-2005.

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. However, in relation to day services, certain existing services, for example, early intervention services and home support services, will not necessarily be freed up when a 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 Services.

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

RESIDENTIAL SUPPORT SERVICE CHANGE

The database indicates that 369 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 2001-2005. Additional or alternative support services are required by 181 individuals, and 188 individuals require their existing service to be upgraded. An analysis of these service requirements is outlined in Table 4.13.

The principal needs of this group include

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

**TABLE 4.12 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000
PATTERN OF MOVEMENT OF INDIVIDUALS FROM CURRENT DAY SERVICE 2001-2003.**

Current Day Service:	Day service required in the period 2001-2005																											
	HS	ES	OPS	SFS	CEDC	OS	RT	SCP	SCS	SS	SVT	AC	PE	SHS	SI	SWC	SEC	MS	DR	OTH	E	SE	OE	GVT	GD	HH	ALL	
Home support (HS)	8	0	12	22	4	7	0	0	0	7	2	16	6	0	1	15	0	0	0	0	0	0	1	0	0	0	0	101
Early Services (ES)	2	2	82	109	12	15	13	11	0	12	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	259
Ordinary pre-school (OPS)	5	0	3	7	2	44	11	23	0	33	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	128
Special pre-school (SPS)	6	1	19	24	40	31	17	67	0	170	2	0	0	0	1	0	0	2	0	3	0	0	0	0	0	0	0	383
Child Education and Development Centre (CEDC)	4	0	0	1	25	0	0	8	1	24	1	122	0	13	10	0	1	0	0	0	0	0	0	0	0	0	0	210
Ordinary school (OS)	5	0	0	1	0	24	92	49	118	33	25	2	0	0	0	3	2	2	0	36	2	4	0	11	0	0	409	
Resource Teacher (RT)	1	0	12	0	2	25	47	3	28	35	7	0	0	0	0	0	0	21	0	0	0	2	0	3	0	0	186	
Special class - primary (SCP)	4	0	0	0	2	4	8	8	332	25	19	6	0	0	2	15	0	7	0	9	0	3	2	9	0	0	455	
Special class - secondary (SCS)	0	0	0	0	0	0	0	0	2	1	38	16	0	0	12	0	0	0	7	2	5	0	14	0	0	0	97	
Special School (SS)	44	0	1	0	16	1	0	4	7	122	883	225	0	38	40	354	24	10	2	18	18	102	45	85	0	0	2039	
Special Vocational training (SVT)	0	0	0	0	1	0	0	0	0	0	44	85	7	7	3	333	17	1	0	2	7	332	90	18	2	0	949	
Activation Centre (AC)	6	0	0	0	0	0	1	0	1	16	731	266	139	319	128	8	0	0	0	0	0	64	3	4	5	0	1691	
Programme for the Elderly (PE)	0	0	0	0	0	0	0	0	0	0	4	77	1	1	2	0	0	0	1	0	0	0	0	0	0	1	0	87
Special High Support Service (SHS)	1	0	0	0	0	0	1	0	0	7	0	23	2	29	123	1	3	0	0	0	0	0	0	0	0	0	0	189
Special Intensive Service (SI)	1	0	0	0	0	0	0	0	1	0	4	1	0	26	1	0	0	0	0	0	0	0	0	0	0	0	0	34
Sheltered Work Centre (SWC)	2	0	0	0	0	0	0	0	0	36	208	144	17	11	301	76	0	1	5	7	336	13	6	1	0	0	1164	
Sheltered Employment Centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	36	0	0	0	0	36	
Multi-disciplinary Supports (MS)	0	0	0	5	0	0	0	1	0	1	7	4	2	2	2	4	0	5	0	4	0	8	0	0	0	0	1	46
Other day service (OTH)	2	0	2	21	3	2	0	0	0	3	12	49	27	4	8	29	3	0	0	1	1	13	4	2	0	0	100	
Enclave within open employment (E)	0	0	0	0	0	0	0	0	0	0	0	2	12	0	0	0	0	0	0	5	1	0	0	0	0	0	0	20
Supported employment (SE)	0	0	0	0	0	0	0	0	0	0	5	0	5	0	1	0	2	1	0	14	0	23	24	2	0	0	0	77
Open employment (OE)	0	0	0	0	0	0	0	0	0	0	2	2	0	0	0	0	2	1	0	0	0	3	3	1	0	0	0	23
General Vocational Training (GVT)	0	0	0	0	0	0	0	0	0	0	4	3	0	0	0	31	9	0	0	0	1	22	4	2	0	0	0	76
Generic Day Service (GD)	0	0	0	0	0	0	0	0	0	2	15	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	19
Home Help (HH)	1	0	0	1	1	0	0	0	0	0	0	2	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	8
All Services	91	3	131	191	108	153	190	174	488	475	1105	1519	551	230	548	1239	147	50	3	105	39	935	188	160	12	1	1	8876

