



HRB Statistics Series 6

Annual Report of the National Intellectual Disability Database Committee 2008

Fionnola Kelly, Caraiosa Kelly, Gabriel Maguire and Sarah Craig

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Health Research Board
An Bord Taighde Sláinte

Improving people's health through research
and information

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About the HRB

The Health Research Board (HRB) is the lead agency supporting and funding health research in Ireland. We also have a core role in maintaining health information systems and conducting research linked to national health priorities. Our aim is to improve people's health, build health research capacity, underpin developments in service delivery and make a significant contribution to Ireland's knowledge economy.

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The HRB is responsible for managing five national information systems. These systems ensure that valid and reliable data are available for analysis, dissemination and service planning. Data from these systems are used to inform policy and practice in the areas of alcohol and drug use, disability and mental health.

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The main subjects of HRB in-house research are child health, disability, mental health and alcohol and drug use. The research that we do provides evidence for changes in the approach to service delivery. It also identifies additional resources required to support people who need services for problem alcohol and drug use, mental health conditions and intellectual, physical and sensory disabilities.

The **Disability Databases Unit** manages two national service-planning databases for people with disabilities on behalf of the Department of Health and Children: the National Intellectual Disability Database (NIDD), established in 1995, and the National Physical and Sensory Disability Database (NPSDD), established in 2002. These databases inform decision making in relation to the planning of specialised health and personal social services for people with intellectual, physical or sensory disabilities.

The **HRB Statistics series** compiles data on problem alcohol and drug use, child health, disability and mental health from a single point or period in time.

The HRB Statistics series replaces the annual reports published by the Disability Databases Unit and the Mental Health Research Unit. Previous reports associated with this series are:

- Activities of Irish Psychiatric Units and Hospitals (1965–2005)
- National Physical and Sensory Disability Database Committee Annual Reports (2004–2007)
- National Intellectual Disability Database Committee Annual Reports (1996–2007)



Statistics series publications to date

Tedstone Doherty D, Walsh D, Moran R and Bannon F (2007) *High support community residences census 2006*. HRB Statistics Series 1. Dublin: Health Research Board.

Kelly F, Kelly C and Craig S (2007) *Annual report of the National Intellectual Disability Database Committee 2007*. HRB Statistics Series 2. Dublin: Health Research Board.

O'Donovan MA, Doyle A and Craig S (2007) *National Physical and Sensory Disability Database Committee annual report 2007*. HRB Statistics Series 3. Dublin: Health Research Board.

Daly A, Walsh D and Moran R (2007) *Activities of Irish psychiatric units and hospitals 2006*. HRB Statistics Series 4. Dublin: Health Research Board.

Daly A, Walsh D and Moran R (2008) *Activities of Irish psychiatric units and hospitals 2007*. HRB Statistics Series 5. Dublin: Health Research Board.



Table of contents

List of tables and figures	6
Members of the National Intellectual Disability Database Committee 2008	9
Chairperson's Statement	11
Executive Summary	12
1. The National Intellectual Disability Database	17
2. Profile of the population	21
3. Service provision in 2008	33
4. Assessment of need 2009–2013	53
5. Conclusion	82
References	84
Appendix A National Intellectual Disability Database data form	85
Appendix B National Intellectual Disability Database – Service categories – Day service groupings	89
Appendix C Supplementary table	92
Appendix D National Intellectual Disability Database publications	94



List of tables and figures

Tables

Table 2.1	Individuals registered on the NIDD, by age, gender, and degree of intellectual disability, 2008	22
Table 2.2	Age and degree of intellectual disability (moderate, severe and profound) and prevalence, 1974, 1981, 1996, 2008	26
Table 2.3	NIDD registrations, by HSE region, 2008	30
Table 2.4	Number of people registered with a physical and/or sensory disability by gender, 2008	32
Table 3.1	Overall service provision in 2008	34
Table 3.2	Main residential circumstances, by degree of intellectual disability and by age group, 2008	37
Table 3.3	Main residential circumstance and overall level of residential service provision, 2008	39
Table 3.4	Crisis or planned respite nights availed of in the period 2004–2008	40
Table 3.5	Use of respite nights, by HSE region and by LHO area of residence, 2008	43
Table 3.6	Residential status of people availing of day services, by degree of intellectual disability and by age group, 2008	44
Table 3.7	Principal day service availed of, by degree of intellectual disability and by age group, 2008	47
Table 3.8	Principal day service and overall level of day service provision by age group, 2008	49
Table 3.9	Overall provision of multidisciplinary support services by age and access to early intervention teams (EIT), 2008	50
Table 3.10	Service provision by HSE region of registration, 2008	52
Table 4.1	Number of new places required to meet need 2009–2013, by HSE region of registration	55
Table 4.2	Future full-time residential service requirements of individuals receiving no residential service in 2008, by degree of intellectual disability	58
Table 4.3	Future day service requirements of individuals receiving no day service in 2008, by degree of intellectual disability	59
Table 4.4	Future residential support service requirements of individuals receiving no residential support services in 2008, by degree of intellectual disability	60
Table 4.5	Category of service change required 2009–2013, by degree of intellectual disability	62
Table 4.6	Number of places requiring change 2009–2013	62

Table 4.7	Pattern of movement of individuals from existing residential services to future residential services 2009–2013	64
Table 4.8	Pattern of movement of individuals from existing day services to future day services 2009–2013	68
Table 4.9	Additional residential support services required by people availing of residential support services in 2008	71
Table 4.10	Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2008	72
Table 4.11	Day service requirements of people appropriately accommodated in psychiatric hospitals in 2008	73
Table 4.12	Residential service requirements of people resident in psychiatric hospitals in 2008, who require to be transferred to the intellectual disability sector	73
Table 4.13	Day service requirements of people resident in psychiatric hospitals in 2008 who require to be transferred to the intellectual disability sector	74
Table 4.14	Pattern of full-time residential service provision required 2009–2013	78
Table 4.15	Pattern of day service provision required 2009–2013	81
Table B1	Details of main residential circumstances, degree of intellectual disability and age group	92

Figures

Figure 2.1	Profile of the population registered on the NIDD in 2008	21
Figure 2.2	NIDD registrations by degree of intellectual disability and by age group, 2008	23
Figure 2.3	Proportion of people with moderate, severe or profound intellectual disability by age group: 1974, 1981, 1996, 1998–2008.	29
Figure 2.4	Prevalence of NIDD registrations per 1,000 of the general population, by HSE local health office area of residence, 2008	31
Figure 2.5	Proportion of people presenting with multiple disabilities, by age group, 2008	32
Figure 3.1	Summary of service provision, by age group, 2008	33
Figure 3.2	Number of people in receipt of respite nights (planned and/or crisis) and average number of respite nights received, by level of intellectual disability, 2008	41
Figure 3.3	Total number of respite nights (planned and/or crisis) received by those in receipt of respite care by HSE region of residence, 2008	42
Figure 4.1	Summary of the service requirements of those registered on the NIDD in 2008	54
Figure 4.2	Multidisciplinary support services received in 2008 and required in the period 2009–2013	76

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- the Health Service Executive, in particular the database co-ordinators, the database administrators/managers and the database committees;
- the National Federation of Voluntary Bodies providing services to people with intellectual disability;
- the parents and families of people with an intellectual disability and their representative bodies; and
- all those in intellectual disability services throughout Ireland.

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Chairperson's Statement

I am very pleased to present this, the eleventh Annual Report of the National Intellectual Disability Database (NIDD). The report for 2008 presents data for a full calendar year. This change in reporting was undertaken to assist service planners in the process of making decisions about the allocation of resources for intellectual disability services. The report is based on over 26,000 registrations.

The objective of the NIDD is to ensure that information is available to provide appropriate services to people with an intellectual disability and their families. In the current economic climate it is now more important than ever that we ensure that information on which to plan services is up to date, timely and accessible to those who are involved in the delivery of services. In this respect, the Department of Health and Children welcomes the publication of the report. It also welcomes the fact that the Disability Databases Unit of the Health Research Board makes data available to the Health Service Executive at the level of local health office.

Information is presented in this report on the demographic profile of those who are registered on the NIDD, on their current usage of day and residential services, and of a range of multidisciplinary supports. It also presents information on the needs of people with intellectual disability for such services into the future.

The report also draws attention to some interesting trends in the data in the last number of years. It highlights, in particular, that people with intellectual disability are surviving into old age and that they are requiring services appropriate to their age group. In recognition of this growing trend, the Department of Health and Children welcomes the work undertaken by the Disability Databases Unit in the HRB earlier this year on the service usage and service need of those aged 50 years and over who are registered on the NIDD.

I would like to thank the NIDD committee members for all their work and for getting this report to its final stage. I would also like to acknowledge the efforts of those working in the Disability Databases Unit of the Health Research Board whose responsibility it was to prepare and publish this report on behalf of the Committee.

Dermot Ryan

Chairperson

National Intellectual Disability Database Committee

Executive Summary

Demographic profile

There were 26,023 people registered on the National Intellectual Disability Database (NIDD) in December 2008, representing a prevalence rate of 6.14 per 1,000 population. The administrative prevalence rate for mild intellectual disability was 2.02 per 1,000 and the prevalence rate for moderate, severe and profound intellectual disability was 3.61 per 1,000. There were more males than females at all levels of intellectual disability, with an overall ratio of 1.30 to 1. The total number with moderate, severe or profound intellectual disability has increased by 36% since the first Census of Mental Handicap in the Republic of Ireland was carried out in 1974. One of the factors contributing to this increase in numbers is the growth in the general population over the period. The proportion of people with moderate, severe or profound intellectual disability who are aged 35 years and over increased from 29% in 1974 to 38% in 1996, and to 48% in 2008. This reflects an increase in the lifespan of people with intellectual disability. This changing age profile observed in the data over the past three decades has major implications for service planning, including an ongoing high level of demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability. This helps to explain the ongoing demand for additional resources for this sector.

Service provision in 2008

The numbers registered on the NIDD in December 2008 were as follows:

- 25,433 people with intellectual disability who were in receipt of services, representing 98% of the total population registered on the NIDD. This was the highest number of people in receipt of services since the Database was established in 1995.
- 289 people (1% of those registered) who were without services in 2008 and who were identified as requiring appropriate services in the period 2009–2013.
- 301 people (1%) who were not availing of services and had no identified requirement for services during the planning period 2009–2013.

Of the 25,433 people who were in receipt of services in 2008:

- 8,290 (32.6%) were in receipt of full-time residential services, an increase of 28 since 2007 and the highest figure recorded on the NIDD since 2001. This is the fifth consecutive year in which the data indicate that more people live in community group homes than in residential centres.



- The number of people with intellectual disability accommodated in psychiatric hospitals decreased by 21 (6.4%), from 329 in 2007 to 308 in 2008.
- 25,319 (99.6%) people availed of at least one day programme in 2008. This was the highest number of day services availed of since NIDD data were first reported in 1996. Of this group, 8,199 were in full-time residential placements and 5,310 were in receipt of residential support services such as respite care.
- 20,971 (82.5%) people availed of one or more multidisciplinary support service. The services most commonly availed of by adults were social work, medical services and psychiatry. The services most commonly availed of by children were speech and language therapy, social work and occupational therapy.

Sixty-four per cent of those registered on the NIDD (16,708 individuals) lived at home with parents, siblings, relatives or foster parents in 2008. More than one in four people who had a moderate, severe or profound intellectual disability and who were aged 35 years or over in 2008 lived in a home setting. As the carers of adults with intellectual disability begin to age beyond their care-giving capacity, formal supervised living arrangements will be needed. Because people with intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years. These data highlight the importance of planning for such eventualities and avoiding crisis situations.

Since the first report from the NIDD in 1996, there has been significant growth in the level of provision of full-time residential services, residential support services, and day services. This reflects, in particular, the significant investment programme in the intellectual disability sector between 2000 and 2002 and again in 2005. Key developments during the period 1996 to 2008 include:

- an increase of more than 60% in the number of people with intellectual disability living full-time in community group homes;
- a 68% reduction in the number of people with intellectual disability accommodated in psychiatric hospitals;
- a continued expansion in the availability of residential support services, particularly planned or emergency centre-based respite services, which have grown by a substantial 428%; 4,599 people availed of this type of service in 2008, allowing them to continue living with their families and in their communities;
- increased provision in almost all areas of adult day services and in the level of support services delivered as part of a package of day services to both children and adults.

Service requirements

The 2008 data indicate that 4,627 new residential, day and/or residential support places will be needed to meet service requirements. The following services will be needed in the period 2009–2013 (most service needs were recorded as being immediate):

- 2,256 full-time residential placements, an increase of 75, or 3%, since 2007 and the highest number since the Database was established. The number of new full-time residential places required has been increasing consistently following a slight downward trend during the years 2000 to 2002. The demographic profile of people with intellectual disability in Ireland suggests that the number of new full-time residential places required is likely to continue to increase over the coming years as those with a more severe disability and those who care for them advance in age.
- 2,129 residential support services, an increase of 41, or 2%, since 2007. This high level of need is presenting even though there were over 5,000 people availing of residential support services in 2008.
- 242 day programmes. The number of new day places required (this figure excludes multidisciplinary support services and services provided by early intervention teams) has been decreasing since NIDD data were first reported in 1996 and is now at its lowest since the Database was established.
- A group of 188 individuals who were living in psychiatric hospitals in 2008 have been identified as needing to transfer from these locations to more appropriate accommodation.

Of those in receipt of services in 2008, 11,823 people required alternative, additional, or enhanced services in the period 2009 to 2013, a decrease of 105, or 1%, since 2007. This group included people who required an increased level of service provision, increased support within their existing services, transfer to more appropriate placements, or a service change to coincide with transition periods in their lives, for example, movement from child to adult services, or from education to training and/or employment placements. To address the required service changes over the next five years:

- 10,248 day places will require changes or enhancements. Health funded services are required by 7,102 individuals (69.3%), employment services are required by 1,311 individuals (12.8%), educational services are required by 1,161 individuals (11.3%) and generic services are required by 674 individuals (6.6%). Of the 1,161 service changes required within education, 857 (73.8%) are requirements for an alternative service and 304 (26.2%) are requirements for an enhancement of the

individual's existing service. A large proportion of the 1,530 individuals who were attending special schools in 2008, require adult day services within the period 2009 to 2013. Of this group, almost one quarter (368 individuals) require rehabilitative training, 335 (21.9%) require vocational training and 179 (11.7%) require activation programmes.

- 3,094 residential places will require changes or enhancements.
- 1,654 residential support places will require changes or enhancements.

Despite high levels of service provision in 2008, there remained a significant demand for new and enhanced multidisciplinary support services. Three quarters (19,512 individuals) of the population registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2009 to 2013. There was substantial demand for all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy.

The 2008 dataset, in line with data in recent years, indicated that, despite substantial levels of service provision in day, residential, residential support and multidisciplinary support services, there was an ongoing demand for new intellectual disability services and a need to enhance existing services. The numbers of new full-time residential and residential support places required were at their highest since the Database was established in 1995. This need is presenting against a background of significant investment in intellectual disability services in recent years. While the data in recent years highlight the corresponding growth in services, demographic factors and historical under-funding of intellectual disability services are likely to be contributing factors to long waiting lists for these services. The increased birth rate in the 1960s and 1970s has resulted in a large adult population moving through the services at present, contributing to an ongoing demand for services. In addition to this, people with intellectual disability are living longer than previously, which not only contributes to the ongoing demand for services but also reduces the number of service placements being relinquished each year. The service demands identified in the report outstrip the level of resources that have been put in place under the multi-annual funding package 2006–2009. In the medium term, it is expected that the increased demand for intellectual disability services will continue.



1. The National Intellectual Disability Database

Background

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

The Database was established on the principle that minimum information with maximum accuracy was preferred; hence, it incorporates only three basic elements of information: demographic details, current service provision and future service requirements. Information is generally collected on day, residential and multidisciplinary support service usage and future service need (the form used to collect information and details of the service categories that are included on the NIDD are presented in Appendices A and B). 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. However, the National Intellectual Disability Database Committee is reviewing this issue and a plan to pilot questions on diagnosis/additional needs is under way. The data held on any individual represent the information available for that individual 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.

The information now available from the NIDD provides a much better basis for decision making than was previously the case. Priorities can be set based on 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 HSE is responsible for the administration of the Database. This includes the implementation and maintenance of structures for the identification of individuals and the collection, review and updating of data. The initial step in the generation of the national dataset is the completion of a data form for each identified individual (Appendix A). Responsibility for providing this information to the HSE lies primarily with the service providers, local health office (LHO) personnel and school principals. The designated data providers supply this information to their LHO and a local database is compiled. Data from the local databases enable more sophisticated service planning at local level and promote effective co-ordination of services within the area.

Information (excluding personal details such as name and address) is extracted from the NIDD at the end of the annual review and update period. This information forms the national dataset for that year. The Health Research Board (HRB), on behalf of the Department of Health and Children, manages the national dataset. In 2008 the date for extraction of the national dataset was changed so that the information in the annual report now covers a full calendar year as opposed to half of one year and half of the next.

Data quality

The HRB oversees a system of ongoing validation which aims to identify and correct gaps and inconsistencies in the data. The Database guidelines and protocols are revised and refined in response to issues highlighted by the HRB, HSE areas and service providers. Such refinements ensure greater standardisation of data collection throughout the country. In addition, the NIDD software contains a series of technical checks which enable routine data validation to be carried out by service providers and HSE areas. There are ongoing efforts to ensure continued improvement of data quality at local, regional and national levels. As part of these efforts a national audit of the NIDD was undertaken in 2007, the recommendations of which are being currently implemented.

2008 annual report

This is the eleventh report of the National Intellectual Disability Database Committee. The report is based on validated data extracted from the NIDD in December 2008. In addition to this report, a summary bulletin and a complete set of tables are produced for each HSE LHO.

Prevalence rates per thousand population are based on up-to-date data from the 2006 Census of Population (Central Statistics Office, 2007).

The nature of service provision in the intellectual disability area in Ireland ensures that an almost complete capture 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, or are attending an intellectual disability service as adults, or if they are considered likely to require such a service within the next five years. Some of those in the average ability and borderline intellectual disability categories are registered on the NIDD but have been excluded from analyses because services for this group are not usually provided within intellectual disability services. In the 2008 dataset, there were 480 people recorded as being of average ability and 689 people in the borderline intellectual disability category. The HSE areas are involved in an ongoing appraisal of the appropriateness of such registrations on the Database. The disability category described as 'not verified' has been included in the analyses as members of this group have an intellectual disability but the level of disability has not been confirmed. Accordingly, the data presented include the 'not verified' category in addition to those with a mild, moderate, severe or profound intellectual disability.

The 2008 dataset consists of information in relation to 26,023 individuals. Of the 26,023 registrations, less than 1% of records (203, 0.8%) were not updated since the completion of the 2007 review and update of NIDD information, and their last known data are documented in this report. This is a considerable improvement on 2007, when 897 records (3.5%) were not updated, and highlights the dedication and commitment of HSE and service provider staff to the Database and to the recognised need for accurate and timely data.

