

National Intellectual Disability Database Committee

Annual Report 2001



Fiona Mulvany



National Intellectual Disability Database

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

2001

Fiona Mulvany

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

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

The Intellectual Disability Database enables those involved with the planning and delivery of services to identify not only the level of need amongst those awaiting placement in services, but also the service changes required by those already in receipt of services. 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.

This Database is building the evidence for effective health care for people with intellectual disability, enabling services to be planned and delivered on the basis of the best available evidence and knowledge, thus helping to achieve the goals of the Government's health strategy *Quality and Fairness – A Health System for You*.

The data presented in this report reflect the first full year of a three-year programme of significant investment in intellectual disability services by the last government during the period 2000-2002. An additional €87.23 million was invested in service developments in 2000 and the impact of that investment is demonstrated in the growth in services documented in Chapter 3. The full impact on services of the additional €105.39 million invested in this sector in 2001 is not represented in this report, as the data on which the report is based were collected in the first half of 2001. A further €51.53 million was provided for service developments in 2002.

As in previous reports, I would like to take the opportunity to thank all those involved with the work of the database at both service provider and health board level. As Chairman of the National Intellectual Disability Database Committee I would like to draw attention to two issues raised in this report. The first is the timely return of information to both the regional databases and the national database and the second is the urgent need to address specific data-quality issues which are highlighted by this report. Both issues need urgent attention to preserve the integrity of the database. The 2002 Annual Report from the database is scheduled for publication this autumn and if the 2003 data is received by the mid-year deadline it is planned to publish this data by the end of the year.

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

Brendan Ingoldsby
Chairman
National Intellectual Disability Database Committee

Executive Summary

Demographic Profile

There were 26,668 people registered on the National Intellectual Disability Database in 2001, representing a prevalence rate of 7.35 per 1,000 population. The administrative prevalence rate of mild intellectual disability is 2.91 per 1,000 and the prevalence rate of moderate, severe, and profound intellectual disability is 4.06 per 1,000. There are more males than females at all levels of intellectual disability, with an overall ratio of 1.26 to 1. The total number with moderate, severe, and profound intellectual disability has increased by 31% since the first Census of Mental Handicap was carried out in 1974 and prevalence has risen from 3.80 per 1,000 to 4.06 per 1,000 over the same period. This increase is attributed to the general population increase over the period, improved standards of care, and an increase in the lifespan of people with intellectual disability. A changing age profile among those with moderate, severe, and profound intellectual disability is observed in the data over the intervening decades, with fewer children and more adults currently availing of, or in need of, intellectual disability services. This has major implications for service planning, including an ongoing high level of demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability, and helps to explain the ongoing demand for additional resources for this sector.

Current service provision

There are 23,888 people with intellectual disability currently in receipt of specialised health services, representing 89.6% of the total population registered on the National Intellectual Disability Database. There are 515 people (1.9% of those registered) who are without services at present and are wait-listed for appropriate services in the period 2002-2006. The remaining 8.5%, most of whom have a mild degree of intellectual disability or have not had their degree of intellectual disability verified, have no identified requirement for services during the planning period 2002-2006.

There are 8,296 people in receipt of full-time residential services, an increase of 394 since 2000. The number of people with intellectual disability accommodated in psychiatric hospitals continues to fall, down by 129 since 2000, to 677. Day programmes are availed of by 22,748 people. Of this group, 7,362 are in full-time residential placements and the remainder attend services on a day basis. Almost two-thirds of all children and adults with intellectual disability live in a home setting with parents, siblings, relatives, or foster parents. Just over one in four of the population with moderate, severe, or profound intellectual disability aged 35 years and over continue to live with their families. Planning for the future care of these individuals and avoiding crisis situations when family carers can no longer provide care is critical.

Recent years have seen a growth in full-time residential services, residential support services, and day services, reflecting a significant investment programme in the intellectual disability sector. Since data from the National Intellectual Disability Database first became available in 1996, the numbers receiving full-time residential services have risen by 10%. Advances have also been made in terms of the location of these services. The period has seen a 29% growth in the number of people with intellectual disability living within local communities and a 30% reduction in the number of people accommodated in psychiatric hospitals. Residential support services, which enable large numbers of

people with intellectual disability to continue to live with their families, have also experienced tremendous growth, in particular service-based respite services, which have grown by 204%. Increases are also observed in almost all areas of adult day services and in the level of provision of support services delivered as part of a package of day services to both children and adults.

Service requirements

There are 2,440 people who are currently either without services or without a major element of service. The provision of 1,638 full-time residential placements and 876 day programmes is required to meet the needs of this group in the period 2002-2006. In addition, 1,107 people will require residential support services during this period. Most service needs arise immediately. A group of 410 individuals currently living in psychiatric hospitals has been identified as needing to transfer from these locations to more appropriate accommodation over the five-year period.

A further 10,182 people who are currently receiving services require alternative, additional, or enhanced services within the next five years. This group includes people who require an increased level of service provision, increased support within their existing services, transfers to more appropriate placements, or service changes to coincide with transition periods in their lives, for example movement from child to adult services, or from training to employment services. Individuals who already avail of services have significant funding allocated to them and in most instances changes to their existing placements will incur minimal costs.

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

Chapter one

1. The National Intellectual Disability Database

Background

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

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

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

Structure

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

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

Data Quality

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

This Report

This is the fourth report of the National Intellectual Disability Database Committee. The report is based on validated data received from seven of the regional databases in June 2001 and from the eighth in February 2002, eight months after the scheduled export date. The importance of adhering to scheduled export dates to ensure timely reporting of data by the HRB and to enable accurate comparisons between regional datasets is emphasised.

Prevalence rates per thousand population are based on the latest available age data from the Central Statistics Office, the 1996 Census of Population (Central Statistics Office, 1997a, 1997b), and therefore do not reflect the 8% increase in the total population as indicated in preliminary reports from the 2002 Census of Population (Central Statistics Office, 2002).

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 usually provided within intellectual disability services.¹ In the 2001 dataset, there are 141 people recorded as being of normal ability and 703 people in the borderline intellectual disability categories, a reduction of 1 and 22 respectively since 2000. 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.

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

Chapter two

2. Profile of the Population

National Level

NUMBERS AND PREVALENCE

In April 2001 there were 26,668 people registered on the National Intellectual Disability Database. Table 2.1 summarises the numbers and prevalence rates at each level of intellectual disability. The administrative prevalence rate for mild intellectual disability is 2.91/1000, compared to 2.99/1000 in 2000, and the prevalence rate for moderate, severe and profound intellectual disability is 4.06/1000, the same as in 2000.

Table 2.1. National Intellectual Disability Database, Ireland 2001.
Prevalence of intellectual disability by degree of intellectual disability.
Numbers, percentages, and prevalence rates per 1,000.

	n	%	rate
Mild	10555	39.6	2.91
Moderate	9623	36.1	2.65
Severe	4018	15.1	1.11
Profound	1102	4.1	0.30
Not Verified	1370	5.1	0.38
All Levels	26668	100.0	7.35

Overall, the numbers registered on the National Intellectual Disability Database have decreased by 92 since 2000. During the twelve months prior to the 2001 export of data from the health boards to the national dataset, 195 people were removed from the database because they had died. The reduction in overall numbers and in the administrative prevalence of mild intellectual disability is mainly attributed to ongoing efforts to refine the database. In recent years emphasis has been placed on including and retaining on the National Intellectual Disability Database only those people with mild intellectual disability who are in receipt of, or in need of, intellectual disability services. The numbers of people with mild intellectual disability registered on the database fell by 271 between 2000 and 2001. Table 2.2 summarises the age and gender distribution of this population by degree of disability.

GENDER DIFFERENCES

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 8.27/1000 males and 6.46/1000 females.

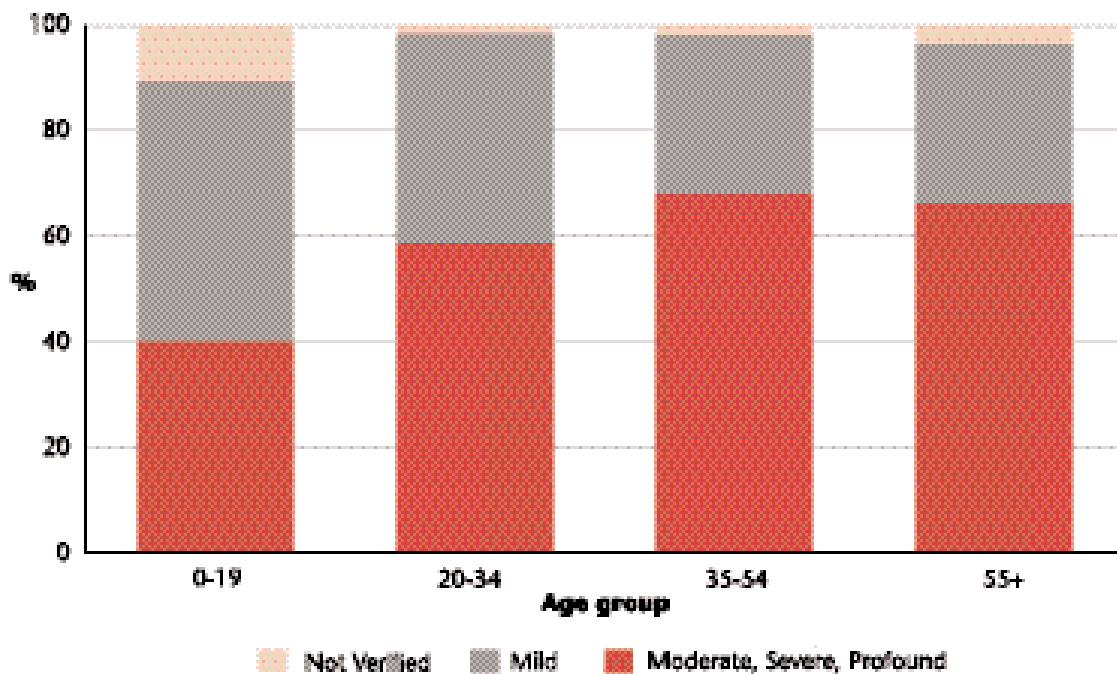
**Table 2.2. National Intellectual Disability Database, Ireland 2001.
Age, gender and degree of intellectual disability.
Numbers and prevalence rates per 1,000.**

Age Group	Numbers																	
	Not Verified		Mild		Moderate		Severe		Profound		All Levels							
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total						
0-4	257	352	609	70	110	180	65	95	160	28	33	61	6	5	11	426	595	1021
5-9	06	155	261	286	459	745	236	417	653	96	139	235	32	29	61	756	1199	1955
10-14	22	40	62	601	1061	1662	321	501	822	109	174	283	23	33	56	1076	1809	2885
15-19	19	26	45	750	1215	1965	403	572	975	121	169	290	38	48	86	1331	2030	3361
20-34	63	83	146	1356	1734	3090	1374	1609	2983	497	695	1192	185	201	386	3475	4322	7797
35-54	68	87	155	1065	1071	2136	1402	1504	2906	684	801	1485	159	256	415	3378	3719	7097
55 & over	46	46	92	408	369	777	618	506	1124	235	237	472	38	49	87	1345	1207	2552
All ages	581	789	1370	4536	6019	10555	4419	5204	9623	1770	2248	4018	481	621	1102	11787	14881	26668
	Prevalence Rates																	
0-4	2.11	2.73	2.43	0.58	0.85	0.72	0.53	0.74	0.64	0.23	0.26	0.24	0.05	0.04	0.04	3.50	4.62	4.08
5-9	0.77	1.07	0.92	2.08	3.16	2.63	1.72	2.87	2.31	0.70	0.96	0.83	0.23	0.20	0.22	5.49	8.25	6.91
10-14	0.14	0.24	0.19	3.79	6.34	5.10	2.02	2.99	2.52	0.69	1.04	0.87	0.14	0.20	0.17	6.78	10.81	8.85
15-19	0.11	0.15	0.13	4.53	6.98	5.79	2.43	3.29	2.87	0.73	0.97	0.85	0.23	0.28	0.25	8.04	11.67	9.90
20-34	0.15	0.20	0.18	3.33	4.27	3.80	3.38	3.96	3.67	1.22	1.71	1.47	0.45	0.49	0.47	8.54	10.64	9.59
35-54	0.15	0.19	0.17	2.35	2.35	2.35	3.09	3.31	3.20	1.51	1.76	1.64	0.35	0.56	0.46	7.45	8.18	7.81
55 & over	0.12	0.14	0.13	1.07	1.14	1.10	1.62	1.56	1.59	0.62	0.73	0.67	0.10	0.15	0.12	3.52	3.73	3.62
All ages	0.32	0.44	0.38	2.48	3.34	2.91	2.42	2.89	2.65	0.97	1.25	1.11	0.26	0.34	0.30	6.46	8.27	7.35

AGE DIFFERENCES

Of the persons recorded on the National Intellectual Disability Database, 34.6% are aged 19 years and under, 29.2% are aged between 20 and 34 years, 26.6% are aged between 35 and 54 years, and 9.6% are 55 years of age and over. Figure 1 illustrates the proportion in each age group at each level of intellectual disability. The larger proportion with mild intellectual disability in the 0-19 age group reflects the numbers of children in special education who receive support services from the intellectual disability sector, many of whom do not transfer to the intellectual disability services after school. There is also a higher proportion in the not verified category in this age group, as many young children do not receive a definitive diagnosis in their earlier years.

Figure 1. National Intellectual Disability Database, Ireland 2001.
Age profile of total population, showing proportion at each level of intellectual disability in each age group.



RECENT TRENDS

Compared to the published data for previous years (National Intellectual Disability Database Committee, 1996; Mulvany, 2000, Mulvany, 2001), the 2001 data in Table 2.2 represent

- increased prevalence rates in the 0-4 age group since 2000 (except in those with profound intellectual disability) although rates had been falling consistently since 1998,
- an overall upward trend in prevalence among the 5-9 year age group in 2001 although rates had been falling consistently since 1998,
- a general downward trend in prevalence rates in the age groups between 10 and 34 years over the last four datasets (1998-2001),

- a consistent upward trend in prevalence in those with moderate, severe and profound intellectual disability in the 35-54 year age group since 1998, and
- a very slight decrease in prevalence in the oldest age group (55 years and over) since the 2000 dataset though the general trend observed over the last four datasets was a slight increase in rates, particularly among those in the more severe categories of intellectual disability.

