



HRB Statistics Series

Annual Report of the National Intellectual Disability Database Committee 2007

Fionnola Kelly, Caraiosa Kelly and Sarah Craig

Disability Database Unit
Health Research Board

design by drawinginc



Helen Flynn

**National Intellectual Disability Database Committee Annual Report
2007 cover design competition winner**

Helen has been attending the Old Beehive Weaving & Craft Centre at Stewarts Hospital for 10 years. Over this time Helen has developed her artistic skills. Helen has specialised in the areas of weaving, embroideries, painting and mosaics. While Helen has a quiet temperament, she enjoys the company of her friends and colleagues and is always eager to join in with various activities and have fun. Some of Helen's interests include, music, dancing, horse riding and shopping. The winning Embroidery is an original piece of Helen's work and it involved her doing her own drawing, fabric painting and many hours of detailed stitching.

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Fionnola Kelly, Caraíosa Kelly and Sarah Craig

National Intellectual Disability Database
Health Research Board

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.

Our information systems

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.

Our research activity

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 Database 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 Research series** reports original research material on problem alcohol and drug use, child health, disability and mental health.





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- the Disability Services Section of the Department of Health and Children;
- 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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Chairman's Statement

This is the tenth Annual Report of the National Intellectual Disability Database. The database has in excess of 25,000 registrations.

Since the database was set up there have been many changes in the health services and the disability services. The governance and service provision frameworks have changed dramatically. We now have the Health Service Executive, the Health Information and Quality Authority implementing Government policy as outlined in the National Disability Strategy, the Disability Act, Departmental Sectoral Plans and a multi annual investment programme.

The National Intellectual Disability Database was established to ensure that information would be available to provide appropriate services to people with an intellectual disability and their families. Its rationale is as appropriate now as it was when it was established in 1995. However, it must recognise the changing environment of health and in particular disability services. I am pleased to note that the Disability Database Unit of the Health Research Board proposes to review the databases to consider any changes needed, with particular reference to the implementation of the Disability Act and identifying the data requirements under the Act and Sectoral Plan. The Unit's review will feed into the Department of Health and Children's and the Health Service Executive's review, in the context of the Sectoral Plan, of the information needs of all relevant stakeholders in order to provide the most effective method of collecting data for the purposes of planning services to meet the needs of people with disabilities.

In addition I understand that the Disability Database Unit, in recognition of the implementation of the needs assessment process for under 5 year olds under the Disability Act, is to produce a paper looking at this group of children on the intellectual disability database and their current and future needs.

A national audit of the Intellectual Disability Database is underway. It will assess the level of accuracy of the data on the database. Ultimately, the findings of the audit will be used to improve the accuracy and reliability of the information on the database.

I would like to acknowledge the hard work of those working in the Disability Database Unit of the Health Research Board whose responsibility it was to complete this report on behalf of the Committee.

Dermot Ryan

Chairman

National Intellectual Disability Database Committee



Executive Summary

Demographic profile

There were 25,613 people registered on the National Intellectual Disability Database (NIDD) in April 2007, representing a prevalence rate of 6.04 per 1,000 population. The administrative prevalence rate for mild intellectual disability is 1.96 per 1,000 and the prevalence rate for moderate, severe and profound intellectual disability is 3.48 per 1,000. There are more males than females at all levels of intellectual disability, with an overall ratio of 1.29 to 1. The total number with moderate, severe and profound intellectual disability has increased by 31% 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 general population growth over the period. Proportionately, the number of people with moderate, severe, and profound intellectual disability that are aged 35 years and over has increased from 29% in 1974 to 38% in 1996, and to 48% in 2007. 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, and helps to explain the ongoing demand for additional resources for this sector.

Service provision in 2007

The numbers registered on the NIDD in April 2007 are as follows:

- 24,898 people with intellectual disability in receipt of services, representing 97% of the total population registered on the NIDD. This is the highest number of people recorded as in receipt of services since the database was established in 1995.
- 305 people (1% of those registered) who are without services at present and are identified as requiring appropriate services in the period 2008–2012.
- 410 people (2%) who are not availing of services and have no identified requirement for services during the planning period 2008–2012. Forty-five per cent of this group (186 people) are in the mild or 'not verified' range of intellectual disability and their continued registration on the NIDD is being reviewed. However, the remaining 224 people in this group have a moderate, severe or profound intellectual disability and the need for continued monitoring of these individuals' circumstances is highlighted.

