



National Intellectual Disability Database Committee

Annual Report 2003

Steve Barron and Fiona Mulvany



National Intellectual Disability Database

**Annual Report
of the National Intellectual
Disability Database Committee
2003**

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Chairman's Statement

It gives me great pleasure to introduce the sixth Annual Report from the Intellectual Disability Database. This report provides a profile of the population with intellectual disability as it was on 30 May 2003 and details the existing level of specialised health service provision for this group. It includes an assessment of need for specialised health services for the upcoming five-year period that outlines the pattern of care required in both residential and day care services for the years 2004 to 2008 and highlights some of the issues which must be addressed in planning and delivering services.

The Intellectual Disability Database enables those involved with the planning and delivery of services to identify not only the level of need amongst those awaiting placement in services, but also the service changes required by those already in receipt of services. As noted in previous reports, this continues to be of particular importance as the population with intellectual disability is predominantly an adult one with a growing need for both residential and day services that are flexible and can change to meet long-term needs. Each health board receives a regional breakdown of the data presented in this report.

As in previous reports, I would like to take the opportunity to thank all those involved with the work of the database at both service provider and health board level. I would like to emphasise the importance of timely returns to both the regional databases and the national database. The 2004 data have been received and it is hoped that this data will be published by the end of the year ensuring that service planning for 2005 will be based on the most up-to-date information possible.

The Department of Health and Children is undertaking a strategic review of existing service provision in accordance with a commitment in "Sustaining Progress", the Social Partnership Agreement 2003 to 2005, and in consultation with relevant interests, with a view to enhancing health and personal social services to meet the needs of people with intellectual, physical, and sensory disabilities and autism. This review will be looking at a number of specific areas of service provision. Having taken advice from various stakeholders regarding the format and content of the review, the Department has established a number of Specialist Study Groups to look at particular topics, identify relevant issues and make recommendations on future policy in relation to the group's specific topic. One of the topics to be examined relates to information and databases. The outcome of this review will advise the Department on the strategic direction of information systems designed to support the provision of disability services over the coming years.

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

Brendan Ingoldsby
Chairman
National Intellectual Disability Database Committee

Executive Summary

DEMOGRAPHIC PROFILE

There were 25,557 people registered on the National Intellectual Disability Database (NIDD) in 2003, representing a prevalence rate of 6.52 per 1,000 population. The administrative prevalence rate for mild intellectual disability is 2.38 per 1,000 and the prevalence rate for moderate, severe, and profound intellectual disability is 3.72 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 30% since the first Census of Mental Handicap in the Republic of Ireland was carried out in 1974; since 1996 this increase in numbers is confined to those over 35 years of age. This increase is attributed to the general population increase over the period, improved standards of care, and an increase in the lifespan of people with intellectual disability. There has been a steady increase in the proportion of people with moderate, severe, and profound intellectual disability aged 35 years and over, from 29% in 1974, to 38% in 1996, and increasing to 46% in 2003. This changing age profile observed in the data over the past three decades has major implications for service planning, including an ongoing high level of demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability, and helps to explain the ongoing demand for additional resources for this sector.

SERVICE PROVISION IN 2003

In 2003 there were 23,464 people with intellectual disability in receipt of specialised services, representing 91.8% of the total population registered on the National Intellectual Disability Database. There are 356 people (1.4% of those registered) who are without services at present and are identified as requiring appropriate services in the period 2004-2008. This number has reduced by 112, or 24%, since 2002. The remaining 1,737 people (6.8%) are not availing of services and have no identified requirement for services during the planning period 2004-2008. Most of this group (69%) are in the mild or 'not verified' range of intellectual disability and their continued registration on the NIDD is being reviewed. However, the remaining 31% of this group have a moderate, severe, or profound degree of intellectual disability and the need for continued monitoring of the circumstances of these people is highlighted.

There are 8,092 people in receipt of full-time residential services, a net decrease of 10 since 2002. The number of people with intellectual disability accommodated in psychiatric hospitals has decreased by 21 since 2002, to 494. Day programmes are availed of by 23,011 people. Of this group, 7,676 are in full-time residential placements and the remainder attend services on a day basis. Almost 61% of all children and adults with intellectual disability live in a home setting with parents, siblings, relatives, or foster parents. As the carers of adults age beyond their caring capacity, formal supervised living arrangements will need to be established. Because people with intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years. These data highlight the importance of planning for such eventualities and avoiding crisis situations.

Since 1996 there has been significant growth in the level of provision of full-time residential services, residential support services, and day services reported on the National Intellectual

Disability Database, reflecting, in particular, the significant investment programme in the intellectual disability sector between 2000 and 2002. Key developments noted in this report include:

- 43% growth in the number of people with intellectual disability living in full-time residential placements within local communities;
- 165% increase in the provision of intensive placements designed to meet the needs of individuals with challenging behaviours;
- 49% reduction in the number of people accommodated in psychiatric hospitals;
- continued expansion in the availability of residential support services, in particular service-based respite services, which have grown by 314%, with an additional 520 people reported as being in receipt of these services between 2002 and 2003 alone;
- 106% increase in the number of people availing of regular part-time care; and
- increased provision in almost all areas of adult day services and in the level of provision of support services delivered as part of a package of day services to both children and adults.

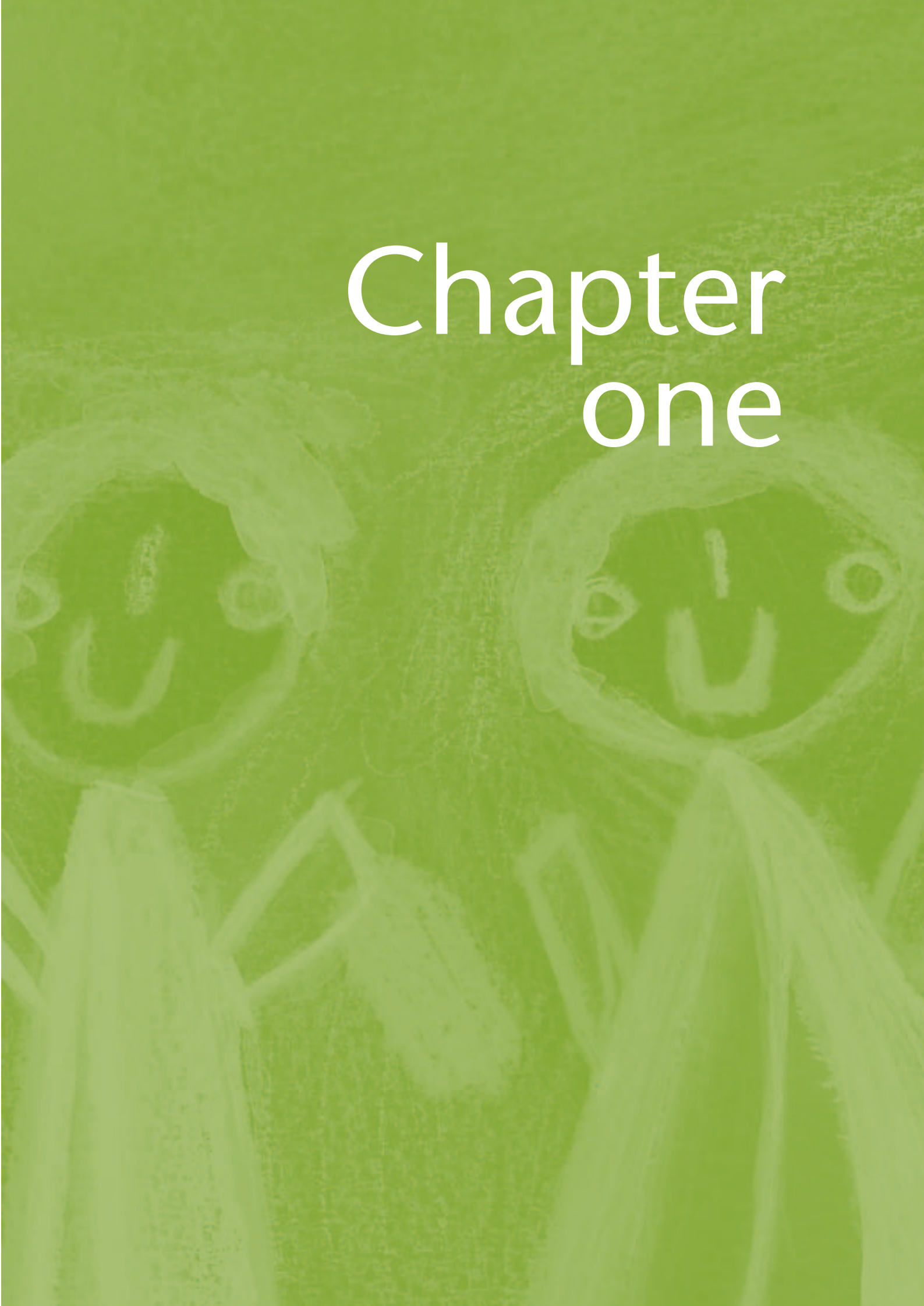
SERVICE REQUIREMENTS

In 2003 there were 2,284 people who were either without services or without a major element of service, an increase of twenty-two since 2002. The provision of 1,776 full-time residential placements and 546 day programmes is required to meet the needs of this group in the period 2004-2008, an increase of 143 residential placements and a decrease of 136 day programmes since 2002. In addition, 1,637 people will require residential support services during this period, an increase of 191 since 2002. Most service needs arise immediately. A group of 307 individuals living in psychiatric hospitals in 2003 has been identified as needing to transfer from these locations to more appropriate accommodation over the five-year period, a reduction of 73 since 2002.

In 2003 a further 11,135 people were receiving services but require alternative, additional, or enhanced services within the next five years, down by 1,381 (11%) since 2002. 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. In particular, the number requiring full-time residential services has increased for the first time since 2000 and is the highest recorded figure since formal reporting through the National Intellectual Disability Database was established.

Chapter one



1. The National Intellectual Disability Database

BACKGROUND

The National Intellectual Disability Database was established in 1995 to ensure that information is available to enable the Department of Health and Children, the health boards and the voluntary agencies in 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 pertaining to diagnosis is specifically excluded, as the database is not designed as a medical epidemiological tool. The data held in any individual record represent the information available for that person at a specified point in time only. The record is updated whenever there are changes in the person's circumstances or during the annual review process in the spring of each year.

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

STRUCTURE

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

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

DATA QUALITY

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

2003 ANNUAL REPORT

This is the sixth report of the National Intellectual Disability Database Committee. The report is based on validated data received from all eight of the regional databases in June 2003. This is the first time that all eight regional data sets were received within the specified timeframe. Adherence to scheduled export dates ensures timely reporting of data by the HRB and enables accurate comparisons between regional datasets.

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

The extent of current service provision in Ireland ensures that an almost 100% ascertainment of all persons with a moderate, severe or profound intellectual disability is possible and expected. Inclusion of persons with a mild level of intellectual disability is sought if they are in special classes or special schools for children with intellectual disability, attending an intellectual disability service as adults, or if they are considered likely to require such a service within the next five years. Those in the average ability and borderline intellectual disability categories have been excluded from analyses because services for this group are not usually provided within intellectual disability services.¹ In the 2003 dataset, there are 115 people recorded as being of average ability and 679 people in the borderline intellectual disability categories, a reduction of 31 and increase of 13 respectively since 2002. 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 2003 there were 25,557 people registered on the National Intellectual Disability Database. Table 2.1 summarises the numbers and prevalence rates at each level of intellectual disability. The administrative prevalence rate for mild intellectual disability in 2003 is 2.38/1000, compared to 2.40/1000 in 2002, and the prevalence rate for moderate, severe and profound intellectual disability in 2003 is 3.72/1000, compared to 3.71/1000 in 2002.

Table 2.1. National Intellectual Disability Database, Ireland 2003.

Prevalence of intellectual disability by degree of intellectual disability.

	n	%	rate
Mild	9320	36.5	2.38
Moderate	9549	37.4	2.44
Severe	3977	15.6	1.02
Profound	1064	4.2	0.27
Not Verified	1647	6.4	0.42
All levels	25557	100.0	6.52

Overall, the numbers registered on the National Intellectual Disability Database have increased by 109 (0.4%) since 2002 (Mulvany and Barron, 2003). During the review and update period prior to the 2003 export of data from the health boards to the national dataset, 905 people were removed from the database. This total consisted of 241 people who had died, 24 people who it was deemed would be more appropriately registered on the National Physical and Sensory Disability Database, 21 people who had emigrated, 494 who no longer required intellectual disability services (438 of whom were in the mild range of intellectual disability, 54 of whom were recorded as level of disability 'not verified', one was in the borderline range of intellectual disability, and one was in the moderate range of intellectual disability), and 125 individuals where the reason for removal was either not stated or described as 'other'. The large reduction in numbers with mild intellectual disability registered on the database is due to a national emphasis on including and retaining on the National Intellectual Disability Database only those people with mild intellectual disability who are in receipt of, or in need of, intellectual disability services.

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

Table 2.2. National Intellectual Disability Database, Ireland 2003.
Age, gender and degree of intellectual disability.

Numbers												
Age Group	Not Verified			Mild			Moderate			Severe		
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
0-4	311	407	718	58	81	123	56	77	133	17	41	58
5-9	107	189	296	258	385	644	205	415	620	107	150	257
10-14	38	52	90	533	828	1302	317	494	811	114	153	267
15-19	23	29	52	690	1111	1765	394	549	943	102	181	283
20-34	76	102	178	1199	1457	2629	1314	1578	2892	452	680	1132
35-54	86	110	196	977	1115	2146	1459	1537	2996	685	807	1492
55 & over	48	69	117	388	312	711	628	526	1154	244	244	488
All ages	689	958	1647	4031	5289	9320	4373	5176	9549	1721	2256	3977
Prevalence Rates												
0-4	2.29	2.87	2.59	0.31	0.57	0.44	0.41	0.54	0.48	0.13	0.29	0.21
5-9	0.83	1.39	1.12	2.02	2.83	2.44	1.60	3.05	2.35	0.83	1.10	0.97
10-14	0.27	0.36	0.32	3.40	5.67	4.56	2.27	3.38	2.84	0.82	1.05	0.93
15-19	0.15	0.18	0.17	4.28	6.93	5.64	2.58	3.42	3.01	0.67	1.13	0.90
20-34	0.16	0.22	0.19	2.48	3.08	2.78	2.78	3.33	3.06	0.96	1.44	1.20
35-54	0.16	0.21	0.19	1.98	2.14	2.06	2.80	2.95	2.87	1.31	1.55	1.43
55 & over	0.11	0.19	0.15	0.95	0.85	0.90	1.49	1.44	1.47	0.58	0.67	0.62
All ages	0.35	0.49	0.42	2.05	2.72	2.38	2.22	2.66	2.44	0.87	1.16	1.02
All Levels												
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
	432	612	1044									
	707	1171	1878									
	973	1548	2521									
	1200	1908	3108									
	3179	3997	7176									
	3446	3825	7271									
	1352	1207	2559									
	11289	14268	25557									

Gender differences

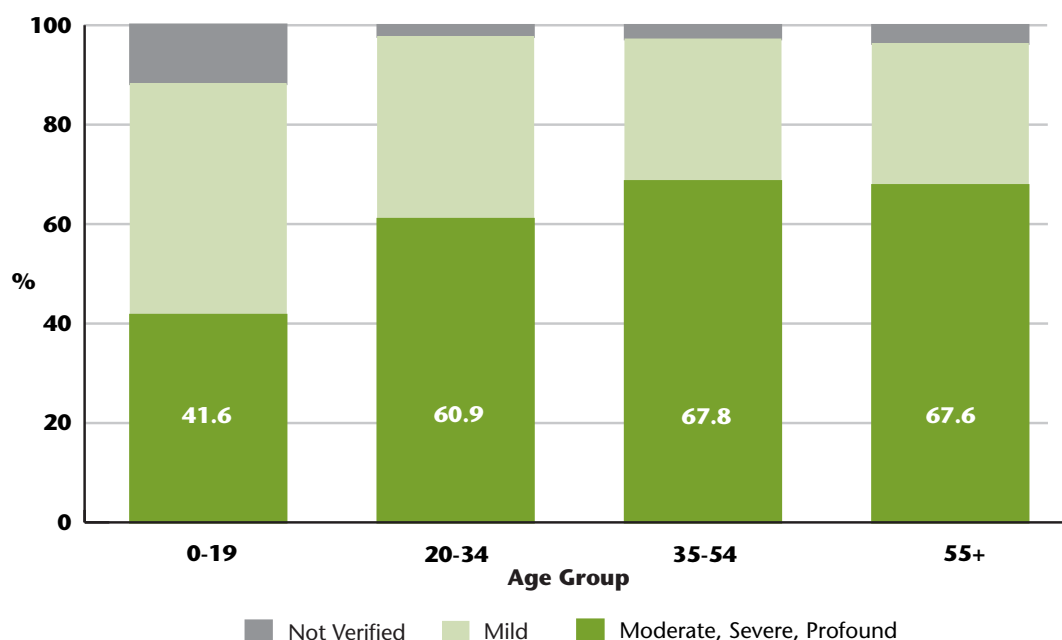
As Table 2.2 indicates, the number of males at all levels of intellectual disability exceeds the number of females, with an overall male to female ratio of 1.26:1. This represents a prevalence rate of 7.33/1000 males and 5.73/1000 females.

Age differences

Of the persons recorded on the National Intellectual Disability Database, 33.5% (8, 551) are aged 19 years and under, 28.1% (7,176) are aged between 20 and 34 years, 28.5% (7, 271) are aged between 35 and 54 years, and 10.0% (2,559) are 55 years of age and over. Figure 1 illustrates the proportion in each age group at each level of intellectual disability. The larger proportion with mild intellectual disability in the 0-19 year age group reflects the number of children in special education who receive support services from the intellectual disability sector, 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 who have an intellectual disability do not receive a definitive diagnosis of their level of intellectual disability in their earlier years.