National Disability Survey 2006

In 2006 the Central Statistics Office (CSO) conducted a National Disability Survey (NDS) to establish the severity and impact of disability in Ireland. The preliminary results were published in October 2008. Data from the survey indicate that 50,400 people in Ireland have a diagnosed intellectual disability (CSO, 2008). This information differs greatly from what is recorded on the NIDD, for two main reasons:

- Intellectual disability is defined differently by the two data sources: the NIDD is based on the WHO International Classification of Diseases, Tenth Edition (ICD-10), while the NDS is based on the WHO International Classification of Functioning (ICF). In addition, the data-collection methods differ. For inclusion on the NIDD a person is usually assessed by a multidisciplinary team, and his/her level of intellectual disability (mild, moderate, severe or profound) is established based on this assessment. The response to the question in the NDS pertaining to whether or not the individual had a diagnosed intellectual disability was self-interpreted in a guided interview context. Almost 14,000 individuals whose main

disability was classified as dyslexia or a specific learning difficulty answered 'Yes' to this question, as did over 2,500 individuals (or their proxy) whose disability was classified as attention deficit disorder (CSO 2008, unpublished data). This question was also answered positively by a large number of people who had an acquired brain injury. People diagnosed with the conditions mentioned above are not generally included on the NIDD unless they have a diagnosed intellectual disability as defined by the WHO ICD-10, where disability is estimated on a scale ranging from mild to moderate to severe to profound (WHO, 1996).

- As a general principle, the NIDD registers data only on individuals with an intellectual disability for whom specialised health services are being provided or who, following a needs assessment, are considered to require specialised services in the next five years. Almost everyone with a moderate, severe or profound intellectual disability is expected to be included on the NIDD as they are likely to be in receipt of or require intellectual disability services. The number of people on the NIDD with a mild intellectual disability may, however, be underestimated as they are less likely to require specialised intellectual disability services. By contrast, the number of people recorded by the NDS includes all individuals who defined themselves as having an intellectual disability, regardless of whether they receive or require intellectual disability services.

2. Profile of the population

National level

Summary

Figure 2.1 shows that there were 26,023 people registered on the NIDD in 2008. There were more males (56.6%) than females (43.4%) registered on the Database, with the highest proportion of both males and females diagnosed as having a moderate level of intellectual disability. Figure 2.1 also indicates that the largest proportions of people registered were in the HSE South region (28.4%) and were aged between 35 and 54 years (29.0%).

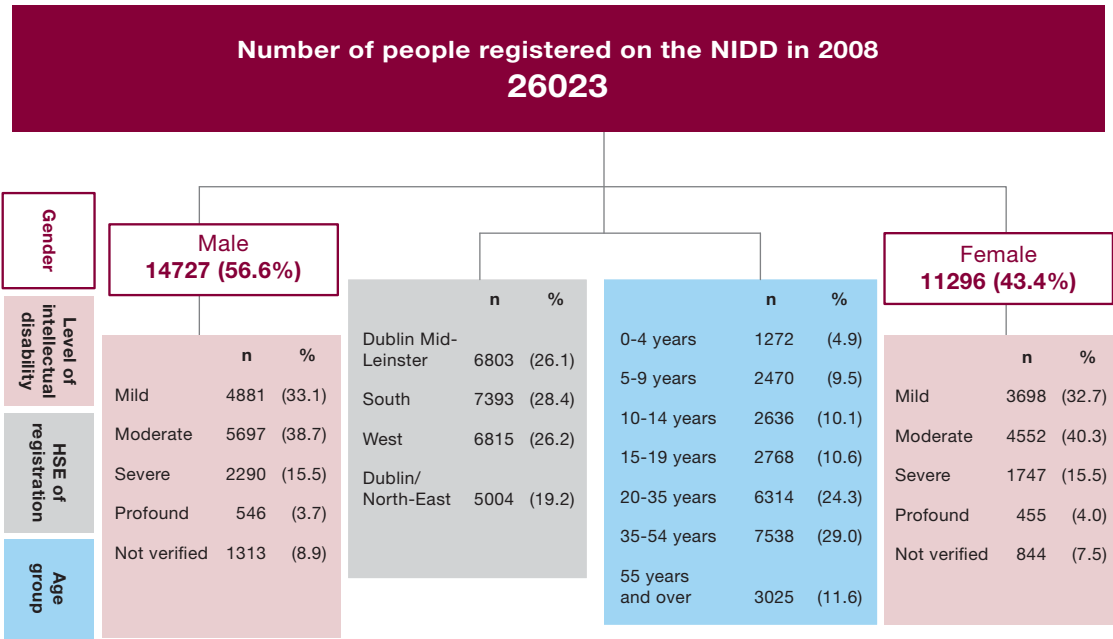


Figure 2.1 Profile of the population registered on the NIDD in 2008

During the review and update period prior to the 2008 extract of data from the NIDD, 1,080 people were removed from the Database¹ and there were 1,490 new or reactivated registrations.

Table 2.1 summarises the age and gender distribution of those registered on the Database by degree of intellectual disability and shows the corresponding prevalence² rates per thousand of the population.

1. Records of those who had died, who had no requirement for intellectual disability services, or who no longer wanted their information to be held on a national system were among those removed from the Database.
2. Prevalence is a term used to describe the proportion of people in a population who have a disease or condition at a specific point in time. For example, in 2008, 300 people with an intellectual disability received services in a specific LHO area. The prevalence is the total number of cases (300) divided by the population living in the LHO area (35,000) expressed per given number of the population, i.e. per 100, per 1,000, per 10,000 etc. The calculation in this case is as follows: $(300/35,000) \times 1,000$, which gives a prevalence rate of 8.6 per 1,000 of the specific LHO area population in 2008.

Table 2.1 Individuals registered on the NIDD, by age, gender, and degree of intellectual disability, 2008

Age group	Not verified			Mild			Moderate			Severe			Profound			All levels		
	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total
0-4	463	599	1062	41	65	106	25	51	76	9	11	20	3	5	8	541	731	1272
5-9	212	489	701	257	519	776	218	471	689	103	153	256	28	20	48	818	1652	2470
10-14	20	43	63	465	783	1248	343	592	935	131	195	326	32	32	64	991	1645	2636
15-19	14	14	28	503	853	1356	432	612	1044	119	170	289	29	22	51	1097	1671	2768
20-34	56	53	109	972	1152	2124	1192	1637	2829	402	617	1019	105	128	233	2727	3587	6314
35-54	56	69	125	1031	1132	2163	1571	1678	3249	682	859	1541	196	264	460	3536	4002	7538
55 & over	23	46	69	429	377	806	771	656	1427	301	285	586	62	75	137	1586	1439	3025
All ages	844	1313	2157	3698	4881	8579	4552	5697	10249	1747	2290	4037	455	546	1001	11296	14727	26023
Prevalence rates – numbers per 1,000 of the general population for each age group³																		
0-4	3.13	3.88	3.51	0.28	0.42	0.35	0.17	0.33	0.25	0.06	0.07	0.07	0.02	0.03	0.03	3.66	4.73	4.21
5-9	1.51	3.30	2.43	1.83	3.51	2.69	1.55	3.18	2.39	0.73	1.03	0.89	0.20	0.14	0.17	5.83	11.16	8.57
10-14	0.15	0.31	0.23	3.49	5.57	4.56	2.57	4.21	3.41	0.98	1.39	1.19	0.24	0.23	0.23	7.43	11.71	9.62
15-19	0.10	0.09	0.10	3.54	5.75	4.67	3.04	4.13	3.60	0.84	1.15	1.00	0.20	0.15	0.18	7.72	11.27	9.54
20-34	0.11	0.10	0.10	1.85	2.14	1.99	2.27	3.03	2.66	0.77	1.14	0.96	0.20	0.24	0.22	5.19	6.65	5.93
35-54	0.10	0.12	0.11	1.82	1.96	1.89	2.77	2.90	2.84	1.20	1.49	1.35	0.35	0.46	0.40	6.23	6.93	6.58
55 & over	0.05	0.11	0.08	0.93	0.91	0.92	1.67	1.59	1.63	0.65	0.69	0.67	0.13	0.18	0.16	3.43	3.49	3.46
All ages	0.40	0.62	0.51	1.75	2.30	2.02	2.15	2.69	2.42	0.82	1.08	0.95	0.21	0.26	0.24	5.33	6.94	6.14

3. Prevalence rates per thousand population are based on Census of Population 2006 figures (CSO, 2007)

Prevalence

The administrative prevalence rate for mild intellectual disability in 2008 was 2.02/1000, a slight increase on the 2007 rate of 1.96/1000. This figure does not reflect the true prevalence as only those with mild intellectual disability accessing or requiring intellectual disability services are included in the Database. The prevalence rate for moderate, severe and profound intellectual disability in 2008 was 3.61/1000, compared to 3.48/1000 in 2007.

Gender differences

As Table 2.1 indicates, the number of males exceeded the number of females at all levels of intellectual disability and in all age groups except the 55 years and over group. The overall male to female ratio was 1.30:1. This represents a prevalence rate of 6.94/1000 males and 5.33/1000 females.

Age differences

Of the people recorded on the NIDD, 9,146 (35.1%) were aged 19 years or under; 6,314 (24.3%) were aged between 20 and 34 years; 7,538 (29.0%) were aged between 35 and 54 years; and 3,025 (11.6%) were 55 years or over. Figure 2.2 illustrates the proportion in each age group at each level of intellectual disability.

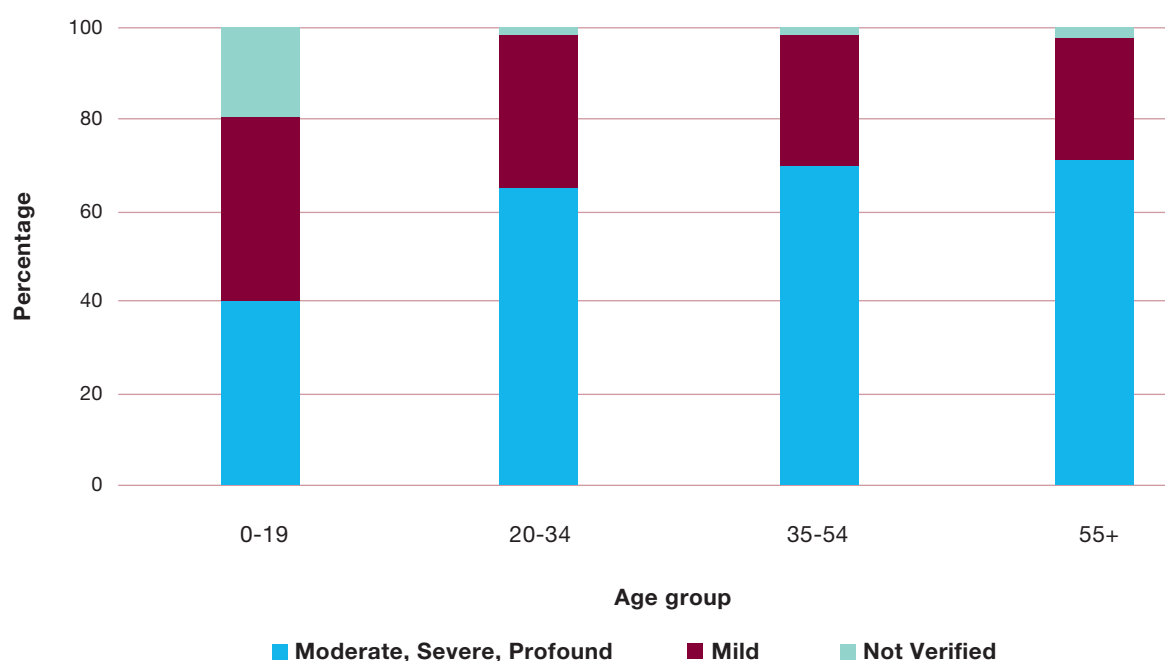


Figure 2.2 NIDD registrations by degree of intellectual disability and by age group, 2008

Trends over time

Prevalence rates for moderate, severe and profound intellectual disability for 1996 and 2008 are compared in Table 2.2. The 1996 prevalence rates are calculated using NIDD data from 1996 and census of population data from 1996. The 2008 prevalence rates are calculated using NIDD data from 2008 and census of population data from 2006. Compared to the 1996 data (National Intellectual Disability Database Committee, 1997), the 2008 data in Table 2.2 demonstrate the following trends:

- A reduced prevalence rate for the 0–4-year age group. The decrease of 0.90/1000 in the prevalence rate is associated with a 69.3% drop in numbers in this age group registered on the Database between 1996 and 2008 and an increase in this age group in the general population between the 1996 and the 2006 Census of Population. The prevalence rate in 2008 for the 0–4-year age group, at 0.34/1000, was considerably lower than expected. Applying the prevalence rate of 4.58/1000 for the 10–14-year age group, which is the internationally accepted age range for maximum ascertainment of individuals with an intellectual disability, it is estimated that the number of children aged 0–4 years, as recorded on the NIDD in 2008, was underestimated by somewhere in the region of 1,200 cases. A more detailed trend analysis of young children registered on the NIDD was published in 2008 (Kelly and Craig, 2008).
- A small increase in the prevalence among the 5–9-year age group of 0.07/1000. While there was a decline of 7.5% in the number in this age group registered on the Database between 1996 and 2008, there was a proportionately greater decline in the number in this age group in the general population, which has led to the increase in the prevalence rate.
- An overall increase in prevalence among the 10–14-year age group of 0.98/1000, despite a 1.6% fall in numbers in this age cohort registered on the Database over the thirteen-year period. The prevalence may have increased because the number of children in this age group in the general population declined by 4% over the two census periods.
- A marginal increase in prevalence among the 15–19-year age group of 0.05/1000. This increase is associated with a decrease of almost 20% in the general population in this age group between the 1996 and 2006 censuses, while the numbers in this age group registered on the Database declined by only 12.5% between 1996 and 2008.

- A downward trend in the prevalence in the 20–34-year age group of 2.48 per 1,000. The prevalence among 20–34-year-olds fell consistently over the thirteen-year period. From 1996 to 2002 this age group exhibited a higher prevalence of moderate, severe or profound intellectual disability than any other age group (Mulvany and Barron, 2003). The consistent decrease in prevalence over time resulted in this group no longer exhibiting the highest prevalence of moderate, severe or profound intellectual disability in the six datasets from 2003 to 2008.
- An overall decrease in prevalence among the 35–54-year age group of 0.56/1000 since 1996. The number of NIDD registrations in this age cohort increased by 1,098 over this time but the prevalence rate reflects the corresponding increase of 26.1% for this demographic in the general population.
- An overall increase in prevalence of 0.35/1000 in the 55-years-and-over age group. The number of people in this age group registered on the Database increased by 716 (49.9%) between 1996 and 2008.

The 2006 Census of Population data used in calculating the 2008 prevalence rates may have had a significant impact on the observed rates noted above. A detailed discussion of the possible impacts can be found in the NIDD Annual Report 2007 (Kelly *et al.*, 2007).

Table 2.2 Age and degree of intellectual disability (moderate, severe and profound)* and prevalence†, 1974, 1981, 1996, 2008

Age group	Moderate				Severe				Profound				All levels			
	1974	1981	1996	2008	1974	1981	1996	2008	1974	1981	1996	2008	1974	1981	1996	2008
0-4	189	214	226	76	143	92	83	20	99	26	30	8	431	332	339	104
5-9	809	955	736	689	617	330	260	256	224	99	77	48	1650	1384	1073	993
10-14	752	1035	948	935	583	428	305	326	292	117	93	64	1627	1580	1346	1325
15-19	698	1203	1072	1044	445	508	378	289	241	154	132	51	1384	1865	1582	1384
20-34	1498	2419	2997	2829	1017	1129	1350	1019	441	340	460	233	2956	3888	4807	4081
35-54	1321	1559	2626	3249	626	612	1183	1541	201	97	343	460	2148	2268	4152	5250
55 & over	669	715	987	1427	307	248	394	586	84	24	53	137	1060	987	1434	2150
All ages	5936	8100	9592	10249	3738	3347	3953	4037	1582	857	1188	1001	11256	12304	14733	15287

Prevalence rates – numbers per 1,000 of the general population for each age group																
0-4	0.60	0.62	0.83	0.25	0.45	0.27	0.30	0.07	0.31	0.07	0.11	0.03	1.36	0.97	1.24	0.34
5-9	2.55	2.73	2.31	2.39	1.95	0.94	0.82	0.89	0.71	0.28	0.24	0.17	5.20	3.95	3.37	3.44
10-14	2.52	3.08	2.72	3.41	1.95	1.27	0.88	1.19	0.98	0.35	0.27	0.23	5.45	4.70	3.86	4.84
15-19	2.61	3.79	3.20	3.60	1.66	1.60	1.13	1.00	0.90	0.48	0.39	0.18	5.17	5.88	4.72	4.77
20-34	2.78	3.33	3.93	2.66	1.88	1.56	1.77	0.96	0.82	0.47	0.60	0.22	5.48	5.35	6.31	3.83
35-54	2.13	2.43	3.25	2.84	1.01	0.95	1.46	1.35	0.32	0.15	0.42	0.40	3.46	3.53	5.14	4.58
55 & over	1.08	1.09	1.45	1.63	0.50	0.38	0.58	0.67	0.14	0.04	0.08	0.16	1.71	1.51	2.11	2.46
All ages	1.99	2.35	2.72	2.42	1.25	0.97	1.12	0.95	0.53	0.25	0.34	0.24	3.80	3.60	4.18	3.61

* Based on NIDD data

† Based on CSO Census of Population data

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 34 years (Table 2.2).

The number of people on the NIDD with a moderate, severe or profound intellectual disability increased by 4,031 (35.8%) between 1974 and 2008; this proportion closely matches the general population increase over that period. The number of people with a moderate, severe or profound disability was 15,287 in 2008, compared to 11,256 in 1974. The 2008 prevalence rate of 3.61 per 1,000 is slightly lower than that reported in 1974 (3.80 per 1,000). Of particular interest from the point of view of service delivery is that, since 1996, this increase in numbers was confined to the two older age groups (35–54 years and 55 years and over). With the exception of the 55-years-and-over age group in 2002, the two older age groups continued to increase in numbers each year since 1996. A number of factors contributed to the increase; the general population increase in these age groups during the period, improved standards of care and an increase in the lifespan of people with intellectual disability.

The graphical representation of the combined data for moderate, severe, and profound intellectual disability (Figure 2.2) indicates a distinct change in the age profile over the 34-year period, with fewer children and young adults and more older adults availing of or in need of, intellectual disability services. There were fewer children and young people, aged 0–19 years, with moderate, severe, or profound intellectual disability in 2008 than in 1974, 1981, or 1996. This may reflect the decline in the birth rate in Ireland between 1980 and 1995, improved antenatal care, and the effectiveness of early intervention services, but also raises questions regarding the under-registration of children. It is reasonable to assume that there are children with intellectual disability in mainstream services who do not have contact with specialised health services. Reluctance of parents to allow information about their children to be recorded on the Database may also have an impact, particularly in the 0–4-year age group. The implementation of the Disability Act 2005 on assessment of need for children in the 0–5-year age group is likely to generate further information about this cohort.