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 2000.

RESIDENTIAL SUPPORT SERVICES REQUIRED BY PEOPLE CURRENTLY AVAILING OF RESIDENTIAL SUPPORT SERVICES.

Current residential Support service	Residential Support Service required 2001-2005.										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	4	1	9	5	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	20		
Living independently	0	2	11	1	4	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	20	
Living Semi-independently	0	0	12	1	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	14	
Holiday residential placement	0	0	0	2	2	8	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	3	16	
Crisis & Relief Centre	2	0	9	7	161	12	1	1	17	4	11	4	4	0	0	0	0	0	0	0	0	0	0	0	2	226
Occasional respite care (host family)	0	0	0	8	32	5	0	0	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	54
Shared care /guardianship	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
Regular part-time care (2/3 days per week)	0	0	0	0	3	0	0	0	4	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	9
Regular part-time care (every weekend)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Regular part-time care (alternate weeks)	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	3
Other residential service	1	0	1	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4
All Services	5	2	37	20	215	30	2	26	7	18	7	18	160	12	1	369										

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 806 individuals with intellectual disability, 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.

	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	23	61	84	4	48	209	261	345
Resident in Psychiatric Hospital - with day programme	3	61	159	223	5	73	159	237	460
Resident in Psychiatric Hospital - with day programme and Residential Support	0	1	0	1	0	0	0	0	1
All residents	3	85	220	308	9	121	368	498	806

For 308 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 2001-2005. Of this group, 28% have a mild intellectual disability and 71% have a moderate, severe or profound disability. Within this group are 84 people who currently have no formal day programme (27% mild disability, 73% moderate, severe or profound disability). The day service needs of this group, and the overall service needs of people currently considered to be appropriately accommodated in psychiatric hospitals, need to be reviewed.

Of the remaining 498 who require services, 27 will continue to reside within the psychiatric hospital setting. Of this group, 33% have a mild intellectual disability and 67% have a moderate, severe or profound intellectual disability. Of this group of 27 people, 25 will require appropriate day services in the period 2001-2005. At present, 8 of this group have no day service and require home support services (3 people), activation programmes (2 people), a programme for older people (2 people) and one person requires special vocational training. The remaining 17 are in receipt of day programmes that need to be enhanced or upgraded, as outlined in Table 4.15. Activation programmes are required by 7 individuals, 5 require specific programmes designed for older people, 4 require high-support services, and one requires home support services.

In addition, 3 of this group of 27 people will also require residential support services within the period. One needs respite care, 1 needs shared care and one needs an unspecified residential support service.

Services required:	Home support	Special vocational training	Activation Centre	Programme for the Elderly	Special high support day service	All services
Currently receiving:						
No day programme	3	1	2	2	0	8
Activation Centre	0	0	0	0	1	1
Programme for the Elderly	1	0	1	0	0	2
Other day programme	0	0	6	5	3	14
All services	4	1	9	7	4	25

Of the population currently resident in psychiatric hospitals, 471 need to transfer to the intellectual disability services. Of this group, 24% have a mild intellectual disability, 74% have a moderate, severe or profound intellectual disability and 2% have not had their level of disability verified. The majority (341 people) will require residential and day placements and 130 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.