Figure 1. National Intellectual Disability Database, Ireland 2003.

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



Trends over time

Recent trends

Prevalence rates for moderate, severe and profound intellectual disability for 1996 and 2003 are compared in Table 2.3. The two years provide a good comparison as data from the National Intellectual Disability Database is available for both years and a national census of the Irish population was taken in 1996 and 2002. Compared to the 1996 data (National Intellectual Disability Database Committee, 1997), the 2003 data in Table 2.3 demonstrate the following trends:

- A reduced prevalence rate for the 0-4 year age group. The decrease of 0.51/1000 in prevalence rate is associated with a 40% drop in numbers in this group between 1996 and 2003.
- An overall upward trend in prevalence among the 5-9 year and 10-14 year age groups. This upward trend is observed despite a respective fall of 13% and 16% in numbers in these age groups over the seven-year period.
- A downward trend in prevalence in the 15-19 year, 20-34 year and 35-54 year age groups. The prevalence among 20-34 year olds has been falling consistently over the seven-year period and the 2003 dataset is the first in which this age group does not exhibit the highest prevalence of moderate, severe or profound intellectual disability. The 35-54 year age group has the highest prevalence of moderate, severe and profound intellectual disability. This age group shows a drop in prevalence from 1996 to 2003, despite a consistent increase in numbers.
- An increase in the prevalence rate for the 55 years and over age group, which exhibited a 21% increase in numbers during the period.

It is felt that the 2002 census of population data, which is used in calculating the above prevalence rates, is having a significant impact on the observed rates. A detailed discussion of the effects can be found in the National Intellectual Disability Committee Annual Report 2002 (Mulvany and Barron, 2003).

The prevalence rate for the 0-4 year age group, at 0.73/1000, is considerably lower than expected. Applying the prevalence rate of 3.95/1000 for the 10-14 year age group, which is the internationally accepted age range for maximum ascertainment, it is estimated that the number of children aged 0-4 years, as recorded on the database, may be underestimated by somewhere in the region of 894 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.

Past three decades

Data from the 1974 and 1981 Censuses of Mental Handicap, carried out by the Medico-Social Research Board (Mulcahy, 1976; Mulcahy and Ennis, 1976; Mulcahy and Reynolds, 1984), enable us to monitor trends in this group over the past 29 years (Table 2.3).

The total number of those more severely affected is 14,590 in 2003, compared to 11,256 in 1974 (an increase of 30% or 3,334 individuals). The prevalence rate in 1974 was 3.80 per thousand and is now 3.72 per thousand (Table 2.3). Of particular interest, from the point of view of service delivery, is that since 1996 this increase in numbers is confined to the two older age groups, the 35-54 year age group and the 55 years and over age group. With the exception of the 55 years and over age group in 2002, the two older age groups have shown a continued increase in numbers each year since 1996. The overall increase in numbers is influenced by a number of factors, including the general population increase during this period, improved standards of care, and an increase in the lifespan of people with intellectual disability.

Table 2.3. National Intellectual Disability Database, Ireland 2003.

Age and degree of intellectual disability (moderate, severe and profound): 1974, 1981, 1996, 2003.

Numbers												
Age Group	Moderate			Severe			Profound			All Levels		
	1974	1981	1996	2003	1974	1981	1996	2003	1974	1981	1996	2003
0-4	189	214	226	133	143	92	83	58	99	26	30	12
5-9	809	955	736	620	617	330	260	257	224	99	77	61
10-14	752	1035	948	811	583	428	305	267	292	117	93	51
15-19	698	1203	1072	943	445	508	378	283	241	154	132	65
20-34	1498	2419	2997	2892	1017	1129	1350	1132	441	340	460	345
35-54	1321	1559	2626	2996	626	612	1183	1492	201	97	343	441
55 & over	669	715	987	1154	307	248	394	488	84	24	53	89
All Ages	5936	8100	9592	9549	3738	3347	3953	3977	1582	857	1188	1064
Prevalence Rates												
0-4	0.60	0.62	0.83	0.48	0.45	0.27	0.30	0.21	0.31	0.07	0.11	0.04
5-9	2.55	2.73	2.31	2.35	1.95	0.94	0.82	0.97	0.71	0.28	0.24	0.23
10-14	2.52	3.08	2.72	2.84	1.95	1.27	0.88	0.93	0.98	0.35	0.27	0.18
15-19	2.61	3.79	3.20	3.01	1.66	1.60	1.13	0.90	0.90	0.48	0.39	0.21
20-34	2.78	3.33	3.93	3.06	1.88	1.56	1.77	1.20	0.82	0.47	0.60	0.36
35-54	2.13	2.43	3.25	2.87	1.01	0.95	1.46	1.43	0.32	0.15	0.42	0.42
55& over	1.08	1.09	1.45	1.47	0.50	0.38	0.58	0.62	0.14	0.04	0.08	0.11
All Ages	1.99	2.35	2.72	2.44	1.25	0.97	1.12	1.02	0.53	0.25	0.34	0.27
					3.80	3.60	4.18	3.72				

The graphical representation of the combined data for moderate, severe and profound intellectual disability shown in Figures 2 and 3 indicates a distinct changing age profile over the 29-year period, with fewer children and young adults and more older adults availing of, or in need of, intellectual disability services.

Cohort effect

There is a population bulge originating in the 1960s and lasting until the mid-1970s currently moving through the intellectual disability services. The growth in numbers with intellectual disability during the 1960s and 1970s is attributed to a high birth rate and improved obstetric and paediatric care. Data from the previous Censuses of Mental Handicap allow us to monitor the progress of this group through the services. In 1974 there was a high prevalence rate in the 10-14 year age group. The two subsequent datasets (1981 and 1996) have indicated that the highest prevalence rate was among the 15-19 year age group (1981) and then among the 20-34 year age group (1996). Data from 2002 indicated that this cohort had begun to reach the 35-54 year age group as the prevalence rate among this age group approached that of the 20-34 year age group. This trend has continued in 2003, with prevalence and numbers among the 35-54 year age group now higher than in any other age group. This is the first year of available data (1974, 1981, 1996, 1998 to 2003) that the 35-54 year age group displays the highest prevalence rate and numbers of any age group with moderate, severe and profound intellectual disability.

Ageing population

Figure 4 provides further evidence that the population of people with intellectual disability in the Republic of Ireland is an ageing population. Increased longevity in this population is attributed in the research literature to improved health and well-being, the control of infectious diseases, the move to community living, improved nutrition, and the quality of health care services. By grouping people with a moderate, severe, or profound intellectual disability into two groups, people aged under 35 years and people aged 35 years and over, it can be seen that 29% of this population were aged 35 years and over in 1974, while 27% fell into this age category in 1981. A steady increase in the proportion aged 35 and over has been observed in each dataset since 1996, from 38% in 1996 to 46% in the 2003 dataset. This increase between 1996 and 2003 represents 1,074 more people with a moderate, severe or profound intellectual disability aged 35 years and over.

Impact of observed trends

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

- As will be shown in Chapter 3, residential services are primarily used by adults with a more severe intellectual disability. As the number of individuals in this group increases, increased pressure will be experienced by residential services. This is reflected in the current waiting lists for full-time residential services.
- Improved life expectancy among adults with a more severe intellectual disability will place an increased demand on the health services and pose new challenges to health care professionals. Fewer places will become free over time, a higher degree of support within day and residential services will be required, and specific geriatric support services will be needed.

Figure 2. National Intellectual Disability Database, Ireland 2003.
Prevalence of moderate, severe, and profound intellectual disability (combined)
by age group: 1974, 1981, 1996, 2003.

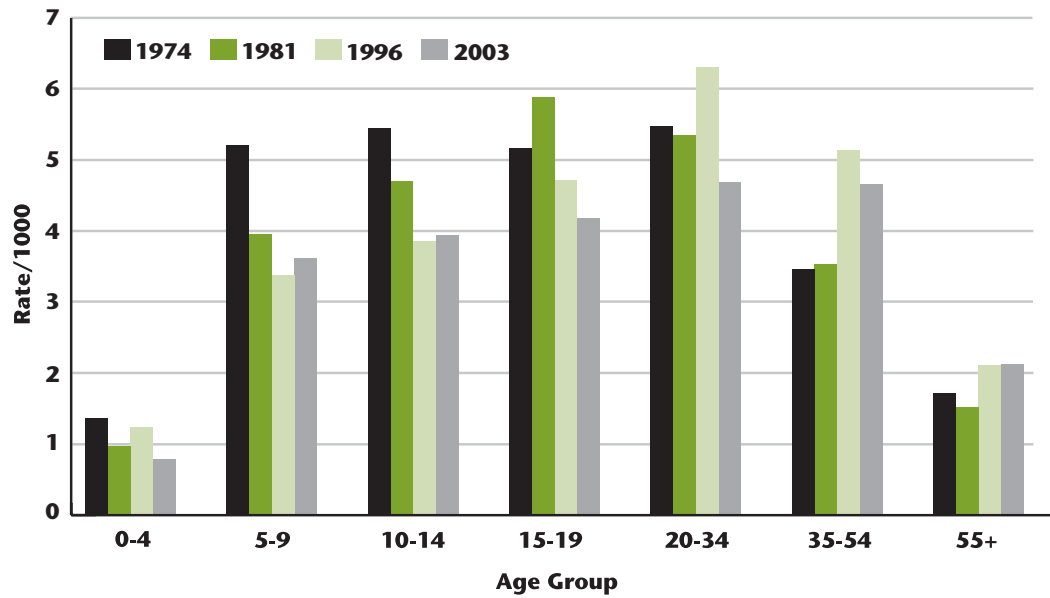
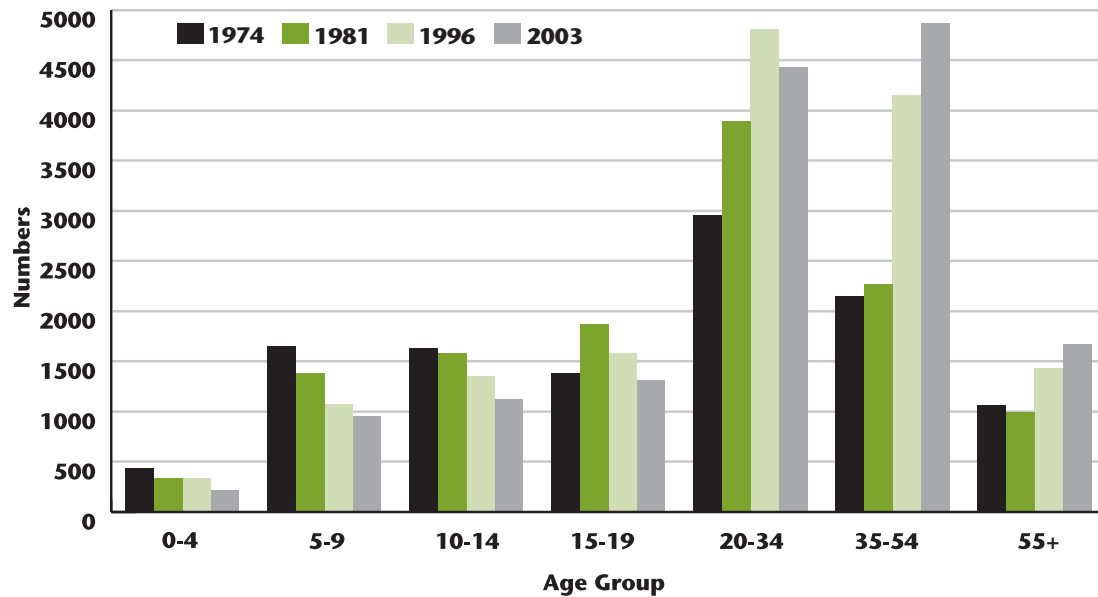


Figure 3. National Intellectual Disability Database, Ireland 2003.
Prevalence of moderate, severe, and profound intellectual disability (combined)
by age group: 1974, 1981, 1996, 2003.

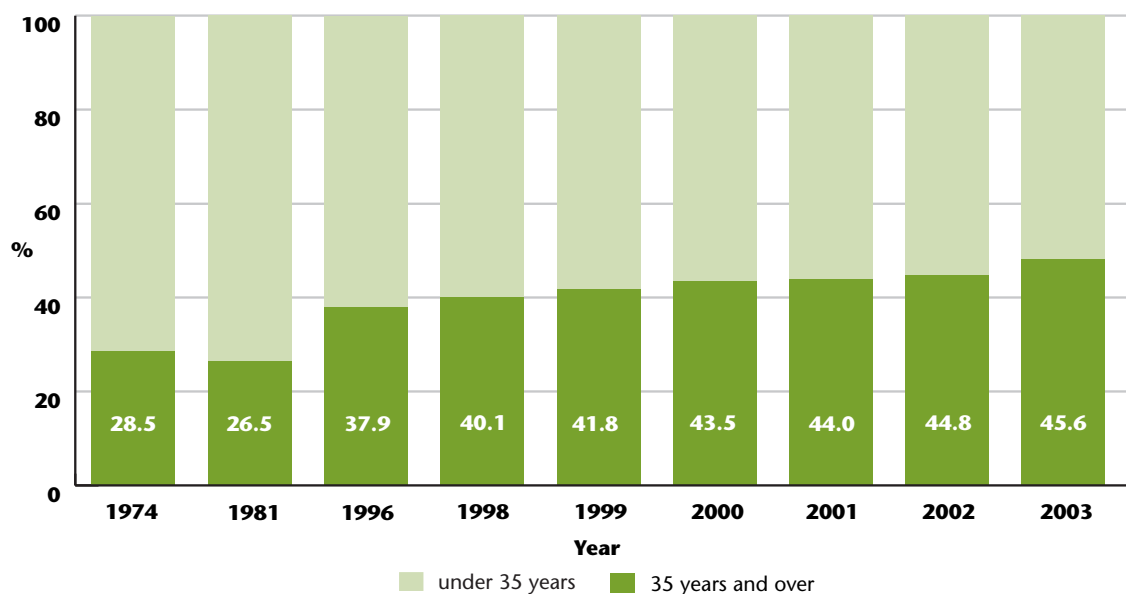


- Chapter 3 indicates that the majority of adults with intellectual disability continue to live with their families. As these caregivers age beyond their care-giving capacity, residential supports will be required.
- Additional therapeutic support services will also be required for people who wish to continue to live with their families to enable this caring arrangement to continue.

Taken together, the combined effects of the baby-boom generation and increased longevity will result in significant demand for additional resources. This demand is now presenting, and will continue to present, major challenges to service planners and providers. The National Intellectual Disability Database will assist service planning as it can indicate the type and level of service provision required over the next five years as well as monitor changing demographic trends in the population with intellectual disabilities.

Figure 4. National Intellectual Disability Database, Ireland 2003.

Proportion of people with moderate, severe, and profound intellectual disability (combined) over 35 years: 1974, 1981, 1996, 1998-2003.



HEALTH BOARD LEVEL

Numbers on each regional database

Table 2.4 details the number of individuals included on each of the regional databases in June 2003. 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 2003.

Number of people included on each Regional Intellectual Disability Database.

	n	%
Eastern Regional Health Authority	8574	33.5
Midland Health Board	1366	5.3
Mid-Western Health Board	2423	9.5
North-Eastern Health Board	2017	7.9
North-Western Health Board	1773	6.9
South-Eastern Health Board	3147	12.3
Southern Health Board	3603	14.1
Western Health Board	2654	10.4
Total	25557	100.0

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

Table 2.5. National Intellectual Disability Database, Ireland 2003.