Cohort effect⁴

Between 1974 and 2008 there was a significant increase in the number of adults availing of, or in need of, intellectual disability services. Closer examination of recent NIDD data suggests that this increase almost certainly reflects a cohort effect, whereby a population bulge originating in the 1960s and lasting until the mid-1970s has moved through the services, translating into large numbers of adults in the older age groups. This population bulge is attributable to a high birth rate in the 1960s and 1970s and improved obstetric and paediatric care over this period. Data from the previous censuses of mental handicap allow us to monitor the progress of this group through the services. In 1974, there was a high prevalence rate in the 10–14-year age group, which translated into the peak prevalence rate in 1981 in the 15–19-year age group. The peak prevalence rate from 1996 to 2002 was observed in the 20–34-year age group. As this cohort continued to age, the peak prevalence rate each year from 2003 to 2006 was observed in the 35–54-year age group. However, the prevalence rate in this age group decreased from 4.82/1000 in 2006 to 4.46/1000 in 2007. This was reversed in 2008 with the prevalence rate rising to 4.58/1000. What is of particular interest is that from 2007 the peak prevalence rate for individuals with moderate, severe or profound intellectual disability was observed in the 10–14-year age group. As outlined in the 2007 annual report (Kelly *et al.*, 2007), this change can be attributed to an increase in the numbers in this age group on the NIDD since 2002. Simultaneously, there has been a decrease of 4% in this age group in the general population as recorded in the Census of Population for this period.

Ageing population

Figure 2.3 provides evidence to suggest that people with intellectual disability in Ireland are living longer. 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. It can be seen that 28.5% of people with moderate, severe or profound intellectual disability were aged 35 years or over in 1974, while 26.5% fell into this age category in 1981. A steady increase in the proportion aged 35 years or over has been observed in each dataset since 1996, from 37.9% in 1996 to 48.4% in 2008. This increase represents 1,814 more people with a moderate, severe or profound intellectual disability aged 35 years or over.

4. Any effect associated with being a member of a group born at roughly the same time and bonded by common life experiences (e.g. growing up in the 1960s).

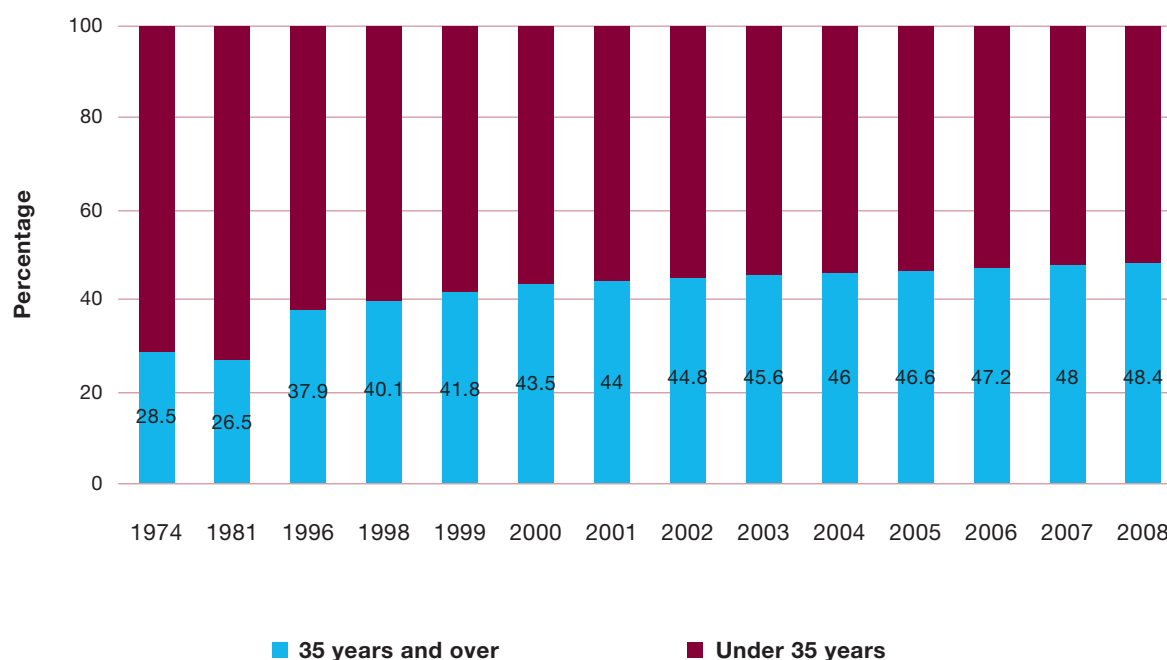


Figure 2.3 Proportion of people with moderate, severe or profound intellectual disability by age group: 1974, 1981, 1996, 1998-2008.

Impact of observed trends

As previous reports from the NIDD have highlighted, the changing age profile of the population 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. Key issues include:

- Residential services are primarily used by adults with a moderate, severe or profound intellectual disability. As the number of individuals in this group increases, more pressure is being placed on residential services. This is reflected in the waiting lists observed for full-time residential services.
- Improved life expectancy among adults with a more severe intellectual disability places an increased demand on the health services and poses new challenges to health care professionals. Fewer places are becoming free over time, a higher degree of support within day and residential services is required, and specific support services for older people are needed (for more detail see Kelly *et al.*, 2009).
- The majority of adults with intellectual disability continue to live with their families. As these caregivers age beyond their care-giving capacity, residential supports are required.
- Additional therapeutic support services are 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 are resulting in significant demand for additional resources. This demand is now presenting, and will continue to present major challenges to service planners and providers – as the generation born in the 1960s and 1970s will begin to reach age 55 in 2015.

Regional level

Numbers in each HSE region

Table 2.3 shows the number of individuals registered in each HSE region in 2008. The numbers registered in each region were broadly in line with what would be expected based on the general population size of that area. The category 'Out of state' refers to individuals who were funded by the state but received services outside the state.

Table 2.3 NIDD registrations, by HSE region, 2008

	N	% of NIDD	% of total population
HSE Dublin/Mid-Leinster ⁵	6803	26.1	28.7
HSE South ⁶	7393	28.4	25.5
HSE West ⁷	6815	26.2	23.9
HSE Dublin/North-East ⁸	5004	19.2	21.9
Out of state	8	<0.1	<0.1
Total	26023	100.0	100.0

Figure 2.4 presents the prevalence of NIDD registrations by the local health office (LHO) area in which the client lives. The national prevalence rate was 6.14/1000. The Sligo/Leitrim LHO area has the highest prevalence rate at 9.31/1000 of the population, while the lowest prevalence rate can be observed in the Dublin South City LHO area (2.84/1000).

5. An additional 3 individuals received services in the HSE Dublin/Mid-Leinster Region but have not been included in the overall figures as they did not give consent for their information to be included on the national system.
6. An additional 78 individuals received services in the HSE South Region but have not been included in the overall figures as they did not give consent for their information to be included on the national system.
7. An additional 95 individuals received services in the HSE West Region but have not been included in the overall figures as they did not give consent for their information to be included on the national system.
8. An additional 26 individuals received services in the HSE Dublin/North East Region but have not been included in the overall figures as they did not give consent for their information to be included on the national system.

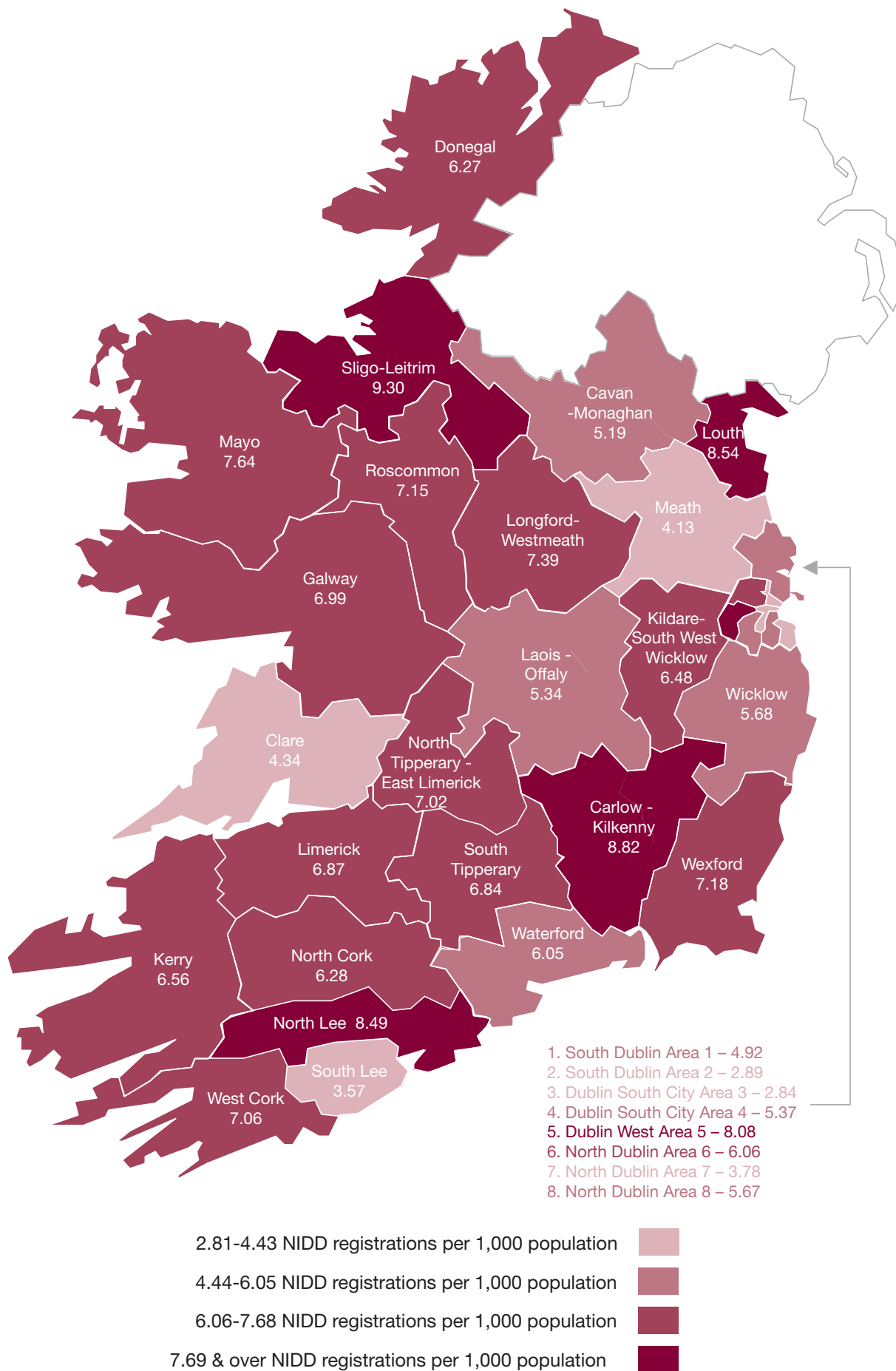


Figure 2.4 Prevalence of NIDD registrations per 1,000 of the general population, by HSE local health office area of residence, 2008

Co-morbidity within the NIDD population

As Table 2.4 indicates, 7,380 (28.4%) of the people registered on the NIDD had a physical and/or sensory disability in addition to their intellectual disability; Figure 2.5 shows that the likelihood of having a physical/sensory disability in addition to an intellectual disability increases with age. In 2008 just over one quarter of those aged 0–18 years were recorded on the NIDD as having a physical/sensory disability, compared to 36.3% of those aged 55 years or over. Individuals with multiple disabilities are likely to have more complex service needs than those with intellectual disability alone. In order to plan effective interventions for this group into the future, services need to reflect the changing needs of this cohort, particularly as they age, so that appropriate services and treatments are made available to meet their specific requirements.

Table 2.4 Number of people registered with a physical and/or sensory disability by gender, 2008

	Male		Female		Total	
	n	%	n	%	n	%
Intellectual and physical/sensory disability	3833	26.0	3547	31.4	7380	28.4
Intellectual disability only	10856	73.7	7719	68.3	18575	71.4
Not reviewed	38	0.3	30	0.3	68	0.3
Total	14727	100.0	11296	100.0	26023	100

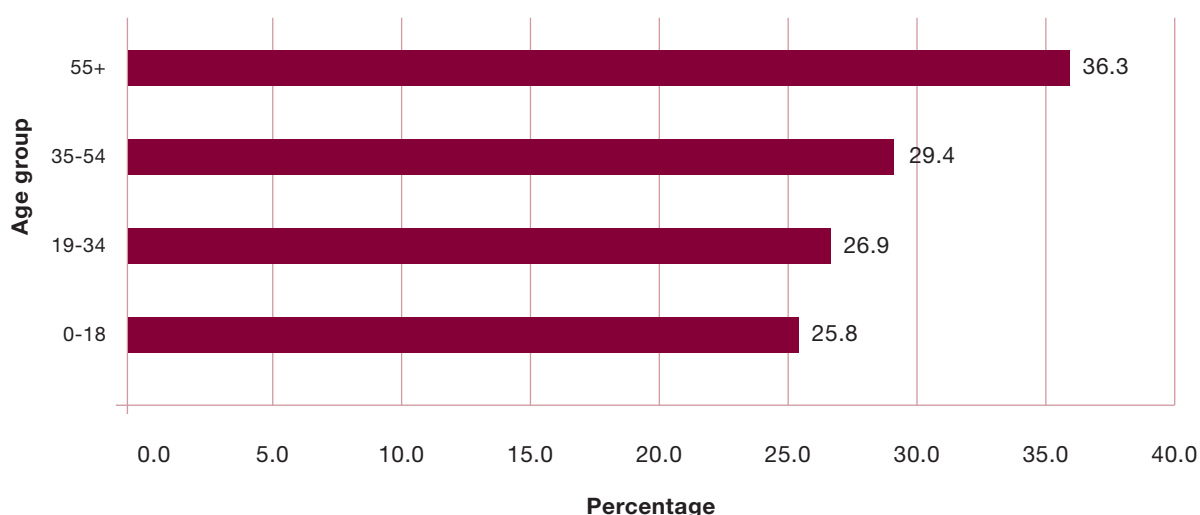


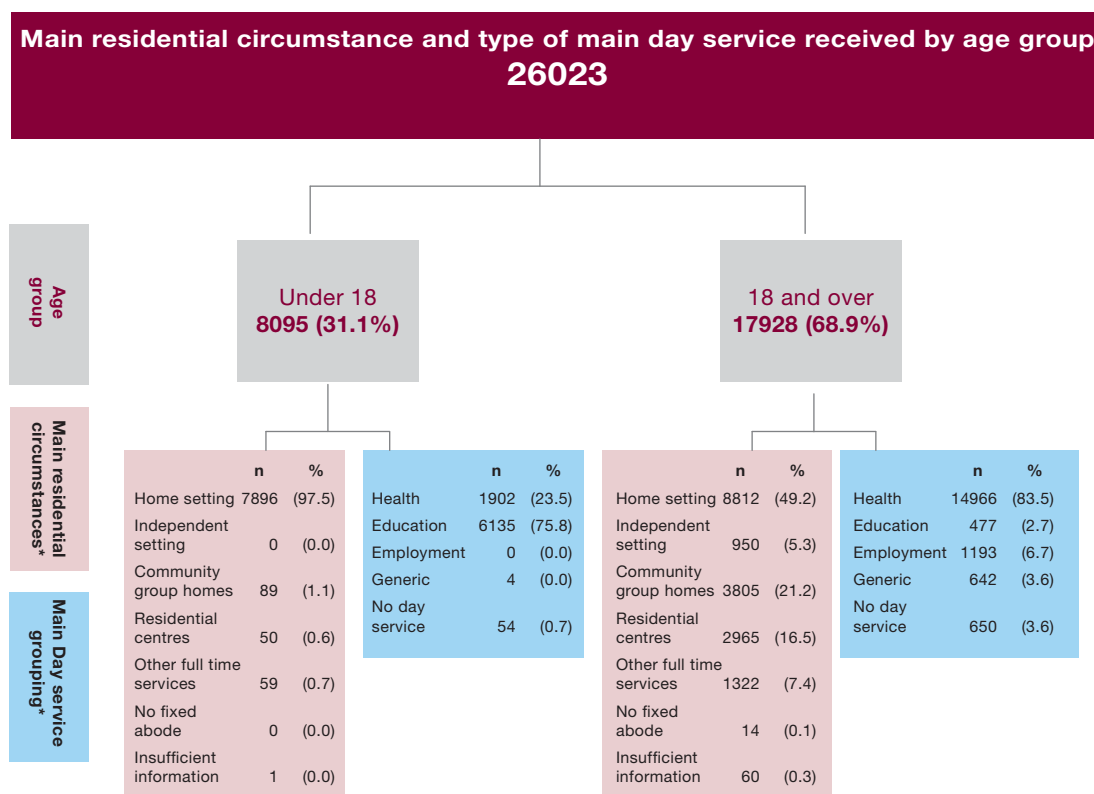
Figure 2.5 Proportion of people presenting with multiple disabilities, by age group, 2008

3. Service provision in 2008

National level

Summary of service provision

Figure 3.1 displays summary data for main day and residential services provided to adults (aged 18 years and over) and children (aged under 18 years) registered on the NIDD in 2008. Day services were availed of by 97.3% of all those registered on the NIDD in 2008. The majority of services accessed by adults were health related and the majority accessed by children were educational. Figure 3.1 also shows that a larger proportion (3.6%) of adults were without day services compared to their younger counterparts (0.7%). The residential circumstances for both age groups also differed in 2008; 97.5% (7,896) of those aged under 18 years lived at home, compared to 49.2% (8,812) of those aged 18 years and over. Almost 50% of adults lived in full-time residential services, including community group homes and residential centres.



* The NIDD permits the recording of two different types of residential service and three different types of day service for each person on the Database. The data above represents each persons main day and main residential service only. The overall service provision are detailed in Tables 3.3 and 3.7.

Figure 3.1 Summary of service provision, by age group, 2008

In 2008, 25,433 people with intellectual disability were receiving services, which accounted for 97.7% of the total population registered on the NIDD. This was the highest number of people recorded as being in receipt of services since the Database was established in 1995. A further 590 (2.3%) people were not in receipt of services, of whom 289 (1.1%) had expressed a need for services in the period 2009–2013. The overall level of service provision in 2008 is provided in Table 3.1 (a comprehensive list of the types of service availed of are outlined in Appendix B).