TABLE 4.16 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000. RESIDENTIAL SERVICE REQUIREMENTS OF PEOPLE CURRENTLY RESIDENT IN PSYCHIATRIC HOSPITALS WHO REQUIRE TO BE TRANSFERRED TO THE INTELLECTUAL DISABILITY SECTOR.				
	Year in which residential service is required			
	2001	2004	2005	2001-2005
5-day Community Group Home	1	0	0	1
7-day (48-week) Community Group Home	3	0	0	3
7-day (52-week) Community Group Home	113	0	0	113
7-day (48-week) Residential Centre	10	0	0	10
7-day (52-week) Residential Centre	108	1	1	110
Nursing Home	14	0	0	14
Intensive placement (Challenging Behaviour)	127	0	0	127
Intensive placement (Profound/Multiple Disability)	66	0	0	66
Unspecified intellectual disability service	27	0	0	27
All residential services	469	1	1	471

Of the 471 people who need to transfer from psychiatric to intellectual disability services for their residential services, 41% will require intensive placements (two-thirds of these need to be specially designed to cater for challenging behaviours), 25% will require community group home places, 25% need places in residential centres, and 3% need to move into nursing homes. A further 6% have an unspecified residential requirement within the intellectual disability services. Almost all of the need arises immediately.

Of the 471 people who need to transfer to intellectual disability services for their residential service, 341 will also require an appropriate day service. The greatest demand is for home support services (43%), followed by activation programmes (25%), high-support or intensive day programmes (25%), a programme for older people (4%), sheltered work placements (3%), sheltered employment placements (1%) and one person needs special vocational training. As with the demand for residential services, the vast majority of day services are required immediately.

TABLE 4.17 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000. 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			
	2001	2002	2005	2001-2005
Home support	143	1	1	145
Special vocational training	1	0	0	1
Activation Centre	84	0	0	84
Programme for the Elderly	12	0	0	12
Special high support day service	73	0	0	73
Special intensive day service	14	0	0	14
Sheltered work centre	9	0	0	9
Sheltered employment centre	3	0	0	3
All day services	339	1	1	341

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 enhancement 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 full-time residential services over the next five years comes from three distinct groups:

- 1,711 individuals currently living at home who require full-time residential services for the first time,
- 471 individuals currently resident in psychiatric hospitals who require to transfer to the intellectual disability services, and
- 2,075 individuals currently in full-time residential services within the intellectual disability sector who require changes to their existing placement. Of this group, 1,534 require alternative services and 541 require their existing service to be enhanced. When placed in their new services, this group will free up places for use by the previous two groups. Not all of the group which requires service enhancement will move to new placements. For example, 295 out of the 541 individuals require increased supervision in their existing placements. However, they have been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading their services.

Table 4.18 outlines the pattern of full-time residential service provision that will be required in the period 2001-2005 to meet this demand. A total of 2,182 residential places will be required - an increase of 12 since 1999. 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, 1,792 community-based placements will be required during the period, a reduction of 126 on projections made in 1999. One consequence of this will be the availability of 368 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 789 intensive residential placements that will occur. Demand for such placements has increased by 51 since 1999. 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 2000.
PATTERN OF FULL-TIME RESIDENTIAL SERVICE PROVISION REQUIRED 2001-2005.**

	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	294	1	57	198	-154
7-day (48-week) Community Group Home	345	3	303	155	-496
7-day (52-week) Community Group Home	645	113	603	219	-1142
5-day Residential Centre	21	0	17	128	90
7-day (48-week) Residential Centre	65	10	145	331	111
7-day (52-week) Residential Centre	172	110	323	772	167
Nursing Home	9	14	25	14	-34
De-designated Unit	0	0	0	93	93
Psychiatric Hospital	0	0	1	0	-1
Intensive placement (Challenging Behaviour)	93	127	378	51	-547
Intensive placement (Profound/Multiple Disability)	67	66	223	114	-242
Unspecified intellectual disability service	0	27	0	0	-27
Total	1711	471	2075	2075	-2182