Of the 24,898 people in receipt of services in 2007:

- 8,262 are in receipt of full-time residential services, which is an increase of 81 since 2006 and is the highest figure recorded on the NIDD since 2001. This is the fourth consecutive year of data indicating that more people live in group homes within their communities than in residential centres.
- The number of people with intellectual disability accommodated in psychiatric hospitals has decreased by 19 since 2006, to 329.
- 24,729 people are availing of at least one day programme. This is the highest number availing of day services since NIDD data were first reported in 1996. Of this group, 8,125 are in full-time residential placements and 5,028 are in receipt of residential support services such as respite care.
- 19,799 people avail of one or more multidisciplinary support service. The most commonly availed of services by adults are medical services, social work and psychiatry. The most commonly availed of services by children are speech and language therapy, social work and psychology.

Sixty-four per cent of all children and adults with intellectual disability (16,366 individuals) live at home with parents, siblings, relatives or foster parents.

More than one in four people with a moderate, severe or profound intellectual disability who are aged 35 years or over are living in home settings. As the carers of adults with intellectual disability begin to age beyond their caring capacity, formal supervised living arrangements will need to be established. Because people with intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years. These data highlight the importance of planning for such eventualities and avoiding crisis situations.

Since 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 2007 noted in this report include:

- An increase in the number of people with intellectual disability living full-time in group homes within local communities, which has more than doubled in the eleven-year period;



- A 66% reduction in the number of people with intellectual disability accommodated in psychiatric hospitals;
- A continued expansion in the availability of residential support services, in particular planned or emergency centre-based respite services, which have grown by 414%; 4,480 people avail of this type of residential support service, 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

In 2007 there are 2,430 people who are either without services or without a major element of service (either a full-time residential service, or a day service, or both) and require services, an increase of 59, or 2%, since 2006. To meet the needs of these individuals the following will be required during the period 2008–2012 (though most service needs arise immediately):

- 2,181 full-time residential placements, an increase of 63, or 3%, since 2006 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.
- 267 day programmes. The number of new day places required has been decreasing since NIDD data were first reported in 1996 and is now at its lowest since the database was established. This suggests that significant progress has been made in meeting the demand for day services.
- 2,088 residential support services, an increase of 134, or 7%, since 2006 and the highest number since the database was established. This high level of need is presenting even though there are over 5,000 people currently availing of residential support services.

- A group of 207 individuals living in psychiatric hospitals in 2007 have been identified as needing to transfer from these locations to more appropriate accommodation.

In 2007 a further 11,928 people are receiving services but require alternative, additional, or enhanced services within the next five years, an increase of 110, or 1%, since 2006. This group includes people who require an increased level of service provision, increased support within their existing services, transfer to more appropriate placements, or service changes to coincide with transition periods in their lives, for example, movement from child to adult services, or from training to employment placements.

The 2007 dataset, in line with data in recent years, indicates that despite substantial levels of service provision in day, residential, residential support and multidisciplinary support services, there is significant ongoing demand for new intellectual disability services and a growing requirement to enhance existing services. The number of new full-time residential and residential support places required is at its 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 contributing 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 freed up through death. 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. The objective is to obtain this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service. Information pertaining to diagnosis is specifically excluded, as the database is not designed as a medical, epidemiological tool. The data held in any individual record represent the information available for that person at a specified point in time only. The record is updated whenever there are changes in the person's circumstances or during the annual review process in the spring of each year.

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

Structure

The 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 database form for each identified individual (Appendix A). Responsibility for providing this information to the HSE lies primarily with the service providers, Local Health Office personnel and school principals.

The designated data providers supply this information to their Local Health Office 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 by the Department of Health and Children at the end of the annual review and update period of NIDD information. 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.

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, the 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 took place in September of 2007.

2007 Annual Report

This is the tenth report of the National Intellectual Disability Database Committee. The report is based on data extracted from the NIDD and validated in April 2007. In addition to this report, a summary bulletin and a complete set of tables is produced for each HSE Local Health Office.