The increasing prevalence rate in the 0-9 age group is a different pattern to that observed in recent years and possibly reflects improved ascertainment of cases at a younger age. The overall downward trend in prevalence observed in those aged between 10 and 34 years may be explained by the natural progression of a cohort of individuals born in the 1960s into the 35-54 age group. This feature will be explored further later in this chapter. Similarly, the increasing prevalence rates in those with moderate, severe and profound intellectual disability in the 35-54 age group possibly reflects the movement of this cohort into this age grouping. While the prevalence rates in oldest age group, 55 years and over, show a decline from the 2000 data, analysis later in this chapter will show that the prevalence rate is increasing when compared to data collected over the past 27 years.

TRENDS OVER THREE DECADES

Data from the 1974 and 1981 Censuses of Mental Handicap, carried out by the Medico-Social Research Board (Mulcahy, 1976; Mulcahy and Ennis, 1976; Mulcahy and Reynolds, 1984), enable us to monitor trends in this group over the past 27 years.

Increase in numbers and prevalence

The total number of those more severely affected has risen from 11,256 in 1974 to 14,743 in 2001 (an increase of 31%) and prevalence has risen from 3.80 per thousand to 4.07 per thousand over the same period (Table 2.3). Of particular interest, from the point of view of service delivery, is that this increase in both numbers and prevalence is now reflected only in the 35-54 and 55 years and over age groups. This overall increase is influenced by a number of factors, including the general population increase during this period, improved standards of care, and an increase in the lifespan of people with intellectual disability.

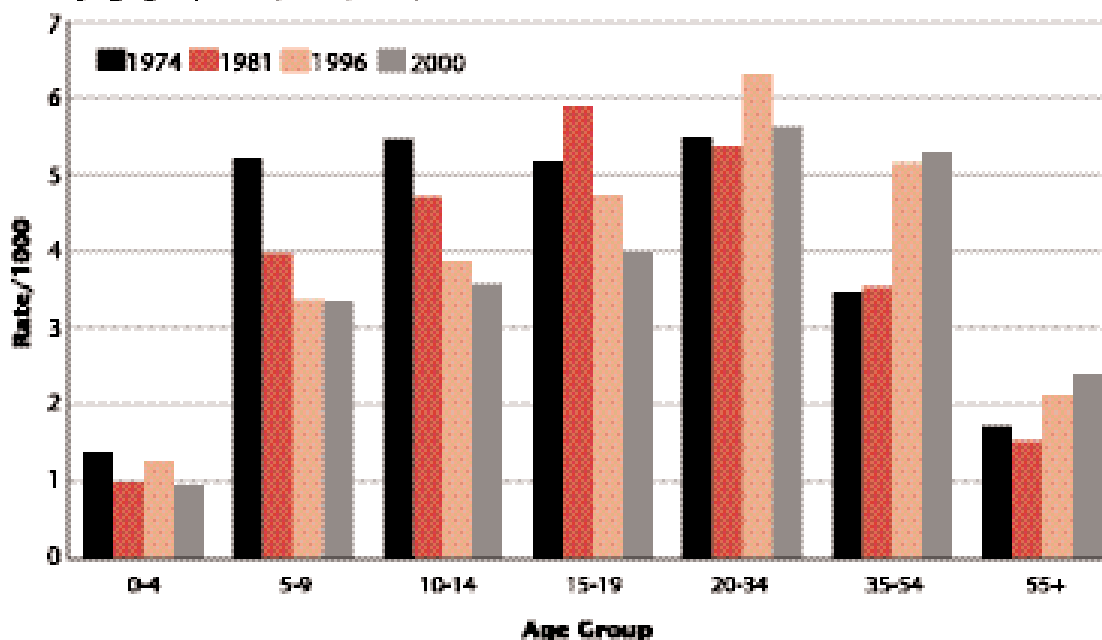
Changing age profile

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 27-year period, with fewer children and more adults currently availing of, or in need of, intellectual disability services. Figure 2 demonstrates an overall trend over time 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, at 0.93/1000, is still lower than that reported in 1981 but has increased since 2000. However, this observed prevalence rate is considerably lower than the overall prevalence rate of 4.07/1000 and it is estimated that the number of children aged 0-4 years recorded on the database may be underestimated by somewhere in the region of 750-800 cases. In compiling the database, attempts are made to discover every child with intellectual disability at the earliest possible age so as to plan the most comprehensive treatment and education possible, but respect is also given to the growing number of situations where parents are reluctant to register their child on the database at a very early age.

Table 2.3. National Intellectual Disability Database, Ireland 2001.
Age and degree of intellectual disability (moderate, severe and profound): 1974, 1981, 1996, 2001.
Numbers and prevalence rates per 1,000.

		Numbers															
		Moderate				Severe				Profound				All Levels			
Age Group		1974	1981	1996	2001	1974	1981	1996	2001	1974	1981	1996	2001	1974	1981	1996	2001
0-4		189	214	226	160	143	92	83	61	99	26	30	11	431	332	339	232
5-9		809	955	736	653	617	330	260	235	224	99	77	61	1650	1384	1073	949
10-14		752	1035	948	822	583	428	305	283	292	117	93	56	1627	1580	1346	1161
15-19		698	1203	1072	975	445	508	378	290	241	154	132	86	1384	1865	1582	1351
20-34		1498	2419	2997	2983	1017	1129	1350	1192	441	340	460	386	2956	3888	4807	4561
35-54		1321	1559	2626	2906	626	612	1183	1485	201	97	343	415	2148	2268	4152	4806
55 & over		669	715	987	1124	307	248	394	472	84	24	53	87	1060	987	1434	1683
All Ages		5936	8100	9592	9623	3738	3347	3953	4018	1582	857	1188	1102	11256	12304	14733	14743
		Prevalence Rates															
0-4		0.60	0.62	0.83	0.64	0.45	0.27	0.30	0.24	0.31	0.07	0.11	0.04	1.36	0.97	1.24	0.93
5-9		2.55	2.73	2.31	2.31	1.95	0.94	0.82	0.83	0.71	0.28	0.24	0.22	5.20	3.95	3.37	3.35
10-14		2.52	3.08	2.72	2.52	1.95	1.27	0.88	0.87	0.98	0.35	0.27	0.17	5.45	4.70	3.86	3.56
15-19		2.61	3.79	3.20	2.87	1.66	1.60	1.13	0.85	0.90	0.48	0.39	0.25	5.17	5.88	4.72	3.98
20-34		2.78	3.33	3.93	3.67	1.88	1.56	1.77	1.47	0.82	0.47	0.60	0.47	5.48	5.35	6.31	5.61
35-54		2.13	2.43	3.25	3.20	1.01	0.95	1.46	1.64	0.32	0.15	0.42	0.46	3.46	3.53	5.14	5.29
55 & over		1.08	1.09	1.45	1.59	0.50	0.38	0.58	0.67	0.14	0.04	0.08	0.12	1.71	1.51	2.11	2.39
All Ages		1.99	2.35	2.72	2.65	1.25	0.97	1.12	1.11	0.53	0.25	0.34	0.30	3.80	3.60	4.18	4.07

Figure 2. National Intellectual Disability Database, Ireland 2001.
Prevalence of moderate, severe and profound intellectual disability (combined)
by age group: 1974, 1981, 1996, 2001.



Cohort effect

There is a population bulge originating in the 1960s and lasting until the mid-1970s currently moving through the intellectual disability services. The growth in numbers with intellectual disability during the 1960s and 1970s is attributed to a high birth rate and improved obstetric and paediatric care. Data from the previous Censuses of Mental Handicap allow us to monitor the progress of this group through the services. In 1974 there was a high prevalence rate in the 10-14 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 1996 and 2001. Closer examination of the graph shows that the concentration of this cohort in the 20-34 age group has peaked and that the cohort is now moving into the 35-54 age group. This pattern is clearly shown in Figure 3 which presents prevalence data for moderate, severe, and profound intellectual disability for the five datasets compiled from the National Intellectual Disability Database between 1996 and 2001.

Increased longevity

Figure 4 illustrates the increased longevity in this population, attributed in the research literature primarily to improved health and well-being, the control of infectious diseases, the move to community living, improved nutrition, and the quality of health care services. By grouping people with moderate, severe and profound intellectual disability in the 35-54 and the 55-and-over age groups, it can be seen that in 1974, 29% of this population, and in 1981, 27% of this population, were aged 35 years and over. A steady increase in the proportion aged 35 and over has been observed in each dataset since 1996, from 38% in 1996 to 44% in the 2001 dataset.

Figure 3. National Intellectual Disability Database, Ireland 2001.
Prevalence of moderate, severe, and profound intellectual disability (combined)
by age group: 1996, 1998, 1999, 2000, 2001.

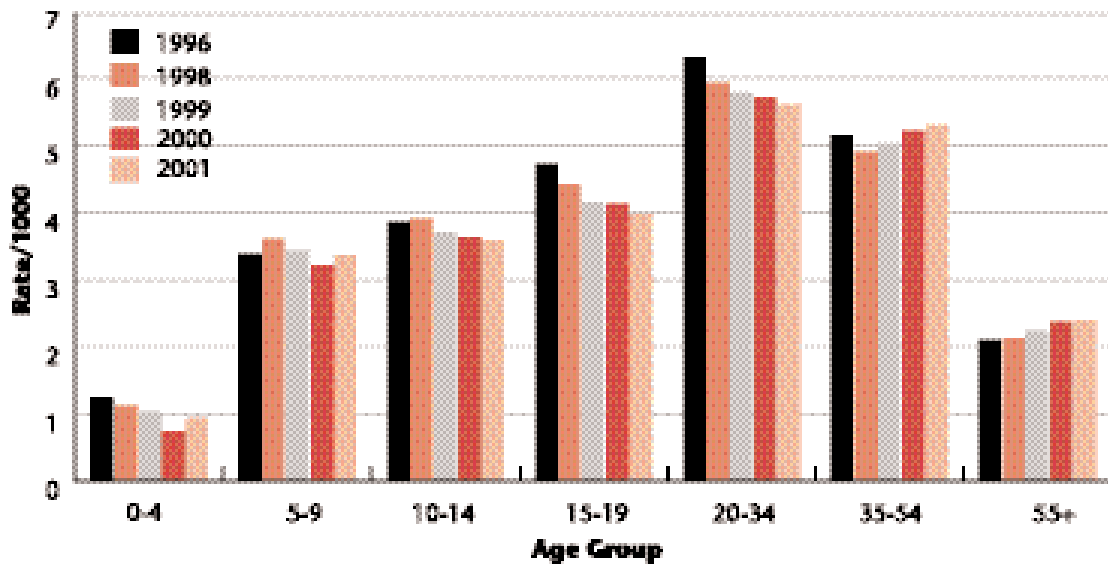
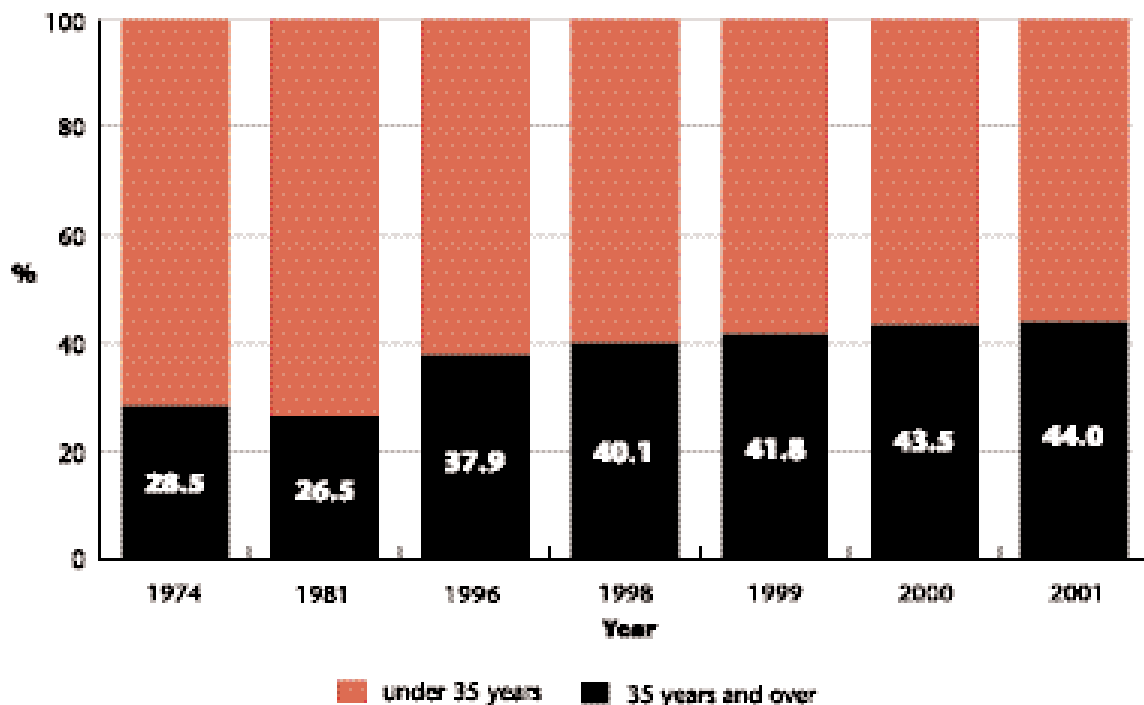


Figure 4. National Intellectual Disability Database, Ireland 2001.
Proportion of people with moderate, severe, and profound intellectual disability (combined)
over 35 years: 1974, 1981, 1996, 1998-2001.



IMPACT OF OBSERVED TRENDS

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 high prevalence rate observed among young adults will mean that the pressure currently being experienced by adult day services will increase as this group ages and requires residential services. This is reflected in the current waiting lists for full-time residential services in Ireland.
- Improved life expectancy among adults with severe intellectual disability will place an increased demand on the health services and pose new challenges to health care professionals.
- The majority of adults with intellectual disability continue to live with their families and as these caregivers age beyond their care-giving capacity, residential supports will be required.
- Additional therapeutic support services will also be required for people who wish to continue to live with their families to enable this caring arrangement to continue.
- Another implication of ageing and the increase in the severely disabled population will be the demand for a higher degree of support within day and residential services and the need to develop specific geriatric support services.

Taken together, the combined effects of the baby boom generation and increased longevity, will result in significant demand for additional resources and will present major challenges to service planners and providers – this baby boom generation, born in the 1960s and 1970s will begin to reach age 55 in 2015, just 12 years away. Failure to anticipate the associated service needs often results in crisis situations for families and for service providers. The National Intellectual Disability Database is an invaluable resource in providing a sound evidence base for service planning and delivery. Not only does it allow us to identify specific individual service requirements arising in the next five years, but the demographic information also allows us to look further into the future and anticipate the impact of changing demographic trends.

Health Board Level

NUMBERS ON EACH REGIONAL DATABASE

Table 2.4 details the number of individuals included on each of the regional databases in April 2001. Each health board has responsibility for collecting the required information for all individuals who are in receipt of, or in need of, intellectual disability services within their health board region.