Table 3.1 Overall service provision in 2008

	n	%
Attending services on a day basis	17120	65.8
Receiving 5- or 7-day residential services	7982	30.7
Resident in a psychiatric hospital	308	1.2
Receiving residential support services only	23	0.1
Receiving no service – on waiting list	289	1.1
No identified service requirements	301	1.2
Total	26023	100.0

Note:

5,310 day attendees and 490 full-time residents receive residential support services in addition to their principal service; 8,199 full-time residents receive a day service in addition to their full-time residential service.

Residential circumstances

Table 3.2 provides an overview of the main residential circumstances of those registered on the NIDD in 2008 by degree of intellectual disability and age group (a further breakdown is presented in Table 3.3 below).

The main groupings of individuals consisted of

- 16,708 individuals (64.2%) who lived at home with parents, relatives, or foster parents. This figure does not take account of those in the mild intellectual disability category who may be living at home/independently without supports or services and are under-represented on the NIDD.
- 8,290 individuals (31.9%) who lived in full-time residential services, mainly in community group homes, residential centres, psychiatric hospitals, and intensive placements. This represented an increase of 28 on the 2007 figure and was the largest number of full-time residents recorded on the Database since 2001.
- 950 individuals (3.7%) who lived independently or semi-independently.



The most commonly availed of residential settings were community group homes. The year 2008 was the fourth consecutive year of data that indicated that more full-time residents lived in homes in the community (3,894) than in residential centres (3,015). The numbers of people accommodated in community group homes had increased and in residential centres had decreased on an almost continuous basis, since data collection commenced in 1995. This trend reflects a shift towards community living in the provision of residential services to people with an intellectual disability.

In 2008, 367 people with an intellectual disability resided full time in mental health services, either in psychiatric hospitals (308 individuals, compared with 329 individuals in 2007) or in mental health community residences (59 individuals) (Table 3.3).

Age difference

There were notable differences in the age profiles of those in the various categories of accommodation (Table 3.2). The proportion of people who lived in a home setting in 2008 decreased with age – 96.8% of individuals aged 0–19 years lived in a home setting, declining to 71.1% of those aged 20–34 years, 38.1% of those aged 35–54 years, and 16.2% of those aged 55 years or over.

By contrast, the proportion of people in the different age categories who lived in full-time residential services increased with age; in 2008 3.1% of all 0–19-year-olds received full-time residential services, compared with 25.6% of 20–34-year-olds, 54.4% of 35–54-year-olds, and 75.7% of those aged 55 years or over.

The data indicate that more than one in four people with a moderate, severe, or profound intellectual disability aged 35 years or over lived with their families in 2008. As the carers of adults with intellectual disability begin to age beyond their care-giving 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. Of the 950 individuals who lived in an independent or semi-independent setting in 2008, 79.7% were aged 35 years or over and three-quarters had a mild intellectual disability.

Degree of intellectual disability

There were also noticeable variations between level of ability and type of residential situation (Table 3.2). Of those with a mild intellectual disability, 75.6% lived in a home setting, compared to 53.6% of those with a moderate, severe, or profound intellectual disability. The proportion of people in full-time residential services increased within the more severe categories of disability. Only 15.9% of people with a mild intellectual disability lived in full-time residential services but this increased to 44.8% in the case of those with a moderate, severe or profound disability.

Where individuals were in full-time residential services in 2008, the type of service varied according to level of intellectual disability. Full-time residents with a mild intellectual disability were in the past more likely to be accommodated in community group homes, while full-time residents with a moderate, severe or profound intellectual disability were more likely to be accommodated in residential centres. However, since 2007 the number of full time residents with a moderate, severe or profound intellectual disability living in community group homes surpassed the number living in residential centres.

- Of those in full-time residential services in 2008 who had a moderate, severe or profound intellectual disability, 43.4% were in community group homes, 40.4% were in residential centres, and 16.2% were in other full-time residential services such as nursing homes or intensive placements.
- Of those in the mild range of intellectual disability who were in full-time residential services, 65.7% were in community group homes, 16.8% were in residential centres, and 17.5% were in other full-time residential services in 2008.



Table 3.2 Main residential circumstances, by degree of intellectual disability and by age group, 2008

	Not verified					Mild					Moderate, severe or 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	1839	93	77	26	2035	3431	1727	1133	191	6482	3584	2672	1663	272	8191	8854	4492	2873	489	16708
Independent setting	1	8	31	14	54	4	149	417	151	721	0	31	84	60	175	5	188	532	225	950
Community group home	4	7	6	4	21	39	172	421	265	897	93	606	1650	627	2976	136	785	2077	896	3894
Residential centre	0	0	3	11	14	3	27	88	112	230	72	460	1346	893	2771	75	487	1437	1016	3015
Other full-time services ⁹	10	1	8	14	33	9	45	99	86	239	55	299	477	278	1109	74	345	584	378	1381
No fixed abode	0	0	0	0	0	0	3	5	1	9	0	1	2	2	5	0	4	7	3	14
Insufficient information	0	0	0	0	0	0	1	0	0	1	2	12	28	18	60	2	13	28	18	61
Total	1854	109	125	69	2157	3486	2124	2163	806	8579	3806	4081	5250	2150	15287	9146	6314	7538	3025	26023

9. Other full-time services include psychiatric hospitals, intensive placements, nursing homes, mental health community residences and full-time residential support places.

Table 3.3 outlines the main residential circumstances (a more detailed breakdown of main residential circumstance is presented in Table B1 in Appendix C) and overall level of residential service provision of those registered on the NIDD in 2008. The NIDD permits the recording of two different types of residential service. The overall level of residential service provision in Table 3.3 is a combination of the main and secondary residential services, while the main residential circumstance is the place in which the individual resides most of the time. Of particular note is the number of residential support services available in addition to a person's principal residential service; these include holiday residential placements, crisis or planned respite care, occasional respite with a host family, overnight respite in the home and regular part-time care.

Between 1996 and 2008 there has been significant growth in the number of residential support places available. In particular, the data show a significant increase of 428.0% (3,728) in the number of individuals who availed of centre-based respite services, either as a planned or emergency intervention, bringing the total number of respite services availed of in 2008 to 4,599 (Table 3.3).

Table 3.3 Main residential circumstance and overall level of residential service provision, 2008

	Main residential circumstances			Overall level of residential provision/circumstance		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home setting	7896	8812	16708	7903	8819	16722
At home with both parents	6117	5215	11332	6117	5215	11332
At home with one parent	1528	2417	3945	1528	2417	3945
At home with sibling	6	884	890	6	884	890
At home with other relative	51	154	205	51	154	205
Lives with non-relative	3	25	28	3	25	28
Adoption	13	17	30	13	17	30
Foster care and boarding out arrangements	178	100	278	185	107	292
Independent setting	0	950	950	0	955	955
Lives independently	0	626	626	0	628	628
Living semi-independently	0	324	324	0	327	327
Community group homes	89	3805	3894	89	3805	3894
5-day community group home	38	433	471	38	433	471
7-day (48-week) community group home	13	573	586	13	573	586
7-day (52-week) community group home	38	2799	2837	38	2799	2837
Residential setting	50	2965	3015	50	2965	3015
5-day residential centre	7	78	85	7	78	85
7-day (48-week) residential centre	15	387	402	15	387	402
7-day (52-week) residential centre	28	2500	2528	28	2500	2528
Other full time residential services	59	1322	1381	59	1322	1381
Nursing home	0	153	153	0	153	153
Mental health community residence	0	59	59	0	59	59
Psychiatric hospital	0	308	308	0	308	308
Intensive placement (challenging behaviour)	15	470	485	15	470	485
Intensive placement (profound or multiple handicap)	21	239	260	21	239	260
Occupying a full time support place	8	36	44	8	36	44
Other full time residential service	15	57	72	15	57	72
Residential support service	0	0	0	1379	3878	5257
Holiday residential placement	0	0	0	6	220	226
Crisis or planned respite	0	0	0	1247	3352	4599
Occasional respite with host family	0	0	0	90	147	237
Overnight respite in the home	0	0	0	8	4	12
Shared care or guardianship	0	0	0	1	9	10
Regular part-time care (2/3 days per week)	0	0	0	18	77	95
Regular part-time care (every weekend)	0	0	0	4	11	15
Regular part-time care (alternate weeks)	0	0	0	5	58	63
Other residential service	0	0	0	5	25	30
No fixed abode	0	14	14	0	0	0
Insufficient information	1	60	61	0	0	0
	8095	17928	26023	9485	21769	31254¹⁰

10. The total number exceeds the actual number of people with an intellectual disability as a number of people availed of two different types of residential service.

Respite services

As illustrated in Table 3.3, the majority of residential support services are service-based respite breaks. The NIDD allows for the recording of each person's need for respite services. Respite services are further categorised on the NIDD according to the number of planned or crisis respite nights availed of over a twelve-month period.

The number of people who received planned respite breaks increased by 20.5% over the period 2004 to 2008 (Table 3.4). The total number of planned respite nights availed of increased by 40.8% over the same period, while the average number of planned respite nights received (for those in receipt of respite) increased from 25.8 nights in 2004 to 30.1 nights in 2008.

The number of people who received crisis respite breaks decreased by 15.0% over the five- year period 2004–2008 (Table 3.4). The total number of crisis respite nights received decreased by 26.8% over the same period, while the average number of crisis respite nights received (for those in receipt of respite) decreased from 21.1 nights in 2004 to 18.2 nights in 2008.

Table 3.4 Crisis or planned respite nights availed of in the period 2004–2008¹¹

	2004	2005	2006	2007	2008
Planned respite nights					
Total number of people	3774	3849	4107	4248	4549
Total number of nights	97236	108070	114103	123443	136928
Average nights per person	25.8	28.1	27.8	29.1	30.1
Crisis respite nights					
Total number of people	254	240	241	215	216
Total number of nights	5362	4598	5483	4300	3923
Average nights per person	21.1	19.2	22.8	20.0	18.2

Degree of intellectual disability

Figure 3.2 highlights a clear relationship between level of disability and average number of nights availed of (for those in receipt of respite). As would be expected, people with moderate, severe or profound levels of intellectual disability required on average more respite nights than those with a mild level of intellectual disability.

11. Individuals who had 'unknown' recorded as the number of planned or crisis respite nights have been excluded from Table 3.4. An individual may have received both planned and crisis respite nights in a given year.

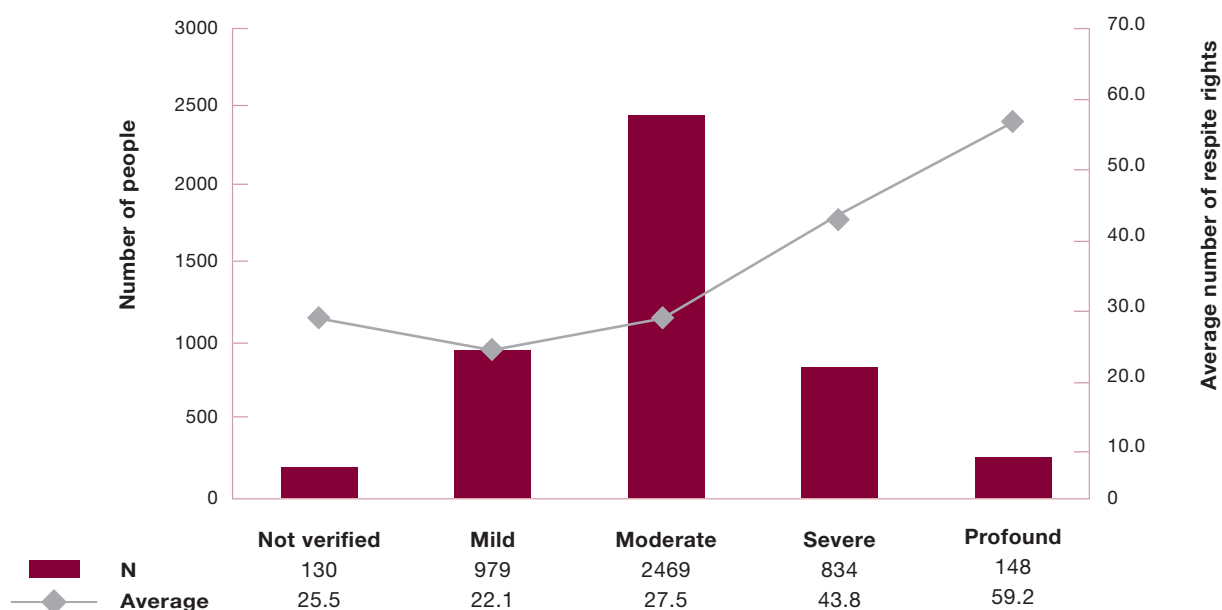


Figure 3.2 Number of people in receipt of respite nights (planned and/or crisis) and average number of respite nights received, by level of intellectual disability, 2008¹²

Geographical variation in respite provision

Figure 3.3 displays the total number of respite nights received for those who were in receipt of respite in 2008 and who were living within each of the four regions of the Health Service Executive (HSE). Table 3.5 presents data on respite for each of the HSE local health office (LHO) areas. Both the figure and the table show that there were marked differences in the total number of respite nights received in 2008. The total number of respite nights received ranged from 24,461 nights in the HSE South to 47,251 nights in the HSE West. The average number of respite nights received varied from 23.5 in the South to 37.4 in the West. The average number of respite nights received is even more marked when examined by LHO area; the figure varies from 11.6 in Laois/Offaly to 54.1 in Galway.

12. The total number of individuals recorded as receiving planned or crisis respite in Figure 3.2 (4,560 individuals) is less than that recorded in Table 3.3 (4,599 individuals) as 39 individuals had 'unknown' recorded as the number of respite nights and thus have been excluded from Figure 3.2.

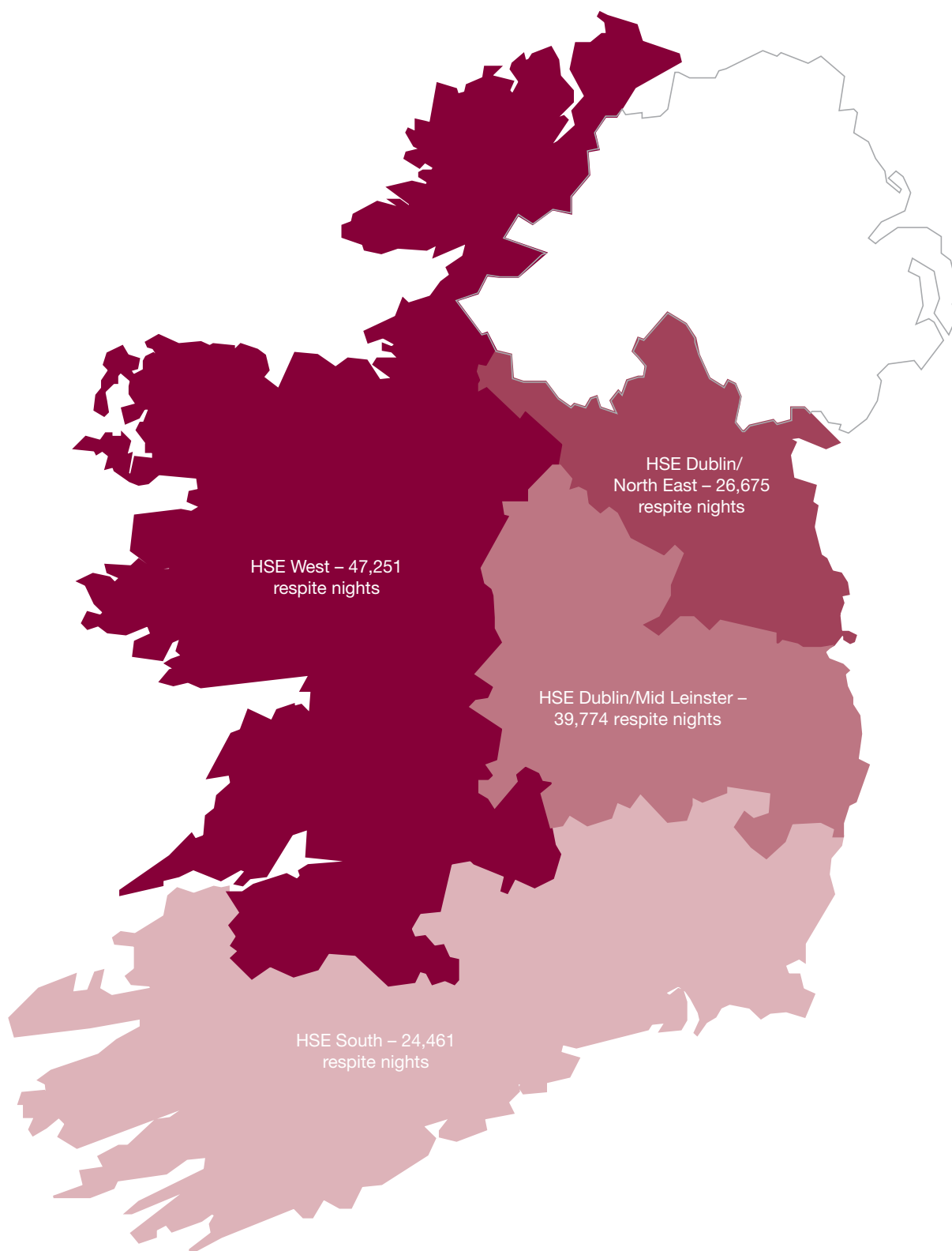


Figure 3.3 Total number of respite nights (planned and/or crisis) received by those in receipt of respite care by HSE region of residence, 2008



Table 3.5 Use of respite nights, by HSE region and by LHO area of residence, 2008¹³

	Total number of respite nights received	Average number of respite nights received	Number of people in receipt of respite nights
HSE Dublin/Mid Leinster	39774	29.4	1355
East Coast Area 1	4089	29.2	140
East Coast Area 2	1544	28.1	55
South-Western Area 3	2681	28.2	95
South-Western Area 4	6626	28.9	229
South-Western Area 5	6449	42.2	153
South-Western Area 9	6449	28.2	229
East Coast Area 10	4903	48.1	102
Midland Area Laois-Offaly	1992	11.6	171
Midland Area Longford-Westmeath	5041	27.9	181
HSE South	24461	23.5	1043
South-Eastern Area Carlow-Kilkenny	2516	27.3	92
South-Eastern Area Tipperary SR	1937	16.8	115
South-Eastern Area Waterford	1557	14.7	106
South-Eastern Area Wexford	2589	17.5	148
Southern Area Cork North Lee	3248	25.0	130
Southern Area Cork South Lee	3540	28.5	124
Southern Area North Cork	2944	29.7	99
Southern Area West Cork	2018	36.0	56
Southern Area Kerry	4112	23.8	173
HSE West	47251	37.4	1265
Mid-Western Area Limerick	5135	31.3	164
Mid-Western Area Tipperary NR	4557	46.5	98
Mid-Western Area Clare	2659	20.8	128
Western Area Galway	16120	54.1	298
Western Area Mayo	7835	40.8	192
Western Area Roscommon	1801	34.0	53
North-Western Area Donegal	5798	27.3	212
North-Western Area Sligo-Leitrim	3346	27.9	120
HSE Dublin/North East	26675	29.7	897
Northern Area 6	4923	29.5	167
Northern Area 7	2258	20.5	110
Northern Area 8	7371	25.2	293
North-Eastern Area Cavan-Monaghan	2362	26.2	90
North-Eastern Area Louth	5302	51.5	103
North-Eastern Area Meath	4459	33.3	134
All regions	138161	30.3	4560

13. The total number of individuals recorded as receiving planned or crisis respite in Table 3.5 (4,560 individuals) is less than that recorded in Table 3.3 (4,599 individuals) as 39 individuals had 'unknown' recorded as the number of respite nights and thus have been excluded from Table 3.5.