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	681 7.9	3036 35.4	3284 38.3	1231 14.4	342 4.0	8574 100.0
Midland Health Board	73 5.3	392 28.7	639 46.8	221 16.2	41 3.0	1366 100.0
Mid-Western Health Board	95 3.9	1002 41.4	884 36.5	353 14.6	89 3.7	2423 100.0
North-Eastern Health Board	153 7.6	732 36.3	749 37.1	306 15.2	77 3.8	2017 100.0
North-Western Health Board	191 10.8	615 34.7	634 35.8	284 16.0	49 2.8	1773 100.0
South-Eastern Health Board	215 6.8	1255 39.9	1044 33.2	450 14.3	183 5.8	3147 100.0
Southern Health Board	160 4.4	1300 36.1	1359 37.7	580 16.1	204 5.7	3603 100.0
Western Health Board	79 3.0	988 37.2	956 36.0	552 20.8	79 3.0	2654 100.0
Total	1647 6.4	9320 36.5	9549 37.4	3977 15.6	1064 4.2	25557 100.0

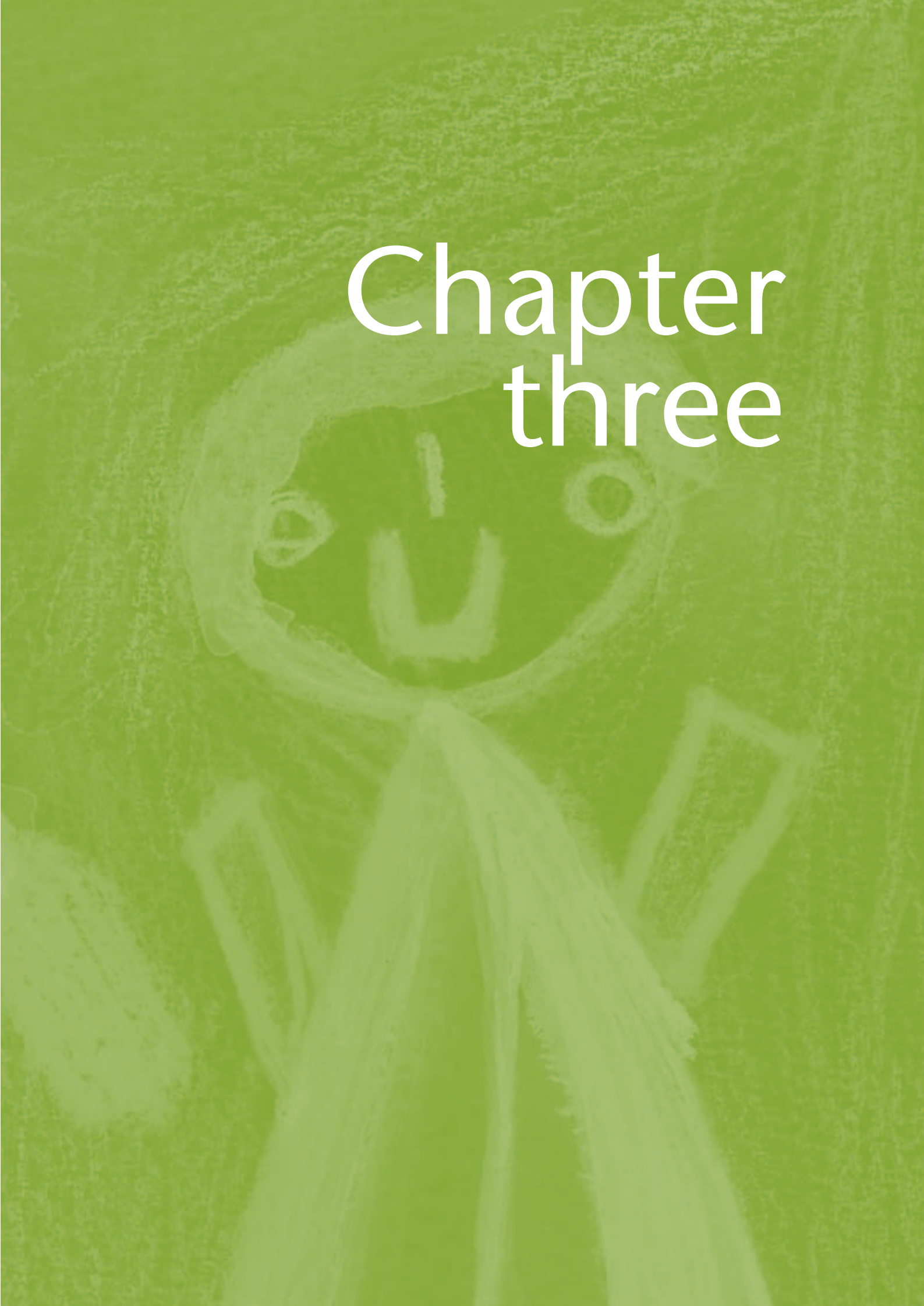
Regional variation in prevalence

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 an individual aged under 25 years, the health board with responsibility for providing services to that person is recorded and, as this would generally be the health board in which the person was born, the prevalence rates for the 0-19 year age groups are compared with some confidence (Table 2.6). There is some variation in prevalence rates between health board areas. The prevalence of moderate, severe and profound intellectual disability in the 0-19 year age group is highest in the Western Health Board and lowest in the North-Eastern Health Board. There is a geographical pattern observable in this table, with the highest rates observed in sequence by the health boards along the western seaboard and the Midland Health Board. The lowest rates are observed in the health boards along the eastern seaboard. These variations are most probably due to demographic factors such as higher migration from rural areas and older maternal age, and may also be due to differences in ascertainment and classification practices.

Table 2.6. National Intellectual Disability Database, Ireland 2003.
**Prevalence rates for 0-19 year age groups by geographical region
(moderate, severe and profound intellectual disability combined).**

	0-4 years	5-9 years	10-14 years	15-19 years	0-19 years
	n	n	n	n	n
	rate	rate	rate	rate	rate
Eastern Regional Health Authority	47	277	351	419	1094
	0.49	3.12	3.72	3.91	2.83
Midland Health Board	17	56	82	89	244
	0.97	3.38	4.59	4.75	3.46
Mid-Western Health Board	14	74	115	123	326
	0.59	3.19	4.63	4.40	3.26
North-Eastern Health Board	7	89	96	99	291
	0.26	3.56	3.56	3.50	2.70
North-Western Health Board	7	60	70	89	226
	0.44	3.75	3.93	4.81	3.31
South-Eastern Health Board	30	128	127	130	415
	0.97	4.29	3.85	3.78	3.24
Southern Health Board	44	127	168	205	544
	1.11	3.26	4.01	4.44	3.26
Western Health Board	37	127	120	137	421
	1.45	4.93	4.14	4.27	3.75
All Regions	203	938	1129	1291	3561
Rate	0.73	3.55	3.95	4.12	3.12

Chapter three



3. Service Provision in 2003

NATIONAL LEVEL

Summary of service provision

In 2003, 23,464 people with intellectual disability were receiving services, which accounted for 91.8% of the total population registered on the National Intellectual Disability Database, compared to a service provision level of 90.6% in 2002. A further 2,093 (8.2%) people were identified as not being in receipt of services, of whom 356 (1.4%) expressed a need for services in the period 2004-2008. A summary of the overall level of service provision in 2003 is provided in Table 3.1.

Table 3.1. National Intellectual Disability Database, Ireland 2003.

Summary of service provision in 2003.

	n	%
Receiving day services	15335	60.0
Receiving 5- or 7-day residential services	7598	29.7
Resident in a psychiatric hospital	494	1.9
Receiving residential support services only	37	0.1
Receiving no service	356	1.4
No identified service requirements	1737	6.8
Total	25557	100.0
Note:		
4,065 day attenders and 456 full-time residents receive residential support services in addition to their principal service.		
7,676 full-time residents receive a day service in addition to their full-time residential service.		

Table 3.2 summarises service provision in 2003 by degree of intellectual disability and age group.

Without services

In 2003 there were 356 people (1.4%) without services and who had identified service needs in the period 2004-2008, details of which are presented in Chapter 4. This figure represents a reduction of 112, or 24%, in the number of people in this category since 2002. Almost two-thirds of this group are in the 'not verified' (7.8%) and mild (56.5%) categories of intellectual disability and 35.7% have a moderate, severe or profound level of intellectual disability. Eighty-nine per cent are aged 19 and over.

Table 3.2. National Intellectual Disability Database, Ireland 2003.

Summary of service provision in 2003 by degree of intellectual disability and age group.

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Receiving day services	1057	276	1333	3369	3407	6776	2995	4231	7226	7421	7914	15335
Receiving 5- or 7-day residential services	7	62	69	78	1135	1213	253	6063	6316	338	7260	7598
Resident in a psychiatric hospital	0	4	4	0	132	132	0	358	358	0	494	494
Receiving residential support services only	2	1	3	3	13	16	1	17	18	6	31	37
Receiving no service	6	22	28	24	177	201	9	118	127	39	317	356
No service requirements in 2003	70	140	210	73	909	982	36	509	545	179	1558	1737
Total	1142	505	1647	3547	5773	9320	3294	11296	14590	7983	17574	25557

A further 1,737 people (6.8%) were also without services but had no identified requirement for services within the five-year period 2004-2008. This number has decreased by 193 (10.0%) since 2002 and by 528 (23.3%) since 2001. Of this group with no identified service requirements, 454 have their circumstances formally reviewed annually and 292 have contingency service plans identified on the database. Ninety per cent of the group (1,558) are aged 19 or over. Sixty-nine per cent of the group (1,192) who are without services and have no identified service requirements in the five-year period 2004-2008 have a mild or 'not verified' level of intellectual disability and it is not unreasonable to assume that they genuinely do not require services at this time. The appropriateness of registering people with mild intellectual disability who have no identified need for specialised health services on the database is being monitored on an ongoing basis.

However, 31% of the group (545 people) who were without services but had no identified need for services between 2004 and 2008 have either a moderate, severe or profound degree of intellectual disability. Of this group, 201 have their circumstances formally reviewed annually and 140 have contingency service plans identified on the database. While these people may not wish to avail of services at this time, it is essential that their needs are monitored on a regular basis so that changing circumstances can be identified and responded to in a timely manner. Failure to anticipate the needs of this group can result in emergency admissions to services which may not be tailored to the specific needs of the individual. The National Intellectual Disability Database Committee remains concerned about the circumstances of 36 children within this group who have a moderate, severe, or profound intellectual disability and are not availing of services and have no identified need for services in the period 2004-2008. Though this figure has fallen from 50 in 2002, the Committee again urges health boards to monitor the circumstances of these children.

Availing of services

As mentioned in Chapter 2, there is a clear relationship between level of disability, age and the type of service availed of. Individuals attending services on a day basis tend to be younger and in the less severe range of intellectual disability, while residential services are used primarily by adults with moderate, severe and profound levels of intellectual disability.

Of the 15,335 individuals accessing services on a day basis in 2003, 44% (6,776) had a mild level of intellectual disability and 48% (7,421) were aged 18 years and under. There were 7,598 full-time residents in intellectual disability services in 2003, of whom 83% (6,316) had a moderate, severe or profound degree of disability, and 96% (7,260) were aged 19 years and over. All 494 individuals with an intellectual disability residing in psychiatric hospitals were aged 19 years and over, and 72% (358) had a moderate, severe or profound degree of intellectual disability. A further 37 individuals registered on the database in 2003 were availing of residential support services only.

Residential circumstances

Table 3.3 outlines the main residential circumstances of those registered on the National Intellectual Disability Database in 2003. Almost two-thirds (61%, or 15,563 individuals) live in a home setting with parents, relatives, or foster parents. The remainder of the population live in full-time residential services (32%, or 8,092 individuals), mainly residential centres, community group homes, and psychiatric hospitals, or they live independently or semi-

independently (3% or 713 individuals). There are 12 people registered on the database who have no fixed abode. There is insufficient information on the residential circumstances of 1,177 people registered on the database (5%), a reduction of 54 people since 2002. This group needs to be further reviewed as a matter of urgency to improve the overall quality of data available from the National Intellectual Disability Database. Of the 1,177 records with insufficient information, 1,174 (99.7%) were returned by the Eastern Regional Health Authority.

There were 8,092 people in receipt of full-time residential services in 2003, a net reduction of 10 people since 2002. It is possible that this reduction is due to the deaths of individuals in inappropriate full-time residential placements that are not being refilled, and the previous registration on the database of individuals with mild intellectual disability who were living in non-specialised services, such as nursing homes, but were removed from the database during recent refinements as they did not meet the registration criteria for the database. The absence of funding for new residential service developments at the beginning of 2003 may also be impacting. Of these 8,092, 3,430 (42%) live in community group homes (an increase of 163 on 2002), 3,510 (43%) live in residential centres (an increase of 49 on 2002), 503 (6%) receive special intensive placements, either because they have profound or multiple disabilities or because they have special requirements due to challenging behaviour (the same number as in 2002), and 82 (1%) reside in nursing homes.

The 2003 data indicate that 31 of the full-time residents were occupying residential support places on a full-time basis, thereby blocking these services from their intended use. The corresponding figure for 2002 was 103. As part of the 2003 review and update of the National Intellectual Disability Database, the Health Research Board asked health boards to validate records which indicate that the individual is occupying a residential support place on a full-time basis. Health boards were also asked to review records where the service description is 'other' to establish if an existing residential service code could be used to describe the placement. This review has resulted in the number of people recorded as receiving 'other' full-time residential services falling from 199 in 2002 to 42 in 2003.

In 2003 there were 494 people with intellectual disability accommodated in psychiatric hospitals, a reduction of 21 (4%) since 2002.

Main residential circumstances: age group and degree of intellectual disability

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

Age differences

There are striking differences in the age profile of individuals in the various categories of accommodation. The proportion of people living in a home setting decreases with age – 94% of individuals aged 0-19 years live in a home setting, declining to 64% of those aged between 20-34 years, 35% of those aged 35-54 years, and 17% of those aged 55 years and over.

In contrast, the proportion of people in the different age categories who are living in full-time residential services increases with age – 5% of all 0-19-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 70% of those aged 55 years and over.

The data indicate that 30% of all people with intellectual disability, and 25% of those with moderate, severe and profound intellectual disability, aged 35 years and over continue to live with their families. Planning for the future care of these individuals and avoiding crisis situations when family carers can no longer provide care is of paramount importance.

Table 3.3. National Intellectual Disability Database, Ireland 2003.

Main residential circumstances.

	n	%
Home setting	15563	60.9
At home with both parents	10705	41.9
At home with one parent	3432	13.4
At home with sibling	849	3.3
At home with other relative	271	1.1
Living with non-relative	44	0.2
Adoption	28	0.1
Foster care and boarding-out arrangements	234	0.9
Independent setting	713	2.8
Living independently	513	2.0
Living semi-independently	200	0.8
Community group homes	3430	13.4
5-day community group home	588	2.3
7-day (48-week) community group home	682	2.7
7-day (52-week) community group home	2160	8.5
Residential centres	3510	13.7
5-day residential centre	127	0.5
7-day (48-week) residential centre	606	2.4
7-day (52-week) residential centre	2777	10.9
Other full-time services	1152	4.5
Nursing home	82	0.3
Psychiatric hospital	494	1.9
Intensive placement (challenging behaviour)	284	1.1
Intensive placement (profound or multiple handicap)	219	0.9
Occupying a residential support place	31	0.1
Other full-time residential service	42	0.2
No fixed abode	12	0.0
Insufficient information	1177	4.6
Total	25557	100.0

Table 3.4. National Intellectual Disability Database, Ireland 2003.
Main residential circumstances, degree of intellectual disability and age group.

	Not Verified					Mild					Moderate, Severe & Profound					All Levels				
	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total
Home setting	1106	128	102	39	1375	3677	1918	986	142	6723	3224	2546	1435	260	7465	8007	4592	2523	441	15563
Independent setting	0	5	29	15	49	3	152	293	86	534	1	21	72	36	130	4	178	394	137	713
Community group home	5	4	13	8	30	70	189	386	189	834	114	697	1365	390	2566	189	890	1764	587	3430
Residential centre	2	3	8	15	28	9	54	104	118	285	141	752	1550	754	3197	152	809	1662	887	3510
Other full-time services	2	1	4	8	15	17	47	81	81	226	51	275	369	216	911	70	323	454	305	1152
No fixed abode	0	0	0	0	0	1	3	3	0	7	0	2	2	1	5	1	5	5	1	12
Insufficient information	41	37	40	32	150	57	266	293	95	711	30	76	136	74	316	128	379	469	201	1177
Total	1156	178	196	117	1647	3834	2629	2146	711	9320	3561	4369	4929	1731	14590	8551	7176	7271	2559	25557

Degree of intellectual disability

There are also noticeable variations between level of ability and type of residential situation. Of those people with a mild intellectual disability, 72% live in a home setting, compared to 51% of those with a moderate, severe or profound intellectual disability. The proportion of people in full-time residential services is increased among the more severe categories of disability. Only 14% of people with a mild intellectual disability live in full-time residential services but this increases to 46% in the case of those with a moderate, severe or profound disability.

Where individuals are in full-time residential services, the type of service varies according to level of intellectual disability. Of those in the mild range of intellectual disability who are in full-time residential services, 62% are in community group homes, 21% are in residential centres, and 17% are in other full-time residential services. Of those in full-time residential services who have a moderate, severe or profound intellectual disability, 38% are in community group homes, 48% are in residential centres and 14% are in other full-time residential services.

Day services

In 2003, 23,011 people, representing 90% of all those registered on the National Intellectual Disability Database, were availing of day services. This represents an increase of 568 (2.5%) people availing of day services since 2002.

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 2003.

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

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Residents	6	65	71	78	1207	1285	244	6076	6320	328	7348	7676
Day attenders	1057	276	1333	3369	3407	6776	2995	4231	7226	7421	7914	15335
Total	1063	341	1404	3447	4614	8061	3239	10307	13546	7749	15262	23011

Of those availing of day services, 33% (7,676) 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 (96%). The remaining 67% (15,335) attend services on a daily basis, of whom 44% are in the mild range of intellectual disability and 48% are aged 18 years and under.

The 2003 data indicate that 416 full-time residents have no day activity programme. The day service needs of this group, where identified, are documented in the fourth chapter of this report.

Table 3.6 presents details of the principal day services provided in 2003 both to residents and to those who attend services on a day basis.

The top five day activities availed of by people with intellectual disability in 2003, and accounting for 70% of day service provision, were: activation programmes, sheltered work, special schools, special vocational training, and multidisciplinary support services only (Table 3.6a). People who attend services on a day basis are availing mainly of educational, training and work programmes, reflecting both the higher level of ability and younger age profile of people in this category. Activation programmes are provided to 11% of day attenders. Those in full-time residential services are much more likely to avail of services such as activation programmes, sheltered work, multidisciplinary support services, special high-support programmes, and specific programmes for older people.

Main day services by age group and degree of intellectual disability

Table 3.7 provides details of the principal day services availed of in 2003, categorised by age group and degree of intellectual disability.

Age differences

Of those availing of day services in 2003 (23,011 individuals), 34% (7,749) are aged 18 years and under, and 66% (15,262) are aged 19 years and over.

In 2003 there were 7,749 individuals aged 18 years and under accessing day services. The majority are in mainstream or special education services at primary and secondary level, availing of early intervention and both mainstream and specialised pre-school services, or are attending child education and development centres. Some young adults at the upper end of the age group have moved into training and employment placements. A small group of those aged 18 years and under are availing of high support or intensive services and activation programmes.

There were 15,262 adults availing of day services in 2003. Most adults attend either activation centres (31%) or sheltered work centres (29%). The next largest groups are concentrated in the areas of special vocational training (10%), multidisciplinary support services only (7%), supported employment (6%), special high-support day services (3%), and programmes for the older person (3%).

Degree of intellectual disability

Of those receiving day services in 2003 (23,011 individuals), 35% (8,061) have a mild intellectual disability, 59% (13,546) have a moderate, severe or profound intellectual disability, and 6% (1404) have not yet had their degree of intellectual disability established.