Table 2.4. National Intellectual Disability Database, Ireland 2001.
Number of people included on each Regional Intellectual Disability Database.

	n	%
Eastern Regional Health Authority	8419	31.6
Midland Health Board	1544	5.8
Mid-Western Health Board	2441	9.2
North-Eastern Health Board	2073	7.8
North-Western Health Board	1800	6.7
South-Eastern Health Board	3284	12.3
Southern Health Board	3940	14.8
Western Health Board	3167	11.9
Total	26668	100.0

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

Table 2.5. National Intellectual Disability Database, Ireland 2001.
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	577 6.9	2996 35.6	3237 38.4	1260 15.0	349 4.1	8419 100.0
Midland Health Board	22 1.4	638 41.3	639 41.4	201 13.0	44 2.8	1544 100.0
Mid-Western Health Board	43 1.8	1079 44.2	885 36.3	343 14.1	91 3.7	2441 100.0
North-Eastern Health Board	83 4.0	824 39.7	776 37.4	312 15.1	78 3.8	2073 100.0
North-Western Health Board	176 9.8	650 36.1	645 35.8	273 15.2	56 3.1	1800 100.0
South-Eastern Health Board	258 7.9	1372 41.8	1020 31.1	447 13.6	187 5.7	3284 100.0
Southern Health Board	113 2.9	1573 39.9	1395 35.4	626 15.9	233 5.9	3940 100.0
Western Health Board	98 3.1	1423 44.9	1026 32.4	556 17.6	64 2.0	3167 100.0
Total	1370 5.1	10555 39.6	9623 36.1	4018 15.1	1102 4.1	26668 100.0

REGIONAL VARIATION IN PREVALENCE

The 1981 Census revealed considerable differences between health board areas in the prevalence rates of moderate, severe and profound intellectual disability. The data collection method used by the 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 prevalence rates for the 0-19 years age groups are compared with some confidence (Table 2.6). There is some variation in prevalence rates between health board areas. 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. There is a geographical pattern observable in this table, with the highest rate in the Midland Health Board, followed in sequence by the health boards along the western seaboard and the lowest rates being observed in the health boards along the eastern seaboard. These variations are most likely due to demographic factors such as higher migration from rural areas and older maternal age, and may also be due to differences in ascertainment and classification practices.

Table 2.6. National Intellectual Disability Database, Ireland 2001.
Prevalence rates for 0-19 age groups by geographical region (moderate, severe and profound intellectual disability combined).
Numbers and prevalence rates per 1000.

Rates	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	42 0.46	284 2.94	375 3.50	403 3.41	1104 2.68
Midland Health Board	29 1.98	59 3.49	95 4.67	91 4.53	274 3.81
Mid-Western Health Board	25 1.15	72 2.91	100 3.40	132 4.31	329 3.09
North-Eastern Health Board	6 0.28	99 3.84	93 3.08	122 4.15	320 2.99
North-Western Health Board	19 1.31	58 3.35	75 3.73	91 4.56	243 3.38
South-Eastern Health Board	20 0.73	115 3.62	117 3.20	144 3.86	396 2.98
Southern Health Board	50 1.35	167 3.98	189 3.85	221 4.35	627 3.51
Western Health Board	41 1.77	95 3.41	117 3.51	147 4.40	400 3.40
All Regions	232	949	1161	1351	3693
Rate	0.93	3.35	3.56	3.98	3.08

Chapter three

3. Current Service Provision

National Level

SUMMARY OF CURRENT SERVICE PROVISION

There are 23,888 people with intellectual disability currently in receipt of services, which accounts for 89.6% of the total population registered on the National Intellectual Disability Database, compared to a service provision level of 89.8% in 2000. Since 2000, the numbers in receipt of full-time residential services within the intellectual disability sector have increased by 517. The new places were assigned to 388 people coming into full-time residential services for the first time and 129 former residents in psychiatric hospitals. The number in receipt of day services only has reduced by 475 since 2000, reflecting the movement of day attenders into full-time residential services, the overall reduction in the numbers of children within the services, and the ongoing refinement of the database. A further 2,780 people who are not currently availing of services are registered on the National Intellectual Disability Database, of whom 515, or 18.5%, have expressed a need for services in the period 2002-2006. A summary of the overall level of current service provision is provided in Table 3.1.

**Table 3.1. National Intellectual Disability Database, Ireland 2001.
Summary of current service provision.**

	n	%
Receiving day services	15386	57.7
Receiving 5- or 7-day residential services	7619	28.6
Resident in a psychiatric hospital	677	2.5
Receiving residential support services only	206	0.8
Receiving no service	515	1.9
No current service requirements	2265	8.5
Total	26668	100.0
Note:		
3,657 day attenders and 214 full-time residents receive residential support services in addition to their principal service.		
7,362 residents receive a day service in addition to their full-time residential service.		

Without services

The 2001 data indicate that 515 people (1.9%) are without services and have service needs in the period 2002-2006, details of which are presented in Chapter 4. This represents an increase of 40 people in this category since 2000. Of this group, 65% are in the 'not verified' and mild categories of intellectual disability and 35% have a moderate, severe or profound level of intellectual disability.

A further 2,265 people (8.5%) are also without services but have no identified requirement for services within the five-year period 2002-2006. Over two-thirds of this group (67%) are in the 'not verified' and mild categories of intellectual disability. Of this group who have no current service requirements, 808 have their circumstances formally reviewed on an annual basis and 520 of the group have contingency service plans identified on the database. The appropriateness of registering people with mild intellectual disability who have no identified need for services on the database is being monitored on an ongoing basis, as the primary function of the database is to register only people who are 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 five-year period 2002-2006 have a mild intellectual disability and it is reasonable to assume that they genuinely do not require services at this time.

However, one-third of the group who are without services at present and are not identified as requiring services between 2002 and 2006 have either a moderate, severe or profound degree of intellectual disability (743 people). Of this group, 340 have their circumstances formally reviewed on an annual basis and 242 of the group have contingency service plans identified on the database. While these people may not wish to avail of services at this time, it is essential that their needs are monitored on a regular basis so that changing circumstances can be identified and responded to in a timely manner. Failure to anticipate the needs of this group can result in emergency admissions to services which may not be appropriate to the specific needs of the individual.

Table 3.2 summarises current service provision in 2001 by degree of intellectual disability and age group. There is a clear relationship between level of disability, age and utilisation of services. Day services tend to be accessed by younger individuals of higher ability, while residential services are utilised primarily by adults with moderate, severe and profound levels of intellectual disability. Of the 15,386 individuals who avail of services on a day basis, 48% are in the mild range of intellectual disability and 51% are aged 18 years and under. There are 7,619 full-time residents in intellectual disability services, of whom 83% have a moderate, severe or profound degree of disability, and 93% are aged 19 years and over. None of the 677 residents in psychiatric hospitals are under the age of 18 and 74% of the adult residents have a moderate, severe or profound degree of intellectual disability. Of the 515 individuals currently without services who are wait-listed for services within the period 2002-2006, 55% are in the mild range of disability and 87% are aged 19 years and over. Of the group of 2,265 individuals identified as having no requirement for services, 58% have a mild intellectual disability and 90% are aged over 18 years. However, the National Intellectual Disability Database Committee is particularly concerned about the circumstances of 53 children within this group who have a moderate, severe, or profound intellectual disability but are not currently availing of services and are not wait-listed for services in the period 2002-2006. The HRB will conduct a review of this group during the 2003 review and update of the National Intellectual Disability Database.

Table 3.2. National Intellectual Disability Database, Ireland 2001.
Summary of current service provision by degree of intellectual disability and age group.

	Not Verified		Mild		Moderate, Severe & Profound		All Levels					
	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over				
Receiving day services	870	167	1037	3959	3435	7394	2952	4003	6955	7781	7605	15386
Receiving 5- or 7-day residential services	17	30	47	145	1131	1276	373	5923	6296	535	7084	7619
Resident in a psychiatric hospital	0	9	9	0	170	170	0	498	498	0	677	677
Receiving residential support services only	0	14	14	2	120	122	4	66	70	6	200	206
Receiving no service	24	29	53	26	255	281	19	162	181	69	446	515
No current service requirements	54	156	210	115	1197	1312	53	690	743	222	2043	2265
Total	965	405	1370	4247	6308	10555	3401	11342	14743	8613	18055	26668

RESIDENTIAL CIRCUMSTANCES

Table 3.3 outlines the main residential circumstances of those included on the National Intellectual Disability Database in 2001. Almost two-thirds (61%) live in a home setting with parents, relatives, or foster parents. The remainder of the population live in full-time residential services (31%), mainly residential centres, community group homes, and psychiatric hospitals, or they live independently or semi-independently (3%). There are 13 people registered on the database who have no fixed abode, an increase of three since 2000. There is insufficient information on the residential circumstances of 1,311 people registered on the database (5%), a reduction of 287 people since 2000. This group needs to be further reviewed as a matter of urgency to improve the overall quality of data available from the National Intellectual Disability Database.

Table 3.3. National Intellectual Disability Database, Ireland 2001.		
Main residential circumstances.		
	n	%
Home Setting	16341	61.3
At home with both parents	11467	43.0
At home with one parent	3338	12.5
At home with sibling	948	3.6
At home with other relative	286	1.1
Living with non-relative	40	0.1
Adoption	29	0.1
Foster care and boarding-out arrangements	233	0.9
Independent Setting	707	2.7
Living independently	525	2.0
Living semi-independently	182	0.7
Community Group Homes	3097	11.6
5-day community group home	620	2.3
7-day (48-week) community group home	829	3.1
7-day (52-week) community group home	1648	6.2
Residential Centres	3444	12.9
5-day residential centre	144	0.5
7-day (48-week) residential centre	827	3.1
7-day (52-week) residential centre	2473	9.3
Other full-time services	1755	6.6
Nursing home	78	0.3
De-designated unit ^a	314	1.2
Psychiatric hospital	677	2.5
Intensive placement (challenging behaviour)	201	0.8
Intensive placement (profound or multiple handicap)	201	0.8
Occupying a residential support place	91	0.3
Other full-time residential service	193	0.7
No fixed abode	13	0.0
Insufficient information	1311	4.9
Total	26668	100.0

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

There are 8,296 people in receipt of full-time residential services, an increase of 394 people since 2000. Within this group, 3,097 live in community group homes, 3,444 are in residential centres and 402 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, 314 individuals live in de-designated units and 78 reside in nursing homes. Ninety-one residents are occupying residential support places on a full-time basis, thereby blocking these services from their intended use. A further 193 people receive full-time residential services described as 'other'. The 2001 data indicate that there are 677 people with intellectual disability accommodated in psychiatric hospitals, a reduction of 129 (16%) since 2000.

Main residential circumstances: age group and degree of intellectual disability

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

AGE DIFFERENCES

There are striking differences in the age profile of individuals in the various categories of accommodation. The proportion of people living in a home setting decreases with age – 91% of all 0- to 19-year olds live in a home setting, declining to 63% of those aged between 20-34 years, 35% of those aged 35-54 years, and 20% of those aged 55 years and over.

The data indicate that 31% of all people with intellectual disabilities, and 26% of those with moderate, severe and profound intellectual disability, aged 35 years and over continue to live with their families (compared to 32% and 27% respectively in 2000). Again, the importance of planning for the future care of these individuals and avoiding crisis situations when family carers can no longer provide care is highlighted.

The proportion of people in the different age categories who are living in full-time residential services increases with age – 7% of all 0- to 19-year olds are in receipt of full-time residential services compared to 28% of 20-34 year-olds, 53% of 35-54 year-olds, and 67% of those aged 55 years and over.

In 2000, 51% of those aged 35-54 years, and 63% of those aged 55 years and over were in full-time residential services and the improvement in the proportions of these age groups in residential services in 2001 reflects the increase in the number of residential places during the twelve-month period.

DEGREE OF INTELLECTUAL DISABILITY

There are also noticeable variations between level of ability and type of accommodation. Of those people with a mild intellectual disability, 74% live in a home setting, compared to 50% of those with a moderate, severe or profound intellectual disability. In the more severe categories of disability, the proportion of people in full-time residential services is increased. Only 14% of people with a mild intellectual disability have a full-time residential service but this increases to 46% in the case of those with a moderate, severe or profound disability.

Where individuals are in full-time residential services, the type of service varies according to level of intellectual disability. Of those in the mild range of intellectual disability who are in full-time residential services, 53% are in community group homes, 20% are in residential centres, and 27% are

Table 3.4. National Intellectual Disability Database, Ireland 2001.																				
Main residential circumstances, degree of intellectual disability and age group.																				
	Not Verified				Mild				Moderate, Severe & Profound				All Levels							
	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total					
Home setting	910	99	75	32	1116	4314	2264	1014	199	7791	3188	2546	1408	292	7434	8412	4909	2497	523	16341
Independent setting	0	5	21	14	40	6	166	265	100	537	0	18	81	31	130	6	189	367	145	707
Community group home	2	1	5	4	12	72	196	361	143	772	122	720	1188	283	2313	196	917	1554	430	3097
Residential centre	7	3	2	4	16	14	58	108	105	285	216	865	1496	566	3143	237	926	1606	675	3444
Other full-time services	9	4	5	10	28	70	68	109	142	389	115	297	482	444	1338	194	369	596	596	1755
No fixed abode	0	1	0	0	1	0	6	3	0	9	0	2	1	0	3	0	9	4	0	13
Insufficient information	49	33	47	28	157	76	332	276	88	772	52	113	150	67	382	177	478	473	183	1311
Total	977	146	155	92	1370	4552	3090	2136	777	10555	3693	4561	4806	1683	14743	9222	7797	7097	2552	26668

in other full-time residential services. However, of those in full-time residential services who have a moderate, severe or profound intellectual disability, 34% are in community group homes, 46% are in residential centres and 20% are in other full-time residential services.

DAY SERVICES

At present, 22,748 people, representing 85.3% of the total population with an intellectual disability, avail of day services. This represents a decrease of 162 people availing of day services since 2000.

Residential status of people availing of day services

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

Table 3.5. National Intellectual Disability Database, Ireland 2001.
Category of persons availing of day services, degree of intellectual disability and age group.

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Residents	15	31	46	138	1139	1277	370	5669	6039	523	6839	7362
Day Attenders	870	167	1037	3959	3435	7394	2952	4003	6955	7781	7605	15386
Total	885	198	1083	4097	4574	8671	3322	9672	12994	8304	14444	22748

Of those availing of day services, 32% (7,362) are also in full-time residential services, the majority of whom are in the moderate, severe or profound range of intellectual disability (82%) and aged 19 years and over (93%). The remaining 68% (15,386) attend services on a daily basis, of whom 48% are in the mild range of intellectual disability and 51% are aged 18 years and under.