PATTERN OF CARE REQUIRED IN DAY SERVICES

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

- 861 individuals currently without day services,
- 341 individuals currently resident in psychiatric hospitals who will require an appropriate day service when they transfer to the intellectual disability services,
- 25 individuals appropriately placed in psychiatric hospitals but requiring a day programme within that setting, and
- 8,876 individuals currently in day services within the intellectual disability sector who require changes to, or enhancement of, their existing placement. Of this group 7,368 require alternative or additional services and 1,508 require their existing service to be enhanced. 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. Not all of the group which requires service enhancement will move to new placements. Again, as was seen with the requirement for enhancement of residential placements, 860 out of the 1,508 identified individuals require increased supervision in their existing placements. However, the entire group has been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading their services.

Table 4.19 outlines the pattern of day service provision that will be required in the period 2001-2005 to meet demand. The data in the table have been adjusted to reflect the fact that not all existing services will be freed up. A total of 1,827 day places will be required - a reduction of 502 since 1999. The table shows two distinct trends - a decrease in the numbers of young children requiring certain services and a huge demand for the full spectrum of adult services.

Over the next five years there will be small reductions nationally in the number of children requiring special pre-school services, mainstream classes and special classes at primary level and placements in child education and development centres. There will be a significant reduction in the number of children requiring special schools. However, there is a small demand within this group for mainstream pre-school services and early 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 2001-2005, 97 generic vocational training places and 241 special vocational training places will be required. Over the next five years, 978 supported employment placements and 186 open employment placements need to be developed to meet the demand that exists for those services. There will also be a shortfall of 174 sheltered work and 139 sheltered employment opportunities during this time. An additional 123 places in activation centres are needed, as are 618 programme placements designed specifically to meet the needs of older people with intellectual disability. Home support services will be required by an additional 250 people during the period. As with residential services, there is significant demand for high-support and intensive placements. Between 2001 and 2005, 200 high-support day placements and 598 intensive day placements will be required. These services involve a higher staff to client ratio and more specialist intervention to address needs arising from behavioural problems, multiple disabilities and the effects of ageing.

**TABLE 4.19 NATIONAL INTELLECTUAL DISABILITY DATABASE, IRELAND 2000.
PATTERN OF DAY SERVICE PROVISION REQUIRED 2001-2005.**

	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	10	145	4	91	0	-250
Early Services	4	0	0	3	0	-7
Ordinary pre-school	4	0	0	131	128	-7
Special pre-school	8	0	0	191	383	184
Child Education and Development Centre	5	0	0	108	210	97
Ordinary school	0	0	0	153	409	256
Resource Teacher	3	0	0	190	0	-193
Special class - primary	2	0	0	174	455	279
Special class - secondary	1	0	0	488	97	-392
Special School	5	0	0	475	2039	1559
Generic vocational training	13	0	0	160	76	-97
Special vocational training	83	1	1	1105	949	-241
Activation Centre	202	84	9	1519	1691	-123
Programme for the Elderly	135	12	7	551	87	-618
Special high support day service	62	73	4	250	189	-200
Special intensive day service	70	14	0	548	34	-598
Sheltered work centre	90	9	0	1239	1164	-174
Sheltered employment centre	25	3	0	147	36	-139
Multidisciplinary support services	2	0	0	50	0	-52
Centre-based day respite service	0	0	0	3	0	-3
Other day service	6	0	0	105	190	79
Enclave within open employment	4	0	0	39	20	-23
Supported employment	100	0	0	955	77	-978
Open employment	21	0	0	188	23	-186
Generic Day Services	2	0	0	12	19	5
Home Help	4	0	0	1	0	-5
All Services	861	341	25	8876	8276	-1827

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Requests for additional information