The age profile of these groups is quite different. Less than one in four (24%) 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 (43%) of the population with mild intellectual disability who are availing of day services is aged 18 years and under. The higher number of children with mild intellectual disability in receipt of services reflects the number of

Table 3.6. National Intellectual Disability Database, Ireland 2003.

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

	Residents	Day Attenders	Total
Home support	2	256	258
Home help	0	16	16
Early services	2	541	543
Mainstream pre-school	4	201	205
Special pre-school for intellectual disability	8	572	580
Child education and development centre	56	346	402
Mainstream school	2	718	720
Resource/visiting teacher	1	248	249
Special class - primary level	10	553	563
Special class - secondary level	14	241	255
Special school	241	3969	4210
Special vocational training centre	283	1252	1535
Activation centre	3047	1678	4725
Programme for the older person	381	95	476
Special high-support day service	412	102	514
Special intensive day service	174	51	225
Sheltered work centre - includes long-term training schemes	1915	2484	4399
Sheltered employment centre	22	104	126
Multidisciplinary support services only	679	466	1145
Centre-based day respite service	6	8	14
Day respite in the home	0	2	2
Other day service	153	217	370
Enclave within open employment	5	12	17
Supported employment	145	789	934
Open employment	30	123	153
Generic vocational training	35	244	279
Generic day services	49	47	96
Total	7676	15335	23011

Table 3.6a. National Intellectual Disability Database, Ireland 2003.

Top five day activities for people with intellectual disability.

Top five day activities All	%	Top five day activities Day attenders	%	Top five day activities Residents	%
Activation centre	20.5	Special school	25.9	Activation centre	39.7
Sheltered work centre	19.1	Sheltered work centre	16.2	Sheltered work centre	24.9
Special school	18.3	Activation centre	10.9	Multidisciplinary support services only	8.8
Special vocational training	6.7	Special vocational training	8.2	Special high-support service	5.4
Multidisciplinary support services only	5.0	Supported employment	5.1	Programme for older people	5.0

children in special education, many of whom do not transfer to the adult intellectual disability services upon leaving school.

Of the 7,749 children availing of day services in 2003, 44% (3,447) have a mild degree of intellectual disability, most of whom avail of special education services, with smaller numbers in mainstream schools and pre-school services. Forty-two per cent (3,239) of the children in receipt of day services have a moderate, severe or profound intellectual disability and, while most are receiving special education services, smaller numbers are in mainstream education or pre-school services and some also avail of more intensive services such as child education and development centres. The remaining 14% (1,063) of children availing of day services have not had their degree of intellectual disability verified as yet.

Of the 15,262 adults in receipt of day services in 2003, 30% (4,614) have a mild degree of intellectual disability, 68% (10,307) are in the moderate, severe, or profound range, and 2% (341) have not had their degree of intellectual disability established. Most adults availing of day services with a mild degree of intellectual disability who are registered on the database attend sheltered work centres (35%), are in receipt of special vocational training (13%), are in supported employment (13%), or avail of activation programmes (12%). The adults with moderate, severe or profound intellectual disability availing of day services are most likely to be in receipt of activation programmes (39%), followed by sheltered work (26%), special vocational training (8%), multidisciplinary support services only (8%), and high-support programmes (4%).

Overall level of service provision in 2003

Background

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

The 2003 dataset is the seventh in a series that commenced in 1996, and was continued in each of the five years from 1998 to 2002. The first and fourth datasets, from 1996 (National Intellectual Disability Database Committee, 1997) and 2000 (Mulvany, 2001), have been selected for comparison with the 2003 data. The 1996 dataset is selected because it is the first in the series and the 2000 dataset is selected as a benchmark at the beginning of the significant investment programme in intellectual disability services over the period 2000-2002. The development within services over the three datasets is illustrated in Figures 5 and 6. If a particular service did not exist or was not captured by the National Intellectual Disability Database in 1996, growth rates are reported for the period 2000-2002 only.

The total 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 residential service and three different types of day service.

Table 3.7. National Intellectual Disability Database, Ireland 2003.

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	49	12	61	14	60	74	19	104	123	82	176	258
Home help	3	2	5	0	5	5	0	6	6	3	13	16
Early services	442	0	442	41	0	41	60	0	60	543	0	543
Mainstream pre-school	103	0	103	62	1	63	36	3	39	201	4	205
Special pre-school for intellectual disability	214	0	214	118	0	118	242	6	248	574	6	580
Child education and development centre	19	1	20	4	0	4	324	54	378	347	55	402
Mainstream school	78	1	79	450	20	470	170	1	171	698	22	720
Resource/visiting teacher	24	1	25	177	3	180	42	2	44	243	6	249
Special class - primary level	32	2	34	300	42	342	182	5	187	514	49	563
Special class - secondary level	3	0	3	151	34	185	58	9	67	212	43	255
Special school	68	0	68	2003	116	2119	1971	52	2023	4042	168	4210
Special vocational training centre	1	42	43	35	604	639	21	832	853	57	1478	1535
Activation centre	0	65	65	4	570	574	17	4069	4086	21	4704	4725
Programme for the older person	0	23	23	0	78	78	0	375	375	0	476	476
Special high-support day service	3	3	6	4	35	39	19	450	469	26	488	514
Special intensive day service	1	1	2	5	15	20	12	191	203	18	207	225
Sheltered work centre	0	86	86	5	1635	1640	5	2668	2673	10	4389	4399
Sheltered employment centre	0	6	6	0	90	90	0	30	30	0	126	126
Multidisciplinary support service	16	40	56	23	239	262	32	795	827	71	1074	1145
Centre-based day respite service	0	1	1	1	2	3	1	9	10	2	12	14
Day respite in the home	0	0	0	0	0	0	0	2	2	0	2	2
Other day service	5	3	8	30	141	171	25	166	191	60	310	370
Enclave within open employment	0	0	0	0	9	9	0	8	8	0	17	17
Supported employment	0	24	24	2	585	587	0	323	323	2	932	934
Open employment	0	5	5	4	118	122	0	26	26	4	149	153
Generic vocational training	2	23	25	13	186	199	3	52	55	18	261	279
Generic day services	0	0	0	1	26	27	0	69	69	1	95	96
Total	1063	341	1404	3447	4614	8061	3239	10307	13546	7749	15262	23011

Overall level of residential service provision in 2003

Table 3.8 details the overall number of residential services provided to people with intellectual disabilities in 2003.

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

Trends in residential service provision: 1996 to 2003

Figure 5 illustrates the growth in full-time residential services and residential support services during the period 1996-2003.

Key developments in the provision of full-time residential services in the period 1996-2003 include a 43% (1,037) increase in the number of people with intellectual disability living in community group homes and a 165% (177) increase in the number of intensive placements specially designed to cater for the needs of people with challenging behaviours. There has been a 49% (476) reduction in the number of people with intellectual disability accommodated in psychiatric hospitals within the period 1996-2003.

Between 1996 and 2003 there has been significant growth in the number of residential support places available. In particular, the data show a 314% (2,739) increase in the number of individuals availing of service-based respite services either as a planned or emergency intervention, including an additional 520 people recorded as being in receipt of planned or emergency respite services between 2002 and 2003, bringing the total number availing of respite services to 3,610. There has also been a 106% (100) increase in the number of people in receipt of regular part-time care and a 91% (96) increase in the number of people living semi-independently over the seven-year period.

Overall level of day service provision in 2003

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

Trends in day service provision: 1996 to 2003

Figure 6 illustrates the growth in day services during the period 1996-2003.

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

Table 3.8. National Intellectual Disability Database, Ireland 2003.

Overall level of residential service provision in 2003, degree of intellectual disability and age group.

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
5-day community group home	1	6	7	31	128	159	22	400	422	54	534	588
7-day (48-week) community group home	1	1	2	10	133	143	25	512	537	36	646	682
7-day (52-week) community group home	2	19	21	22	510	532	46	1561	1607	70	2090	2160
5-day residential centre	0	1	1	3	6	9	26	91	117	29	98	127
7-day (48-week) residential centre	0	0	0	1	60	61	32	513	545	33	573	606
7-day (52-week) residential centre	1	26	27	3	212	215	59	2476	2535	63	2714	2777
Nursing home	0	6	6	1	18	19	1	56	57	2	80	82
Psychiatric hospital	0	4	4	0	132	132	0	358	358	0	494	494
Intensive placement (challenging behaviour)	1	0	1	2	38	40	13	230	243	16	268	284
Intensive placement (profound or multiple disability)	1	1	2	0	9	9	21	187	208	22	197	219
Other full-time residential place	0	1	1	2	16	18	4	19	23	6	36	42
Occupying a residential support place	0	1	1	3	5	8	4	18	22	7	24	31
Holiday residential placement	0	2	2	6	74	80	2	128	130	8	204	212
Crisis or planned respite	58	25	83	154	498	652	1012	1863	2875	1224	2386	3610
Occasional respite with host family	3	0	3	17	13	30	50	51	101	70	64	134
Overnight respite in the home	1	0	1	0	2	2	4	2	6	5	4	9
Shared care or guardianship	0	1	1	0	1	1	0	2	2	0	4	4
Regular part-time care (2/3 days per week)	2	0	2	5	12	17	35	69	104	42	81	123
Regular part-time care (every weekend)	1	0	1	2	2	4	3	7	10	6	9	15
Regular part-time care (alternate weeks)	0	0	0	1	4	5	10	41	51	11	45	56
Other residential service	1	0	1	2	3	5	3	5	8	6	8	14
Foster care and boarding-out arrangements	19	3	22	90	44	134	55	32	87	164	79	243
Living semi-independently	0	5	5	0	145	145	0	51	51	0	201	201
Living independently	0	44	44	2	391	393	0	80	80	2	515	517

Figure 5. National Intellectual Disability Database, Ireland 2003.
Changes in overall level of residential service provision 1996, 2000, 2003.

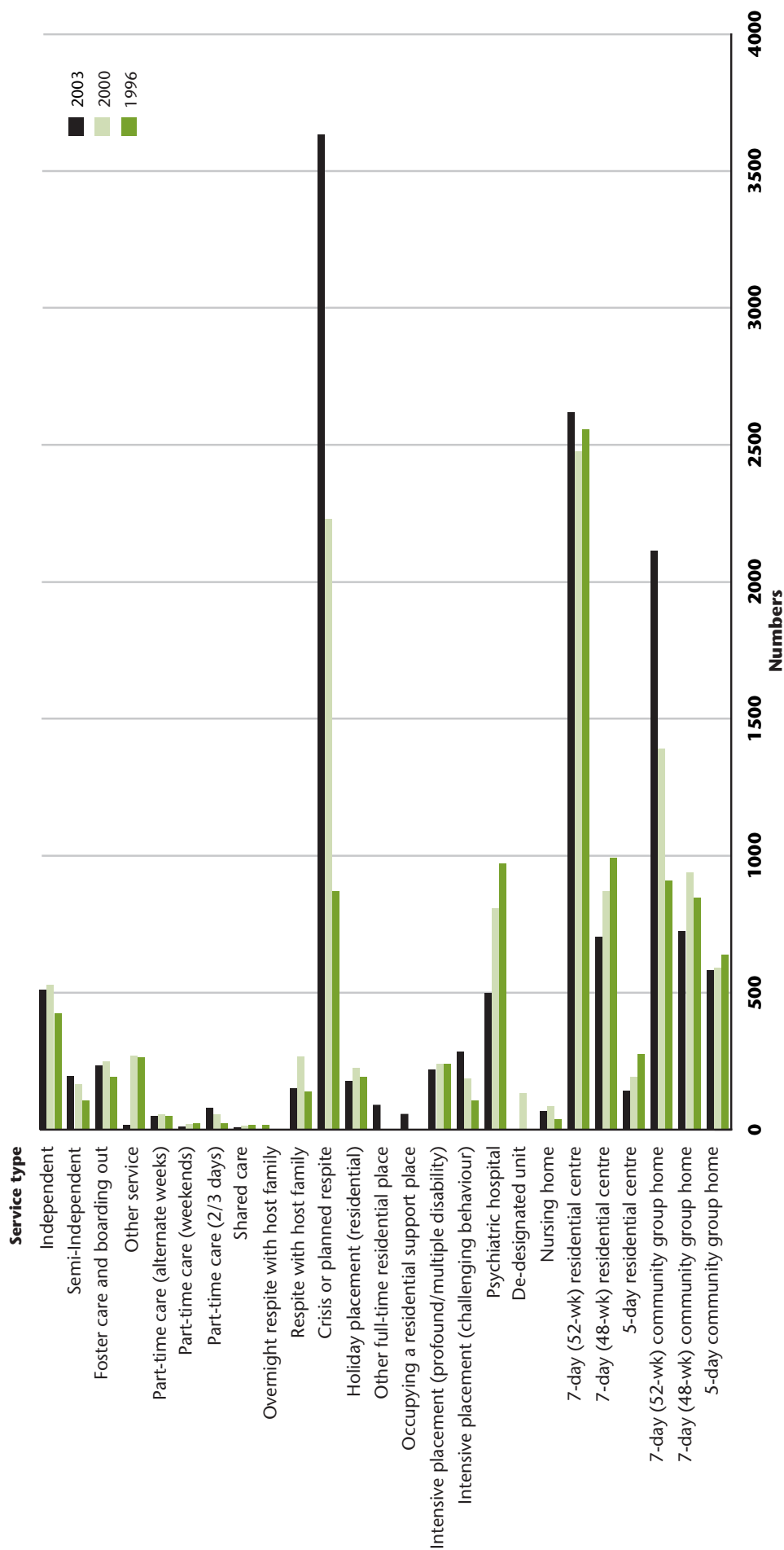
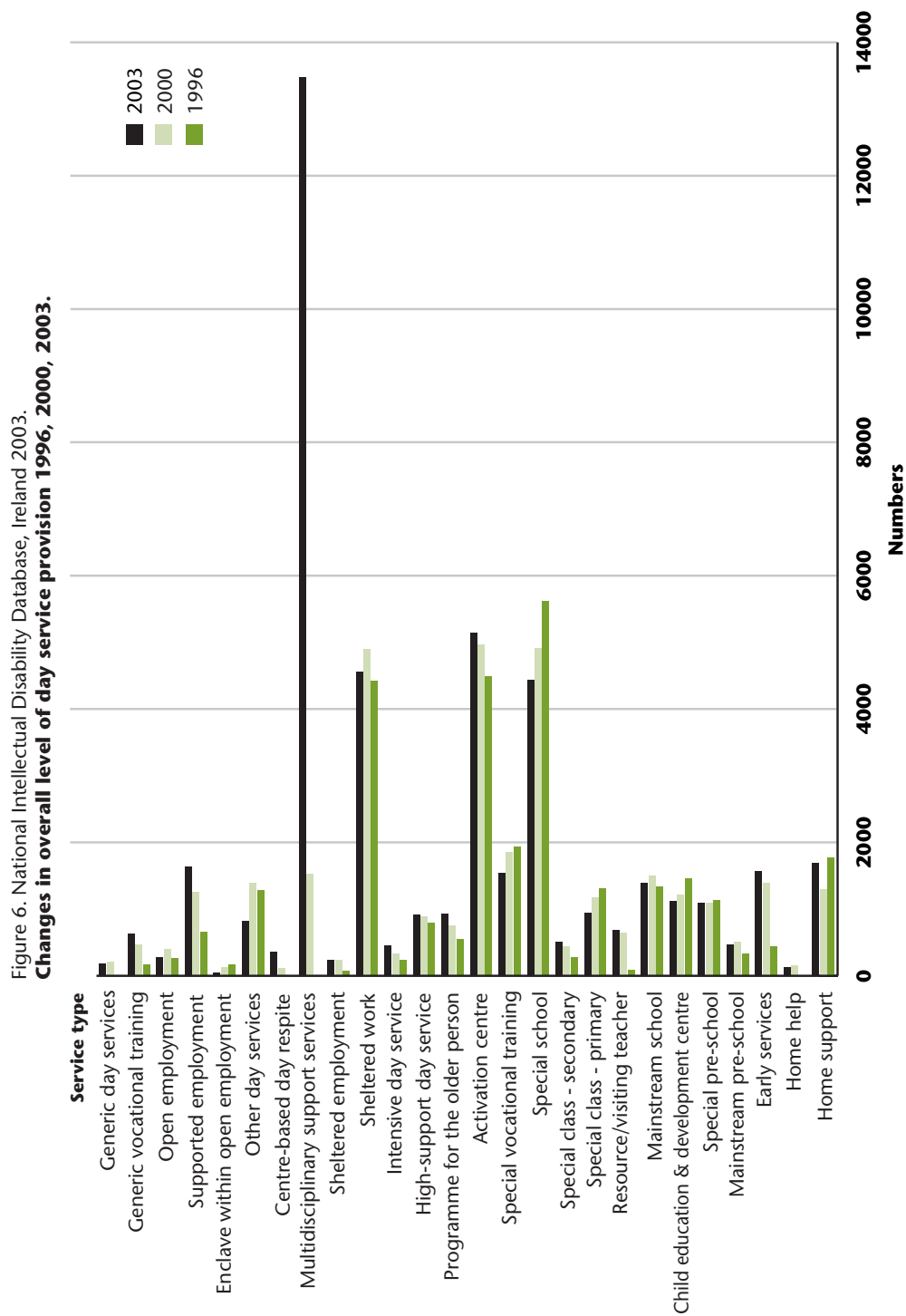


Table 3.9. National Intellectual Disability Database, Ireland 2003.

Overall level of day service provision in 2003, degree of intellectual disability and age group.