Day services

In 2008, 25,319 people, representing 97.3% of all those registered on the NIDD, received day services (Table 3.6). This is the highest number of NIDD registrations since the Database was established.

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 also by people who are receiving full-time residential services.

Of the 25,319 individuals who availed of day services in 2008, 8,199 (32.4%) were in full-time residential services, the majority of whom were in the moderate, severe, or profound range of intellectual disability (82.8%) and aged 18 years or over (97.6%). The remaining 17,120 (67.6%) attended services on a day basis, of whom 40.7% were in the mild range of intellectual disability and 45.8% were aged under 18 years (Table 3.6).

The 2008 data indicated that 91 full-time residents had no formal day programme. The day service needs of this group, where identified, are documented in Chapter 4 of this report.

Table 3.6 Residential status of people availing of day services, by degree of intellectual disability and by age group, 2008

	Not verified			Mild			Moderate, severe or profound			Total		
	Under 18	18 and over	Total	Under 18	18 and over	Total	Under 18	18 and over	Total	Under 18	18 and over	Total
Residents	14	53	67	37	1308	1345	146	6641	6787	197	8002	8199
Day attendees	1794	252	2046	2954	4018	6972	3096	5006	8102	7844	9276	17120
Total	1808	305	2113	2991	5326	8317	3242	11647	14889	8041	17278	25319

Main day services by age group and degree of intellectual disability

As in 2007, the top three day activities availed of by people with an intellectual disability in 2008, and accounting for more than half of principal day service provision, were: activation programmes, special schools, and sheltered work (Table 3.7).

Age difference

Of the 25,319 individuals who availed of day services in 2008, 8,041 (31.8%) were under 18 years, and 17,278 (68.2%) were aged 18 years or over (Table 3.7).

The principal day services accessed by the majority of those aged under 18 years were mainstream or special education services at primary and secondary level, early intervention services, mainstream or specialised pre-school services and child education and development services.

Of the 17,278 adults who availed of at least one day service in 2008, most attended either activation centres (31.3%) or sheltered work centres (23.4%) as their principal day service. Smaller proportions availed of rehabilitative training (9.5%), multidisciplinary support services only (9.0%), and supported employment (5.7%).

Degree of intellectual disability

Of those who received day services in 2008 (25,319 individuals), 8,317 (32.8%) had a mild intellectual disability, 14,889 (58.8%) had a moderate, severe, or profound intellectual disability and 2,113 (8.3%) had not yet had their degree of intellectual disability established (Table 3.7).

The age profiles of these groups are quite different. Just over one in five (3,242, 21.8%) of the population with moderate, severe or profound intellectual disability who availed of day services in 2008 were aged under 18 years, whereas more than one in three (2,991, 36.0%) of the population with mild intellectual disability who availed of day services were aged under 18 years.

Of the 8,041 under-18s who availed of day services in 2008:

- 2,991 (37.2%) had a mild degree of intellectual disability; most of this group availed of special education services as their principal day service, with smaller numbers in mainstream schools and pre-school services.
- 3,242 (40.3%) had a moderate, severe or profound intellectual disability and, while most were receiving special education services as their principal day service, smaller numbers were in mainstream education or pre-school services and some also availed of more intensive services such as child education and development centres.
- 1,808 (22.5%) had not had their degree of intellectual disability verified.

Of the 17,278 adults in receipt of day services in 2008:

- 5,326 (30.8%) had a mild degree of intellectual disability, most of whom attended sheltered work centres, were in receipt of activation programmes, availed of rehabilitative training, or were in supported employment.
- 11,647 (67.4%) were in the moderate, severe or profound range and were most likely to be in receipt of activation programmes, followed by sheltered work and rehabilitative training.
- 305 (1.8%) had not had their degree of intellectual disability established.

Table 3.7 Principal day service availed of, by degree of intellectual disability and by age group, 2008

	Not verified			Mild			Moderate, severe or profound			All levels		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home support	70	19	89	6	62	68	15	84	99	91	165	256
Home help	4	1	5	1	7	8	3	7	10	8	15	23
Early intervention team	506	0	506	43	0	43	28	0	28	577	0	577
Special pre-school for intellectual disability	357	0	357	63	0	63	133	0	133	553	0	553
Child education and development centre	3	0	3	1	1	2	151	8	159	155	9	164
Mainstream education ¹⁴	334	1	335	848	48	896	484	22	506	1666	71	1737
Resource/visiting teacher	74	0	74	82	16	98	44	7	51	200	23	223
Special class – primary level	70	0	70	176	1	177	188	8	196	434	9	443
Special class – secondary level	3	0	3	65	24	89	63	22	85	131	46	177
Special school	285	0	285	1642	165	1807	2059	164	2223	3986	329	4315
Rehabilitative training	0	54	54	13	764	777	1	824	825	14	1642	1656
Activation centre	0	28	28	0	816	816	2	4570	4572	2	5414	5416
Programme for the older person	0	12	12	0	104	104	0	493	493	0	609	609
Special high-support day service	0	1	1	0	49	49	5	554	559	5	604	609
Special intensive day service	0	0	0	6	43	49	20	312	332	26	355	381
Sheltered work centre	0	36	36	0	1596	1596	0	2417	2417	0	4049	4049
Sheltered employment centre	0	12	12	0	56	56	0	21	21	0	89	89
Multidisciplinary support services	43	44	87	24	356	380	18	1154	1172	85	1554	1639
Centre-based day respite service	2	1	3	0	11	11	2	8	10	4	20	24
Day respite in the home	6	0	6	1	1	2	0	2	2	7	3	10
Other day service	50	0	50	18	166	184	25	271	296	93	437	530
Enclave within open employment	0	1	1	0	3	3	0	10	10	0	14	14
Supported employment	0	37	37	0	573	573	0	383	383	0	993	993
Open employment	0	4	4	0	143	143	0	39	39	0	186	186
Vocational training	1	9	10	2	189	191	1	73	74	4	271	275
Generic day services	0	45	45	0	132	132	0	194	194	0	371	371
Total	1808	305	2113	2991	5326	8317	3242	11647	14889	8041	17278	25319

14. This includes mainstream pre-schools, primary schools and secondary schools. A small proportion of this group (71 individuals), were aged 18 or 19 years in 2008 but were still attending secondary schools.

Table 3.8 outlines the main day service and overall level of day service provision for those registered on the NIDD in 2008. The NIDD permits the recording of three different types of day service. The overall level of day service provision shown in Table 3.8 is a combination of the main, secondary and tertiary day programmes. Of note is the number of support services available to people with an intellectual disability in addition to their principal day service; these include services such as home support services, early intervention services, educational support services, centre-based and home-based day respite services, home help services, and multidisciplinary support services.

Between 1996 and 2008 there was significant growth in overall day service provision. In particular, the data show:

- An increase of 466.6% (1,535 people) in the number in supported employment. The 2008 data indicate that 1,864 people were in supported employment placements.
- Increases in both high-support and intensive day places. The number of high-support day places increased by 57.0% (228 people) and the number of intensive day places increased by 238.8% (277 people). The data indicate that 628 and 393 people attended high-support and intensive day services respectively in 2008.
- An increase of 140.1% (388 people) in the number in receipt of day programmes specific to the older person. The number of people who attended such services in 2008 was 665.
- An increase of 30.3% (1,312 people) in the number who attended activation centres, bringing the total number to 5,638 in 2008.
- An increase of 160.2% (213 people) in the number who were in open employment. Much of this increase occurred in recent years, with the number of open employment places increasing from 164 in 2004 to 401 in 2005. There was a slight downturn to 388 places in 2006, and the 2008 figure was less again at 346.

Increases were also observed over the thirteen-year period in the number of individuals who availed of mainstream schools, resource teachers, and vocational training. Although the numbers who availed of mainstream services were proportionately low, the growth was in a positive direction and continue for consistent and sustained support in line with best international practice.

Table 3.8 Principal day service and overall level of day service provision by age group, 2008

	Principal day service			Overall level of day service provision		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home support	91	165	256	1168	825	1993
Home help	8	15	23	93	58	151
Early intervention team	577	0	577	1786	0	1786
Special pre-school for intellectual disability	553	0	553	572	0	572
Child education and development centre	155	9	164	164	9	173
Mainstream education ¹⁵	1666	71	1737	1769	72	1841
Resource/visiting teacher	200	23	223	728	60	788
Special class - primary level	434	9	443	437	9	446
Special class - secondary level	131	46	177	132	46	178
Special school	3986	329	4315	3996	332	4328
Rehabilitative training	14	1642	1656	14	1696	1710
Activation centre	2	5414	5416	6	5632	5638
Programme for the older person	0	609	609	0	665	665
Special high-support day service	5	604	609	12	616	628
Special intensive day service	26	355	381	28	365	393
Sheltered work centre	0	4049	4049	0	4271	4271
Sheltered employment centre	0	89	89	0	93	93
Multidisciplinary support services	85	1554	1639	5227	13958	19185
Centre-based day respite service	4	20	24	352	382	734
Day respite in the home	7	3	10	42	10	52
Other day service	93	437	530	513	661	1174
Enclave within open employment	0	14	14	0	17	17
Supported employment	0	993	993	1	1863	1864
Open employment	0	186	186	0	346	346
Vocational training	4	271	275	4	319	323
Generic day services	0	371	371	7	412	419
Total	8041	17278	25319	17051	32717	49768¹⁶

Multidisciplinary support services

In the case of multidisciplinary support services (which include services delivered by early intervention teams), the large difference between the principal day service provision and the overall day service provision (Table 3.8) arises because multidisciplinary support and early intervention services are only recorded as a principal day service if they are the sole day service that an individual receives. The majority of people who are in receipt of such services also receive another service as their principal day service.

15. This includes mainstream pre-schools, primary schools and secondary schools. A small proportion of this group (71 individuals), were aged 18 or 19 years in 2008 but were still attending secondary schools.

16. The total number exceeds the actual number of people with an intellectual disability as a number of people availed of two or more day services.

Table 3.9 details the overall provision of specific therapeutic inputs. Specific inputs are only recorded if the individual has received, or will receive, at least four inputs of that service in a twelve-month period.

- Overall, in 2008, 20,971 individuals received one or more multidisciplinary support services (including those provided by early intervention teams). This was an increase of 1,172 people since 2007. As in 2007, the most commonly availed of multidisciplinary support services were social work (10,143 individuals), medical services (8,966 individuals), psychology (8,232 individuals), and speech and language therapy (7,839 individuals).
- The services most commonly availed of by adults were social work (6,550 adults), medical services (6,322 adults) and psychiatry (6,096 adults).
- The services most commonly availed of by children were speech and language therapy (1,755 children aged six years or under and 3,689 children aged 7–17 years), social work (1,295 children aged six years or under and 2,298 children aged 7–17 years), and occupational therapy (1,417 children aged six years or under and 2,083 children aged 7–17 years).
- Early intervention teams usually provide services to children aged six years or under and 1,738 children (80.5%) in this age group received multidisciplinary support services from an early intervention team in 2008. There were also 48 children aged seven years or over who received services from an early intervention team in 2008.

Table 3.9 Overall provision of multidisciplinary support services by age and access to early intervention teams (EIT), 2008

	Aged 6 or under			Aged 7–17			Aged 18 or over	Total
	Provided by an EIT	Not provided by an EIT	Total	Provided by an EIT	Not provided by an EIT	Total		
Medical services	996	140	1136	13	1495	1508	6322	8966
Nursing	856	135	991	18	1101	1119	5168	7278
Nutrition	307	54	361	3	457	460	2343	3164
Occupational therapy	1130	287	1417	34	2049	2083	2595	6095
Physiotherapy	1146	247	1393	23	1513	1536	2837	5766
Psychiatry	62	23	85	0	458	458	6096	6639
Psychology	976	253	1229	31	2232	2263	4740	8232
Social work	1123	172	1295	25	2273	2298	6550	10143
Speech and language therapy	1388	367	1755	41	3648	3689	2395	7839
Other	536	65	601	23	1276	1299	3936	5836
Number of people	1738	421	2159	48	4806	4854	13958	20971

Note

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

Regional level

Table 3.10 provides summary details of the level of service provision in 2008 within the four HSE regions.

Nationally, 25,433 individuals (97.7%) with an intellectual disability registered on the NIDD were in receipt of services in 2008. The HSE South and HSE Dublin/North East regions had the highest levels of service provision, with 98.0% of the population registered on the Database in both regions receiving services. The HSE West Region had the lowest level of service provision, where 97.1% of the population registered on the Database were in receipt of services.

Nationally, 8,290 individuals (31.9%) registered on the NIDD in 2008 were in receipt of a full-time residential service. Regionally this proportion varied from 29.4% in the HSE South to 33.3% in the HSE Dublin/North-East.

At national level, 17,120 (65.8%) attended services on a day basis and this proportion ranged from 64.4% in the HSE West Region to 68.4% in the HSE South Region.

Nationally, a small proportion (289, 1.1%) of registrations were without services but were identified as requiring services in the five-year period 2009–2013. The HSE West region had the highest proportion of people without any service and awaiting services within the next five years (1.9%).

It is encouraging to note that the number of people described as having no identified service requirements in 2008 had fallen by over one third, from 410 in 2007 to 301 in 2008, which represented just 1.2% of the total registrations. This highlights the impact of the multi-annual funding that has been available for disability as well as the commitment to meet the needs of those registered on the Database.

Table 3.10 Service provision by HSE region of registration, 2008

	Attending services on a day basis	Receiving 5- or 7-day residential services	Resident in a psychiatric hospital	Receiving residential support services only	Receiving no service	No service requirements in 2008	Total
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	N
Dublin/Mid-Leinster	4430 (65.1)	2208 (32.5)	14 (0.2)	10 (0.1)	59 (0.9)	82 (1.2)	6803
South	5060 (68.4)	2081 (28.1)	99 (1.3)	4 (0.1)	73 (1.0)	76 (1.0)	7393
West	4386 (64.4)	2184 (32.0)	36 (0.5)	8 (0.1)	127 (1.9)	74 (1.1)	6815
Dublin/North-East	3240 (64.7)	1506 (30.1)	159 (3.2)	1 (0.0)	29 (0.6)	69 (1.4)	5004
Out of state	4 (50.0)	3 (37.5)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)	8
All areas	17120 (65.8)	7982 (30.7)	308 (1.2)	23 (0.1)	289 (1.1)	301 (1.2)	26023

4. Assessment of need 2009–2013

The NIDD provides an assessment of the needs of people with an intellectual disability. Four distinct categories of need are identified, as follows:

A - Unmet need: applies to people who, in 2008, were without a major element of service such as day or residential, or who were without residential support services, or who were without any service and require these services in the period 2009–2013. It excludes those whose only requirement was for multidisciplinary support services as these are dealt with in category D below.

B - Service change: applies to those who already had an intellectual disability service in 2008 but will require that service to be changed or upgraded during the period 2009–2013, and includes children who will require access to health-funded services in the period. It excludes those whose only service change requirement was for multidisciplinary support services (see in category D below).

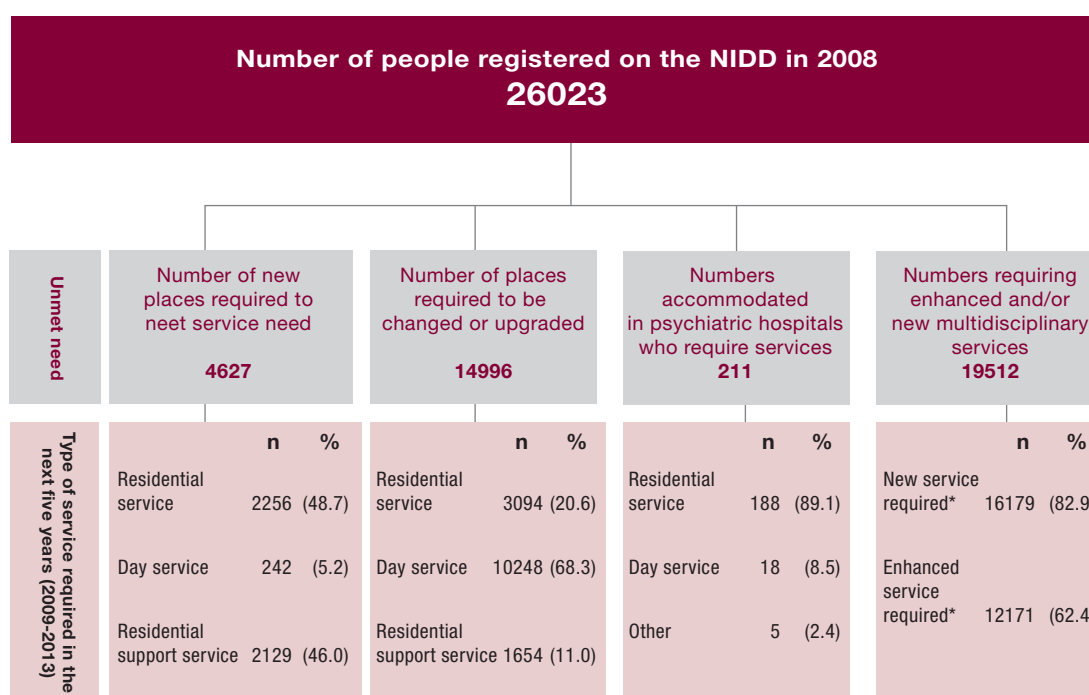
C - Persons with intellectual disability who were accommodated in psychiatric hospitals in 2008: includes people who need to transfer out of psychiatric hospitals in the period 2009 to 2013 and people who were resident in the psychiatric services in 2008 but require an appropriate day service in the period 2009–2013. For completeness, multidisciplinary support service requirements, where applicable, are noted in the tables.

D - Multidisciplinary support services: documents the multidisciplinary support services that will be required in the period 2009–2013 by all individuals registered on the NIDD in 2008. This section includes the multidisciplinary support service requirements of the unmet need and service change groups as well as those of people with an intellectual disability within the psychiatric services.

The NIDD facilitates the recording of two future residential services and two future day services for each individual. To avoid double-counting of individuals, only the first service identified is reported in the tables in this report relating to the unmet need, service change, and people with intellectual disability within the psychiatric services groups, but the level of additional need of these individuals is noted in the relevant sections of the text as well as in the multidisciplinary support services section.