The current data indicate that 859 full-time residents have no day activity programme. The day service needs of this group are identified in the fourth chapter of this report.

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

The top five day activities availed of by people with intellectual disability, and accounting for 72% of day service provision, are: activation programmes, sheltered work, special schools, special vocational training, and supported employment (Table 3.6a). People who attend services on a day basis are availing mainly of educational, training and work programmes, reflecting both the higher level of ability and younger age profile of people in these services. Activation programmes are provided to 10% of day attenders. Those in full-time residential services are much more likely to avail of services such as activation programmes, special high-support programmes, and specific programmes for older people. Twenty-seven per cent of residents avail of sheltered work programmes and smaller proportions (4.2%) attend special schools.

**Table 3.6. National Intellectual Disability Database, Ireland 2001.
Principal day service by category of persons availing of day services.**

	Residents	Day Attenders	Total
Home support	4	231	235
Home help	0	26	26
Early services	1	489	490
Mainstream pre-school	1	150	151
Special pre-school for intellectual disability	5	575	580
Child education and development centre	106	447	553
Mainstream school	1	787	788
Resource/visiting teacher	4	257	261
Special class - primary level	21	702	723
Special class - secondary level	23	241	264
Special school	309	4077	4386
Special vocational training centre	277	1388	1665
Activation centre	3332	1533	4865
Programme for the older person	281	79	360
Special high-support day service	344	65	409
Special intensive day service	139	31	170
Sheltered work centre – includes long-term training schemes	1962	2616	4578
Sheltered employment centre	18	103	121
Multidisciplinary support service	27	183	210
Centre-based day respite service	0	7	7
Other day service	274	221	495
Enclave within open employment	19	9	28
Supported employment	147	722	869
Open employment	20	201	221
Generic vocational training	28	168	196
Generic day services	19	78	97
Total	7362	15386	22748

Table 3.6a. National Intellectual Disability Database, Ireland 2001.**Top five day activities for people with intellectual disability.**

Top five day activities		Top five day activities		Top five day activities	
All	%	Day attenders	%	Residents	%
Activation centre	21.4	Special school	26.5	Activation centre	45.3
Sheltered work centre	20.1	Sheltered work centre	17.0	Sheltered work centre	26.7
Special school	19.3	Activation centre	10.0	Special high-support service	4.7
Special vocational training	7.3	Special vocational training	9.0	Special school	4.2
Supported employment	3.8	Mainstream school	5.1	Programme for older people	3.8

Main day services by age group and degree of intellectual disability

Table 3.7 provides details of the principal day services by age group and degree of intellectual disability.

AGE DIFFERENCES

Of those availing of day services, 37% are aged 18 years and under, and 63% are 19 years and over.

There are 8,304 individuals aged 18 years and under currently accessing day services. The majority are in mainstream or special education services at primary and secondary level, availing of early intervention and both mainstream and specialised pre-school services, or are attending Child Education and Development Centres. Some young adults at the upper end of the age group have moved into training and employment placements.

There are 14,444 adults currently availing of day services. Most adults attend either activation centres (33%) or sheltered work centres (32%). The next largest groups are concentrated in the areas of special vocational training (11%), supported employment (6%), special high-support day services (3%), and programmes for older people (2%).

DEGREE OF INTELLECTUAL DISABILITY

Almost four out of every ten people receiving day services have a mild intellectual disability, 57% have a moderate, severe or profound intellectual disability, and 5% have not yet had their degree of intellectual disability established.

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

**Table 3.7. National Intellectual Disability Database, Ireland 2001.
Principal day service, degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Home support	23	11	34	17	58	75	21	105	126	61	174	235
Home help	2	3	5	0	8	8	0	13	13	2	24	26
Early services	333	0	333	85	0	85	72	0	72	490	0	490
Mainstream pre-school	63	0	63	56	1	57	30	1	31	149	2	151
Special pre-school for intellectual disability	189	0	189	151	0	151	236	4	240	576	4	580
Child education and development centre	39	0	39	5	0	5	443	66	509	487	66	553
Mainstream school	50	2	52	549	34	583	150	3	153	749	39	788
Resource/visiting teacher	71	0	71	154	4	158	29	3	32	254	7	261
Special class - primary level	21	0	21	464	32	496	198	8	206	683	40	723
Special class - secondary level	1	0	1	174	37	211	47	5	52	222	42	264
Special school	52	1	53	2264	80	2344	1929	60	1989	4245	141	4386
Special vocational training centre	1	41	42	64	708	772	35	816	851	100	1565	1665
Activation centre	0	35	35	5	521	526	30	4274	4304	35	4830	4865
Programme for the older person	0	11	0	0	78	78	0	271	271	0	360	360
Special high-support day service	4	4	8	7	26	33	31	337	368	42	367	409
Special intensive day service	1	0	1	8	6	14	9	146	155	18	152	170
Sheltered work centre	0	39	39	6	1700	1706	8	2825	2833	14	4564	4578
Sheltered employment centre	0	4	4	2	88	90	0	27	27	2	119	121
Multidisciplinary support service	25	7	32	16	85	101	9	68	77	50	160	210
Centre-based day respite service	0	1	1	2	0	2	0	4	4	2	5	7
Other day service	8	10	18	41	178	219	40	218	258	89	406	495
Enclave within open employment	0	0	0	0	12	12	0	16	16	0	28	28
Supported employment	0	16	16	2	542	544	1	308	309	3	866	869
Open employment	0	6	6	7	194	201	0	14	14	7	214	221
Generic vocational training	2	7	15	15	145	160	3	24	27	20	176	196
Generic day services	0	0	0	3	37	40	1	56	57	4	93	97
Total	885	198	1083	4097	4574	8671	3322	9672	12994	8304	14444	22748

Half of the children availing of day services have a mild degree of intellectual disability, most of whom avail of services within mainstream or special education. Forty per cent of the children in receipt of day services have a moderate, severe or profound intellectual disability and, while most are receiving mainstream or special education services, some also avail of more intensive services such as child education and development centres.

Of the 14,444 adults in receipt of day services, 32% have a mild degree of intellectual disability, 67% are in the moderate, severe, or profound range, and 1% have not had their degree of intellectual disability established. Most adults with a mild degree of intellectual disability who are registered on the database attend sheltered work centres (37%), are in receipt of special vocational training (15%), are in supported employment (12%), or avail of activation programmes (11%). The adults with moderate, severe or profound intellectual disability are most likely to be in receipt of activation programmes (44%), followed by sheltered work (29%), special vocational training (8%), high-support programmes (3%), and supported employment (3%).

The primary service delivered to 471 people with intellectual disability is a support service, which would not generally be considered to constitute a full day service. Home support services are the main input for 235 people, of whom 54% have a moderate, severe or profound degree of intellectual disability. Two hundred and ten people are dependent on multidisciplinary support services as their main day service, of whom 37% are in the moderate, severe, or profound range of intellectual disability. Twenty six people rely on the home help service as the primary service, and 50% of these have a moderate, severe, or profound intellectual disability.

OVERALL LEVEL OF CURRENT SERVICE PROVISION

Background

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

The 2001 dataset is the fifth in a series that commenced in 1996, followed by 1998, 1999, and 2000. The first and third datasets, from 1996 and 1999, have been selected for comparison with the current data and the development within services over the period is illustrated in Figures 5 and 6. If a particular service did not exist or was not captured by the National Intellectual Disability Database in 1996, growth rates are reported for the period 1999-2001 only.

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

Current residential service provision

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

In addition to the range of full-time residential services which were reported earlier in this chapter, there exists a wide range of residential support services which are designed to assist people with

intellectual disabilities to continue living with their families and in their communities. These residential supports range from holiday breaks with host families and service-based respite breaks, to the provision of regular, part-time care and supported living arrangements.

Trends in residential service provision: 1996 to 2001

Figure 5 illustrates the growth in full-time residential services and residential support services during the period 1996-2001.

During this period, intellectual disability services have experienced a 10% growth in the numbers of people with intellectual disability availing of full-time residential places, rising from 7,572 individuals in 1996 to 8,296 individuals in 2001. The key developments in this area have been:

- A 29% increase in the number of people with intellectual disability living in community group homes,
- An 88% increase in the number of intensive placements specially designed to cater for the needs of people with challenging behaviours,
- A 10% reduction in the number of people with intellectual disability who are living in large residential centres with most of this group moving to residential placements in the community, and
- A 30% reduction in the number of people with intellectual disability accommodated in psychiatric hospitals.

The period 1996-2001 has also seen tremendous growth in the number of residential support places. During this period there has been:

- A 204% increase in the numbers of individuals availing of service-based respite services either as a planned or emergency intervention: in 1996, 871 people availed of these respite services and by 2001 numbers had grown to 2,647,
- A 30% growth in the numbers availing of holiday placements within a residential service,
- A 62% increase in the use of host families for the provision of respite services,
- A 57% increase in the numbers availing of regular part-time care,
- A 27% growth in the numbers of individuals living with foster families or living in 'boarding-out' situations,
- A 73% increase in the numbers of people with intellectual disability who are living semi-independently, and
- A 25% increase in the numbers of people with intellectual disability who live independently.

Current day service provision

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

Table 3.8. National Intellectual Disability Database, Ireland 2001.
Overall level of current residential service provision, degree of intellectual disability and age group.

	Not Verified		Mild		Moderate, Severe & Profound		All Levels	
	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over
		All ages		All ages		All ages		All ages
5-day community group home	2	3	5	164	32	419	451	620
7-day (48-week) community group home	0	1	1	173	25	630	655	829
7-day (52-week) community group home	0	6	6	435	47	1160	1207	1648
5-day residential centre	2	0	2	8	29	105	134	144
7-day (48-week) residential centre	1	2	3	89	62	670	732	827
7-day (52-week) residential centre	4	7	11	185	72	2205	2277	2473
Nursing home	0	3	3	31	0	44	44	78
De-designated unit	0	2	2	30	0	282	282	314
Psychiatric hospital	0	9	9	170	0	498	498	677
Intensive placement (challenging behaviour)	1	0	1	27	16	157	173	201
Intensive placement (profound or multiple disability)	4	1	5	9	32	155	187	201
Occupying a residential support place	1	0	1	18	21	51	72	91
Other full-time residential place	2	5	7	104	37	45	82	193
Holiday residential placement	1	1	2	59	56	132	188	249
Crisis or planned respite	37	8	45	423	861	1318	2179	2647
Occasional respite with host family	3	0	3	27	108	86	194	224
Shared care or guardianship	0	0	0	4	5	7	12	16
Regular part-time care (2/3 days per week)	0	1	1	17	25	49	74	92
Regular part-time care (every weekend)	0	0	0	1	4	3	7	8
Regular part-time care (alternate weeks)	0	0	0	9	5	34	39	48
Other residential service	3	5	8	110	42	52	94	212
Foster care and boarding-out arrangements	10	3	13	148	51	33	84	245
Living semi-independently	0	8	8	122	0	52	52	182
Living independently	0	32	32	420	0	80	80	532

Figure 5. National Intellectual Disability Database, Ireland 2001.
Changes in level of overall current residential service provision 1996, 1999, 2001.