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

The extent of current service provision in Ireland ensures that an almost complete ascertainment of all persons with a moderate, severe or profound intellectual disability is possible and expected. Inclusion of persons with a mild level of intellectual disability is sought if they are in special classes or special schools for children with intellectual disability, attending an intellectual disability service as adults, or if they are considered likely to require such a service within the next five years. Those in the average ability and borderline intellectual disability categories have been excluded from analyses because services for this group are not usually provided within intellectual disability services. In the 2007 dataset, there are 172 people recorded as being of average



ability and 664 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 2007 dataset consists of information in relation to 25,613 individuals. Of the 25,613 total registrations, 897 records (3.5%) were not updated since the completion of the 2006 review and update of NIDD information and their last known data are documented in this report. This is a considerable improvement on 2006 when 2,129 records (8.3%) were not updated and highlights the dedication and commitment of HSE staff to the database and emphasises the continued need for accurate and timely data.



2. Profile of the Population

National Level

Numbers and prevalence

In 2007 there are 25,613 people registered on the NIDD. Table 2.1 summarises the numbers and prevalence rates at each level of intellectual disability. The administrative prevalence rate for mild intellectual disability in 2007 is 1.96/1000, compared to 2.18/1000 in 2006. This figure is not a true reflection of the prevalence of mild intellectual disability 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 2007 is 3.48/1000, compared to 3.74/1000 in 2006. It is important to note that the prevalence rates for 2007 have been calculated using the 2006 census; the population has increased by 8% since 2002, whereas the numbers registered on the NIDD have increased by just 0.4% (95 people) since 2006, this explains the small decline in the prevalence rates from 2006 to 2007.

Table 2.1 Degree and prevalence of intellectual disability

	n	%	Rate per 1,000*
Mild	8320	32.5%	1.96
Moderate	9742	38.0%	2.30
Severe	3967	15.5%	0.94
Profound	1028	4.0%	0.24
Not verified	2556	10.0%	0.60
All levels	25613	100.0	6.04

*Prevalence rates per thousand population are based on Census of Population 2007 figures (Central Statistics Office, 2007)

During the review and update period prior to the 2007 extract of data from the NIDD, 998 people were removed from the database and the balance is accounted for by new or reactivated registrations.

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



Table 2.2 Age, gender, and degree of intellectual disability

Age group	Numbers																																			
	Not verified						Mild						Moderate						Severe						Profound						All levels					
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total						
0-4	378	526	904	32	41	73	27	42	69	12	7	19	5	1	6	454	617	1,071																		
5-9	230	572	802	263	488	751	210	395	605	108	152	260	25	25	50	836	1,632	2,468																		
10-14	42	109	151	420	693	1,113	326	569	895	118	186	304	32	24	56	938	1,581	2,519																		
15-19	35	50	85	572	902	1,474	392	548	940	115	161	276	22	31	53	1,136	1,692	2,828																		
20-34	80	112	192	989	1,181	2,170	1,206	1,607	2,813	418	635	1,053	127	141	268	2,820	3,676	6,496																		
35-54	130	136	266	971	1,044	2,015	1,511	1,616	3,127	658	849	1,507	202	270	472	3,472	3,915	7,387																		
55 & over	59	97	156	391	333	724	706	587	1,293	291	257	548	61	62	123	1,508	1,336	2,844																		
All ages	954	1,602	2,556	3,638	4,682	8,320	4,378	5,364	9,742	1,720	2,247	3,967	474	554	1,028	11,164	14,449	25,613																		
Prevalence rates – numbers per 1,000 of the general population for each age group																																				
0-4	2.56	3.40	2.99	0.22	0.27	0.24	0.18	0.27	0.23	0.08	0.05	0.06	0.03	0.01	0.02	3.07	3.99	3.54																		
5-9	1.64	3.87	2.78	1.87	3.30	2.60	1.50	2.67	2.10	0.77	1.03	0.90	0.18	0.17	0.17	5.96	11.03	8.56																		
10-14	0.31	0.78	0.55	3.15	4.93	4.06	2.44	4.05	3.27	0.88	1.32	1.11	0.24	0.17	0.20	7.03	11.25	9.20																		
15-19	0.25	0.34	0.29	4.03	6.08	5.08	2.76	3.70	3.24	0.81	1.09	0.95	0.15	0.21	0.18	8.00	11.41	9.74																		
20-34	0.15	0.21	0.18	1.88	2.19	2.04	2.30	2.98	2.64	0.80	1.18	0.99	0.24	0.26	0.25	5.37	6.81	6.10																		
35-54	0.23	0.24	0.23	1.71	1.81	1.76	2.66	2.80	2.73	1.16	1.47	1.32	0.36	0.47	0.41	6.12	6.78	6.45																		
55 & over	0.13	0.24	0.18	0.85	0.81	0.83	1.53	1.42	1.48	0.63	0.62	0.63	0.13	0.15	0.14	3.26	3.24	3.25																		
All ages	0.45	0.76	0.60	1.72	2.21	1.96	2.07	2.53	2.30	0.81	1.06	0.94	0.22	0.26	0.24	5.27	6.81	6.04																		