Summary

Figure 4.1 indicates that 4,627 new residential, day and/or residential support places will be needed to meet service requirements in the period 2009–2013, with almost half required by residential services. Of the existing places available in 2008, 14,996 need to be changed or upgraded, with just over two thirds of the changes/upgrades required by day services. Figure 4.1 also shows that the 211 people accommodated in psychiatric hospitals in 2008 require specialist services; almost 90% of this group require residential services. In 2008 the number of people recorded as requiring new or enhanced multidisciplinary services increased to 19,512, which is the highest number since national data collection began.



* 'New service required' refers to a new type of therapeutic input that the individual does not currently receive. 'Enhanced service required' refers to a change in the delivery of a therapeutic input that the individual currently receives. There are 8,838 individuals whose multidisciplinary support service change involves both a new service and an enhanced service, therefore, the actual number of people requiring a new and/or enhanced service (16,179+12,171)-8,838=19,512.

Figure 4.1 Summary of the service requirements of those registered on the NIDD in 2008

A - Unmet need

Number of places required to meet need

The number of new residential, day and residential support places required to meet need is identified in Table 4.1 and is broken down by HSE region.

Table 4.1 Number of new places required to meet need 2009–2013, by HSE region of registration

	Residential	Day	Residential support	% of total NIDD registrations
Dublin/Mid-Leinster	593	58	461	26.1
South	576	54	733	28.4
West	533	111	596	26.2
Dublin/North-East	554	19	339	19.2
Total	2256	242	2129	100

The key figures and trends are summarised below.

- The number of new day places required has been falling steadily since 1996. The 2008 figure of 242 is the lowest since the Database was established. This figure does not, however, take account of the individuals who require a change or enhancement to their day service (see Figure 4.1); for example, those who are leaving education and require a training/employment service. This is considered in Section B below.
- Following a slight downward trend during the years 2000 to 2002, the number of new residential places required has increased by almost 40% (623 places) over the past six years. The 2008 figure of 2,256 is the highest since the Database was established. This figure reflects an increase of 75 places required since 2007. Seven out of ten of those requiring a new residential place (1,589 individuals, 70.4%) had a moderate, severe or profound intellectual disability in 2008. Chapter 2 notes that the numbers in this group are increasing due to a cohort of people born in the 1960s and mid-1970s currently moving through the services. Chapter 3 shows that full-time residential services are more likely to be availed of by older people with a moderate, severe or profound intellectual disability. This information would suggest that the number of new full-time residential places required is likely to continue to increase over the coming years as those with a moderate, severe or profound disability advance in age. Other related factors include family members being unable or unwilling to care for their family member full-time, or situations where the individual wishes to move out of the family home.

- The demand for residential supports has increased steadily since 1998. The 2008 figure of 2,129 represents a small increase of 41 (2.0%) since 2007. This high level of need is presenting even though there were over 5,000 people availing of residential support services in 2008.

Full-time residential services

Of the 2,256 people who required full-time residential services in 2008 (Table 4.2):

- 1,589 (70.4%) individuals had a moderate, severe, or profound level of intellectual disability, of whom 1,304 required placements in community group homes, 155 required placements in a campus setting, and 123 required specialised intensive placements because of their increased dependency.
- 614 (27.2%) individuals had a mild intellectual disability, of whom 536 required placements in community group homes, 53 required residential placements in a campus setting, and 21 required specialised intensive placements due to their increased dependency.
- 53 (2.3%) had not had their level of intellectual disability verified in 2008.

Of those who required full-time residential services, 2,250 (99.7%) lived at home (2,163 individuals) or independently/semi-independently (87 individuals) in 2008 and 2,232 (98.9%) were in receipt of a day service or a residential support service.

Day services

As in previous years, demand for day services among those reported as not being in receipt of such services is confined almost exclusively to adult services (Table 4.3). Of the 242 individuals who required day services, 218 (90.1%) lived either at home (203 individuals) or independently/semi-independently (15 individuals). The largest demand came from 212 people who had no service whatsoever in 2008. Of the 212 people who had no service:

- Over half (116 individuals, 54.7%) had a mild intellectual disability and their principal service requirements were in the training and employment fields.
- 83 individuals (39.2%) had a moderate, severe or profound intellectual disability and their principal service requirements were for activation programmes, sheltered work and rehabilitative training.



Residential support services

Residential support services, such as respite and regular part-time care, were required by 2,129 people (Table 4.4). Of this group, 1,854 individuals (87.1%) lived either at home (1,784 individuals) or independently/semi-independently (70 individuals) and 1,820 individuals (85.5%) were in receipt of a day service or had no day service (35 individuals, 1.6%) in 2008. An additional 274 individuals (12.9%) were full-time residents and needed a residential support service either to enhance, or as an alternative to, their existing services.

- People with moderate, severe, or profound intellectual disability accounted for more than half (1,118 individuals) of the demand for residential support services in 2008, while people with mild intellectual disability accounted for 41.7% (888 individuals). The remaining 123 individuals (5.8%) had not had their degree of intellectual disability verified in 2008.
- Most of the demand in 2008 was for crisis or planned respite services (1,290 individuals, 60.6%), semi-independent and independent living arrangements (411 individuals, 19.3%), and holiday residential placements (166 individuals, 7.8%).

Table 4.2 Future full-time residential service requirements of individuals receiving no residential service in 2008, by degree of intellectual disability

	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	3	4		0	0	1	1		2	115	187	304		2	116	191	309	
7-day (48-week) community group home	0	0	3	3		0	0	0	0		4	88	215	307		4	88	218	310	
7-day (52-week) community group home	1	4	3	8		0	1	1	2		15	327	891	1233		16	332	895	1243	
5-day residential centre	0	1	0	1		0	0	0	0		0	3	14	17		0	4	14	18	
7-day (48-week) residential centre	1	0	0	1		0	1	0	1		3	12	37	52		4	13	37	54	
7-day (52-week) residential centre	0	0	4	4		0	0	0	0		24	36	100	160		24	36	104	164	
Nursing home	0	0	0	0		0	0	0	0		1	3	6	10		1	3	6	10	
Mental health community residence	0	0	0	0		0	0	0	0		0	1	1	2		0	1	1	2	
Intensive placement (challenging behaviour)	0	0	1	1		0	0	0	0		0	19	53	72		0	19	54	73	
Intensive placement (profound or multiple disability)	0	0	2	2		0	0	1	1		2	2	66	70		2	2	69	73	
All services	2	6	16	24		0	2	3	5		51	606	1570	2227		53	614	1589	2256	

Note

NV refers to a level of intellectual disability that has not been verified and MSP refers to a moderate, severe or profound level of intellectual disability

Table 4.3 Future day service requirements of individuals receiving no day service in 2008, by degree of intellectual disability

	No service – requires day service				Receives residential support only – requires day service				Receives residential service only – requires day service				Overall need			
	NV	Mild	MSP	ALL	NV	Mild	MSP	ALL	NV	Mild	MSP	ALL	NV	Mild	MSP	ALL
Home support	1	1	5	7	0	0	0	0	0	0	0	0	1	1	5	7
Home help	1	0	1	2	0	0	0	0	0	0	0	0	1	0	1	2
Mainstream pre-school	3	3	1	7	0	0	0	0	0	0	0	0	3	3	1	7
Special pre-school	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Child education and development centre	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Mainstream school	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Resource/visiting teacher	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special class – primary	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special class – secondary	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special school	1	0	1	2	0	0	0	0	0	0	0	0	1	0	1	2
Rehabilitative training	1	26	13	40	0	0	0	0	0	1	0	1	1	27	13	41
Activation centre	1	8	20	29	0	0	3	3	1	1	9	11	2	9	32	43
Programme for the older person	1	2	4	7	0	0	0	0	0	1	1	2	1	3	5	9
Special high-support day service	0	0	2	2	0	0	0	0	0	1	1	2	0	1	3	4
Special intensive day service	0	0	2	2	0	0	0	0	0	2	0	2	0	2	2	4
Sheltered work centre	0	14	16	30	0	1	0	1	0	1	1	2	0	16	17	33
Sheltered employment centre	0	2	1	3	0	0	0	0	0	0	0	0	0	2	1	3
Centre-based day respite service	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Day respite in the home	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Other day service	0	1	1	2	0	0	0	0	0	0	0	0	0	1	1	2
Enclave within open employment	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Supported employment	1	22	5	28	0	2	0	2	0	3	0	3	1	27	5	33
Open employment	1	10	1	12	0	1	0	1	0	0	0	0	1	11	1	13
Vocational training	2	24	7	33	0	0	0	0	0	0	0	0	2	24	7	33
Generic day services	0	3	0	3	0	0	0	0	0	0	0	0	0	3	0	3
All services	13	116	83	212	0	4	3	7	1	10	12	23	14	130	98	242

Note

This table excludes people who are receiving no day service and whose only day requirements are multidisciplinary support services (including those delivered by an early intervention team). These people are reported in the multidisciplinary support services section later in this chapter.

Table 4.4 Future residential support service requirements of individuals receiving no residential support services in 2008, by degree of intellectual disability

	No service – requires residential support					Receives day service – requires residential support					Receives residential service – requires residential support					Receives residential and day services – requires residential support					Overall need				
	NV	Mild	MSP	All		NV	Mild	MSP	All		NV	Mild	MSP	All		NV	Mild	MSP	All		NV	Mild	MSP	All	
Foster care and boarding-out	0	0	0	0		0	0	0	2		0	0	0	0		0	0	0	0		0	0	0	2	
Living independently	1	4	0	5		3	52	7	62		0	1	0	1		0	8	1	9		4	65	8	77	
Living semi-independently	0	5	2	7		9	189	45	243		0	0	0	0		1	58	25	84		10	252	72	334	
Holiday residential placement	0	1	2	3		0	38	36	74		0	0	0	0		0	7	82	89		0	46	120	166	
Crisis or planned respite	2	9	5	16		93	432	725	1250		0	1	0	1		0	1	22	23		95	443	752	1290	
Occasional respite care with host family	0	1	0	1		7	34	50	91		0	0	0	0		0	0	2	2		7	35	52	94	
Overnight respite in the home	0	0	0	0		4	6	10	20		0	0	0	0		0	0	0	0		4	6	10	20	
Shared care or guardianship	0	0	0	0		0	4	4	8		0	0	0	0		1	0	2	3		1	4	6	11	
Regular part-time care (2/3 days per week)	0	0	0	0		0	3	13	16		0	0	0	0		0	0	0	0		0	3	13	16	
Regular part-time care (every weekend)	0	0	0	0		0	3	6	9		0	0	0	0		0	1	1	2		0	4	7	11	
Regular part-time care (alternate weeks)	0	0	0	0		0	3	6	9		0	0	0	0		0	0	1	1		0	3	7	10	
Other residential service	0	0	3	3		2	16	18	36		0	0	0	0		0	11	48	59		2	27	69	98	
All services	3	20	12	35		118	780	922	1820		0	2	0	2		2	86	184	272		123	888	1118	2129	

B – Service change

The term ‘service change’ applies to those who already had an intellectual disability service in 2008 but who require that service to be changed or upgraded during the period 2009–2013, and includes children who availed of educational services in 2008 and who will require access to health-funded services in the future. Changes in service provision relate to:

- upgrading of 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.

Not included in the ‘service change’ category in this report are people whose only service change requirement is for multidisciplinary support services (including those to be delivered by an early intervention team). Multidisciplinary support service requirements are detailed in the multidisciplinary support services section later in this chapter.

Categories of service change requirements

Table 4.5 indicates that 11,823 people who were receiving services in 2008 will require a change to their existing service provision in the period 2009–2013, a decrease of 105 (0.8%) since 2007. Of the 11,823 who were recorded as requiring a service change:

- 7,923 (67.0%) were day attendees (of whom 806 also availed of residential support services),
- 3,094 (26.2%) were full-time residents (of whom 2,325 also availed of day services),
- 806 (6.8%) received residential support services only.

A breakdown of the category of service change required by level of intellectual disability is also provided in Table 4.5.

- People in the moderate, severe and profound ranges of intellectual disability accounted for 7,556 (63.9%) of the service changes required,
- People in the mild range required 3,273 (27.7%) of the service changes,
- 994 (8.4%) of the service changes were required by people whose level of intellectual disability had not been verified in 2008.

Table 4.5 Category of service change required 2009–2013, by degree of intellectual disability

	Residential and day	Residential only	Day only	Day and residential support	Residential support only	Total requiring service changes
Not verified	15	17	930	11	21	994
Mild	214	97	2576	202	184	3273
Moderate, severe & profound	2096	655	3569	635	601	7556
All levels	2325	769	7075	848	806	11823

Number of places required to address service changes

The numbers of places involved in addressing the required service changes are summarised in Table 4.6. Day services are described under four headings: health, education, employment and generic. The programmes included under each heading are outlined in Appendix B.

Table 4.6 Number of places requiring change 2009–2013

Residential	3094
Day	10248
Of which:	
Health services	7102
Education services	1161
Employment services	1311
Generic services	674
Residential support	1654

The number of places requiring change exceeds the number of people who required service changes in 2008 because some people required changes in both their residential and day services. In addition, it is important to note that, although 11,823 people required service changes in 2008, this demand does not translate into 11,823 new places. In many 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 young adults leaving school. It is also important to note that this entire group got some level of service in 2008, so a certain level of funding is already committed to these individuals.

Summary of service change requirements

Details of the types of service change required by people who need alternative or enhanced full-time residential, day and residential support services are set out in Tables 4.7, 4.8 and 4.9.

Residential service change

Table 4.7 indicates that 3,094 individuals in full-time residential services in 2008 will require an upgrading or change of accommodation within the next five years. For over 60% of this group (1,900 individuals, 61.4%) a change of service type is required, as follows:

- Residential placements in the community are required by 1,062 individuals (34.3%).
- Intensive services for either challenging behaviour or profound or multiple disability are required by 652 individuals (21.1%).
- Centre-based placements are required by 140 individuals (4.5%).
- Nursing home placements are required by 46 individuals (1.5%).

The remaining 1,194 individuals (38.6%) require an enhancement in their existing service type, as follows:

- 367 individuals need their existing service upgraded to include care at weekends and holiday times.
- 17 individuals require less care and could return to their families at weekends and holiday times.
- 810 individuals need an enhancement of their existing service provision (shaded area of Table 4.7).

Table 4.7 Pattern of movement of individuals from existing residential services to future residential services 2009–2013

Full-time residential service required in the period 2009–2013										
	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/MD)	Total services 2008
Full-time residential service in 2008										
5-day community group home (CGH)	14	59	151	1	0	18	0	2	0	245
7-day (48-week) community group home	0	55	117	1	4	8	1	11	5	202
7-day (52-week) community group home	7	6	512	0	4	31	18	59	40	677
5-day residential centre (RC)	8	7	31	2	5	9	0	2	2	66
7-day (48-week) residential centre	1	64	90	0	27	26	5	15	14	242
7-day (52-week) residential centre	2	16	698	1	3	109	18	218	261	1326
Nursing home	1	1	31	0	0	5	4	1	3	46
Intensive placement (challenging behaviour) (CB)	1	1	52	1	4	53	2	46	10	170
Intensive placement (profound or multiple disability) (P/MD)	0	3	27	0	1	4	0	2	41	78
Occupying a residential support place	2	0	16	0	1	0	2	2	2	25
Other residential service	0	0	10	0	1	3	0	2	1	17
Total services required	36	212	1735	6	50	266	50	360	379	3094

The abbreviations in the sub-column headings refer to the placement descriptions which are given more fully in column one.

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

Day service change

Within the next five years, 10,248 individuals will require a change, enhancement, or upgrading of their day service (Table 4.8).

- Health-funded services are required by 7,102 individuals (69.3%).
- Employment services are required by 1,311 individuals (12.8%).
- Educational services are required by 1,161 individuals (11.3%).
- Generic services are required by 674 individuals (6.6%).

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

Health services

Of the 7,102 service changes required within health-funded services, 5,216 (73.4%) are requirements for an alternative or additional service and 1,886 (26.6%) are requirements for an enhancement of the person's existing service (Table 4.8). The majority of the demand for alternative or additional health-funded services arises as follows:

- 978 individuals require high-support or intensive placements, the majority of whom currently attend activation programmes (409 individuals), or receive multidisciplinary support services as their only day service (230 individuals).
- 865 individuals require activation programmes, the majority of whom currently receive multidisciplinary support services as their only day service (355 individuals), attend special schools (179 individuals), or attend sheltered work (131 individuals).
- 806 individuals require services specific to older people, the majority of whom currently attend activation programmes (368 individuals) or sheltered work (201 individuals).
- 563 individuals require rehabilitative training, the majority of whom currently attend special schools (368 individuals).

There are also 1,886 individuals who need to have their existing health-funded service enhanced (shaded area of Table 4.8). Most of these people are attending activation centres (974 individuals, 51.6%) or sheltered work (370 individuals, 19.6%). The main enhancements required are an increased level of support and an increased level of service provision from part-time to full-time.

Employment services

Of the 1,311 service changes required within employment services, 1,232 (94.0%) are requirements for an alternative placement and 79 (6.0%) are requirements for an enhancement of the person's existing placement (Table 4.8).

Most of the demand for alternative employment opportunities comes from 1,115 individuals who require supported employment, the majority of whom currently attend sheltered work (460 individuals) or rehabilitative training (243 individuals).

There are 79 individuals who require their existing employment placement to be enhanced (shaded area of Table 4.8).

Educational services

Of the 1,161 service changes required within educational services, 857 (73.8%) are requirements for an alternative service and 304 (26.2%) are requirements for an enhancement of the child's existing service (Table 4.8).

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

- 267 children who require special classes, particularly at secondary level. The majority of those requiring special classes at secondary level (172 children) currently attend special classes at primary level (102 children).
- 306 children who require a mainstream school placement, the majority of whom currently attend a mainstream (139 children) or specialised (92 children) pre-school.
- 223 children who require a special school placement, the majority of whom currently attend special pre-schools (122 children).

There are 304 children who require their existing educational placement to be enhanced (shaded area of Table 4.8), the majority of whom currently attend mainstream schools (132 children). There is also a significant demand for increased support within existing educational placements.

A large proportion of the 1,530 children who were attending special schools in 2008 require adult services in the period 2009–2013. Of this group, almost one quarter (368 individuals) require rehabilitative training, 335 (21.9%) require vocational training and 179 (11.7%) require activation programmes.



Generic services

Of the 674 service changes required within generic services, 644 (95.5%) are requirements for an alternative service and 30 (4.5%) are requirements for an enhancement of the person’s existing service (Table 4.8).

Most of the demand for alternative generic services comes from 607 individuals who require vocational training, the majority of whom currently attend special schools (335 individuals).

Five individuals attending vocational training and 25 individuals availing of generic day services require their existing generic service to be enhanced (shaded area of Table 4.8).