	Not Verified			Mild			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	139	29	168	117	154	271	442	471	913	698	654	1352
Home help	22	2	24	7	20	27	19	20	39	48	42	90
Early services	790	0	790	223	0	223	415	0	415	1428	0	1428
Mainstream pre-school	156	0	156	100	1	101	74	3	77	330	4	334
Special pre-school	224	0	224	121	0	121	244	6	250	589	6	595
Child education and development centre	19	2	21	4	1	5	378	56	434	401	59	460
Mainstream school	81	1	82	452	20	472	192	1	193	725	22	747
Resource/visiting teacher	51	6	57	240	23	263	93	16	109	384	45	429
Special class - primary	33	2	35	302	42	344	184	5	189	519	49	568
Special class - secondary	3	0	3	151	34	185	58	9	67	212	43	255
Special school	74	0	74	2003	116	2119	2002	54	2056	4079	170	4249
Special vocational training	1	42	43	66	631	697	25	856	881	92	1529	1621
Activation centre	0	67	67	4	629	633	26	4155	4181	30	4851	4881
Programme for the older person	0	23	23	0	93	93	0	408	408	0	524	524
High-support day service	3	3	6	5	35	40	27	456	483	35	494	529
Intensive day service	1	1	2	5	15	20	14	197	211	20	213	233
Sheltered work	0	88	88	5	1743	1748	5	2765	2770	10	4596	4606
Sheltered employment	0	6	6	0	94	94	0	30	30	0	130	130
Multidisciplinary support service	108	135	243	1389	2238	3627	2087	7352	9439	3584	9725	13309
Centre-based day respite programme	8	2	10	22	21	43	104	104	208	134	127	261
Day respite in the home	1	0	1	0	0	0	0	4	4	1	4	5
Other day service	9	3	12	48	167	215	45	237	282	102	407	509
Enclave within open employment	0	0	0	0	11	11	0	10	10	0	21	21
Supported employment	0	26	26	2	822	824	1	573	574	3	1421	1424
Open employment	0	5	5	5	127	132	1	35	36	6	167	173
Generic vocational training	2	23	25	14	216	230	3	69	72	19	308	327
Generic day services	0	0	0	1	44	45	1	86	87	2	130	132



illustrates. There has been a substantial increase of 1,095 (333%) in the number of people in supported employment. The number of people receiving either high-support or intensive day services has also increased over the period, with the level of provision of high-support services increasing by 32% (129 individuals) and intensive services by 101% (117 individuals). Provision of specialised programmes designed for older people with intellectual disability has increased by 89% (247 individuals). The number availing of activation programmes has grown by 13% (555 individuals) during the period. There has also been a 261% increase in numbers attending sheltered employment centres but the small numbers (36 in 1996 and 130 in 2003) make this proportional figure sensitive to fluctuations in actual numbers.

Reduced levels of adult service provision are observed in relation to enclaves within open employment, which have experienced a 76% decline, but the number of individuals availing of an enclave within open employment recorded on the database has always been small and has fallen from 86 in 1996 to 21 in 2003. A reduction of 14% (274 individuals) is also observed in special vocational training placements, which stand at 1,621 in 2003. However there have been increases in the numbers availing of generic vocational training opportunities (up from 87 to 327, 276%) and other employment opportunities.

Growth areas within children's services include the availability of resource/visiting teachers, with an additional 385 children (an increase of 975%) availing of this service, and a continued growth in the number of young people attending mainstream pre-school (101%, 168 individuals) and special classes in second-level education (81%, 114 individuals). The numbers attending special pre-schools and mainstream schools show slight increases over the seven-year period.

There is an overall decline since 1996 in the numbers of children availing of special education services, including those in special classes at primary level (down 31% or 256), and those attending special schools (down 17% or 887). Despite this reduction, special schools are still the most commonly availed of day programme by children, with 4,249 individuals attending. A reduction is also observed in the numbers of children attending child education and development centres. The reduction in numbers in these particular elements of service provision is attributed to the increased use of mainstream services described previously, and the overall reduction in the numbers of children with intellectual disability, as outlined in the second chapter of this report.

Examining child and adult services together, a noticeable trend during the 1996-2003 period is the increased number of people availing of mainstream services. Increases are observed in mainstream pre-schools, mainstream schools, resource teachers, generic day services (since their introduction to the database in 1999) and generic vocational training. Although the numbers availing of these services are proportionately low, the growth is in a positive direction and must be encouraged.

The 2003 dataset also demonstrates significant growth in the availability of support services which are delivered as part of a package of day services. Increases can be seen in the numbers of individuals availing of home help and centre-based and home-based day respite. Home support services show a slight reduction of 2% since 1996 but a significant number of individuals (1,352) avail of this service in 2003. There has been phenomenal growth in the

reporting of early services and multidisciplinary support services. There were 1,428 individuals reported as being in receipt of early services in 2003, which represents an 82% increase since 2002. Individual components of early services (e.g. speech and language therapy, occupational therapy; see Appendix A, National Planning Form for full details) could be recorded on the database for the first time in 2003 and this may have prompted data collectors to record these therapeutic inputs, thereby resulting in the dramatic increase in the reporting of these services. Similarly, multidisciplinary support services show a 97% increase in reporting since 2002 with 13,309 individuals reported as receiving one or more therapeutic inputs in 2003. In validating this information, the National Intellectual Disability Database Committee has provided guidelines on what level of input constitutes a multidisciplinary support service, so that the 2004 multidisciplinary support service data will be standardised across service providers to reflect inputs that are ongoing. The large difference in numbers reportedly receiving early services and multidisciplinary support services between Tables 3.6 and 3.7 (principal day service provision) and Table 3.9 (overall day service provision) arises because early services and multidisciplinary support services are indicated separately on the database if an individual receives any other day service (i.e. they are recorded as a principal day service only if they are the sole day service that an individual receives).

Recent investment in intellectual disability services

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

HEALTH BOARD LEVEL

Table 3.10 provides details of the level of service provision in 2003 within each health board region.

Nationally, 91.8% of people (23,464) with an intellectual disability registered on the National Intellectual Disability Database were in receipt of services in 2003. Regionally, the highest level of service provision was in the Midland Health Board where 98.2% of the population registered on the database were receiving services. The lowest level of service provision was in the Eastern Regional Health Authority where 84.7% of the registered population with intellectual disability were in receipt of services.

Nationally, 31.6% (8,092) of those registered on the National Intellectual Disability Database in 2003 were in receipt of a full-time residential service. Regionally, this proportion varied from 25.2% in the North-Eastern Health Board to 33.2% in the North-Western Health Board.

At national level, 60.0% (15,335) of the database population were attending services on a daily basis and this proportion ranged from 51.5% in the Eastern Regional Health Authority to 71.3% in the North-Eastern Health Board.

Nationally, 1.4% (356) were without services but were identified as requiring services in the five-year period 2004-2008. The North-Western Health Board had the highest proportion of people without any service and awaiting services within the next five years (4.7%) and there

are three other health boards above the national average (the Mid-Western Health Board, the South-Eastern Health Board, and the North-Western Health Board). The Eastern Regional Health Authority had the lowest proportion, identifying just 0.5% of their population as being without services and requiring services between 2004 and 2008. 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 was a considerable number of people registered on the database in 2003 (1,737, or 7.6%) who were not availing of services and had no identified need for service within the five-year period 2004-2008. There are two likely explanations for this categorisation. Firstly, it is possible that some of this group are appropriately registered on the database but their service needs have not been adequately identified. Secondly, it is also likely that a proportion of this group, who have a mild degree of intellectual disability, are inappropriately registered on the database, as they are not seeking to avail of specialised health services. The number of people so identified varies widely between health boards. The Eastern Regional Health Authority has the highest proportion of individuals in this category, at 14.8% (1,271 individuals) of their registered population. The Mid-Western Health Board has the second highest level in this category at 4.9% (119) of all the region's registrations. The Midland Health Board has the lowest recorded proportion of registrations with no service requirements, at 1.1% (15 individuals).

While efforts are being made to review and refine the database, the National Intellectual Disability Database Committee feels that the proportion of people with intellectual disability reported as being in receipt of services (91.8%) is still being kept artificially low because of the very high numbers of people described as having no identified service requirements in 2003 (1,737 individuals, of whom 73% are registered in the Eastern Regional Health Authority). Although the number in this category has fallen from 2,265 over the past two years, a critical appraisal of these individuals is required to establish both their possible need for services and the appropriateness of their registration on the National Intellectual Disability Database. The National Intellectual Disability Database Committee urges the health boards involved to prioritise this work and so improve the overall quality of information held on the National Intellectual Disability Database.

Table 3.10. National Intellectual Disability Database, Ireland 2003.
Service provision in 2003 by health board area.

	Receiving day services	Receiving 5- or 7-day residential services	Resident in a psychiatric hospital	Receiving residential support services only	Receiving no service	No service requirements in 2003	Total
	n %	n %	n %	n %	n %	n %	n %
Eastern Regional Health Authority	4412 51.5	2566 29.9	265 3.1	15 0.2	45 0.5	1271 14.8	8574 100.0
Midland Health Board	904 66.2	423 31.0	13 1.0	1 0.1	10 0.7	15 1.1	1366 100.0
Mid-Western Health Board	1452 59.9	758 31.3	23 0.9	5 0.2	66 2.7	119 4.9	2423 100.0
North-Eastern Health Board	1438 71.3	509 25.2	1 0.0	2 0.1	35 1.7	32 1.6	2017 100.0
North-Western Health Board	1056 59.6	586 33.1	1 0.1	8 0.5	83 4.7	39 2.2	1773 100.0
South-Eastern Health Board	2081 66.1	826 26.2	96 3.1	3 0.1	58 1.8	83 2.6	3147 100.0
Southern Health Board	2298 63.8	1122 31.1	32 0.9	2 0.1	28 0.8	121 3.4	3603 100.0
Western Health Board	1694 63.8	808 30.4	63 2.4	1 0.0	31 1.2	57 2.1	2654 100.0
All Boards	15335 60.0	7598 29.7	494 1.9	37 0.1	356 1.4	1737 6.8	25557 100.0



Chapter four

4. Assessment of Need 2004-2008

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

Unmet Need: describes people who are without any service whatsoever, who are without a major element of service such as day or residential, or who are without residential support services, and require these services in the period 2004-2008.

Service Change: describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2004-2008, and includes children who will require access to health-funded services in the period.

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

In 2003 the National Intellectual Disability Database facilitated the recording of two future residential services and two future day services for each individual. To avoid double-counting of individuals, only the first service identified is reported in the tables but the level of additional need of these individuals is noted in the relevant sections of the text.

UNMET NEED

Full-time residential and day services

The data returned in 2003 indicate that 2,284 people will require major elements of service, either a full-time residential service or a day service, or both, in the five-year period 2004-2008 (Table 4.1), an increase of 22 since 2002. Of this group, 348 (15%) have no service and require full-time residential and/or day services; 1,721 (75%) receive a day service but require a residential service; 196 people (9%) receive a residential service but also require a day service; and 19 people (1%) receive residential support services only, and require full-time residential and/or day services. Table 4.1 provides a breakdown of this group by level of intellectual disability. Of the 348 people who were without services in 2003, 36% (124) have a moderate, severe or profound level of intellectual disability and 56% (196) have a mild level of intellectual disability. The group which receives one major element of service, day or residential, but which needs the other element (1,917 individuals), consists mainly (75%) of people in the moderate, severe or profound ranges of intellectual disability.

Three hundred and seventy-four individuals who have an unmet need for a full-time residential service also require an additional future residential service, of whom 97% require a residential support service in the period 2004-2008. Nineteen individuals who have an unmet need for a day service also require one additional future day service in the period 2004-2008.

Table 4.1. National Intellectual Disability Database, Ireland 2003.
Number of people requiring a major element of service 2004-2008.

	No service	Receives minimal residential support only	Receives day only - requires residential	Receives residential only - requires day	Total
Not verified	28	2	39	0	69
Mild	196	9	422	12	639
Moderate, severe & profound	124	8	1260	184	1576
All levels	348^a	19^b	1721	196	2284

^a Of the 348, 31 require residential and day, 15 require residential only, and 302 require day only.

^b Of the 19, 7 require residential and day, 2 require residential only, and 10 require day only.

Residential support services

The 2003 data indicate that 1,597 people are without residential support services and will require these services in the period 2004-2008, an increase of 186 (13%) since 2002 (Table 4.2). Ninety-nine per cent of this group (1,589) are already in receipt of a major element of service. Eight individuals who require residential support services were without services in 2003, of whom five have a mild level of intellectual disability and three have a moderate intellectual disability.

One hundred and twenty-nine individuals who have an unmet need for a residential support service also require a second future residential service. Seventy-one per cent of these secondary future residential services are also residential support services.

Table 4.2. National Intellectual Disability Database, Ireland 2003.
Number of people requiring residential support services 2004-2008.

	No service	Receives day only - requires residential support	Receives residential & day - requires residential support	Total
Not Verified	0	113	3	116
Mild	5	571	55	631
Moderate, severe & profound	3	731	116	850
All levels	8	1415	174	1597

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 2003.
Number of new places required to meet need 2004-2008.**

Residential	1776
Day	546
Residential Support	1637 ^a
^a The total number of residential support places required is different to the figure in Table 4.2 (n=1,597) as 38 of the group who have no existing service and require a day service will also need a residential support service and 2 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 1,637.	

The number of new residential places required, 1,776, has increased by 143 since 2002 and by 337 since data collection began in 1996. This figure is at its highest since the database was established. The number of new day places required has been falling steadily since 1996. The current figure of 546 is 490 less than it was in 1996 and is the lowest since the database was established. The demand for residential supports has increased steadily since 1998. The current figure of 1,637 represents a 191 increase from 2002 and is at its highest since data collection began.

Year in which services are required

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

**Table 4.4. National Intellectual Disability Database, Ireland 2003.
Year in which service needs arise.**

	2004	2005	2006	2007	2008	All years
Residential	1461	166	81	40	28	1776
Day	531	8	7	0	0	546
Residential support	1526	55	38	8	10	1637

SUMMARY OF UNMET SERVICE REQUIREMENTS

Details of the types of services required by people who were without a major element of service or without residential support services in 2003 are set out in Tables 4.5 to 4.7.

Full-time residential services

Of the group that requires full-time residential services (1,776 individuals, see Table 4.5), 73% (1,289) consists of people in the moderate, severe and profound ranges of intellectual disability, 25% (445) consists of people with mild intellectual disability and 2% (42) have not had their level of intellectual disability verified. Most of the sub-group with moderate, severe and profound intellectual disabilities require residential placements in community group homes (80%), 11% require residential accommodation in a campus setting, and 8% need specialised intensive placements because of their increased dependency. Within the smaller sub-group with mild intellectual disability, 85% require community-based placements, 8% require placements in traditional-style residential centres, and 6% require intensive placements. Approximately 1% of both sub-groups require nursing home placements. Of those requiring full-time residential services, 97% already receive day services (Table 4.5).

Day services

As in previous years, demand for day services among those reported as not being in receipt of such services in 2003 is confined almost exclusively to adult services. The largest demand for day services comes from 333 people who have no service whatsoever at the moment (compared to 445 in 2002). The majority of this group (57%) have a mild intellectual disability and their principal service requirements are in the training and employment fields. Thirty-five per cent of the group fall into the moderate, severe and profound range of intellectual disability and the principal service requirements are for activation programmes, sheltered work, special vocational training, and home support services (Table 4.6).

The other large group with day service needs consists of 196 people who are in full-time residential services but do not have access to formal day programmes (compared to 216 in 2002). Most of this group (94%) 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.

A smaller group of 17 people are accessing residential support services only, and require a variety of day services (compared to 21 in 2002). Of this group, 53% are in the mild range of intellectual disability and 41% have a moderate, severe, or profound intellectual disability.

Residential support services

Residential support services are required by 1,637 people, most of whom live at home and are either in receipt of a day service (86%, 1,415 individuals) or have no day service (3%, 46 individuals). An additional 11% (176 individuals) are full-time residents and need a residential support service either to enhance, or as an alternative to, their existing services. People with moderate, severe and profound intellectual disabilities account for 53% of the demand for residential support services, while people with mild intellectual disability account for 40%. Most of the demand is for centre- and home-based respite services (65%, 1,058 individuals). Semi-independent living arrangements are required by 15% of this group (245 people), of whom 22% (54 people) are currently living in full-time residential placements. Independent living arrangements are required by 4% of this group (67 people), of whom 13% (9 people) are currently living in full-time residential placements. Holiday residential placements are required by 165 individuals (Table 4.7).

Table 4.5. National Intellectual Disability Database, Ireland 2003.

Future full-time residential service requirements of individuals receiving no residential service in 2003.

	No service - requires residential service				Receives residential support only - requires residential service				Receives day service - requires residential service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
5-day community group home	0	1	4	5	0	1	1	2	5	105	208	318	5	107	213	325
7-day (48-week) community group home	1	1	5	7	0	2	0	2	6	59	220	285	7	62	225	294
7-day (52-week) community group home	1	12	10	23	1	2	2	5	19	197	583	799	21	211	595	827
5-day residential centre	0	0	1	1	0	0	0	0	1	6	10	17	1	6	11	18
7-day (48-week) residential centre	0	0	1	1	0	0	0	0	0	5	38	43	0	5	39	44
7-day (52-week) residential centre	0	2	0	2	0	0	0	0	3	23	92	118	3	25	92	120
Nursing home	0	2	3	5	0	0	0	0	2	1	11	14	2	3	14	19
Psychiatric hospital	0	0	0	0	0	0	0	0	0	0	1	1	0	0	1	1
Intensive placement (challenging behaviour)	0	0	1	1	0	0	0	0	3	17	43	63	3	17	44	64
Intensive placement (profound or multiple disability)	0	0	1	1	0	0	0	0	0	9	54	63	0	9	55	64
All services	2	18	26	46	1	5	3	9	39	422	1260	1721	42	445	1289	1776

Table 4.6. National Intellectual Disability Database, Ireland 2003.

Future day service requirements of individuals receiving no day service in 2003.