Gender differences

As table 2.2 indicates, the number of males at all levels of intellectual disability exceeds the number of females. The number of males exceeds the number of females in all age groups except the 55 years and over age group. The overall male to female ratio is 1.29:1. This represents a prevalence rate of 6.81/1000 males and 5.27/1000 females.

Age differences

Of the persons recorded on the NIDD, 34.7% (8,886) are aged 19 years and under, 25.4% (6,496) are aged between 20 and 34 years, 28.8% (7,387) are aged between 35 and 54 years, and 11.1% (2,844) are 55 years and over. Figure 1 illustrates the proportion in each age group at each level of intellectual disability. The larger proportion with mild intellectual disability in the 0-19 years age group reflects the number of children in special education who receive support services from the intellectual disability sector, a proportion of whom do not transfer to the intellectual disability services after school. There is also a higher proportion in the 'not verified' category in this age group, as many young children who have an intellectual disability do not receive a definitive diagnosis of their level of intellectual disability in their earlier years.

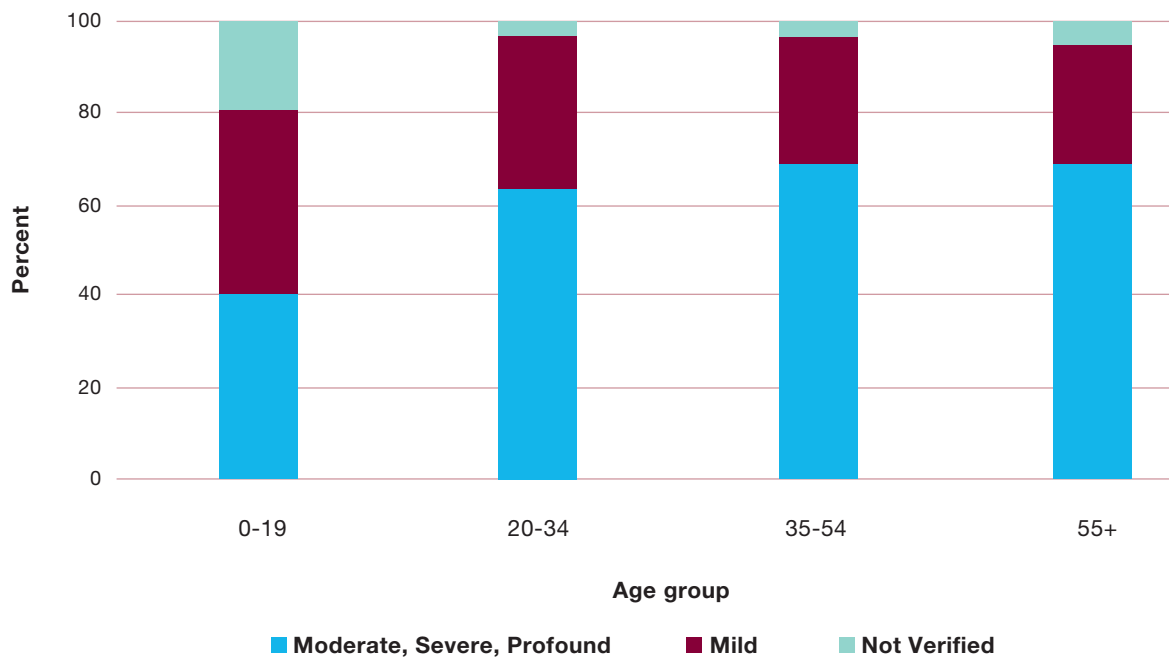


Figure 1 Age profile of total population showing proportion at each level of intellectual disability in each age group