Table 4.8 Pattern of movement of individuals from existing day services to future day services 2009–2013

Day service required in the period 2009–2013																										
Day service in 2008	HS	HH	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	RHT	AC	POP	SHS	SI	SWC	SEC	CDR	DRH	OTH	E	SE	OE	VT	GD	All
Home support (HS)	25	0	11	16	0	7	1	2	2	3	6	7	3	0	1	6	0	1	2	3	0	7	0	3	1	107
Home help (HH)	0	0	1	4	0	0	1	0	1	0	1	1	0	0	0	0	0	1	1	0	0	0	0	0	0	11
Early services	22	0	185	92	1	18	1	18	0	11	0	0	0	0	0	0	0	0	0	4	0	0	0	0	0	352
Mainstream pre-school (MPS)	10	1	20	9	0	139	0	8	0	10	0	0	0	0	1	0	0	3	0	1	0	0	0	0	0	202
Special pre-school (SPS)	15	0	63	46	15	92	2	38	0	122	0	0	0	0	1	0	0	8	0	1	0	0	0	0	0	403
Child education and Development centre (CEDC)	19	0	0	0	6	0	0	0	0	7	0	31	0	1	1	0	0	0	0	5	0	0	0	0	0	70
Mainstream school (MS)	71	1	6	1	0	132	49	13	51	31	11	4	0	1	0	7	1	60	0	33	0	4	3	40	2	521
Resource teacher (RT)	5	0	10	0	0	12	16	0	9	0	6	1	0	0	0	0	0	0	0	0	0	0	0	21	0	80
Special class - primary (SCP)	30	0	0	0	0	20	3	36	102	20	4	5	0	1	1	1	0	6	1	2	0	0	0	1	0	233
Special class - secondary (SCS) (SCS)	6	0	0	0	0	0	1	0	11	1	13	3	0	1	1	4	0	1	0	1	0	8	1	31	0	83
Special school (SS)	151	4	6	1	6	11	1	4	4	109	368	179	0	29	47	138	23	39	6	45	1	19	4	335	0	1530
Rehabilitative training (RHT)	14	1	0	0	0	0	0	0	0	1	35	76	6	1	1	252	15	3	0	13	4	243	6	96	17	784
Activation centre (AC)	50	3	0	0	0	0	2	0	0	0	63	974	368	184	225	100	11	5	0	14	2	180	11	27	3	2222
Programme for the older person (POP)	6	0	0	0	0	0	0	0	0	0	0	11	192	7	42	4	1	0	0	1	0	2	0	0	2	268
Special high support day service (SHS)	1	1	0	0	0	0	0	0	0	0	7	21	13	126	102	10	0	2	0	4	0	6	0	0	0	293
Special intensive day service (SI)	3	1	0	0	0	0	0	1	3	8	1	12	1	13	69	3	0	0	0	2	0	8	1	0	0	126
Sheltered work centre (SWC)	22	3	0	0	0	0	0	0	0	0	27	131	201	27	20	370	23	3	0	21	8	460	31	9	5	1361
Sheltered employment centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	2	0	0	0	1	0	9	0	1	0	15

Table 4.8 Pattern of movement of individuals from existing day services to future day services 2009–2013 (continued)

Day service required in the period 2009–2013																										
Day service in 2008	HS	HH	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	RHT	AC	POP	SHS	SI	SWC	SEC	CDR	DRH	OTH	E	SE	OE	VT	GD	All
Multidisciplinary support services	12	6	5	5	1	2	0	0	0	3	22	355	169	83	147	36	3	2	1	10	1	42	13	27	1	946
Centre-based day respite service (CDR)	0	0	1	0	0	0	0	0	0	1	2	1	2	0	0	1	0	1	0	0	0	0	0	4	0	13
Day respite in the home	0	0	0	3	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	1	0	0	0	6
Other day service (OTH)	3	1	4	16	0	5	0	11	0	5	17	13	29	7	10	34	1	1	1	21	0	20	2	6	0	207
Enclave within open employment (E)	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	3	1	0	0	6
Supported employment (SE)	9	4	0	0	0	0	0	0	0	0	1	1	8	1	0	9	5	4	0	11	2	71	9	3	2	140
Open employment (OE)	1	1	0	0	0	0	0	0	0	0	2	0	0	0	0	1	0	1	0	2	0	6	8	3	0	25
Vocational training (VT)	3	0	0	0	0	0	0	0	0	0	10	4	1	0	0	12	7	1	0	3	1	69	15	5	4	135
Generic day services (GD)	4	0	0	0	0	0	0	0	0	0	2	7	3	11	10	2	1	0	0	15	1	28	0	0	25	109
Total	482	27	312	193	29	438	77	131	183	332	598	1839	998	493	680	992	91	142	13	213	20	1186	105	612	62	10248

Multidisciplinary support services (including those delivered by early intervention teams) have been excluded from future service requirements and are documented in the multidisciplinary support services section later in this chapter.

The abbreviations in the sub-column headings refer to the placement descriptions which are given more fully in column one.

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

Residential support service change

The database indicates that 1,654 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 2009 to 2013 (Table 4.9). Additional or alternative support services are required by 448 individuals (27.1%) and 1,206 individuals (72.9%) require their existing service to be upgraded (shaded area of Table 4.9).

The principal residential support service changes or enhancements include:

- More frequent centre-based crisis or planned respite breaks for people already availing of this service (1,145 individuals).
- Occasional holiday residential placements and occasional respite care with a host family for people currently availing of crisis or planned respite (56 people).
- Opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (81 people).

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



Table 4.9 Additional residential support services required by people availing of residential support services in 2008

Residential support service required 2009–2013													
Residential support service in 2008	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	2	1	9	2	14	1	0	1	0	0	0	1	31
Living semi-independently	0	10	32	10	6	0	0	0	0	0	0	0	58
Holiday residential placement	0	0	5	0	19	1	0	1	0	5	0	1	32
Crisis or planned respite	2	4	81	21	1145	35	22	58	16	25	4	20	1433
Occasional respite care (host family)	0	1	3	1	26	16	4	2	1	1	2	2	59
Shared care or guardianship	0	0	0	0	2	0	0	0	1	0	0	0	3
Regular part-time care (2/3 days per week)	0	0	1	1	8	0	1	1	2	2	0	0	16
Regular part-time care (every weekend)	0	0	0	0	2	0	0	0	0	0	0	0	2
Regular part-time care (alternate weeks)	0	0	0	0	3	0	0	0	0	1	0	0	4
Overnight respite in the home	0	0	0	0	2	0	0	0	0	0	4	0	6
Other residential service	0	1	1	1	2	0	0	0	0	0	0	5	10
All services	4	17	132	36	1229	53	27	63	20	34	10	29	1654

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

C - Persons with intellectual disability who are accommodated in psychiatric hospitals

The data from the NIDD for 2008 identified 308 individuals with intellectual disability, all aged 20 years or over, who were accommodated in psychiatric hospitals. Table 4.10 details the overall service requirement status of people resident in psychiatric hospitals by level of intellectual disability.

Table 4.10 Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2008

	No service requirements				Has service requirements				Total
	Not verified	Mild	Moderate, severe & profound	All levels	Not verified	Mild	Moderate, severe & profound	All levels	
Resident in a psychiatric hospital, with no day programme	0	0	3	3	0	5	20	25	28
Resident in a psychiatric hospital, with day programme	2	31	60	93	0	50	135	185	278
Resident in a psychiatric hospital, with residential support service and day programme	0	1	0	1	0	1	0	1	2
All residents	2	32	63	97	0	56	155	211	308

Of this group, 211 (68.5%) individuals were recorded as having service requirements in the period 2009 to 2013, of whom:

- 188 had an appropriate alternative residential facility identified for them (95 of whom also required a day service). The residential service requirements of this group are shown in Table 4.12 and their day service requirements are shown in Table 4.13.
- 18 were recorded as appropriately placed within the psychiatric hospital but had identified day service requirements, as shown in Table 4.11.
- Three people were recorded as appropriately placed within the psychiatric hospital but require residential support services.
- Two people were recorded as appropriately placed within the psychiatric hospital but require increased support within a psychiatric hospital.

Table 4.11 Day service requirements of people appropriately accommodated in psychiatric hospitals in 2008

Day service in 2008	Services required 2009–2013						All services
	Vocational training	Activation centre	Programme for the older person	Special high support day service	Supported employment	Other day service	
No day programme	0	2	0	0	0	0	2
Rehabilitative training	0	0	0	0	1	0	1
Activation centre	1	3	0	0	0	1	5
Special intensive day service	0	0	0	1	0	0	1
Sheltered work centre	0	0	0	0	1	0	1
Multidisciplinary support services only	0	3	2	2	0	0	7
Other day programme	0	1	0	0	0	0	1
All services	1	9	2	3	2	1	18

Note

7 of the 18 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.

Of the 188 people who in 2008, were recorded as needing to transfer from psychiatric to intellectual disability services for provision of their residential services, 69 individuals (36.7%) required places in residential centres, 66 individuals (35.1%) required intensive placements, and 52 individuals (27.7%) required community group home places. One individual needed to move to a nursing home. In all cases the need was immediate (Table 4.12).

Table 4.12 Residential service requirements of people resident in psychiatric hospitals in 2008, who require to be transferred to the intellectual disability sector

	Number requiring residential service
7-day (48-week) community group home	2
7-day (52-week) community group home	50
7-day (48-week) residential centre	1
7-day (52-week) residential centre	68
Nursing home	1
Intensive placement (challenging behaviour)	51
Intensive placement (profound/multiple disability)	15
All residential services	188

Of this same group of 188 people, 95 required an appropriate day service. The greatest demand was for high-support or intensive day programmes (52 people, 54.7%), activation programmes (21 people, 22.1%) and programmes for older people (12 people, 12.6%). All day services were required immediately (Table 4.13).

Table 4.13 Day service requirements of people resident in psychiatric hospitals in 2008 who require to be transferred to the intellectual disability sector

	Number requiring day service
Rehabilitative training	4
Activation centre	21
Programme for the older person	12
Special high-support day service	41
Special intensive day service	11
Sheltered work centre	1
Sheltered employment centre	1
Supported employment	2
Generic day services	2
All day services	95

Note

54 of the 95 also had multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.

The 2008 data suggest that the current day and residential programmes for 97 people with intellectual disability resident in psychiatric hospitals were appropriate and these people had no identified service needs in the period 2009–2013 (Table 4.10). Almost two-thirds (63 people) of this group had a moderate, severe, or profound intellectual disability, one third (32 people) had a mild disability and two individuals' levels of disability were not verified. Within this group, three people had no formal day programme. The day service needs of this group will be reviewed in 2009.

D – Multidisciplinary support services

Although the NIDD facilitates the recording of two future day services that will be required by an individual, earlier sections of this chapter detail only the first future day service so that individuals are not double-counted. Future multidisciplinary support services, including those to be delivered by early intervention teams, are only recorded as a first future day service if these support services are the only future day service required. In reality, these services are required in addition to a more substantial day service component. To avoid under-reporting the demand for these services, they are excluded from the unmet need, service change, and psychiatric hospitals sections above and they are reported separately below in Figure 4.2. A 'requirement' refers to a new type of therapeutic input that the individual did not receive in 2008 and an 'enhancement' refers to a change in the delivery of a therapeutic input that the individual received in 2008 (e.g. an increase in the provision of the specific service or a change in service provider). Data from Table 3.9 are reproduced in Figure 4.2 to compare service provision in 2008 with the demand for services in the period 2009–2013.

In 2008 multidisciplinary support services were availed of by 20,971 people, 16,798 of whom had further requirements for such services. A further 2,714 individuals who did not access such services in 2008 require them. Therefore, there are 19,512 (16,798 plus 2,714) individuals with a need for multidisciplinary support services; those needs involve either an enhancement of a type of service received in 2008 (3,333 individuals), a requirement for a new type of service (7,341 individuals), or both (8,838 individuals). Of the 19,512 people with future multidisciplinary support service needs, 158¹⁷ received no service whatsoever in 2008. Ninety-nine per cent of the demand was immediate.

Despite high levels of service provision in 2008, there was substantial demand for new services and enhanced services relating to all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy. For example, 8,232 individuals received a psychology service in 2008, 4,039 of whom needed an enhancement of their service, and a further 7,337 individuals who did not receive a psychology service in 2008 require one in the period 2009–2013.

The data suggest that there was a significant shortfall in nutrition services as this was the only therapeutic input where the demand for a new service exceeded service provision in 2008. For example, 3,164 individuals were in receipt of a nutrition service in 2008, 1,374 of whom needed an enhancement of their service, and a further 4,377 individuals who were not in receipt of a nutrition service in 2008 require it in the immediate future.

17. 97 of the 158 also have other future service requirements that are included in the 'unmet need' section at the beginning of this chapter.

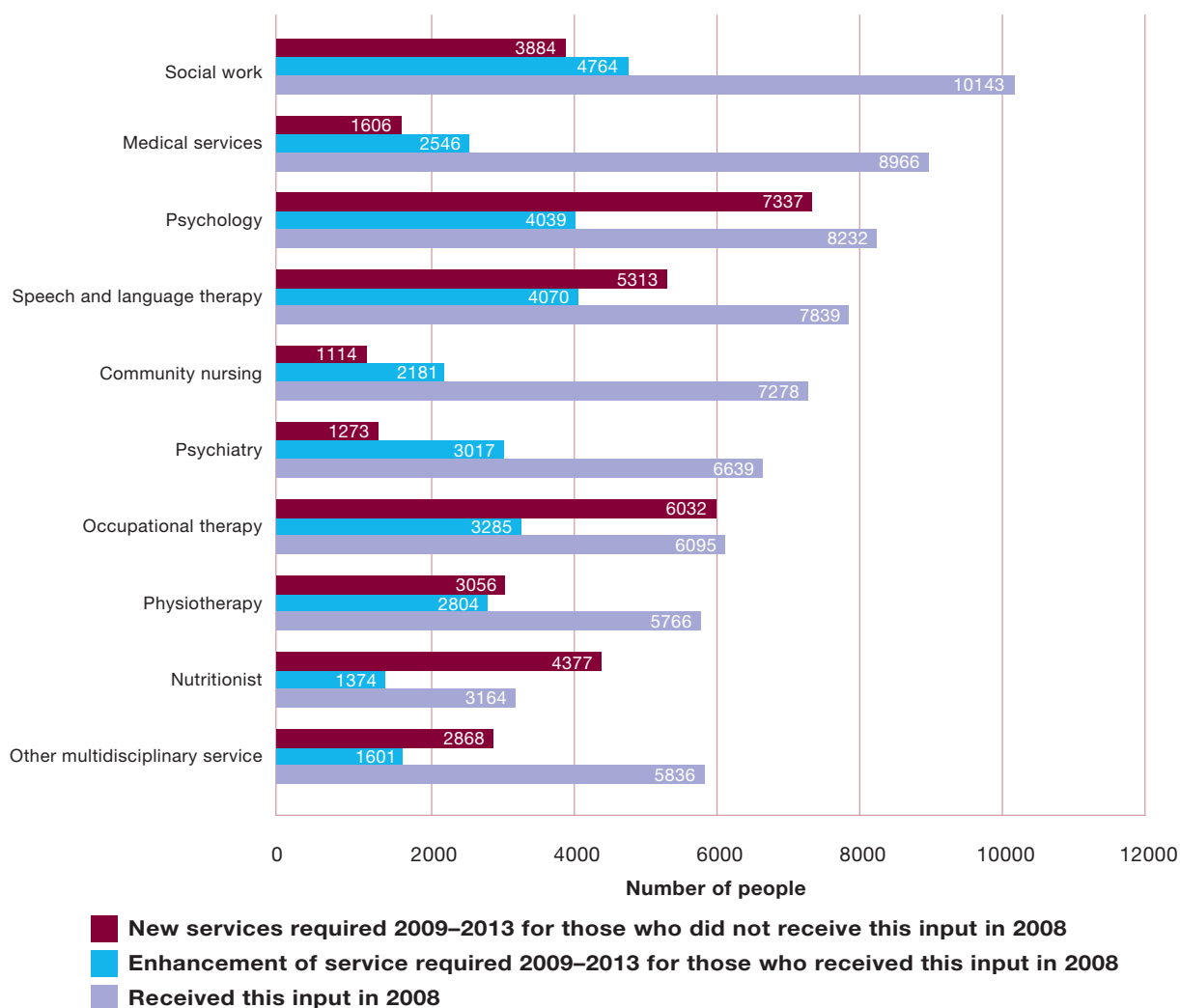


Figure 4.2 Multidisciplinary support services received in 2008 and required in the period 2009-2013

Overall service provision to people with intellectual disability and the pattern of care required in the period 2009-2013

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 2008 data indicate that there were large numbers of people who required residential services for the first time in 2008 and also that there were significant numbers who required changes to, or enhancements of, their existing residential or day placements (or both). 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.

Pattern of care required in full-time residential services

As indicated in Table 4.14, demand for full-time residential services in the period 2009–2013 come from three distinct groups already identified in this chapter:

- 2,256 individuals who lived at home in 2008 and who were recorded as requiring full-time residential services for the first time in 2008;
- 188 individuals who resided in psychiatric hospitals in 2008 and who were recorded as requiring to transfer to the intellectual disability services; and
- 3,094 individuals who were in full-time residential services within the intellectual disability sector in 2008 and who required changes to their existing placement. Of this group, 1,900 required alternative services and 1,194 required their existing service to be enhanced. Not all of the group who required service enhancements will move to new 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 4.14 outlines the pattern of full-time residential service provision that will be required in the period 2009–2013 to meet this demand. A total of 2,469 residential places will be required – an increase of 48 since 2007.

- 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, 2,773 community-based placements will be required during the period, an increase of 58 placements (2.1%) since 2007.
- There will also be a shortfall of 703 intensive residential placements, a decrease of 56 placements (7.4%) since 2007. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

Table 4.14 Pattern of full-time residential service provision required 2009–2013

	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	309	0	36	245	-100
7-day (48-week) community group home	310	2	212	202	-322
7-day (52-week) community group home	1243	50	1735	677	-2351
5-day residential centre	18	0	6	66	42
7-day (48-week) residential centre	54	1	50	242	137
7-day (52-week) residential centre	164	68	266	1326	828
Nursing home	10	1	50	46	-15
Mental health community residence	2	0	0	0	-2
Psychiatric hospital	0	0	0	0	0
Intensive placement (challenging behaviour)	73	51	360	170	-314
Intensive placement (profound or multiple disability)	73	15	379	78	-389
Other/unspecified intellectual disability service	0	0	0	17	17
Designated residential support placement	0	0	0	{25a}	0
Total	2256	188	3094	3069	-2469

^a25 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.

Pattern of care required in day services

As can be seen from Table 4.15, demand for day services over the next five years comes from four distinct groups:

- 242 individuals who were without day services in 2008;
- 95 individuals who were resident in psychiatric hospitals in 2008 and who will require an appropriate day service when they transfer to intellectual disability services;
- 18 individuals appropriately placed in psychiatric hospitals in 2008 but will require a day programme within that setting between 2009 and 2013; and
- 10,248 individuals who were in day services within the intellectual disability sector in 2008 and who required changes to, or enhancements of, their placement. Of this group, 7,950 required alternative or additional services and 2,298 required their service to be enhanced. The majority (7,102) of these service changes were within the health sector. Many of the changes were 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 required service enhancements will move to new placements. However, the entire group has been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading services for these individuals. 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.