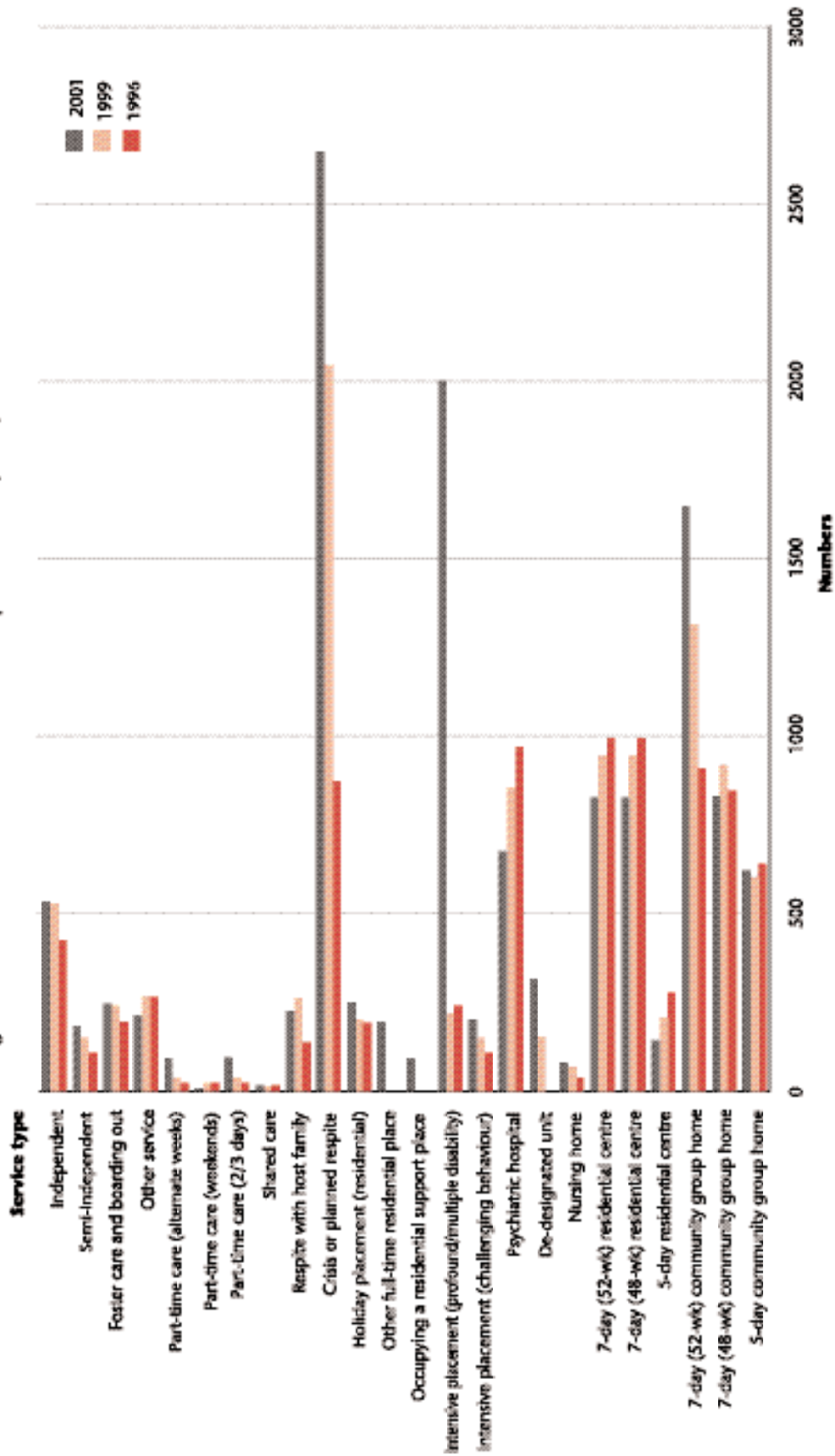
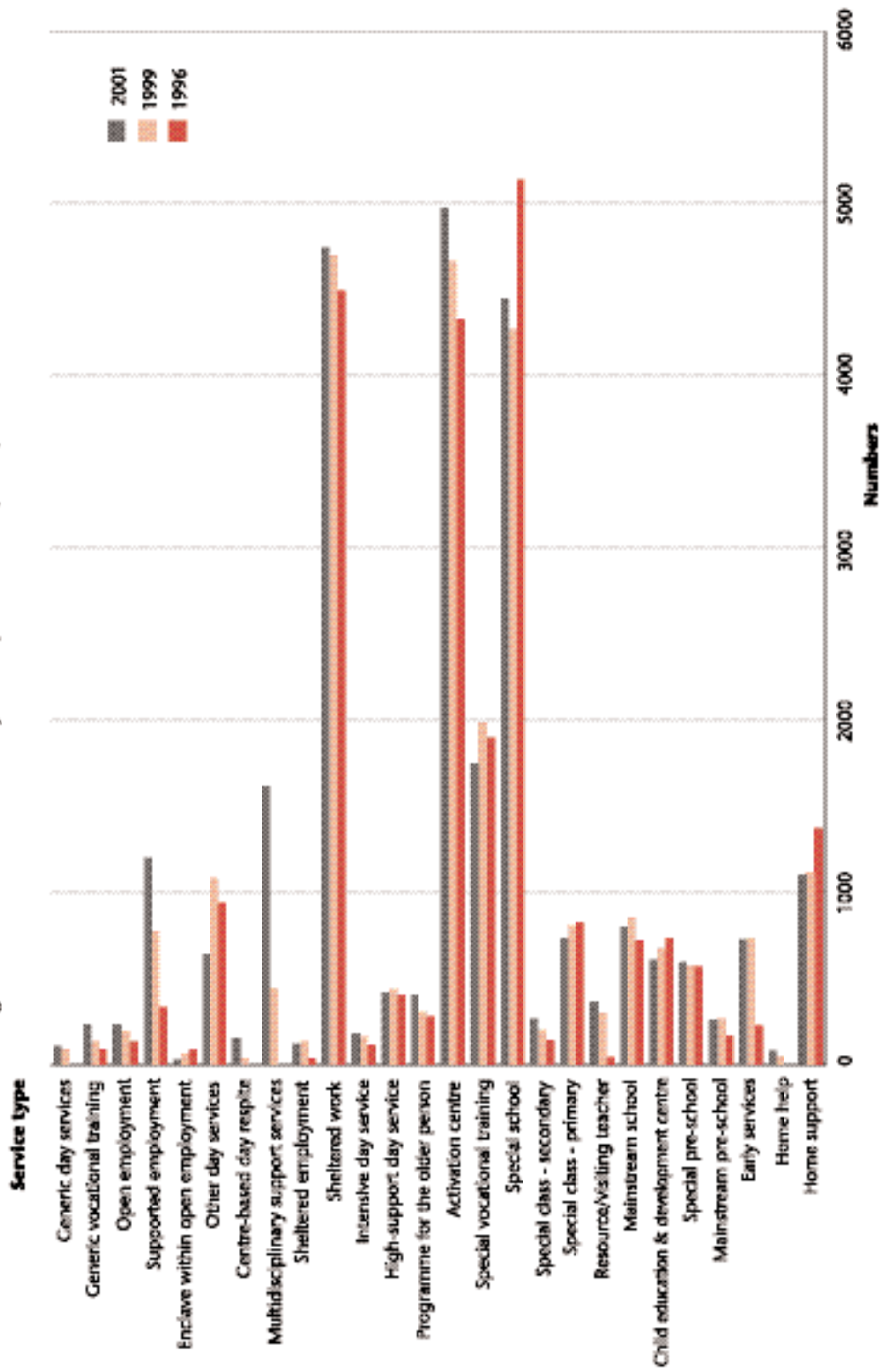


Table 3.9. National Intellectual Disability Database, Ireland 2001.
Overall level of current day service provision, degree of intellectual disability and age group.

	Not Verified		Mild		Moderate, Severe & Profound		All Levels	
	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over	18 and under	19 and over
Home support	79	15	87	112	375	434	541	561
Home help	12	4	7	16	25	18	44	38
Early services	450	0	143	1	134	0	727	1
Mainstream pre-school	89	0	102	1	62	1	253	2
Special pre-school	198	0	155	0	238	5	591	5
Child education and development centre	40	0	5	1	492	67	537	68
Mainstream school	50	2	553	35	152	3	755	40
Resource/visiting teacher	84	4	186	26	46	18	316	48
Special class - primary	21	0	465	35	199	14	685	49
Special class - secondary	1	0	174	37	47	5	222	42
Special school	55	1	2265	80	1983	65	4303	146
Special vocational training	1	41	79	745	48	835	128	1621
Activation centre	0	35	8	560	37	4331	45	4926
Programme for the older person	0	12	0	87	0	301	0	400
High-support day service	4	4	7	26	35	341	46	371
Intensive day service	3	0	8	6	9	152	20	158
Sheltered work	0	40	6	1769	8	2919	14	4728
Sheltered employment	0	4	2	90	0	27	2	121
Multidisciplinary support service	63	11	546	235	375	383	984	629
Centre-based day respite programme	4	1	9	13	50	76	63	90
Other day service	17	14	82	193	79	256	178	463
Enclave within open employment	0	0	0	13	0	17	0	30
Supported employment	0	17	2	684	1	499	3	1200
Open employment	0	6	7	198	0	19	7	223
Generic vocational training	2	7	16	163	4	41	22	211
Generic day services	1	1	5	43	1	57	7	101
		2		48		58		108

Figure 6. National Intellectual Disability Database, Ireland 2001. Changes in level of overall current day service provision 1996, 1999, 2001.



Trends in day service provision: 1996 and 2001

Figure 6 illustrates the growth in day services during the period 1996-2001.

Since 1996 there has been an increase in the numbers of people availing of almost all adult day services. In some areas of service provision these increases are substantial, as Figure 6 illustrates. Some of the largest percentage increases are observed in the following areas:

- The numbers in supported employment have increased by 874 (266%).²
- The numbers in sheltered employment have increased by 242% over the period though numbers are quite small and have been declining since 1999.
- The number of intensive day placements has grown by 54% and the number of high-support day placements has grown by 4%.
- The numbers of people with intellectual disability availing of specialised programmes designed for older people have increased by 44%.
- The numbers in the two major areas of service provision, activation programmes and sheltered work centres, have shown a large increase (645 and 246 respectively) but the proportional increases are not of the same scale as there are already significant numbers within these services. Activation programmes demonstrate a 15% increase in availability and sheltered work centres record a 5% increase.

Reduced levels of service provision are observed in relation to enclaves within open employment, which have experienced a 65% decline but where numbers were always small in any case, and in special vocational training placements, which have declined by 8%.

Of note is the increase in the numbers of people availing of mainstream services for both children and adults and, although numbers are not large at present, growth is in a positive direction and must be encouraged. The most notable developments are:

- A 168% increase in the numbers in generic vocational training programmes, increasing from 87 individuals in 1996 to 233 in 2001,
- An additional 97 individuals in open employment, an increase of 73%,
- A 29% increase in the numbers in receipt of generic day services since 1999, an increase of 24 individuals,
- A 54% increase in the number of children in mainstream pre-schools, rising from 166 to 255 in the period, and
- An increase of 11% in the numbers of children attending mainstream schools, where numbers increased from 716 in 1996 to 795 in 2001.

² A separate analysis of the large increase in numbers in this category is being initiated by the National Intellectual Disability Database Committee

There is a decline in the numbers of children availing of special education services towards the end of the period under comparison, including:

- An 11% reduction in the numbers of children in special classes at primary level, and
- A 13% decrease in the numbers of children attending special schools.

In addition, a 17% reduction is observed in the numbers of children attending Child Education and Development Centres. The reduction in numbers in these particular elements of service provision is attributed to the increased use of mainstream services described above, and the overall reduction in the numbers of children with intellectual disability, as outlined in the second chapter of this report.

Growth areas within children's services include:

- A 5% increase in the numbers of children attending special pre-schools,
- An additional 320 children receiving assistance from resource/visiting teachers, a growth of 727%, and
- An increase of 87% in the numbers of young people attending special classes in second-level education.

The 2001 dataset also demonstrates significant growth in the availability of support services which are delivered as part of a package of day services. This includes:

- An increase since 1999 of 394%, or 122 individuals, receiving centre-based day respite services,
- An additional 1,168 (262%) reported as being in receipt of multidisciplinary support services since 1999,
- Early services being delivered to an additional 504 children in the period 1996-2001, a growth rate of 225%, and
- An increase of 32 people (64%) receiving home help services since 1999.

The only area of support demonstrating a decline is the home support service, levels of which reduced by 20%.

RECENT INVESTMENT IN INTELLECTUAL DISABILITY SERVICES

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

**Table 3.10. National Intellectual Disability Database, Ireland 2001.
Current service provision by health board area.**

	Receiving day services		Receiving 5- or 7-day residential services		Resident in a psychiatric hospital		Receiving residential support services only		Receiving no service		No current service requirements		Total	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Eastern Regional Health Authority	4236	50.3	2478	29.4	292	3.5	27	0.3	50	0.6	1336	15.9	8419	100.0
Midland Health Board	895	58.0	415	26.9	22	1.4	16	1.0	128	8.3	68	4.4	1544	100.0
Mid-Western Health Board	1501	61.5	705	28.9	90	3.7	16	0.7	43	1.8	86	3.5	2441	100.0
North-Eastern Health Board	1372	66.2	473	22.8	19	0.9	26	1.3	47	2.3	136	6.6	2073	100.0
North-Western Health Board	1013	56.3	589	32.7	1	0.1	35	1.9	76	4.2	86	4.8	1800	100.0
South-Eastern Health Board	2106	64.1	796	24.2	133	4.0	17	0.5	95	2.9	137	4.2	3284	100.0
Southern Health Board	2402	61.0	1331	33.8	36	0.9	13	0.3	35	0.9	123	3.1	3940	100.0
Western Health Board	1861	58.8	833	26.3	84	2.7	55	1.7	41	1.3	293	9.3	3167	100.0
All Boards	15386	57.7	7620	28.6	677	2.5	205	0.8	515	1.9	2265	8.5	26668	100.0

Health Board Level

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

Nationally, 89.6% of the population of people with an intellectual disability are known to be in receipt of services at present. Regionally, the highest level of service provision is in the Southern Health Board where 96.0% of the population are currently receiving services. The lowest level of service provision is in the Eastern Regional Health Authority (ERHA) where 83.5% of the registered population with intellectual disability are in receipt of services.

Nationally, 31.1% of those registered on the National Intellectual Disability Database receive a full-time residential service. Regionally, this proportion varies from 23.7% in the North-Eastern Health Board to 34.7% in the Southern Health Board.

At national level, 57.7% of the database population attend services on a daily basis and this proportion ranges from 50.3% in the Eastern Regional Health Authority to 66.2% in the North-Eastern Health Board.

Nationally, 1.9% are currently without any service whatsoever but are wait-listed for services in the five-year period 2002-2006. The Midland Health Board has the highest proportion of people who are currently without any service whatsoever and are awaiting services within the next five years (8.3%). The Eastern Regional Health Authority has the lowest proportion wait-listed for services, identifying just 0.6% of their population as being without services and requiring services between 2002 and 2006. Given that the Eastern Regional Health Authority also exhibits the lowest level of service provision it is likely that the numbers awaiting services in this region are under-reported.

There are 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. At present nationally 8.5% are without services but are not identified as requiring services within the next five years. There are two likely explanations for this. Firstly, it is possible that the needs of this group have not been adequately identified. However, it is also likely that a proportion of this group are inappropriately registered on the database as they are not seeking to avail of specialised health services. The numbers of people so identified varies widely between health boards. The Eastern Regional Health Authority has the highest proportion of individuals in this category, at 15.9% of their registered population. Relatively high proportions are also observed in the Western Health Board (9.3%) and the North-Eastern Health Board (6.6%). The Southern Health Board has the lowest proportion, at 3.1%.

It is the opinion of the National Intellectual Disability Database Committee that the proportion of people with intellectual disabilities reported as being in receipt of services (89.6%) is being kept artificially low because of the very high numbers of people described as having no current service requirements (2,265 individuals). A critical appraisal of these individuals is required to establish both their possible need for services and the appropriateness of their registration on the National Intellectual Disability Database. The National Intellectual Disability Database Committee urges the health boards involved to prioritise this work and so improve the overall quality of information held on the National Intellectual Disability Database. In particular, the Committee notes that the ERHA reports the lowest proportion in receipt of services and the lowest proportion assessed as requiring services in the period 2002-2006. These observations, coupled with the fact that the ERHA has the highest proportion described as having no current requirements for services, suggests that the quality of data returned by the ERHA is not adequate and needs to be examined as a matter of urgency.

Chapter four

4. Assessment of Need 2002-2006

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

Unmet Need: describes people who are without any service whatsoever, who are without a major element of service such as day or residential, or who are without residential support services and require a new service in the period 2002-2006.

Service Change: describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2002-2006, 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

FULL-TIME RESIDENTIAL AND DAY SERVICES

The data indicate that 2,440 people will require major elements of service, either a full-time residential service or a day service, or both, in the five-year period 2002-2006. Of this group, 502 have no service and require full-time residential and/or day services; 1,544 receive a day service but require a residential service; 335 people receive a residential service but also require a day service; and 59 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. The groups currently without services or receiving only residential support services consist mainly of people in the mild intellectual disability range. The group which currently has one major element of service, day or residential, but which needs the other element, consists mainly of people in the moderate, severe or profound ranges of intellectual disability.

Table 4.1. National Intellectual Disability Database, Ireland 2001.

Number of people requiring a major element of service 2002-2006.

	No Current service	Receives minimal residential support only	Receives day only – requires residential	Receives residential only – requires day	Total
Not verified	53	8	24	1	86
Mild	277	28	343	31	679
Moderate, severe & profound	172	23	1177	303	1675
All levels	502^a	59^b	1544	335	2440

^a Of the 502, 61 require residential and day, 14 require residential only, and 427 require day only.

^b Of the 59, 13 require residential and day, 6 require residential only, and 40 require day only.