	No service - requires day service				Receives residential support only - requires day service				Receives residential service only - requires day service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Home support	2	3	10	15	1	0	0	1	0	0	0	0	3	3	10	16
Home help	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Early services	1	0	1	2	0	0	0	0	0	0	0	0	1	0	1	2
Mainstream pre-school	2	0	0	2	0	0	0	0	0	0	0	0	2	0	0	2
Special pre-school	1	3	1	5	0	0	0	0	0	0	0	0	1	3	1	5
Child education and development centre	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Mainstream school	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	1
Resource/visiting teacher	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special class - primary	1	0	0	1	0	0	0	0	0	0	0	0	1	0	0	1
Special class - secondary	0	3	0	3	0	0	0	0	0	0	0	0	0	3	0	3
Special school	1	1	2	4	0	0	1	1	0	0	5	5	1	1	8	10
Special vocational training	4	48	14	66	0	2	0	2	0	2	0	2	4	52	14	70
Activation centre	5	20	38	63	0	1	4	5	0	2	122	124	5	23	164	192
Programme for the older person	2	4	8	14	0	0	0	0	0	1	16	17	2	5	24	31
Special high-support day service	0	1	4	5	0	0	1	1	0	0	16	16	0	1	21	22
Special intensive day service	0	1	2	3	0	0	0	0	0	1	22	23	0	2	24	26
Sheltered work centre	2	24	22	48	0	3	0	3	0	2	2	4	2	29	24	55
Sheltered employment centre	0	5	0	5	0	0	0	0	0	0	0	0	0	5	0	5
Multidisciplinary support services	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Centre-based day respite service	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Day respite in the home	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other day service	0	1	1	2	0	0	0	0	0	0	0	0	0	1	1	2
Enclave within open employment	0	1	0	1	0	0	0	0	0	1	0	1	0	2	0	2
Supported employment	2	31	5	38	0	2	1	3	0	3	1	4	2	36	7	45
Open employment	1	14	2	17	0	0	0	0	0	0	0	0	1	14	2	17
Generic vocational training	2	27	5	34	0	1	0	1	0	0	0	0	2	28	5	35
Generic day services	1	1	1	3	0	0	0	0	0	0	0	0	1	1	1	3
All services	27	189	117	333	1	9	7	17	0	12	184	196	28	210	308	546

Table 4.7. National Intellectual Disability Database, Ireland 2003.

Future residential support service requirements of individuals receiving no residential support services in 2003.

	No service - requires residential support				Receives day service - requires residential support				Receives residential service - requires residential support				Receives residential and day services - requires residential support				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Foster care and boarding-out	0	0	0	0	1	0	0	1	0	0	0	0	0	0	2	2	1	0	2	3
Living independently	1	4	0	5	3	45	5	53	0	0	0	0	0	8	1	9	4	57	6	67
Living semi-independently	2	7	3	12	13	133	32	178	0	0	0	0	1	35	19	55	16	175	54	245
Holiday residential placement	0	0	1	1	4	32	64	100	0	0	2	2	1	5	56	62	5	37	123	165
Crisis or planned respite	1	6	11	18	74	286	546	906	0	1	0	1	0	5	25	30	75	298	582	955
Occasional respite care with host family	2	0	0	2	12	40	39	91	0	1	0	1	0	0	1	1	14	41	40	95
Overnight respite in the home	0	0	0	0	4	0	4	8	0	0	0	0	0	0	0	0	4	0	4	8
Shared care or guardianship	0	1	0	1	0	1	1	2	0	0	0	0	0	0	0	0	0	2	1	3
Regular part-time care	0	0	1	1	1	13	10	24	0	0	0	0	0	0	0	0	1	13	11	25
(2/3 days per week)																				
Regular part-time care (every weekend)	0	0	0	0	1	2	3	6	0	0	0	0	0	0	0	0	1	2	3	6
Regular part-time care (alternate weeks)	0	0	0	0	0	3	4	7	0	0	0	0	0	0	0	0	0	3	4	7
Other residential service	1	2	3	6	0	16	23	39	0	0	0	0	1	2	10	13	2	20	36	58
All services	7	20	19	46	113	571	731	1415	0	2	2	4	3	55	114	172	123	648	866	1637

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 2004-2008, and includes children availing of educational services in 2003 who will require access to health-funded services in the period. Changes in service provision relate to

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

Categories of service change requirements

Table 4.8 indicates that 11,135 people who were receiving services in 2003 will require a change to their existing service provision in the period 2004-2008, a reduction of 1,381 (11%) since 2002. Of this group, 7,943 (71%) are day attenders (of whom 678 also avail of residential support services); 2,730 (18%) are full-time residents (of whom 2,087 also avail of day services); and 462 (4%) receive residential support services only. A breakdown of the category of service change required by level of intellectual disability is provided in Table 4.8. People in the moderate, severe and profound ranges of intellectual disability account for 62% (6,949) of the service changes, people in the mild range account for 31% (3,406), and 7% (780) of the service changes are required by people whose level of intellectual disability has not been verified.

Table 4.8. National Intellectual Disability Database, Ireland 2003.
Category of service change required 2004-2008.

	Residential and day	Residential only	Day only	Day and residential support	Residential support only	All service changes
Not verified	12	12	718	24	14	780
Mild	232	106	2838	143	87	3406
Moderate, severe & profound	1843	525	3709	511	361	6949
All levels	2087	643	7265	678	462	11135

There are 2,024 people included in the data presented in the section on Unmet Need above (Table 4.1) who are missing one major element of service and require their existing element of service to be changed in some way. However, to avoid double-counting of individuals, their needs in relation to service changes are not included in this section of the report. It is envisaged that, when funding is made available for their unmet elements, sufficient flexibility will be incorporated within this to allow their required service change to be implemented.

Number of places required to address service changes

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

Table 4.9. National Intellectual Disability Database, Ireland 2003.
Number of places requiring to be changed 2004-2008.

Residential	2730
Day	10030
Of which:	
Health services	7052
Education services	1208
Employment services	1508
Generic services	262
Residential support	1140

The number of places required exceeds the number of people requiring service changes as some people require changes in both their residential and day services. In addition, it is important to note that although 11,135 people require service changes, this demand does not translate into 11,135 new places. In most instances, these individuals will be vacating their existing placement when they receive their change of service. This will free up places for other people requiring a 'service change' and those with 'unmet needs'. For example, when young adults move into sheltered work from training, their training place is freed up for the young adults leaving school. It is also important to note that this entire group gets some level of service at present so a certain level of funding is already committed to these individuals.

Year in which service changes are required

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

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

Table 4.11 indicates that 2,730 individuals in full-time residential services in 2003 will require an upgrading or change of accommodation within the next five years (Table 4.11). For most of this group (74%, 2,033 individuals) a change of service is required. Residential placements in the community are required by 812 individuals (30%), 639 individuals (23%) require intensive services for either challenging behaviour or profound or multiple disability, 92 individuals (3%) require centre-based placements, and 44 individuals (2%) need placements in nursing homes.

Table 4.10. National Intellectual Disability Database, Ireland 2003.

Year in which service changes are required

	2004	2005	2006	2007	2008	All years
Residential	2526	120	26	48	10	2730
Day	8505	766	406	245	108	10030
Of which:						
Health services	5931	509	311	202	99	7052
Education services	1053	96	42	10	7	1208
Employment services	1335	125	32	16	0	1508
Generic services	186	36	21	17	2	262
Residential support	1100	23	16	1	0	1140

Three hundred and eighty-six individuals need their existing service upgraded to include care at weekends and holiday times, and 29 people require less care and could return to their families at weekends and holiday times.

Furthermore, there is a group of 697 individuals who need an enhancement of their existing service (shaded area of Table 4.11). Almost two-thirds of this group need increased support, and among the other enhancements required are transfers to age-appropriate services (11%) and transfers to a location closer to the family home (7%). Some of the needs associated with the enhancement of existing services will be met through the funding which is made available to meet identified needs in existing services.

One hundred and fifty-nine individuals of the 2,730 who require an upgrading or change of accommodation also require an additional future residential service, 75% of which are residential support services.

Day Service Change

Within the next five years, 10,030 individuals will require a change, enhancement, or upgrading of their day service (Table 4.12). Health-funded services are required in 70% (7,053 individuals) of the changes, 12% (1,208 individuals) involve educational services, 15% (1,508 individuals) involve employment services, and 3% (262 individuals) involve generic services. Within this category there are 678 individuals who also require one additional future day service. Future requirements for multidisciplinary supports (e.g. social work, psychology; see Appendix A, National Planning Form for full details) were recorded separately to future requirements for day programmes. The 2003 data indicate that 5,965 people (in addition to the 52 from Table 4.12) require multidisciplinary support services and that 613 children (in addition to the 48 from Table 4.12) will require early services. As stated in Chapter 3, the National Intellectual Disability Database Committee has provided guidelines on the level of input that constitutes a multidisciplinary support service to ensure that the 2004 multidisciplinary support service data provided by the service providers will be standardised.

Table 4.11. National Intellectual Disability Database, Ireland 2003.

Pattern of movement of individuals from existing residential service to future residential service 2004-2008.

	Full-time residential service required in the period 2004-2008									
	5-day CGH	7-day (48-wk) CGH	7-day (52-wk) CGH	5-day RC	7-day (48-wk) RC	7-day (52-wk) RC	Nursing Home	Intensive placement (CB)	Intensive placement (P/M D)	Total Services 2002
Full-time residential service in 2003										
5-day community group home (CGH)	39	80	126	0	2	4	0	12	5	268
7-day (48-week) community group home	1	73	97	1	9	12	1	5	7	206
7-day (52-week) community group home	5	16	346	0	2	31	27	44	50	521
5-day residential centre (RC)	10	7	16	7	16	15	0	13	4	88
7-day (48-week) residential centre	5	105	73	0	58	52	3	34	13	343
7-day (52-week) residential centre	2	21	506	0	7	106	11	231	211	1095
Nursing home	0	0	20	0	1	1	0	2	4	28
Intensive placement (challenging behaviour) (CB)	0	2	25	0	1	10	1	41	4	84
Intensive placement (profound/multiple disability) (P/M D)	0	1	2	0	0	16	0	27	27	73
Occupying a residential support place	2	1	12	0	0	0	0	1	2	18
Other full-time residential place	0	0	2	0	0	2	1	1	0	6
Total services required	64	306	1225	8	96	249	44	411	327	2730

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

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

Health-funded services

Children's services

Of the 7,052 service changes required within the health-funded services, those in respect of just 9% (629 individuals) are specifically identifiable as children's services (early services, pre-school services, child education and development centres and centre-based day respite services) (Table 4.12).

Of the 629 children, 537 require alternative or additional day services. Most of the demand is for mainstream and specialised pre-school services (375 children) and the majority of these children (274, 73%) are receiving early services. The balance of the demand is for centre-based day respite services (84 children), placements in child education and development centres (55 children), and early services (23 children).

Of the 629 children, 92 need to have their existing day service enhanced (shaded areas of Table 4.12). These children are in receipt of early services, or are attending mainstream pre-schools, specialised pre-schools, or child education and development centres. Most of these children need a higher level of support within their existing service, or require their existing service on a more frequent basis.

Adult services

There are 6,423 placements primarily designed for adults and funded from the health budget that will require upgrading or change within the next five years (Table 4.12).

There are 4,683 individuals who require alternative or additional day services between 2004 and 2008. Special vocational training programmes are required by 965 individuals, the majority of whom (79%) are attending special schools. Sheltered work placements are required by 693 individuals, most of whom are in receipt of special vocational training (38%) or are attending special schools (30%). Within the more care-focused services, demand is mainly for high-support or intensive placements, activation programmes, and programmes designed specifically to address the needs of older people with intellectual disability. Demand for high-support or intensive placements (936 people) stems mainly from those attending activation centres (477 people) and those in receipt of multidisciplinary support services as their only day service (216). Demand for activation programmes (887 people) stems from four main groups: those who are attending special schools (242), in sheltered work centres (168), people receiving multidisciplinary support services as their only day service (134), and those attending child education and development centres (111). Programmes to meet the needs of older people with intellectual disability are required by 812 people, primarily by individuals in activation programmes (400), attending sheltered work centres (240), or receiving multidisciplinary support services as their only day service (101).

There are 1,740 individuals who need to have their existing day service enhanced (shaded areas of Table 4.12). Most of this group are receiving activation programmes (51%) or are attending sheltered work centres (29%). Of the 1,740 who require enhanced day services, the majority require either increased support (72%) or an increased level of service provision.

Educational services

Alternative or enhanced educational services will be required by 1,208 children in the period 2004-2008 (Table 4.12).

There are 985 children who require alternative or additional educational services. Most of the demand is for special school placements (292 children), for special classes at secondary level (284 children) or for mainstream schools (241 children). Most of the group who require special school placements (292 children) are currently attending special pre-schools (163 children). Most of those requiring special classes at secondary level (284 children) are currently attending special classes at primary level (226 children). The children requiring a mainstream school (241) are mostly attending mainstream pre-school (91), special pre-school (84), or early services (47).

Two hundred and twenty-three children need their existing educational placement to be enhanced in the period 2004-2008 (shaded areas of Table 4.12). These needs arise among children attending special schools (159 children), availing of the services of a resource/visiting teacher (30 children), attending mainstream schools (26 children), and in special classes at primary level (five children) and secondary level (three children). Most (60%) are identified as requiring their existing services which are delivered at primary school level to be carried through to secondary level. There is also a demand for increased support within existing educational placements (34%).

Employment services

There are 1,508 individuals who will require access to new or enhanced employment opportunities during the period 2004-2008 (Table 4.12).

A total of 1,433 of this group will require new employment opportunities. Supported employment placements account for 88% of this demand (1,268 individuals) and, in the main, these individuals currently avail of sheltered work (532 people), special vocational training (346 people), or activation programmes (145 people). There are 142 people who require open employment and at present they are mainly in generic vocational training (43), special schools (37), special vocational training (18), supported employment (18) or sheltered work centres (16). The remainder of the group requiring new employment opportunities (23 people) require placements in enclaves within open employment. At the moment, most of this group attend sheltered work centres (11) and special schools (6).

There are 75 individuals who need to have their existing employment placement enhanced (shaded areas of Table 4.12). Seventy-one of this group are in supported employment and most of the required changes relate to an increased level of service provision (60%) or an increased level of support (24%).

Generic services

There is a relatively small group of 262 individuals who require access to generic day services during the period 2004-2008 or who need to have their existing placement within the generic services enhanced (Table 4.12).

Of this group, 257 require new placements within the generic services. A total of 230 individuals require generic vocational training opportunities and 27 require access to other, unspecified, generic day services. Of the group requiring generic vocational training, most are currently in special schools (114). Of the group requiring access to other unspecified generic day services, most are currently in sheltered work centres (10).

Four individuals who are in receipt of generic vocational training and one person receiving an unspecified generic day service require their existing service to be enhanced or altered in the period 2004-2008 (shaded area of Table 4.12). Three of these five people need increased support and two need a more frequent service.

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

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

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

The services involved include:

- Home support services
- Early services
- Resource/visiting teacher
- Home help
- Multidisciplinary support services
- Centre-based day respite service
- Day respite in the home

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

Residential support service change

The database indicates that 1,140 individuals receiving residential support services will require an additional or alternative residential support service, or will require their existing support service to be upgraded during the period 2004-2008 (Table 4.13). Additional or alternative support services are required by 330 individuals (29%), and 810 individuals (71%) require their existing service to be upgraded (shaded area of Table 4.13).

The principal needs of this group include

- more frequent centre-based respite breaks for people already availing of this service (791 people),
- more regular part-time care arrangements for people already accessing crisis or planned respite services (101 people),
- opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (32 people).

One hundred and fifty-seven individuals of the 1,140 who are receiving residential support services and require an additional, alternative, or enhanced residential support service also require an additional future residential service, of whom 50% require a residential support service.

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

PERSONS WITH INTELLECTUAL DISABILITY WHO ARE ACCOMMODATED IN PSYCHIATRIC HOSPITALS

The data from the National Intellectual Disability Database for 2003 identify 494 individuals with intellectual disability, all aged 19 years and over, accommodated in psychiatric hospitals. Table 4.14 details the overall service requirement status of this group by level of intellectual disability.

Of this group, 330 (67%) have service requirements in the period 2004-2008, of whom

- 307 have an appropriate alternative residential facility identified for them,
- 18 have identified day service requirements (one of whom also requires a residential support service),
- one is identified as requiring residential support services only,
- four people require increased support within a psychiatric hospital (two of whom also require a day service).

Table 4.13. National Intellectual Disability Database, Ireland 2003.

Additional residential support services required by people availing of residential support services in 2003.

	Residential support service required 2004-2008												
Residential support service in 2003	Foster care and boarding-out	Living independently	Living semi-independently	Holiday residential placement	Crisis or planned respite	Occasional respite care (host family)	Shared care /guardianship	Regular part-time care (2/3 days per week)	Regular part-time care (every weekend)	Regular part-time care (alternate weeks)	Overnight respite in the home	Other residential service	Total
Foster care and boarding-out Livingsemi-independently Holiday residential placement Crisis or planned respite Occasional respite care (host family) Shared care or guardianship Regular part-time care (2/3 days per week) Regular part-time care (every weekend) Regular part-time care (alternate weeks) Overnight respite in the home Other residential service	1	0	4	3	7	0	0	0	0	0	0	0	15
	0	14	12	2	3	0	0	0	0	0	2	0	33
	0	2	4	0	23	0	0	2	0	0	0	0	31
	1	6	32	30	791	25	7	58	9	34	4	0	997
	1	1	0	2	17	5	0	1	0	0	0	0	27
	0	0	0	0	1	0	0	0	0	0	0	0	1
	0	0	0	0	8	1	0	1	4	3	0	0	17
	0	0	0	0	1	1	0	0	0	1	0	0	3
	0	0	0	1	3	1	0	0	1	0	0	0	6
	0	0	0	0	3	0	0	0	0	0	0	2	5
	0	0	1	0	2	0	0	1	0	1	0	0	5
All services	3	23	53	38	859	33	7	63	14	39	6	2	1140

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

Table 4.14. National Intellectual Disability Database, Ireland 2003.

Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2003.

	No service requirements				Has service requirements				
	Not Verified	Mild	Moderate, severe & profound	All levels	Not Verified	Mild	Moderate, severe & profound	All levels	Total
Resident in a psychiatric hospital - no day programme	0	10	39	49	0	19	83	102	151
Resident in a psychiatric hospital - with day programme	1	33	80	114	3	69	155	227	341
Resident in a psychiatric hospital - with residential support service	0	0	1	1	0	0	0	0	1
Resident in a psychiatric hospital - with residential support service and day programme	0	0	0	0	0	1	0	1	1
All residents	1	43	120	164	3	89	238	330	494

Of these 330 people who require services, 23 will continue to reside within the psychiatric hospital. Twenty of these will require day services in the period 2004-2008. Forty per cent (8 individuals) of this group have a mild intellectual disability and 60% (12 individuals) have a more severe intellectual disability. At present, four of this group have no day service, two of whom require a high support day service, one requires special vocational training and one requires a programme for the older person. The remaining 16 people are in receipt of day programmes that need to be enhanced or upgraded, as outlined in Table 4.15. Twelve of the 16 individuals require specific programmes designed for older people.

Two people are identified as requiring residential support services within the period 2004-2008 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. Both individuals require respite care.

Of the 330 residents in psychiatric hospitals who require services (see Table 4.14), 307 people need to transfer to specific intellectual disability services. Twenty-six per cent of this group have a mild intellectual disability, 73% have a moderate, severe or profound intellectual disability and 1% have not had their level of disability verified. Residential and day service requirements are identified for 134 individuals, while 173 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.

Table 4.15. National Intellectual Disability Database, Ireland 2003.

Day service requirements of people appropriately accommodated in psychiatric hospitals.

Day service in 2003	Services required					
	Special vocational training	Activation centre	Programme for the older person	Special high support day service	Supported employment	All services
No day programme	1	0	1	2	0	4
Special Vocational Training	0	0	0	0	1	1
Activation Centre	0	1	0	0	0	1
Multidisciplinary support services only	0	0	9	0	0	9
Other day programme	0	2	3	0	0	5
All services	1	3	13	2	1	20

Of the 307 people who need to transfer from psychiatric to intellectual disability services for their residential services, 40% will require places in residential centres, 31% will require intensive placements, 26% will require community group home places, and 2% need to move to nursing homes. Two individuals are recorded as requiring a transfer to an intellectual disability service but the type of service is unspecified. Almost all of the need arises immediately (Table 4.16).

Table 4.16. National Intellectual Disability Database, Ireland 2003.

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

	Year in which residential service is required			
	2004	2005	2006	2004-2008
7-day (48-week) community group home	2	0	0	2
7-day (52-week) community group home	78	0	1	79
7-day (48-week) residential centre	4	0	0	4
7-day (52-week) residential centre	118	1	0	119
Nursing home	6	0	0	6
Intensive placement (challenging behaviour)	72	0	0	72
Intensive placement (profound/multiple disability)	23	0	0	23
Unspecified intellectual disability service	2	0	0	2
All residential services	305	1	1	307

Of this same group of 330 people, 134 will also require an appropriate day service. The greatest demand is for high-support or intensive day programmes (51%), activation programmes (34%), and programmes for older people (8%). All day services are required immediately (Table 4.17).

Table 4.17. National Intellectual Disability Database, Ireland 2003.

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

	Year in which day service is required
	2004
Special vocational training	2
Activation centre	45
Programme for the older person	11
Special high-support day service	52
Special intensive day service	17
Sheltered work centre	3
Sheltered employment centre	1
Generic day services	2
Centre-based day respite service	1
All day services	134

The 2003 data suggest that the day and residential programmes for 164 people with intellectual disability within the psychiatric services are appropriate and these people have no identified service needs in the period 2004-2008. Twenty-six per cent of this group have a mild intellectual disability, 73% have a moderate, severe or profound disability, and one individual's level of intellectual disability is not verified. Within this group are 49 people who have no formal day programme. The day service needs of this group need to be reviewed.

OVERALL SERVICE PROVISION AND THE PATTERN OF CARE REQUIRED 2004-2008

The data presented in this chapter in relation to unmet need for services and demand for service changes need to be considered together to enable the future pattern of care to be forecast. The database indicates that there are large numbers of people who require day or residential services, or both, for the first time and also that there are significant numbers who require changes to, or enhancements of, their existing placements. Not all service changes will require the individual to move to a new placement as many require enhancements such as increased support which can be made available in their existing placement. Where the enhancement involves a move to a new placement, the freed-up place may become available to others who have an identified need for such a placement. The existing placements occupied by these individuals are secure until their new places become available. Such movement is part of the ongoing development of services and is tangible evidence of the ability of the database to match needs with service provision. Individuals who already avail of services within either intellectual disability or psychiatric services have significant funding allocated to them and changes to their existing placements will incur only minimal costs.

Pattern of care required in full-time residential services

As is indicated in Table 4.18, demand for full-time residential services in the period 2004-2008 will come from three distinct groups already identified in this chapter:

Table 4.18. National Intellectual Disability Database, Ireland 2003.
Pattern of full-time residential service provision required 2004-2008.

	New services required by people living at home	New services required by people transferring from psychiatric hospitals	Service changes required by people in existing full-time residential places	Places vacated by people in full-time residential places	Shortfall (-)/ Excess (+) of places arising from demand
5-day community group home	325	0	64	268	-121
7-day (48-week) community group home	294	2	306	206	-396
7-day (52-week) community group home	827	79	1225	521	-1610
5-day residential centre	18	0	8	88	62
7-day (48-week) residential centre	44	4	96	343	199
7-day (52-week) residential centre	120	119	249	1095	607
Nursing home	19	6	44	28	-41
Psychiatric Hospital	1	0	0	0	-1
Intensive placement (challenging behaviour)	64	72	411	84	-463
Intensive placement (profound or multiple disability)	64	23	327	73	-341
Other/unspecified intellectual disability service	0	2	0	6	4
Designated residential support placement	0	0	0	[18 ^a]	0
Total	1776	307	2730	2712	-2101

^a 18 designated residential support places being blocked by full-time residents will be freed up but they have not been deducted from the total number of full-time residential places required as they should not be made available for full-time use.

- 1,766 individuals living at home who require full-time residential services for the first time,
- 307 individuals resident in psychiatric hospitals who require to transfer to the intellectual disability services, and
- 2,730 individuals in full-time residential services within the intellectual disability sector who require changes to their existing placement. Of this group, 2,033 require alternative services and 697 require their existing service to be enhanced. Not all of the group who require service enhancements will move to new placements. For example, 443 out of the 697 individuals (64%) require increased support in their existing placements. However, they have been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading their services. Where the change involves a move to a new placement, the freed-up place may be available to others who are identified as requiring this service.

Table 4.18 outlines the pattern of full-time residential service provision that will be required in the period 2004-2008 to meet this demand. A total of 2,101 residential places will be required – an increase of 88 since 2002. As expected, there is significant demand for community-based placements both from people who will be coming into residential services for the first time and from people in existing residential placements. In total, 2,127 community-based placements will be required during the period, an increase of 39 since 2002. There will also be a shortfall of 804 intensive residential placements, an increase of 109 since 2002. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

Pattern of care required in day services

As can be seen from Table 4.19, demand for day services over the next five years comes from four distinct groups:

- 546 individuals without day services,
- 134 individuals resident in psychiatric hospitals who will require an appropriate day service when they transfer to the intellectual disability services,
- 20 individuals appropriately placed in psychiatric hospitals but requiring a day programme within that setting, and
- 10,030 individuals in existing day services within the intellectual disability sector who require changes to, or enhancements of, their existing placement. Of this group 7,895 require alternative or additional services and 2,135 require their existing service to be enhanced. Seven thousand and fifty-two of these service changes are within the health sector. Many of the changes are required to address transitional needs such as moving from child to adult services or moving from training into employment. Not all of the group who require service enhancements will move to new placements. Again, as was seen with the requirement for enhancement of residential placements, 1,379 out of the 2,135 identified individuals (65%) require increased support in their existing placements. However, the entire group has been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading their services. Where the change involves a move to a new placement, the freed-up place may be available to others who are identified as requiring this service. However, unlike the situation with full-

Table 4.19. National Intellectual Disability Database, Ireland 2003.
Pattern of day service provision required 2004-2008.

	New services required by people without day services	New services required by people transferring from psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Shortfall (-)/ Excess (+) of places arising from demand
Home support	16	0	0	202	0	-218
Home help	0	0	0	10	0	-10
Early services	2	0	0	48	0	-50
Mainstream pre-school	2	0	0	216	149	-69
Special pre-school	5	0	0	203	414	206
Child education and development centre	0	0	0	78	171	93
Mainstream school	1	0	0	267	255	-13
Resource/visiting teacher	0	0	0	117	0	-117
Special class - primary	1	0	0	86	319	232
Special class - secondary	3	0	0	287	114	-176
Special school	10	0	0	451	1845	1384
Special vocational training	70	2	1	998	794	-277
Activation centre	192	45	3	1772	2111	99
Programme for the older person	31	11	13	974	195	-834
Special high-support day service	22	52	2	475	272	-279
Special intensive day service	26	17	0	595	44	-594
Sheltered work centre	55	3	0	1200	1641	383
Sheltered employment centre	5	1	0	101	22	-85
Multidisciplinary support services	0	0	0	52	0	-52
Centre-based day respite service	1	1	0	107	0	-109
Day respite in the home	0	0	0	3	0	-3
Other day service	2	0	0	18	76	56
Enclave within open employment	2	0	0	23	3	-22
Supported employment	45	0	1	1339	147	-1238
Open employment	17	0	0	146	35	-128
Generic vocational training	35	0	0	234	158	-111
Generic day services	3	2	0	28	35	2
All Services	546	134	20	10030	8800	-1930

time residential services, not all existing places will become available. As previously explained in this chapter, people who are accessing, or who require, home support, early services, resource/visiting teachers, multidisciplinary supports, centre- and home-based day respite or home help services will not be freeing up existing services when their future needs are met.

Table 4.19 outlines the pattern of day service provision that will be required in the period 2004-2008 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 1,930 day places will be required – a decrease of 18 since 2002. 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. The data indicate that over the next five years there will be small reductions nationally in the number of children requiring special pre-school services, mainstream classes and special classes at primary level and placements in child education and development centres. There will be a significant reduction in the number of children requiring special schools. However, there is a small demand within this group for mainstream pre-school services and early services, and a larger demand for additional resource/visiting teachers and for the provision of special classes at secondary level. This demand may be greater than the data indicate due to the possible underestimation of young children on the database mentioned in Chapter 2.

Adult services will continue to experience considerable pressure across the whole spectrum of day services. There will be a shortfall of employment opportunities and vocational training placements, both generic and specialised. In the period 2004-2008, 1,238 supported employment placements and 128 open employment placements need to be developed to meet the demand that exists for those services. There will also be a shortfall of 85 sheltered employment opportunities and 22 placements in enclaves within open employment during this time. One hundred and eleven generic vocational training places and 277 special vocational training places will be required.

The aging population with intellectual disability discussed in Chapter 2 is resulting in increased demand for specific programmes for the older person and there will be a shortfall of 834 such places over the next five years. As with residential services, there is significant demand for high-support and intensive day placements. Between 2004 and 2008, 279 high-support day placements and 594 intensive day placements will be required. These services involve a higher staff to client ratio and more specialist interventions to address needs arising from behavioural problems, multiple disabilities and the effects of ageing. The data indicate that demands for activation programmes and sheltered work placements are likely to be met as other identified service needs are met and existing services are consequently freed up.

CONTINUED DEMAND FOR SERVICES

The 2003 dataset, in line with data in recent years, indicates significant ongoing demand for new intellectual disability services and a growing requirement to enhance existing services. This need is presenting against a background of significant investment in intellectual disability services in the period 2000-2002. While the data in recent years highlight the corresponding growth in services, demographic factors are contributing to long waiting lists for services, most notably for full-time residential services. In particular, there is a large adult population and a growing number of older people with intellectual disability, and these features are contributing to an ongoing demand for services.

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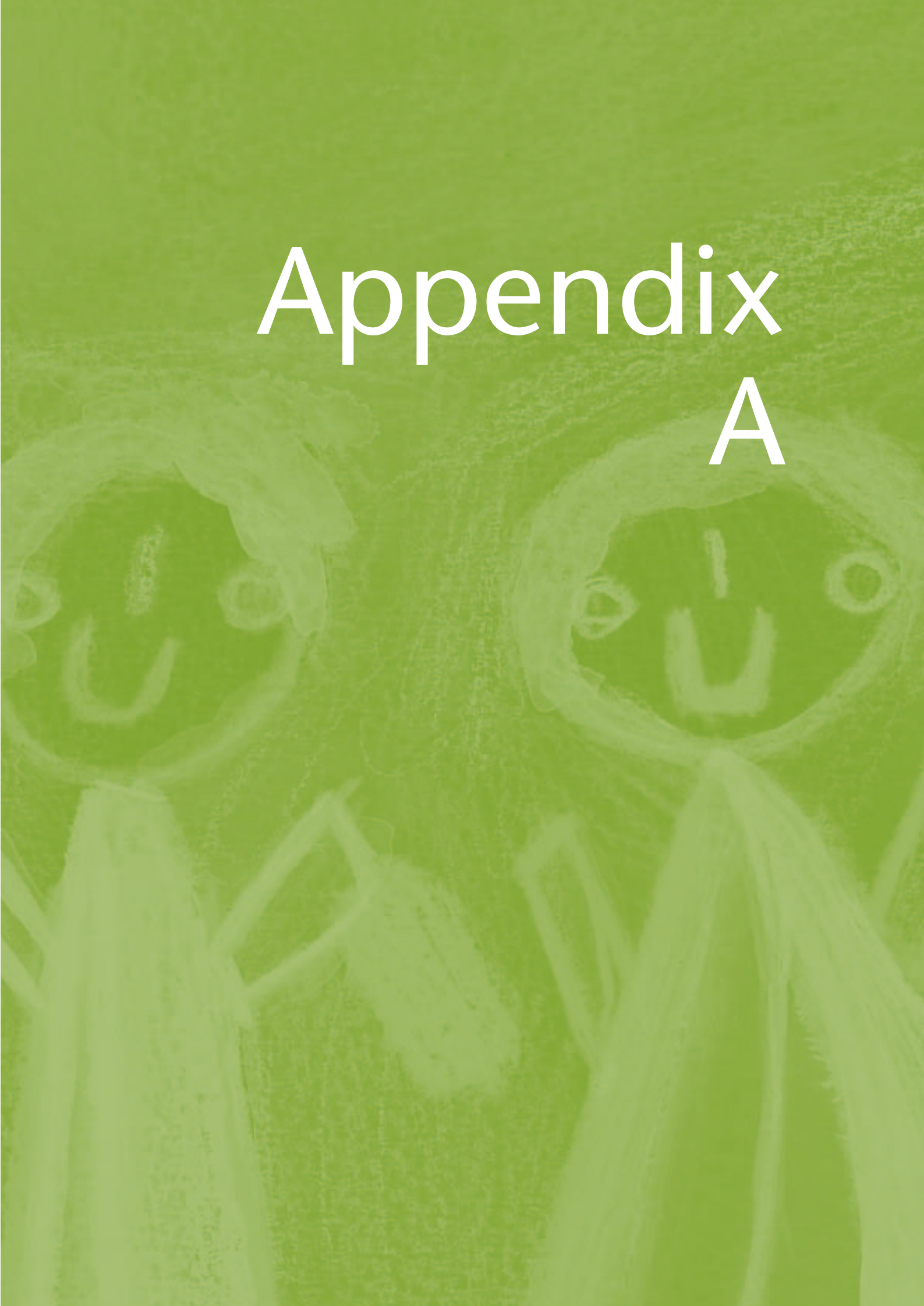
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REQUESTS FOR ADDITIONAL STATISTICAL INFORMATION

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

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

Appendix A



INTELLECTUAL DISABILITY DATABASE

NATIONAL PLANNING DATA FORM

PERSONAL DETAILS

1. Surname _____
2. First Name _____
3. Previous Surname _____
4. Address _____
5. Address _____
6. Address _____
7. Address _____
8. Address (County) _____
9. Date of Birth | | | - | | | - | | | | |
10. Year of birth (where DOB is unknown) | | | | |
11. Health Board Region | | |
12. Community Care Area | | |
13. Sub-area (DED) within Health Board Region | | | |
14. Planning area within Health Board | | |
15. **Personal Identification Number (PIN)** | | | | | | | |
16. Sex | | 1=male 2=female
17. Degree of intellectual disability | | 0=not verified 1=normal range 2=borderline 3=mild 4=moderate 5=severe 6=profound
18. Year of last psychological assessment | | | | |
19. Does this individual have physical and/or sensory disability needs? | | 1=yes 2=no 3=not reviewed
20. If yes, indicate type of physical and/or sensory disability | |

NEXT OF KIN DETAILS

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

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.