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 intervention 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 services¹⁸ 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

18. The services involved include home support services, early intervention team, resource or visiting teacher, home help, multidisciplinary support services, centre-based day respite service, and day respite in the home.

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

Table 4.15 outlines the pattern of day service provision that will be required in the period 2009–2013 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 1,870 day places will be required – a decrease of 47 places on 2007 figures. The table shows that there is less demand by young children for certain services and a considerable demand for the full spectrum of adult services. Trends in the NIDD data indicate that the situation in relation to service requirements in the period 2009–2013 will be as follows:

- More than a 10% reduction in the number of children requiring places in special schools; the number decreased from 1,337 children in 2007 to 1,196 children in 2008. Although the numbers are small there is a demand within this group for mainstream pre-school services, which has increased by over 50%, from 75 children in 2007 to 117 children in 2008. This demand is likely to be greater than the data indicate due to the probable under-recording of young children on the Database discussed in Chapter 2.
- A shortfall of training and employment opportunities. In the period 2009–2013, 511 vocational training placements need to be developed to meet the demand that exists for those services. There will be a shortfall of 1,083 supported employment opportunities and 93 placements in open employment during this time.
- The growth in the ageing population with intellectual disability discussed in Chapter 2 is increasing the demand for specific programmes for the older person and there will be a shortfall of 753 such places over the next five years.
- As with residential services, there is significant demand for high-support and intensive day placements. Over the next five years, 248 high-support day placements and 569 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.

Table 4.15 Pattern of day service provision required 2009–2013

	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	7	0	0	482	0	-489
Home help	2	0	0	27	0	-29
Mainstream pre-school	7	0	0	312	202	-117
Special pre-school	0	0	0	193	403	210
Child education and development centre	0	0	0	29	70	41
Mainstream school	1	0	0	438	521	82
Resource/visiting teacher	0	0	0	77	0	-77
Special class – primary	0	0	0	131	233	102
Special class – secondary	0	0	0	183	83	-100
Special school	2	0	0	332	1530	1196
Rehabilitative training	41	4	0	598	784	141
Activation centre	43	21	9	1839	2222	310
Programme for the older person	9	12	2	998	268	-753
Special high-support day service	4	41	3	493	293	-248
Special intensive day service	4	11	0	680	126	-569
Sheltered work centre	33	1	0	992	1361	335
Sheltered employment centre	3	1	0	91	15	-80
Centre-based day respite service	0	0	0	142	0	-142
Day respite in the home	1	0	0	13	0	-14
Other day service	2	0	1	213	207	-9
Enclave within open employment	1	0	0	20	6	-15
Supported employment	33	2	2	1186	140	-1083
Open employment	13	0	0	105	25	-93
Vocational training	33	0	1	612	135	-511
Generic day services	3	2	0	62	109	42
All services	242	95	18	10248	8733	-1870

5. Conclusion

As a national-level information system on intellectual disability, the NIDD continues its relevance to health service managers and policy makers as a tool for planning services in this area. This annual report from the NIDD, based on information from over 26,000 people who were registered on the Database at the end of December 2008 represents the cumulative specialised health service needs of this group of people. In 2008, a concerted effort was made to ensure that all of the data were up to date, with the result that 99% of all cases were reviewed and updated for this report.

There have been a number of changes to the operation of the NIDD since the 2007 annual report which should be noted. This 2008 report contains a full calendar year of information as opposed to data for half of one year and half of the next. This change has been made to assist service planners and policy makers with the process of planning for and delivery of services. The aim is also to help improve the comparability of annualised data from 2008 onwards.

This report is also the first NIDD annual report to refer to data from the CSO National Disability Survey (2008). The report specifically refers to unpublished data on intellectual disability from the survey. The data show the different definitions of intellectual disability that are applied in both the NDS and the NIDD and how information is captured.

In addition, this 2008 report contains data not reported on in previous annual reports but which the NIDD Committee considers of sufficient importance to the overall provision of services to be included. These data include information on respite service provision and on the co-existence of physical/sensory disability in addition to an individual's intellectual disability.

This report highlights the need to be cognisant of trends over time in the population with intellectual disability, and of how this can impact substantially on the type and quantity of services that are used or required by those who are registered. Trend data in the report are presented for a thirteen-year period from 1996 to 2008 and further information is reported for the past three decades, which allows an opportunity to look back at changes over time and estimate what the consequence of these changes may be for future provision.

Overall, the 2008 data show that there has been a significant increase in the levels of day service, residential service and respite service provision, largely due to the existence of multi-annual funding for disability. Alongside this, however, this report highlights the fact that the changing age profile of individuals with intellectual



disability continues to contribute to high levels of demand for residential services, support services for ageing caregivers and services designed specifically to meet the needs of older people with intellectual disability.

This report shows that the number in receipt of day services is the highest since the Database was established. In addition, many of those in receipt of day services were also benefiting from additional support services such as early intervention services, home support, respite services and home help. A HSE-led national review of day service provision for adults with disability has recently been undertaken and it is likely that the results of this review will impact on the range and nature of day services into the future.

In relation to data on residential services, this report highlights the continuing shift towards community living; for the fourth year in a row the data show that the number of full-time residential placements in the community exceeds that in centre-based settings. The data on respite also show high levels of provision in 2008. Regional/geographical differences are outlined in the data on respite which indicate variable provision across the country. Again, a HSE review of congregated settings is likely to inform future developments in this area.

The data on the co-existence of a physical/sensory disability in addition to an intellectual disability indicate that there is a range of additional needs that require to be met for this cohort, some of which do not come within the ambit of intellectual disability services as we know them. The link between physical/sensory disability and age means that older age groups are more likely to have additional needs. Service providers and planners will need to take this into account in any future planning.

The majority of those registered on the NIDD in 2008 received multidisciplinary support services, with social work, medical services and psychiatry being the services most commonly availed of by adults and speech and language therapy, social work and occupational therapy the services most commonly availed of by children. Despite the high levels of service provision in 2008, there remains a substantial demand for new services and enhanced services relating to all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy in the period 2009–2013.

There remains a significant level of unmet need for a critical number of individuals who are registered on the NIDD. While the data in recent years highlight growth in services, demographic factors and historical under-funding of intellectual disability services are contributing to long waiting lists for these services. It is expected that the demand for intellectual disability services will continue into the future. This will require considerable planning and investment.

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Appendix A

2008 National Intellectual Disability Database data form



National Intellectual Disability Database Data Form

PERSONAL DETAILS

1. Surname
2. First name
3. Previous surname
4. Address
5. Address
6. Address
7. City / Town
- 7a. Phone
- 7b. School Roll Number (if applicable) |_|_|_|_|_|_|_|_|_|_|
8. Address (County) |_|_|
9. Date of birth |_|_| - |_|_| - |_|_|_|_|
10. Year of birth (where DOB is unknown) |_|_|_|_|
11. Health Service Executive area of residence |_|_|
12. Local Health Office of residence |_|_|
13. DED |_|_| |_|_|_|
14. Planning area |_|_|
15. **Personal Identification Number (PIN)** |_|_|_|_|_|_|_|_|_|_| 0=not verified 1=average 2=borderline
3=mild 4=moderate 5=severe 6=profound
16. Sex |_| 1=male 2=female
17. Degree of intellectual disability |_|
18. Year of last psychological assessment |_|_|_|_|
19. Does this individual have physical and/or sensory disability needs? |_| 1=yes 2=no
20. If yes, indicate type of physical and/or sensory disability |_|

NEXT OF KIN DETAILS

	(A)	(B)
Next of Kin name	30a	30b
Next of Kin address	31a	31b
Next of Kin address	32a	32b
Next of Kin address	33a	33b
Next of Kin address	34a	34b
Next of Kin address (County)	35a _ _	35b _ _
Next of Kin telephone number	36a	36b
Next of Kin mobile number	36c	36d
Relationship of Next of Kin	37a	37b

CURRENT SERVICE PROVISION

DAY SERVICES

40. Agency providing main day service
41. Type of main day service
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 second day service
45. Type of second day service
46. Current level of second day service support 0. 1. 2. 3. 4. 5.
47. Second day service: number of days received each week [0.0-7.0]
48. Agency providing third day service
49. Type of third day service
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]

RESIDENTIAL SERVICES

54. Agency providing main residential service
55. Type of main residential circumstance
56. Current level of main residential service support A. B. C. D. Z.
57. Agency providing secondary residential service
58. Type of secondary residential circumstance
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. HSE area responsible for funding current services

MULTIDISCIPLINARY SUPPORT

65. If multidisciplinary support services are received or required, please indicate type(s):

	Yes (✓)	Current Agency	Future		
			Rq	En	Duplication
Medical services	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Nursing	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Nutrition	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Occupational therapy	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Physiotherapy	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Psychiatry	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Psychology	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Social work	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Speech & language therapy	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Other	<input type="radio"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="text"/> <input type="text"/>
Specify _____			_____		

66. Are current services provided by an early intervention team? 1=yes 2=no 3=n/a
67. Year in which future services are required
68. Will future services be provided by an early intervention team? 1=yes 2=no 3=n/a

FUTURE SERVICE REQUIREMENTS

REQUIRED DAY SERVICES

70. Type of day service (1) required |__|
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 and future day service (1) |__|
74. Type of day service (2) required |__|
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 and future day service (2) |__|

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 and contingency day service |__|
84. Primary reason for duplication on future and contingency day service |__|

RESIDENTIAL SERVICES

85. Type of residential service (1) required |__|__|
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 and future residential service (1) |__|
89. Type of residential service (2) required |__|__|
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 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 and contingency residential service |__|
96. Primary reason for duplication on future and contingency residential service |__|

97. HSE area responsible for funding future services |__|__|

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

ADDITIONAL INFORMATION

100. Date of completion/review |_|_|-|_|_|-|_|_|_|_|
 101. Person responsible for update of form _____ |_|_|_|_|_|_|_|_|_|_|
 102. Unit/Centre of person responsible _____ |_|_|_|_|_|_|_|_|_|_|
 103. Agency returning record |_|_|_|_|_|_|_|
 104. HSE area returning record |_|_|
 105. Local Health Office returning record |_|_|
 106. Date consent received |_|_|-|_|_|-|_|_|_|_|
 106a. Consent Reason Awaiting ☐ Consent Received ☐ Refused ☐

107. Reason for removal |_|_|

If transferred (1) please indicate: to HSE |_|_| to LHO |_|_| to Agency |_|_|_|_|_|_|_|_|_|_|

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"/> To NPSDD | <input type="radio"/> Duplication between HSE areas |
| <input type="radio"/> Other reason | <input type="radio"/> Duplication within HSE area |

108. Date of removal |_|_|-|_|_|-|_|_|_|_|

NATIONAL PERFORMANCE INDICATOR (NPI)

To be completed for all people in full-time residential services (codes 115 to 172)

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

SERVICES CODED AS "OTHER"

If a day service or residential service is coded as "Other" please provide the question number and a text description of each "Other" service below.

Question number/Text description

Personally identifying details are not accessible to the Department of Health and Children and the Health Research Board.

Appendix B Service categories and groupings

Service categories

Day programmes

- Home support (assistance provided to the family in terms of assisting with care or facilitating attendance at a social activity)
- Special pre-school for intellectual disability
- Mainstream school (includes mainstream pre, primary and secondary schools)
- Special class – primary level
- Special class – secondary level
- Special school
- Child education and development centre (Programme for children with severe or profound intellectual disability)
- Vocational training (e.g. FAS, VEC, CERT, NTDI)
- Rehabilitative training
- Activation centre/adult day centre (day centre for adults who need ongoing care, training and development)
- Programme for the older person
- Special high-support day service (e.g. relating to challenging behaviour) less than 1:1 staff ratio
- Special intensive day service (e.g. relating to challenging behaviour) 1:1 staff ratio contact or greater
- Sheltered work centre – may include long-term training schemes
- Sheltered employment centre (receives pay and pays PRSI)
- Enclave within open employment (open employment where people with Intellectual Disability work for mainstream employer and receives normal rates for the job)
- Supported employment
- Open employment
- Other day programme
- Resource teacher/visiting teacher
- Early services (multidisciplinary intervention with infants and young children)
- Generic day services (person attends a social, psychiatric or similar centre away from their residence on a regular basis)
- Home help (assistance provided to the family in terms of assisting with domestic tasks)
- Multidisciplinary support services for school age children or adults

- Centre-based day respite service (respite services provided within Intellectual Disability Services)
- Day respite in a home (regular respite provided in the person's residence)

Residential circumstances

- At home, with both parents
- At home, with one parent
- At home with sibling
- At home with relative
- Lives with non-relative (e.g. neighbour or family friend)
- Adoption
- Foster care (includes 'boarding-out' arrangements)
- Living independently
- Living semi-independently – maximum 2 hours supervision daily
- Vagrant or homeless
- 5-day community group home – goes home for weekends/holidays
- 7-day x 48-week community group home – goes home for holidays
- 7-day x 52-week community group home
- 5-day village-type/residential centre – goes home for weekends/holidays
- 7-day x 48-week village-type/residential centre – goes home for holidays
- 7-day x 52-week village-type/residential centre
- Nursing home
- Mental health community residence
- Psychiatric hospital
- Other intensive placement with special requirements due to challenging behaviour
- Other intensive placement with special requirements due to profound or multiple disabilities
- Holiday residential placement
- Crisis or planned respite
- Occasional respite care with a host family in a scheme such as Home Sharing or Share-a-Break
- Shared care or guardianship (usually 5 or 7 days per week)
- Regular part-time care – 2-3 days per week
- Regular part-time care – every weekend
- Regular part-time care – alternate weeks
- Other residential service
- Overnight respite in the home



Day service groupings

Health

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

Education

- Mainstream school
- Resource or visiting teacher
- Special class – primary
- Special class – secondary
- Special school

Employment

- Enclave within open employment
- Supported employment
- Open employment

Generic

- Vocational training
- Generic day services

Appendix C Supplementary table

Table B1 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
	1839	93	77	26	2035	3431	1727	1133	191	6482	3584	2672	1663	272	8191	8854	4492	2873	489	16708
At home with both parents	1559	67	24	1	1651	2480	1263	462	14	4219	2795	2011	647	9	5462	6834	3341	1133	24	11332
At home with one parent	253	24	28	7	312	773	395	463	36	1667	698	592	641	35	1966	1724	1011	1132	78	3945
At home with sibling	1	1	22	16	40	7	14	160	103	284	2	31	339	194	566	10	46	521	313	890
At home with other relative	4	0	1	2	7	41	19	31	31	122	15	10	25	26	76	60	29	57	59	205
Living with non-relative	1	0	0	0	1	1	5	9	2	17	2	2	3	3	10	4	7	12	5	28
Adoption	2	0	0	0	2	8	6	1	0	15	8	4	1	0	13	18	10	2	0	30
Foster care and boarding-out arrangements	19	1	2	0	22	121	25	7	5	158	64	22	7	5	98	204	48	16	10	278
Independent/Semi-independent setting	1	8	31	14	54	4	149	417	151	721	0	31	84	60	175	5	188	532	225	950
Living independently	1	3	25	13	42	2	99	276	110	487	0	19	42	36	97	3	121	343	159	626
Living semi-independently	0	5	6	1	12	2	50	141	41	234	0	12	42	24	78	2	67	189	66	324
Community group home	4	7	6	4	21	39	172	421	265	897	93	606	1650	627	2976	136	785	2077	896	3894
5-day community group home	1	1	3	0	5	27	29	55	8	119	20	106	214	7	347	48	136	272	15	471
7-day (48-week) community group home	0	1	0	0	1	1	25	64	22	112	17	93	320	43	473	18	119	384	65	586
7-day (52-week) community group home	3	5	3	4	15	11	118	302	235	666	56	407	1116	577	2156	70	530	1421	816	2837
Residential centres	0	0	3	11	14	3	27	88	112	230	72	460	1346	893	2771	75	487	1437	1016	3015
5-day residential centre	0	0	0	0	0	1	3	3	2	9	10	24	38	4	76	11	27	41	6	85
7-day (48-week) residential centre	0	0	1	0	1	0	10	19	7	36	20	121	158	66	365	20	131	178	73	402

Table B1 Details of main residential circumstances, degree of intellectual disability and age group (*continued*)

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
7-day (52-week) residential centre	0	0	2	11	13	2	14	66	103	185	42	315	1150	823	2330	44	329	1218	937	2528
Other full-time services	10	1	8	14	33	9	45	99	86	239	55	299	477	278	1109	74	345	584	378	1381
Nursing home	0	0	5	13	18	0	0	8	27	35	0	2	32	66	100	0	2	45	106	153
Mental health community residence	0	0	0	0	0	0	0	7	16	23	0	0	8	28	36	0	0	15	44	59
Psychiatric hospital	0	0	1	1	2	1	9	46	32	88	0	13	91	114	218	1	22	138	147	308
Intensive placement (challenging behaviour)	1	0	1	0	2	1	26	28	4	59	23	172	191	38	424	25	198	220	42	485
Intensive placement (profound or multiple handicap)	5	0	0	0	5	0	3	2	1	6	19	90	125	15	249	24	93	127	16	260
Full-time resident in 'other' residential service	3	1	1	0	5	7	5	5	4	21	6	8	17	15	46	16	14	23	19	72
Full-time resident in residential support place	1	0	0	0	1	0	2	3	2	7	7	14	13	2	36	8	16	16	4	44
No fixed abode	0	0	0	0	0	0	3	5	1	9	0	1	2	2	5	0	4	7	3	14
Insufficient information	0	0	0	0	0	0	1	0	0	1	2	12	28	18	60	2	13	28	18	61
Total	1854	109	125	69	2157	3486	2124	2163	806	8579	3806	4081	5250	2150	15287	9146	6314	7538	3025	26023

Appendix D

National Intellectual Disability Database 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.

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

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

Barron S and Mulvany F (2005) *Annual report of the National Intellectual Disability Database Committee 2004*. Dublin: Health Research Board.

Barron S and Kelly C (2006) *Annual report of the National Intellectual Disability Database Committee 2006*. Dublin: Health Research Board.

Kelly F, Kelly C and Craig S (2007) *Annual report of the National Intellectual Disability Database Committee 2007*. HRB Statistics Series 2. Dublin: Health Research Board.

Kelly F, Craig S and Kelly C (2008) *Trends in demand for services among children aged 0–5 years with an intellectual disability, 2003–2007*. HRB Trends Series 3. Dublin: Health Research Board.

Kelly C, Kelly F and Craig S (2009) *Trends in demand for services among those aged 50 years and over with an intellectual disability, 2003–2007*. HRB Trends Series 5. Dublin: Health Research Board.