RESIDENTIAL SUPPORT SERVICES

The data indicate that 1,107 people are currently without residential support services and will require these services in the period 2002-2006. Ninety-nine per cent of this group are already in receipt of a major element of service. Thirteen individuals who require residential support services are currently without services, of whom nine have a moderate, severe, or profound level of intellectual disability. Table 4.2 provides a breakdown of this group by level of disability.

Table 4.2. National Intellectual Disability Database, Ireland 2001.					
Number of people requiring residential support services 2002-2006.					
	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	48	1	0	49
Mild	4	450	33	1	488
Moderate, severe & profound	9	523	38	0	570
All levels	13	1021	72	1	1107

NUMBER OF PLACES REQUIRED TO MEET NEED

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

Table 4.3. National Intellectual Disability Database, Ireland 2001.	
Number of new places required to meet need 2002-2006.	
Residential	1638
Day	876
Residential Support	1144 ^a

^a The total number of residential support places required is different to the figure in Table 4.2 (n=1,107) as 36 of the group who have no current service and require a day service will also need a residential support service and 1 of the group who currently has a residential service and requires a day service will also need a residential support service, giving a total of 1,144.

YEAR IN WHICH SERVICES ARE REQUIRED

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

Table 4.4. National Intellectual Disability Database, Ireland 2001.						
Year in which new places are required.						
	2002	2003	2004	2005	2006	All years
Residential	1295	130	61	122	30	1638
Day	839	25	2	8	2	876
Residential support	1037	41	33	23	10	1144

Summary of unmet service requirements

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

FULL-TIME RESIDENTIAL SERVICES

Of the group that requires full-time residential services, 75% consists of people in the moderate, severe and profound ranges of intellectual disability, 23% consists of people with mild intellectual disability and 2% have not had their level of intellectual disability verified. Most of the sub-group with moderate, severe and profound intellectual disabilities (76%) require residential placements in community group homes, 13% require residential accommodation in a campus setting, and 10% need specialised intensive placements because of their increased dependency. Within the sub-group with mild intellectual disability, 91% require community-based placements, 4% require placements in traditional-style residential centres, and 4% require intensive placements. Less than 1% of both sub-groups require nursing home placements. Of those requiring full-time residential services, 94% already receive day services (Table 4.5).

DAY SERVICES

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 (55%) have a mild intellectual disability and their principal service requirements are in the training and employment fields. The remainder of the group fall mainly into the moderate, severe and profound range of intellectual disability (34%) and the principal service requirements are for activation programmes, sheltered work, programmes specifically designed for older people, and special vocational training (Table 4.6).

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

Table 4.5. National Intellectual Disability Database, Ireland 2001.

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 AII	NV	Mild	MSP AII	NV	Mild	MSP AII	NV	Mild	MSP AII	
5-day community group home	0	2	3	5	0	0	0	0	0	4	99	177	280
7-day (48-week) community group home	2	2	8	12	1	2	2	5	7	66	240	313	
7-day (52-week) community group home	2	16	16	34	1	3	5	9	4	151	488	643	
5-day residential centre	0	0	1	1	0	0	0	0	0	2	13	15	
7-day (48-week) residential centre	0	0	3	3	0	0	0	0	0	7	54	61	
7-day (52-week) residential centre	0	2	7	9	0	1	0	1	4	4	88	96	
Nursing home	0	1	3	4	0	0	1	1	2	2	4	8	
Intensive placement (challenging behaviour)	0	2	4	6	0	0	0	0	2	6	61	69	
Intensive placement (profound or multiple disability)	0	0	1	1	0	1	2	3	1	6	52	59	
All services	4	25	46	75	2	7	10	19	24	343	1177	1544	
										30	375	1233	1638

Table 4.6. National Intellectual Disability Database, Ireland 2001.
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	NV	Mild	MSP	All
Home support	0	3	8	11	1	2	0	3	0	0	0	0	1	5	8	14
Home help	0	0	2	2	0	1	0	1	0	0	0	0	0	1	2	3
Early services	2	0	0	2	0	0	0	0	0	0	0	0	2	0	0	2
Mainstream pre-school	9	0	0	9	0	0	0	0	0	0	0	0	9	0	0	9
Special pre-school	9	3	5	17	0	0	0	0	0	0	0	0	9	3	5	17
Child education and development centre	1	0	3	4	0	0	0	0	0	0	0	0	1	0	3	4
Mainstream school	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	1
Resource/visiting teacher	1	1	0	2	0	0	0	0	0	0	0	0	1	1	0	2
Special class - primary	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Special class - secondary	0	2	0	2	0	0	0	0	0	0	0	0	0	2	0	2
Special school	0	4	0	4	0	0	0	0	0	0	0	0	0	4	0	4
Special vocational training	3	45	14	62	1	4	1	6	0	2	0	2	4	51	15	70
Activation centre	8	18	58	84	1	1	7	9	1	7	108	116	10	26	173	209
Programme for the older person	4	5	16	25	1	3	4	8	0	15	82	97	5	23	102	130
Special high-support day service	0	0	6	6	0	1	3	4	0	1	58	59	0	2	67	69
Special intensive day service	0	2	3	5	0	0	2	2	0	2	49	51	0	4	54	58
Sheltered work centre	3	41	31	75	2	5	1	8	0	1	4	5	5	47	36	88
Sheltered employment centre	0	16	2	18	0	1	0	1	0	0	0	0	0	17	2	19
Multidisciplinary support services	1	3	2	6	0	0	0	0	0	0	2	2	1	3	4	8
Centre-based day respite service	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Other day service	0	0	1	1	0	1	0	1	0	1	0	1	0	2	1	3
Enclave within open employment	0	7	0	7	0	0	0	0	0	0	0	0	0	7	0	7
Supported employment	6	96	7	109	0	3	2	5	0	2	1	3	6	101	10	117
Open employment	3	18	2	23	0	1	0	1	0	0	0	0	3	19	2	24
Generic vocational training	2	6	2	10	0	2	0	2	0	0	0	0	2	8	2	12
Generic day services	0	0	1	1	0	1	0	1	0	0	0	0	0	1	1	2
All services	52	271	165	488	6	26	20	52	1	31	304	336	59	328	489	876

A smaller group of 52 people currently access residential support services only, and require a wide range of day services – half of this group are in the mild range of intellectual disability and 38% have a moderate, severe, or profound intellectual disability.

RESIDENTIAL SUPPORT SERVICES

Residential support services are required mainly by people who live at home and either attend services on a daily basis (89%) or have no day service (4%). An additional 7% are full-time residents and need a residential support service to enhance their existing services. People with moderate, severe and profound intellectual disabilities account for 52% of the demand for residential support services, while people with mild intellectual disability account for 44%. Most of the demand (71%) is for centre- and home-based respite services. A further 19% require independent and semi-independent living placements (Table 4.7).

Service Change

The term *service change* describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2002-2006, 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, and
- change in current day service, for example from education to training or from training to employment.

CATEGORIES OF SERVICE CHANGE REQUIREMENTS

The database indicates that 10,182 people who currently receive services will require a change in their current service provision in the period 2002-2006. Of this group, 6,240 are day attenders (of whom 1,421 also avail of residential support services); 3,936 are full-time residents (of whom 3,901 also avail of day services and 140 avail of residential support services); and six receive residential support services only. A breakdown of the category of service change required by level of intellectual disability is provided in Table 4.8. People in the moderate, severe and profound ranges of intellectual disability account for 59% of the service changes, people in the mild range account for 36%, and 5% of the service changes are required by people whose level of intellectual disability has not been verified.

There are 1,021 people included in the data presented in the section on Unmet Need above, who are currently receiving one element of service, either day or residential, and require the second element. All the people in this group require 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.

**Table 4.8. National Intellectual Disability Database, Ireland 2001.
Category of service change required 2002-2006.**

	Residential and day	Residential only	Day only	Day and residential support	Residential support only	All service changes
Not verified	8	1	537	6	0	552
Mild	178	104	3287	55	47	3671
Moderate, severe & profound	1331	595	3674	235	124	5959
All levels	1517	700	7498	296	171	10182

NUMBER OF PLACES REQUIRED TO ADDRESS SERVICE CHANGES

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

**Table 4.9. National Intellectual Disability Database, Ireland 2001.
Number of places requiring to be changed 2002-2006.**

Residential	2217
Day	9311
Of which:	
Health services	6245
Education services	1542
Employment services	1345
Generic services	179
Residential support	467

The number of places required exceeds the number of people requiring service changes as some people require to change both their residential and day services. In addition, it is important to note that although 10,182 people require service changes, this does not translate into 10,182 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.

YEAR IN WHICH SERVICE CHANGES ARE REQUIRED

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

Table 4.10. National Intellectual Disability Database, Ireland 2001.						
Year in which service changes are required.						
	2002	2003	2004	2005	2006	All years
Residential	1948	98	95	54	22	2217
Day	7470	887	508	313	133	9311
Of which:						
Health services	5006	558	342	237	102	6245
Education services	1243	157	89	39	14	1542
Employment services	1116	136	51	27	15	1345
Generic services	105	36	26	10	2	179
Residential support	430	10	6	15	6	467

Summary of service change requirements

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

RESIDENTIAL SERVICE CHANGE

The database indicates that 2,217 individuals, currently in full-time residential services, will require an upgrading or change of accommodation within the next five years (Table 4.11).

For most of this group (1,651 people) a change of service is required. Residential placements in the community are required by 615 individuals, 537 individuals require intensive services for either challenging behaviour or profound or multiple disability, 80 people require centre-based placements, 38 people need placements in nursing homes and one person is identified as needing admission to a psychiatric hospital. Three hundred and fifty-five individuals need their service upgraded to include care at weekends and holiday times and 25 people require less care and could return to their families at weekends and holiday times.

Furthermore, there is a group of 566 individuals who need an enhancement of their existing service. Over two-thirds of this group need increased supervision, and among the other enhancements required are transfers to a location closer to the family home or transfers to age appropriate services. Some of the needs associated with the enhancement of existing services will be met through the funding which is made available to meet identified needs in existing services.

**Table 4.11. National Intellectual Disability Database, Ireland 2001.
Pattern of movement of individuals from current residential service to future residential service 2002-2006.**

Full-time residential service required in the period 2002-2006											
	5-day CGH	7-day (48-wk) CGH	7-day (52-wk) CGH	5-day RC	7-day (48-wk) RC	7-day (52-wk) RC	Nursing home	Psychiatric hospital	Int. placement (CB)	Int. placement (P/M D)	Total current services
Current full-time residential service:											
5-day community group home	23	89	102	3	3	5	1	0	10	2	238
7-day (48-week) community group home (CGH)	1	47	80	1	3	11	2	0	6	1	152
7-day (52-week) community group home	5	8	203	0	4	16	14	0	37	26	313
5-day residential centre (RC)	17	12	12	4	21	13	0	1	11	8	99
7-day (48-week) residential centre	7	103	55	1	70	50	5	0	41	10	342
7-day (52-week) residential centre	0	22	270	2	8	157	4	0	161	149	773
Nursing home	0	0	6	0	1	1	0	0	0	2	10
De-designated unit	0	1	57	0	0	1	9	0	25	5	98
Intensive placement (challenging behaviour) (CB)	0	2	15	0	1	4	2	0	27	6	57
Intensive placement (profound/multiple disability) (P/M D)	0	2	3	0	2	12	0	0	27	35	81
Occupying a residential support place	6	8	14	0	4	7	0	0	7	3	49
Other full-time residential place	2	0	1	0	0	1	1	0	0	0	5
Total services required	61	294	818	11	117	278	38	1	352	247	2217

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

DAY SERVICE CHANGE

Within the next five years, 9,311 individuals will require a change, enhancement, or upgrading of their day service (Table 4.12). Health-funded services are required in 67% of the changes, 17% involve educational services, 14% involve employment services, and 2% involve generic services.

Health-funded services

CHILDREN'S SERVICES

Of the 6,245 service changes required within the health-funded services, those in respect of just 8% (496 individuals) are specifically identifiable as children's services.

Four hundred and forty-seven children require alternative or additional day services. Most of the demand is for mainstream and specialised pre-school services (311 children) and the majority of these children (71%) are currently in receipt of early services. The balance of the demand is for centre-based day respite services (73 children), placements in child education and development centres (57 children), and early services (six children). Most of the children requiring these placements are attending special pre-school services.

There are 49 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 a higher level of supervision within their existing service, require their existing service more frequently, or need to receive their service closer to their family home.

ADULT SERVICES

There are 5,749 placements primarily designed for adults and funded from the health budget which will require upgrading or change within the next five years.

There are 4,277 individuals who require alternative or additional day services between 2002 and 2006. Special vocational training programmes are required by 972 individuals, the majority of whom (83%) are currently attending special schools. Sheltered work placements are required by 824 individuals, most of whom are currently attending special schools (41%) or are in receipt of special vocational training (33%). Within the more care-focused services, demand is mainly for activation programmes (756 people), high-support or intensive placements (725 people) and programmes designed specifically to address the needs of older people with intellectual disability (573 people). Demand for activation programmes stems from three main groups, who are currently attending special schools (35%), in sheltered work centres (25%) or attending child education and development centres (17%). Individuals who are currently receiving activation programmes require the majority of the high-support and intensive placements (66%). Programmes to meet the needs of older people with intellectual disability are required primarily by individuals currently in activation programmes (58%) or attending sheltered work centres (33%).

There are 1,472 individuals who need to have their existing day service enhanced. Most of this group are currently receiving activation programmes (55%) or attending sheltered work centres (26%). Of the 1,472 who require enhanced day services, the majority (75%) require increased supervision, and among the other enhancements required are an increased amount of service (13%), the provision of services closer to the family home (5%), and the provision of age-appropriate services (2%).

Table 4.12. National Intellectual Disability Database, Ireland 2001.
Pattern of movement of individuals from current day service to future day service 2002-2006.