CURRENT SERVICE PROVISION

DAY SERVICES

40. Agency providing main day service (Appendix A) |_|_|_|_|_|_|_|_|
41. Type of main day service (Appendix B) |_|_|
42. Current level of main day service support 0. 1. 2. 3. 4. 5.
43. Main day service: number of days received each week [0.0-7.0] |_|_|. |_|_|
44. Agency providing secondary day service (Appendix A) |_|_|_|_|_|_|_|_|
45. Type of secondary day service (Appendix B) |_|_|
46. Current level of secondary day service support 0. 1. 2. 3. 4. 5.
47. Secondary day service: number of days received each week [0.0-7.0] |_|_|. |_|_|
48. Agency providing third day service (Appendix A) |_|_|_|_|_|_|_|_|
49. Type of third day service (Appendix B) |_|_|
50. Current level of third day service support 0. 1. 2. 3. 4. 5.
51. Third day service: number of days received each week [0.0-7.0] |_|_|. |_|_|

MULTIDISCIPLINARY SUPPORT SERVICES

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

	Agency
<input type="radio"/> Community Nursing	_ _ _ _ _ _ _
<input type="radio"/> Nutritionist	_ _ _ _ _ _ _
<input type="radio"/> Medical Services	_ _ _ _ _ _ _
<input type="radio"/> Occupational Therapy	_ _ _ _ _ _ _
<input type="radio"/> Physiotherapy	_ _ _ _ _ _ _
<input type="radio"/> Psychiatry	_ _ _ _ _ _ _
<input type="radio"/> Psychology	_ _ _ _ _ _ _
<input type="radio"/> Social Work	_ _ _ _ _ _ _
<input type="radio"/> Speech & Language Therapy	_ _ _ _ _ _ _
<input type="radio"/> Other multidisciplinary support service	_ _ _ _ _ _ _
Specify	_ _ _ _ _ _ _

For children aged six and under:

53. Are these supports provided by an early intervention team? |_|_| 1=yes 2=no 3=not applicable

RESIDENTIAL SERVICES

54. Agency providing main residential service (Appendix A) |_|_|_|_|_|_|_|_|
55. Type of main residential circumstances (Appendix B) |_|_|_|
56. Current level of main residential service support A. B. C. D. Z.
57. Agency providing secondary residential service (Appendix A) |_|_|_|_|_|_|_|_|
58. Type of secondary residential circumstances (Appendix B) |_|_|_|
59. Current level of secondary residential service support A. B. C. D. Z.
60. If Planned Respite or Crisis Respite is the secondary residential service, indicate number of nights availed of in the past 12 months: Total |_|_|_|_|_| Planned |_|_|_|_|_| Crisis |_|_|_|_|_|
61. Health Board responsible for funding current services |_|_|_|

FUTURE SERVICE REQUIREMENTS

REQUIRED DAY SERVICES

70. Type of day service required (1) (Appendix B)
71. Level of support required in day service (1) 0. 1. 2. 3. 4. 5.
72. Year in which day service (1) is required
73. Primary reason for duplication on current day service and future day service (1)
74. Type of day service required (2) (Appendix B)
75. Level of support required in day service (2) 0. 1. 2. 3. 4. 5.
76. Year in which day service (2) is required
77. Primary reason for duplication on current day service and future day service (2)

MULTIDISCIPLINARY SUPPORT SERVICES

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

Rq	En	Duplication Reason
<input type="radio"/>	<input type="radio"/>	Community Nursing <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Nutritionist <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Medical Services <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Occupational Therapy <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Physiotherapy <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Psychiatry <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Psychology <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Social Work <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Speech & Language Therapy <input type="text"/>
<input type="radio"/>	<input type="radio"/>	Other Multidisciplinary support service <input type="text"/>
		Specify <input type="text"/>

79. Year in which multidisciplinary support services are required

For children aged six and under:

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

CONTINGENCY DAY SERVICES

81. Type of day service required - contingency plan
82. Level of (contingency plan) day support required 0. 1. 2. 3. 4. 5.
83. Primary reason for duplication on current/contingency day service
84. Primary reason for duplication on future day service (1) or (2) and contingency day service

DAY SUPPORT LEVEL CODES

Coding for variables 42, 46, 50, 71, 75 & 82

- 0: NOT APPLICABLE
- 1: MINIMUM (staff to client ratio is 1 to 10+)
- 2: LOW (between 1 to 6 and 1 to 9)
- 3: MODERATE (between 1 to 4 and 1 to 5)
- 4: HIGH (between 1 to 2 and 1 to 3)
- 5: INTENSIVE (1 to 1 or above)

RESIDENTIAL SUPPORT LEVEL CODES

Coding for variables 56, 59, 86, 90 & 94

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

FUTURE SERVICE REQUIREMENTS contd.

RESIDENTIAL SERVICES

85. Type of residential service required (1) (Appendix B)
86. Level of support required in residential service (1) A. B. C. D. Z.
87. Year in which residential service (1) is required
88. Primary reason for duplication on current residential service and future residential service (1)
89. Type of residential service required (2) (Appendix B)
90. Level of support required in residential service (2) A. B. C. D. Z.
91. Year in which residential service (2) is required
92. Primary reason for duplication on current residential service and future residential service (2)

CONTINGENCY RESIDENTIAL SERVICES

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

ADDITIONAL INFORMATION

100. Date of completion/review
101. Person responsible for update of form
102. Unit/Centre of person responsible
103. Agency returning record to Health Board database
104. Date consent received
105. Reason for removal

If transferred (1) please indicate: to HB to CCA to Agency
to National Physical & Sensory Disability Database

If deleted (3) please indicate:

<input type="radio"/> Emigrated	<input type="radio"/> Parents' request
<input type="radio"/> Service no longer required	<input type="radio"/> Client's request
<input type="radio"/> Other reason	<input type="radio"/> Duplication between health boards
	<input type="radio"/> Duplication within health board

106. Date of Removal

NATIONAL PERFORMANCE INDICATOR (NPI)

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

200. **NPI (1):** Does this person have a written Person-Centred Plan 1=yes 2=no

PROGRAMME CODES AND DESCRIPTIONS

Day Programme

- 00. Not applicable
- 01. No day service
- 02. Home support
- 05. Mainstream pre-school
- 06. Special pre-school for intellectual disability
- 07. Mainstream school
- 08. Special class - primary level
- 09. Special class - secondary level
- 10. Special school
- 11. Child education and development centre (Programme for children with severe or profound intellectual disability)
- 12. 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
- 32. Day respite in the home

Values 18-22

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

Residential Circumstances

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

DAY SERVICE GROUPINGS

Health

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

Education

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

Employment

- Enclave within open employment
- Supported employment
- Open employment

Generic

- Generic vocational training
- Generic day services

Appendix B

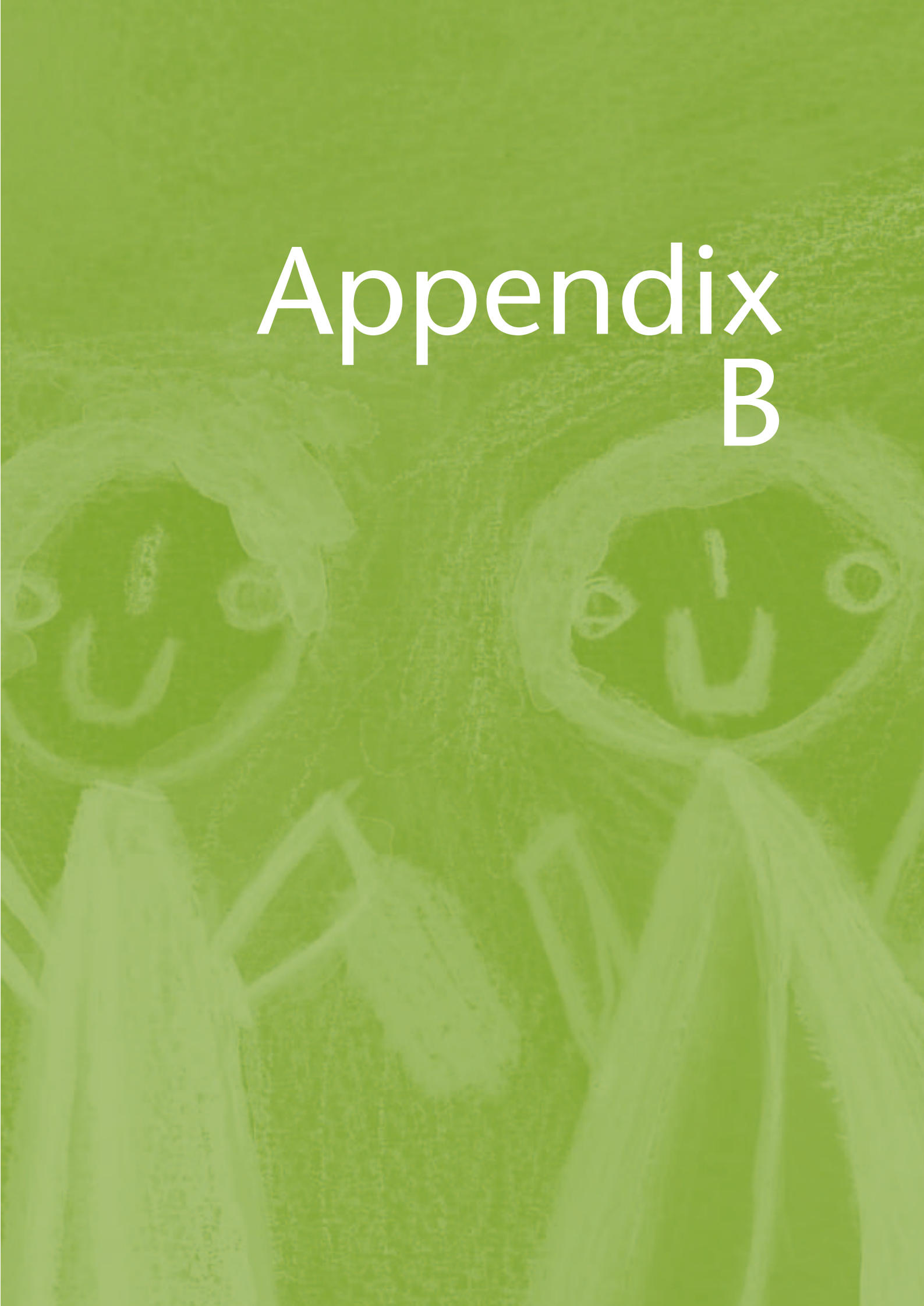


Table B.1. National Intellectual Disability Database, Ireland 2003.

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	1106	128	102	39	1375		3677	1918	986	142	6723		3224	2546	1435	260	7465		8007	4592	2523	441	15563	
At home with both parents	931	91	40	3	1065		2887	1381	381	16	4665		2608	1884	472	11	4975		6426	3356	893	30	10705	
At home with one parent	150	31	35	9	225		635	441	386	18	1480		533	575	583	36	1727		1318	1047	1004	63	3432	
At home with sibling	2	1	18	19	40		7	25	155	76	263		6	40	323	177	546		15	66	496	272	849	
At home with other relative	3	3	7	6	19		41	30	45	29	145		15	18	42	32	107		59	51	94	67	271	
Living with non-relative	0	1	1	1	3		3	10	11	1	25		2	5	8	1	16		5	16	20	3	44	
Adoption	1	0	0	0	1		10	7	0	0	17		5	4	1	0	10		16	11	1	0	28	
Foster care and boarding-out arrangements	19	1	1	1	22		94	24	8	2	128		55	20	6	3	84		168	45	15	6	234	
Independent/Semi-independent setting	0	5	29	15	49		3	152	293	86	534		1	21	72	36	130		4	178	394	137	713	
Living independently	0	4	25	15	44		2	103	217	67	389		1	13	41	25	80		3	120	283	107	513	
Living semi-independently	0	1	4	0	5		1	49	76	19	145		0	8	31	11	50		1	58	111	30	200	
Community group home	5	4	13	8	30		70	189	386	189	834		0	697	1365	390	2452		189	890	1764	587	3430	
5-day community group home	2	3	2	0	7		33	58	56	12	159		29	194	193	6	422		64	255	251	18	588	
7-day (48-week) community group home	1	0	1	0	2		10	38	73	22	143		28	153	324	32	537		39	191	398	54	682	
7-day (52-week) community group home	2	1	10	8	21		27	93	257	155	532		57	350	848	352	1607		86	444	1115	515	2160	
Residential centres	2	3	8	15	28		9	54	104	118	285		141	752	1550	754	3197		152	809	1662	887	3510	
5-day residential centre	1	0	0	0	1		3	4	2	0	9		29	51	35	2	117		33	55	37	2	127	
7-day (48-week) residential centre	0	0	0	0	0		2	18	30	11	61		34	202	258	51	545		36	220	288	62	606	
7-day (52-week) residential centre	1	3	8	15	27		4	32	72	107	215		78	499	1257	701	2535		83	534	1337	823	2777	
Other full-time services	2	1	4	8	15		17	47	81	81	226		51	275	369	216	911		70	323	454	305	1152	
Nursing home	0	0	1	5	6		1	2	5	11	19		1	5	21	30	57		2	7	27	46	82	
Psychiatric hospital	0	1	2	1	4		2	17	50	63	132		0	42	165	151	358		2	60	217	215	494	
Intensive placement (challenging behaviour)	1	0	0	0	1		7	19	14	0	40		19	123	95	6	243		27	142	109	6	284	
Intensive placement (profound or multiple handicap)	1	0	1	0	2		0	1	6	2	9		23	90	79	16	208		24	91	86	18	219	
Fulltime resident in 'other' residential service	0	0	0	1	1		4	5	4	5	18		4	2	6	11	23		8	7	10	17	42	
Fulltime resident in residential support place	0	0	0	1	1		3	3	2	0	8		4	13	3	2	22		7	16	5	3	31	
No fixed abode	0	0	0	0	0		1	3	3	0	7		0	2	2	1	5		1	5	5	1	12	
Insufficient information	41	37	40	32	150		57	266	293	95	711		30	76	136	74	316		128	379	469	201	1177	
Total	1156	178	196	117	1647		3834	2629	2146	711	9320		3561	4369	4929	1731	14590		8551	7176	7271	2559	25557	

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) 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. Completed forms should be returned to:

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

Requesting information from Regional Intellectual Disability Databases

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

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

Name of Applicant: _____

Address: _____

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

Date requested: _____

Details of the type of analysis required:

How will data be used:

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

(Continue on separate page if necessary)

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

Signature of Applicant: _____ Date: _____

=====

Date Request Considered: _____

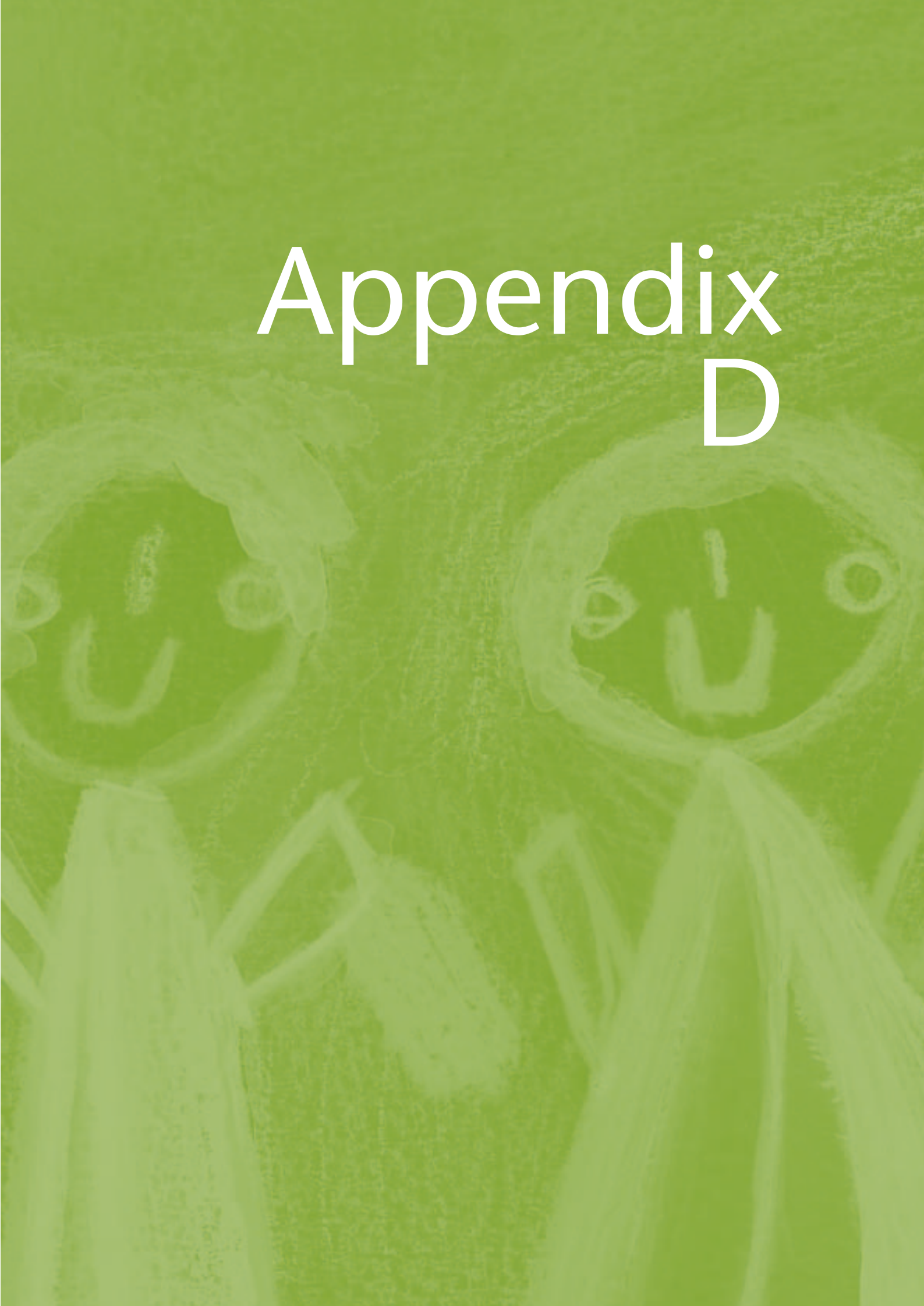
Decision of National Intellectual Disability Database Committee (NIDDC):

Any conditions which are to be applied to the request:

Signed on behalf of NIDDC: _____

Date: _____

Appendix D



DISABILITY DATABASES DIVISION PUBLICATIONS

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

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

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

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

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