Further 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	
1. Surname	2. First Name
201. Previous Surname	202. Next of Kin name
3. Address	203. Next of Kin address
4. Address	204. Next of Kin address.....
5. Address	205. Next of Kin address.....
6. Address	206. Next of Kin address
7. Address (County) _ _	207. Next of kin address (County) _ _
8. Date of Birth _ _ - _ _ - _ _ _ _	208. Next of kin telephone number
8A. Year of birth (where DOB is unknown) _ _ _ _	209. Relationship of next of kin
9. Health Board Region _	
10. Community Care Area _ _	
11. Sub-area (DED) within the Health Board Region _ _ _	
12. Planning area within the Health Board _ _	
13. Personal identification number _ _ _ _ _ _ _ _	
14. Sex 1=male 2=female _	
15. Degree of intellectual disability _ 0=not verified 1=normal range 2=borderline 3=mild 4=moderate 5=severe 6=profound	
CURRENT SERVICE PROVISION	<p>Coding for variables 22, 31 & 34</p> <p>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</p> <p>Coding for variables 26, 28, 41 & 44</p> <p>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</p>
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.	
FUTURE SERVICE REQUIREMENTS	
30. Day service required (Appendix B) _ _ 30A. Reason for duplication on current/ future day service _	
31. Level of day supervision required 0. 1. 2. 3. 4.	
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 - DAY AND RESIDENTIAL SERVICE CODES

Day Programme

- 00. Not Applicable (valid for secondary day service only)
- 01. No day service (valid for main day service, day service required and contingency day service only)
- 02. Home support
- 05. Ordinary pre-school
- 06. Special pre-school for intellectual disability
- 07. Ordinary school
- 08. Special class - primary level
- 09. Special class - secondary level
- 10. Special school
- 11. Child Education and Development Centre (Programme for Children with Severe or Profound Intellectual Disability)
- 12. Generic vocational training (e.g. F.A.S., VEC, CERT, N.T.D.I.)
- 13. Special vocational training centre - such as short-term training
- 14. Activation Centre/Adult Day Centre
- 15. Programme for the Older Person
- 16. Special high support day service (e.g. relating to challenging behaviour) less than 1:1 staff ratio
- 17. Special intensive day service (e.g. relating to challenging behaviour) 1:1 staff ratio contact or greater
- 18. Sheltered work centre - may include long-term training schemes
- 19. Sheltered employment centre (receives pay and pays PRSI)
- 20. Enclave within open employment
- 21. Supported employment
- 22. Open employment
- 23. Other day programme
- 24. Resource Teacher/Visiting Teacher
- 25. Early Intervention Services
- 26. Generic Day Services
- 27. Home Help
- 28. Annual Review
- 29. Multidisciplinary support services for school age children or adults
- 30. Full-time resident with no formal day programme
- 31. Centre-based Day Respite Service

Values 18-22

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

Residential Circumstances

- 000. Not Applicable (valid for secondary residential circumstances only)
- 100. No residential service (valid for main residential circumstances, residential service required and contingency residential service only)
- 101. At home, with both parents

APPENDIX C

102. At home, with one parent
103. At home with sibling
104. At home with relative
105. Lives with non-relative (e.g. neighbour or family friend)
106. Adoption
107. Foster Care (includes 'boarding-out' arrangements)
108. Living independently
109. Living semi-independently - maximum 2 hours supervision daily
110. Vagrant or homeless

115. 5-day community group home - goes home for holidays
120. 7-day x 48-week community group home - goes home for holidays
125. 7-day x 52-week community group home
130. 5-day village-type/residential centre - goes home for holidays
140. 7-day x 48 week village-type/residential centre - goes home for holidays
145. 7-day x 52-week village-type/residential centre
146. Nursing Home
147. De-designated Unit
170. Psychiatric Hospital
171. Other intensive placement with special requirements due to challenging behaviour
172. Other intensive placement with special requirements due to profound or multiple handicap

173. Holiday residential placement
174. Crisis and planned respite
175. Occasional respite care with a host family in a scheme such as Home Sharing or Share-a-Break
176. Shared care or guardianship (usually 5 or 7 days per week)
177. Regular part-time care - 2-3 days per week
178. Regular part-time care - every weekend
179. Regular part-time care - alternate weeks
180. Other

Requesting information from the National Intellectual Disability Database

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

If satisfied on these two points, the committee will authorise the release of the requested information from the National Intellectual Disability Database to assist the person in that particular research project or application.
4. Requests for information concerning the National Intellectual Disability Database will be subject to the following provision:
 - (a) 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: _____

NOTES