Current day service:	Day service required in the period 2002-2006																											
	HS	HH	ES	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	SVT	AC	POP	SHS	SI	SWC	SEC	MSS	DR	OTH	E	SE	OE	GVT	GD	All	
Home support (HS)	5	0	1	6	14	2	4	0	3	0	7	2	9	3	0	1	5	0	0	0	0	1	0	5	1	0	0	69
Home help (HH)	2	0	0	0	1	1	0	0	0	0	0	0	3	0	0	0	2	0	0	0	0	0	0	0	0	1	11	
Early services (ES)	3	0	4	90	132	9	15	5	5	0	7	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	271
Mainstream pre-school (MPS)	1	0	1	4	5	1	45	9	18	1	29	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	116
Special pre-school (SPS)	0	0	1	29	12	34	47	27	55	0	224	1	0	0	0	0	0	0	6	1	1	0	0	0	0	0	0	438
Child education & development centre (CEDC)	5	0	0	0	0	29	0	0	5	0	33	2	125	0	9	13	0	1	3	2	0	0	1	0	0	0	0	228
Mainstream school (MS)	6	0	0	0	1	0	24	70	41	84	29	28	1	0	0	0	3	0	31	6	4	2	5	0	0	10	0	345
Resource/visiting teacher (RT)	0	0	1	8	0	2	31	37	5	29	27	2	0	0	0	0	0	0	56	0	1	0	7	1	5	0	212	
Special class – primary (SCP)	7	0	0	0	0	0	4	11	2	302	30	22	6	1	0	3	8	0	9	3	1	0	4	1	7	0	421	
Special class – secondary (SCS)	1	0	0	0	0	0	0	0	0	2	2	42	17	0	0	0	10	1	2	5	1	1	5	0	29	0	118	
Special school (SS)	46	0	0	0	0	2	1	3	6	6	235	802	262	0	42	23	340	31	37	20	4	21	102	44	76	0	2103	
Special vocational training (SVT)	0	0	0	0	0	1	0	0	0	0	0	49	67	10	9	4	271	12	10	1	8	353	65	15	2	878		
Activation centre (AC)	11	1	0	0	0	2	0	0	0	0	1	14	806	332	134	342	124	9	17	6	0	0	72	2	2	5	1880	
Programme for the older person (POP)	1	0	0	0	0	0	0	0	0	0	0	0	7	100	1	2	3	0	0	0	0	0	0	0	0	0	2	116
Special high-support service (SHS)	0	0	0	0	2	0	0	0	2	0	5	1	15	4	78	59	1	0	0	0	0	1	2	0	0	0	0	170
Special intensive service (SI)	0	0	0	0	0	0	0	1	0	0	1	2	2	0	0	33	2	0	0	3	0	0	2	0	0	0	0	46
Sheltered work centre (SWC)	1	0	0	0	0	0	0	1	0	0	0	20	186	190	27	20	390	42	6	25	6	6	447	13	8	1	1389	
Sheltered employment centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	23	0	0	0	25	
Multidisciplinary support services (MSS)	2	1	2	0	16	2	1	1	2	0	1	10	4	2	1	22	9	2	8	0	3	2	10	3	2	0	0	106
Centre-based day respite service (DR)	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Other day service (OTH)	2	0	0	2	2	1	0	0	0	0	4	9	30	19	3	6	11	0	0	0	3	0	6	2	2	1	103	
Enclave with open employment (E)	0	0	0	0	0	0	0	0	0	0	0	0	1	7	0	0	0	0	0	0	0	0	1	1	0	1	11	
Supported employment (SE)	0	0	0	0	0	0	0	0	0	0	0	4	1	5	0	1	10	4	8	0	11	1	43	28	1	0	117	
Open employment (OE)	0	1	0	0	0	0	0	0	0	0	0	1	1	0	0	0	14	2	1	0	0	1	5	7	3	0	36	
Generic vocational training (GVT)	0	0	0	0	0	0	0	0	0	0	0	7	7	0	0	0	10	7	0	0	0	0	35	6	2	0	74	
Generic day service (GD)	0	0	0	1	2	0	1	0	0	0	0	3	12	0	3	0	0	1	0	0	0	0	1	0	2	1	27	
All services	93	3	10	140	187	86	173	166	144	424	635	1021	1562	673	307	529	1214	112	197	73	38	42	1129	174	165	14	9311	

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

Educational services

Alternative or enhanced educational services will be required by 1,542 children in the period 2002-2006.

Of these, 1,242 children require alternative or additional educational services. Most of the demand is for special classes at secondary level (422 children) or for special school placements (400 children). Of the group who require special classes at secondary level, most are currently in special classes at primary level (72%). Of those requiring places in special schools, most are currently in special pre-schools (56%). The remaining services required by the overall group of 1,242 children include mainstream school placements (required by 149 children – the majority of whom are in mainstream pre-schools and special pre-schools at present), special classes at primary level (required by 142 children – the majority of whom are currently in special pre-schools and mainstream classes), and resource/visiting teachers (required by 129 children – the majority of whom are currently in mainstream classes).

Three hundred children need their current educational placement to be enhanced in the period 2002-2006. These needs arise among children currently attending special schools (235 children), availing of the services of a resource/visiting teacher (37 children), attending mainstream schools (24 children), and in special classes at primary level (two children) and secondary level (two children). Most (56%) 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 (33%).

Employment services

There are 1,345 individuals who will require access to new or enhanced employment opportunities during the period 2002-2006.

A total of 1,295 of this group will require new employment opportunities. Supported employment placements are required for 1,086 individuals. In the main, these individuals currently avail of sheltered work (41%), special vocational training (33%), or attend special schools (9%). There are 167 people who require open employment and at present they are mainly in special vocational training (39%), special schools (26%), and supported employment (17%). The remainder of the group requiring new employment opportunities (42 people) require placements in enclaves within open employment. At the moment, most of this group attend special schools (50%), sheltered work centres (14%), or special vocational training (19%).

There are 50 individuals who need to have their existing employment placement enhanced. Of this group, 43 are in supported employment and seven are in open employment and most of the enhancements identified relate to increased supervision within these placements or an increased level of service provision.

Generic services

There is a much smaller group of 179 individuals who require access to generic day services during the period 2002-2006 or who need to have their existing placement within the generic services enhanced.

Of this group, 176 require new placements within the generic services. A total of 163 individuals require generic vocational training opportunities and 13 require access to other, unspecified generic day services. Of the group requiring generic vocational training, most are currently in special schools (47%), special classes at secondary level (18%) or are receiving special vocational training (9%). Of the group requiring access to other unspecified generic day services, the largest sub-group is currently in activation programmes (38%).

Two individuals currently in receipt of generic vocational training and one person currently receiving an unspecified generic day service require their existing service to be enhanced in the period 2002-2006. One needs increased supervision, one needs a more frequent service and one needs a service to be provided closer to home.

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, certain existing day services, for example, early services and home support services, will not necessarily be freed up when a new service is provided as these are ongoing services that are generally required in addition to 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/visiting teacher
- Home help
- Multidisciplinary support services for school-age children and adults
- Centre-based day respite service.

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

RESIDENTIAL SUPPORT SERVICE CHANGE

The database indicates that 467 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 2002-2006 (Table 4.13). Additional or alternative support services are required by 253 individuals, and 214 individuals require their existing service to be upgraded.

The principal needs of this group include

- more frequent centre-based respite breaks for people currently availing of this service (196 people),
- more regular part-time care arrangements for people currently accessing crisis or planned respite services and respite breaks with host families (79 people),
- more centre-based respite breaks for people currently availing of family-based respite breaks (29 people),
- more family-based respite breaks for people currently accessing centre-based respite and residential placements during holiday times (27 people),
- opportunities to experience semi-independent living arrangements for people currently receiving centre-based respite breaks (21 people),
- more residential placements during holiday times for people currently accessing both centre- and family-based respite breaks (15 people),
- increased supervision for people currently living semi-independently (13 people), and
- increased supervision, in the form of semi-independent living placements, for people currently living independently (12 people).

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

Persons with intellectual disability who are accommodated in psychiatric hospitals

The 2001 health strategy *Quality and Fairness: A Health System for You* acknowledges the inappropriateness of psychiatric hospital accommodation for people with intellectual disability and makes a commitment to transfer those currently resident in psychiatric hospitals to appropriate accommodation no later than 2006.

The data from the National Intellectual Disability Database for 2001 identifies 677 individuals with intellectual disability, all aged 19 years and over, currently accommodated in psychiatric hospitals. Table 4.14 details the overall service requirement status of this group by level of intellectual disability.

Of this group, 432 (64%) have service requirements in the period 2002-2006, of whom 410 have an

Table 4.13. National Intellectual Disability Database, Ireland 2001.
Residential support services required by people currently availing of residential support services

Current residential support service	Residential support service required 2002-2006											Total	
	Foster care and boarding out	Living independently	Living semi-independently	Holiday residential placement	Crisis or planned respite	Occasional respite care (host family)	Shared care / guardianship	Regular part-time care (2/3 days per week)	Regular part-time care (every weekend)	Regular part-time care (alternate weeks)	Other residential service		
Foster care and boarding out	0	0	3	4	9	3	0	0	0	0	0	0	19
Living independently	0	0	12	1	5	0	1	1	0	0	1	1	21
Living semi-independently	0	3	13	1	0	0	0	1	0	0	0	0	18
Holiday residential placement	0	0	1	1	8	6	0	1	0	1	1	1	19
Crisis or planned respite	0	1	21	10	196	21	1	51	8	13	6	6	328
Occasional respite care (host family)	1	0	0	5	29	4	1	3	0	4	0	0	47
Shared care /guardianship	0	0	0	0	3	0	0	0	0	0	0	0	3
Regular part-time care (2/3 days per week)	0	1	0	3	0	0	0	0	0	3	0	0	7
Regular part-time care (alternate weeks)	0	0	0	0	1	0	0	0	1	1	0	0	3
Other residential service	1	0	0	0	0	0	0	0	1	0	0	0	2
All services	2	5	50	25	251	34	3	57	10	22	8	8	467

appropriate alternative residential facility identified for them, 19 have identified day service requirements and three are identified as requiring residential support services only. Two hundred and forty-five individuals have no alternative residential or day service needs identified for them in the 2001 dataset. The National Intellectual Disability Database Committee will be requesting the health boards to review the needs of this group and it is expected that this situation will change given the commitment outlined in the national health strategy.

Those with identified service requirements are statistically significantly more likely to be male and of a younger age. Sixty-nine per cent of males have identified service needs, compared to 56% of females. The average age of those with service requirements is 52.2 years, whereas those with no identified service needs have an average age of 59.4 years.

Table 4.14. National Intellectual Disability Database, Ireland 2001.
Overall service requirements of people with intellectual disability currently resident in psychiatric hospitals.

	No service requirements				Has service requirements				Total
	Not Verified	Mild	Moderate, severe & profound	All levels	Not Verified	Mild	Moderate, severe & profound	All levels	
Resident in a psychiatric hospital – no day programme	0	20	54	74	4	41	201	246	320
Resident in a psychiatric hospital – with day programme	1	51	119	171	4	58	124	186	357
All residents	1	71	173	245	8	99	325	432	677

As already stated, the current day and residential programmes for 245 people with intellectual disability currently within the psychiatric services are deemed to be appropriate and these people have no identified service needs in the period 2002-2006. Twenty-nine per cent of this group have a mild intellectual disability and 71% have a moderate, severe or profound disability. Within this group are 74 people who currently have no formal day programme. 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 432 people who require services, 19 will continue to reside within their psychiatric hospital setting but will require day services in the period 2002-2006. Thirty-two per cent of this group have a mild intellectual disability and 68% have a moderate, severe or profound intellectual disability. At present, five of this group have no day service and require activation programmes (two people), a programme for older people (two people) and one person requires special vocational training. The remaining 14 are in receipt of day programmes that need to be enhanced or upgraded, as outlined in Table 4.15. Activation programmes are required by seven individuals, three require specific programmes designed for older people and four require high-support services.

**Table 4.15. National Intellectual Disability Database, Ireland 2001.
Day service requirements of people appropriately accommodated in
psychiatric hospitals.**

	Services required				
	Special vocational training	Activation centre	Programme for the older person	Special high-support day service	All services
Currently receiving:					
No day programme	1	2	2	0	5
Activation centre	0	0	0	1	1
Programme for the older person	0	1	0	0	1
Special high-support day service	0	1	0	0	1
Other day programme	0	5	3	3	11
All services	1	9	5	4	19

In addition, three people are identified as requiring residential support services within the period 2002-2006 but it is not clear if the intention is for these people to live outside the psychiatric hospital with these support services or if they are to remain within the psychiatric hospital. One person needs respite care, one needs shared care and one needs an unspecified residential support service.

Of the population currently resident in psychiatric hospitals 410 need to transfer to the intellectual disability services. Twenty-three per cent of this group have a mild intellectual disability, 75% have a moderate, severe or profound intellectual disability and 2% have not had their level of disability verified. Residential and day service requirements are identified for 144 individuals, while 244 require only an alternative residential placement. The day and residential services required by this group, and the year in which the service needs will arise, are outlined in Tables 4.16 and 4.17.

Of the 410 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, 26% need places in residential centres, and 3% need to move into nursing homes. A further 5% have an unspecified residential requirement within the intellectual disability services. Almost all of the need arises immediately (Table 4.16).

Of this same group of 410 people, 144 will also require an appropriate day service. The greatest demand is for activation programmes (46%), high-support or intensive day programmes (40%), a programme for older people (8%), sheltered work placements (3%), sheltered employment placements (3%), 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).

Table 4.16. National Intellectual Disability Database, Ireland 2001.
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			
	2002	2004	2005	2002-2006
7-day (48-week) community group home	4	0	0	4
7-day (52-week) community group home	97	0	0	97
7-day (48-week) residential centre	9	0	0	9
7-day (52-week) residential centre	97	1	1	99
Nursing home	14	0	0	14
Intensive placement (challenging behaviour)	101	0	0	101
Intensive placement (profound/multiple disability)	66	0	0	66
Unspecified intellectual disability service	20	0	0	20
All residential services	408	1	1	410

Table 4.17. National Intellectual Disability Database, Ireland 2001.
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		
	2002	2005	2002-2006
Special vocational training	1	0	1
Activation centre	66	0	66
Programme for the older person	11	1	12
Special high-support day service	42	0	42
Special intensive day service	15	0	15
Sheltered work centre	4	0	4
Sheltered employment centre	4	0	4
All day services	143	1	144

Overall service provision to people with intellectual disability and the changing pattern of care

The data presented in this chapter in relation to unmet need for services and demand for service changes need to be considered together to enable the future pattern of care to be forecasted. The database indicates that there are large numbers of people who require day or residential services, or both, for the first time and also that there are significant numbers who require changes to, or enhancements of, their existing placements. When the latter group moves into new services their existing places will be freed up for occupation by others who are currently without services or who are inappropriately accommodated in psychiatric hospitals. The existing placements occupied by these individuals are secure until their new place becomes available. Such movement is part of the ongoing development of services and is tangible evidence of the ability of the database to match needs with service provision. Individuals who already avail of services within either the intellectual disability or psychiatric services already have significant funding allocated to them and changes to their existing placements will incur only minimal costs.

PATTERN OF CARE REQUIRED IN FULL-TIME RESIDENTIAL SERVICES

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

- 1,638 individuals currently living at home who require full-time residential services for the first time,
- 410 individuals currently resident in psychiatric hospitals who require to transfer to the intellectual disability services, and
- 2,217 individuals currently in full-time residential services within the intellectual disability sector who require changes to their existing placement. Of this group, 1,651 require alternative services and 566 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 mentioned above. Not all of the group who require service enhancements will move to new placements. For example, 383 out of the 566 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 2002-2006 to meet this demand. A total of 2,097 residential places will be required – a reduction of 85 since 2000. As expected, there is significant demand for community-based placements both from people who will be coming into residential services for the first time and from people in existing residential placements. In total, 1,872 community-based placements will be required during the period, an increase of 80 on projections made in 2000. One consequence of this will be the availability of 514 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 766 intensive residential placements that will occur. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

**Table 4.18. National Intellectual Disability Database, Ireland 2001.
Pattern of full-time residential service provision required 2002-2006.**

	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	285	0	61	238	-108
7 day (48-week) community group home	330	4	294	152	-476
7 day (52-week) community group home	686	97	818	313	-1288
5 day residential centre	16	0	11	99	+72
7 day (48-week) residential centre	64	9	117	342	+152
7 day (52-week) residential centre	106	99	278	773	+290
Nursing home	13	14	38	10	-55
De-designated unit	0	0	0	98	+98
Psychiatric hospital	0	0	1	0	-1
Intensive placement (challenging behaviour)	75	101	352	57	-471
Intensive placement (profound or multiple disability)	63	66	247	81	-295
Designated residential support placement	0	0	0	[49 ^a]	0
Other/unspecified intellectual disability service	0	20	0	5	-15
Total	1638	410	2217	2168	-2097

^a 49 designated residential support places, currently being blocked by full-time residents, will be freed up but they have not been deducted from the total number of full-time residential places required as they should not be made available for full-time use.

PATTERN OF CARE REQUIRED IN DAY SERVICES

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

- 876 individuals currently without day services,
- 144 individuals currently resident in psychiatric hospitals who will require an appropriate day service when they transfer to the intellectual disability services,
- 19 individuals appropriately placed in psychiatric hospitals but requiring a day programme within that setting, and
- 9,311 individuals currently in day services within the intellectual disability sector who require changes to, or enhancements of, their existing placement. Of this group 7,437 require alternative or additional services and 1,874 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/visiting teachers, multidisciplinary 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 who require service enhancements will move to new placements. Again, as was seen with the requirement for enhancement of residential placements, 1,249 out of the 1,874 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 2002-2006 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 1,709 day places will be required – a reduction of 118 since 2000. The table shows two distinct trends – a decrease in the numbers of young children requiring certain services and a huge demand for the full spectrum of adult services. Over the next five years there will be small reductions nationally in the number of children requiring special pre-school services, mainstream classes and special classes at primary level and placements in child education and development centres. There will be a significant reduction in the number of children requiring special schools. However, there is a small demand within this group for mainstream pre-school services and early services, and a much larger demand for additional resource/visiting teachers and for the provision of special classes at secondary level.

Adult services will continue to experience considerable pressure across the whole spectrum of day services.

There will be a shortfall of vocational training placements, both generic and specialised, and of employment opportunities. In the period 2002-2006, 103 generic vocational training places and 215 special vocational training places will be required. Over the next five years, 1,129 supported employment placements and 162 open employment placements need to be developed to meet the demand that exists for those services. There will also be a shortfall of 110 sheltered employment opportunities and 38 placements in enclaves within open employment during this time.

**Table 4.19. National Intellectual Disability Database, Ireland 2001.
Pattern of day service provision required 2002-2006.**

	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	14	0	0	93	0	-107
Home help	3	0	0	3	0	-6
Early services	2	0	0	10	0	-12
Mainstream pre-school	9	0	0	140	116	-33
Special pre-school	17	0	0	187	438	+234
Child education and development centre	4	0	0	86	228	+138
Mainstream school	1	0	0	173	345	+171
Resource/visiting teacher	2	0	0	166	0	-168
Special class - primary	1	0	0	144	421	+276
Special class - secondary	2	0	0	424	118	-308
Special school	4	0	0	635	2103	+1464
Special vocational training	70	1	1	1021	878	-215
Activation centre	209	66	9	1562	1880	+34
Programme for the older person	130	12	5	673	116	-704
Special high-support day service	69	42	4	307	170	-252
Special intensive day service	58	15	0	529	46	-556
Sheltered work centre	88	4	0	1214	1389	+83
Sheltered employment centre	19	4	0	112	25	-110
Multidisciplinary support services	8	0	0	197	0	-205
Centre-based day respite service	1	0	0	73	0	-74
Other day service	3	0	0	38	103	+62
Enclave within open employment	7	0	0	42	11	-38
Supported employment	117	0	0	1129	117	-1129
Open employment	24	0	0	174	36	-162
Generic vocational training	12	0	0	165	74	-103
Generic day services	2	0	0	14	27	+11
All Services	876	144	19	9311	8641	-1709

An additional 704 programme placements designed specifically to meet the needs of older people with intellectual disability are needed. Multidisciplinary support services will be required by an additional 205 people, home support services by an additional 107 people, centre-based day respite placements by an additional 74 people and home help services by an additional six people during the period. As with residential services, there is significant demand for high-support and intensive placements. Between 2002 and 2006, 252 high-support day placements and 556 intensive day placements will be required. These services involve a higher staff/client ratio and more specialist interventions to address needs arising from behavioural problems, multiple disabilities and the effects of ageing. The data indicate that demands for activation programmes and sheltered work placements should be met as other identified service needs are met and existing services are consequently freed up.

Continued demand for services

Despite significant investment in intellectual disability services in recent years and a corresponding growth in the number of people in receipt of services, demographic factors are contributing to long waiting lists for services, and in particular for full-time residential services. The increased birth rate in the 1960s and 1970s has resulted in large numbers of adults currently ranging in age from late 20s to early 40s requiring full-time residential services. People with an intellectual disability are also living longer than previously, contributing to both an ongoing demand for services and a reduction in the number of places freed up through death. This continuing demand for services has also been the international experience in service provision to this population (Lakin, 1998).

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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, Health Research Board.

Appendix A

INTELLECTUAL DISABILITY DATABASE - NATIONAL PLANNING DATA FORM 2001

PERSONAL DETAILS

1. Surname	18. Next of Kin name
2. First Name	19. Next of Kin address
3. Previous Surname	20. Next of Kin address
4. Address	21. Next of Kin address
5. Address	22. Next of Kin address
6. Address	23. Next of kin address (County)
7. Address	24. Next of kin telephone number
8. Address (County)	25. Relationship of next of kin
9. Date of Birth	
10. Year of birth (where DOB is unknown)	
11. Health Board Region	
12. Community Care Area	
13. Sub-area (NFI) within the Health Board Region	
14. Planning area within the Health Board	
15. Personal identification number	
16. Sex 1-male 2-female	
17. Degree of intellectual disability	0-not verified 1-mild/severe 2-borderline 3-mild 4-moderate 5-severe 6-profound

CURRENT SERVICE PROVISION

30. Agency providing main day service	
31. Type of main day service	
32. Current level of main day service supervision 0. 1. 2. 3. 4. 5.	
33. Agency providing secondary day service	
34. Type of secondary day service	
35. Current level of secondary day service supervision 0. 1. 2. 3. 4. 5.	
40. Agency providing main residential service	
41. Type of main residential circumstances	
42. Current level of main residential service supervision A. B. C. D. /.	
43. Agency providing secondary residential service	
44. Type of secondary residential circumstances	
45. Current level of secondary residential service supervision A. B. C. D. /.	
46. Health Board funding current services	

Coding for variables 32, 35, 51 & 55

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

Coding for variables 42, 45, 51 & 55

Level A: Minimum - no support
 Level B: Staff on duty most of the time plus sleepers
 Level C: Two staff on duty plus sleepers
 Level D: Two staff on duty plus one duty night staff
 Level /: Not applicable

FUTURE SERVICE REQUIREMENTS

50. Type of day service required	
51. Level of day supervision required 0. 1. 2. 3. 4. 5.	
52. Year in which this day service is required	
53. Reason for duplication on current/future day service	
54. Type of day service required - contingency plan	
55. Level of (contingency plan) day supervision required 0. 1. 2. 3. 4. 5.	
56. Reason for duplication on current/contingency day service	
57. Reason for duplication on future/contingency day service	
60. Type of residential service required	
61. Level of residential supervision required A. B. C. D. /.	
62. Year in which this residential service is required	
63. Reason for duplication on current/future residential service	
64. Type of residential service required - contingency plan	
65. Level of (contingency plan) residential supervision required A. B. C. D. /.	
66. Reason for duplication on current/contingency residential service	
67. Reason for duplication on future/contingency residential service	
68. Health Board to fund future services	

ADDITIONAL INFORMATION

100. Date of completion/review | | | | | | | | | |

101. Person responsible for update of database form | | | | | | | | | |

102. Unit/Centre of person responsible | | | | | | | | | |

103. Agency returning record to health board database | | | | | | | |

104. Date consent received | | | - | | - | | | | |

105. Reason for removal | |

If transferred (1), please indicate:

to Health Board | | to CCA | | | to Agency | | | | | | |

If deleted (3), please indicate:

Emigrated | | Parent's request | | Duplication between 2 or more health boards | |

Service no longer required | | Client's request | | Duplication within health board | |

Other reason | |

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

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

Programme Codes and Descriptions

DAY PROGRAMME

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

Values 18-22

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

RESIDENTIAL CIRCUMSTANCES

- 101. At home, with both parents
- 102. At home, with one parent
- 103. At home with sibling
- 104. At home with relative
- 105. Lives with non-relative (e.g. neighbour or family friend)
- 106. Adoption
- 107. Foster care (Includes 'boarding-out' arrangements)
- 108. Living independently
- 109. Living semi-independently - maximum 7 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 or planned respite
- 175. Occasional respite care with a host family in a scheme such as Home Sharing or Share a Break
- 176. Shared care or guardianship (usually 5 or 7 days per week)
- 177. Regular part-time care - 2-3 days per week
- 178. Regular part-time care - every weekend
- 179. Regular part-time care - alternate weeks
- 180. Other residential service

DAY SERVICE GROUPINGS

Health

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

Education

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

Employment

- Enclave within open employment
- Supported employment
- Open employment

Generic

- Generic vocational training
- Generic day services

Appendix B

Table B1. National Intellectual Disability Database, Ireland 2001.
Details of main residential circumstances, degree of intellectual disability and age group.

Residential circumstances	Not Verified					Mild					Moderate-Severe -Profound					All Levels				
	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages
Home Setting	910	99	75	32	1116	4314	2264	1014	199	7791	3188	2546	1408	292	7434	8412	4909	2497	523	16341
At home with both parents	791	72	18	4	885	3528	1672	376	14	5590	2662	1892	423	15	4992	6981	3636	817	33	11467
At home with one parent	106	23	34	4	167	629	467	412	30	1538	445	555	594	39	1633	1180	1045	1040	73	3338
At home with sibling	1	1	18	19	39	5	46	160	112	323	8	51	329	198	586	14	98	507	329	948
At home with other relative	2	1	4	4	11	49	28	48	35	160	14	20	47	34	115	65	49	99	73	286
Living with non-relative	0	0	0	1	1	2	5	10	3	20	2	6	9	2	19	4	11	19	6	40
Adoption	0	0	0	0	0	13	6	0	0	19	6	3	1	0	10	19	9	1	0	29
Foster care and boarding-out arrangements	10	2	1	0	13	88	40	8	5	141	51	19	5	4	79	149	61	14	9	233
Independent/Semi-independent Setting	0	5	21	14	40	6	166	265	100	537	0	18	81	31	130	6	189	367	145	707
Living independently	0	5	15	12	32	6	132	201	76	415	0	7	50	21	78	6	144	266	109	525
Living semi-independently	0	0	6	2	8	0	34	64	24	122	0	11	31	10	52	0	45	101	36	182
Community Group Home	2	1	5	4	12	72	196	361	143	772	122	720	1188	283	2313	196	917	1554	430	3097
5-day community group home	2	1	2	0	5	48	62	52	2	164	37	221	185	8	451	87	284	239	10	620
7-day community group home	0	0	1	0	1	12	49	87	25	173	29	211	376	39	655	41	260	464	64	829
7-day (52-week) community group home	0	0	2	4	6	12	85	222	116	435	56	288	627	236	1207	68	373	851	356	1648
Residential Centres	7	3	2	4	16	14	58	108	105	285	216	865	1496	566	3143	237	926	1606	675	3444
5-day residential centre	2	0	0	0	2	1	4	3	0	8	40	60	30	4	134	43	64	33	4	144
7-day residential centre	1	0	0	2	3	3	24	45	20	92	79	259	330	64	732	83	283	375	86	827
7-day (52-week) residential centre	4	3	2	2	11	10	30	60	85	185	97	546	1136	498	2277	111	579	1198	585	2473
Other full-time services	9	4	5	10	28	70	68	109	142	389	115	297	482	444	1338	194	369	596	596	1755
Nursing home	0	0	1	2	3	0	1	8	22	31	0	1	12	31	44	0	2	21	55	78
De-designated unit	0	0	0	2	2	3	4	9	14	30	0	22	116	144	282	3	26	125	160	314
Psychiatric hospital	0	1	3	5	9	0	17	62	91	170	0	39	227	232	498	0	57	292	328	677
Intensive placement (challenging behaviour)	1	0	0	0	1	5	10	10	2	27	22	91	55	5	173	28	101	65	7	201
Intensive placement (profound or multiple handicap)	4	0	0	1	5	0	1	4	4	9	34	102	41	10	187	38	103	45	15	201
Fulltime resident in 'other' residential service	3	3	1	0	7	57	26	12	9	104	38	9	16	19	82	98	38	29	28	193
Fulltime resident in residential support place	1	0	0	0	1	5	9	4	0	18	21	33	15	3	72	27	42	19	3	91
No fixed abode	0	1	0	0	1	0	6	3	0	9	0	2	1	0	3	0	9	4	0	13
Insufficient information	49	33	47	28	157	76	332	276	88	772	52	113	150	67	382	177	478	473	183	1311
Totals	977	146	155	92	1370	4552	3090	2136	777	10555	3693	4561	4806	1683	14743	9222	7797	7097	2552	26668

Appendix C

REQUESTING INFORMATION FROM THE NATIONAL INTELLECTUAL DISABILITY DATABASE

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

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

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

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

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

Requesting information from Regional Intellectual Disability Databases

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

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

Name of Applicant: _____

Address: _____

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

Date requested: _____

Details of the type of analysis required:

How will data be used:

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

(Continue on separate page if necessary)

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

Signature of Applicant: _____ Date: _____

Date Request Considered:

Decision of National Intellectual Disability Database Committee (NIDDC):

Any conditions which are to be applied to the request:

Signed on behalf of NIDDC: _____

Date: _____