Trends over time

Recent trends

Prevalence rates for moderate, severe and profound intellectual disability for 1996 to 2007 are compared in Table 2.3. The 1996 prevalence rates are calculated using NIDD data from 1996 and national census data from 1996. The 2007 prevalence rates are calculated using NIDD data from 2007 and national census data from 2006. Compared to the 1996 data (National Intellectual Disability Database Committee, 1997), the 2007 data in Table 2.3 demonstrate the following trends:

- A reduced prevalence rate for the 0–4 years age group. The decrease of 0.93/1000 in the prevalence rate is associated with a 72.3% drop in numbers in this age group registered on the database between 1996 and 2007 and an increase in this age group in the general population between the 1996 and the 2006 census. The prevalence rate for the 0–4 years age group, at 0.31 /1000, is considerably lower than expected. Applying the prevalence rate of 4.58/1000 for the 10–14 years 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 database, may be underestimated by somewhere in the region of 1,200 cases. In compiling the database, attempts are made to discover every child with intellectual disability at the earliest possible age, but respect is also given to situations where parents are reluctant to allow information about their young child to be recorded on the database. Indeed significant developmental delay is much less evident in the first two years becoming much more noticeable by age three and age four. Another potential reason for the underestimation of children in this age group is a possible move towards mainstream pre-school education. The National Intellectual Disability Database Committee requests that the HSE prioritise the accurate recording of children in this age group so that more comprehensive services can be planned. The implementation of the Disability Act 2005 and the assessment of need process for those under 5 years old will help to address the service needs of this age group.
- An overall decrease in the prevalence among the 5–9 years age group of 0.20/1000. This decrease coincides with a decline of 14.7% in numbers in this age group registered on the database between 1996 and 2007 and a decline in the general population in this age group during the corresponding census period.

- An overall increase in prevalence among the 10–14 years age group of 0.72/1000, despite a fall of 6.8% in numbers in this age group registered on the database over the eleven year period. One reason for the increase in prevalence is because the number of children in this age group in the general population has declined by 4% over the two census periods.
- An overall decrease in prevalence among the 15–19 years age group of 0.35/1000 between 1996 and 2007. This decrease is associated with a decrease of almost 20% in the numbers in this age group registered on the database between 1996 and 2007 and a decline in the general population in this age group during the corresponding census period.
- A downward trend in the prevalence in the 20–34 years age group of 2.43 per 1,000 since 1996. The prevalence among 20–34 year olds has been falling consistently over the eleven-year period. From 1996 to 2002 (Mulvany and Barron, 2003) this age group exhibited a higher prevalence of moderate, severe or profound intellectual disability than any other age group. The consistent decrease in prevalence over time has resulted in this group no longer exhibiting the highest prevalence of moderate, severe or profound intellectual disability in the five datasets from 2003 to 2007.
- An overall decrease in prevalence among the 35–54 years age group of 0.68/1000 since 1996, but with an upward trend apparent from 2002 to 2006. This upward trend resulted in the 35–54 years age group exhibiting the highest prevalence of moderate, severe or profound intellectual disability of any age group in the four datasets from 2003 to 2006. However with the decrease in prevalence in 2007 this group no longer exhibits the highest prevalence of moderate, severe or profound intellectual disability.
- An overall increase in prevalence of 0.13/1000 in the 55 years or over age group. The number of people in this age group registered on the database has increased by 530 (37.0%) since 1996.

Clearly the 2006 census of population data, which is used as the denominator for calculating prevalence rates for intellectual disability, is having a significant impact on the prevalence rates. The 2006 Census for the Republic of Ireland reports the highest population recorded in the state since 2002. Approximately one-third of the population increase was accounted for by the natural increase in the population (more births than deaths) with the remaining two-thirds due to migration (Central Statistics Office,



2006). The age groups which experienced population growth rates since 2002 were the 0–4 years age group, which experienced growth of 8.9%; the 5–9 years age group which experienced growth of 9.2% and the 20–34 years, 35–54 years and 55 years and over age groups, which experienced growth rates of between 9.8% and 12.6%. As the numbers of individuals with an intellectual disability have not experienced similar increases, the data are now showing a decrease in prevalence in the 0–4, 5–9 and 20–34 years age groups. Two age groups 10–14 years and 15–19 years experienced a decline in population of 4.1% and 7.3% respectively. The numbers of individuals with intellectual disability in these age groups did not experience similar reductions, and so the data show an increased prevalence in these two age groups. For the first time the 10–14 years age group have the highest prevalence of all the age groups. This may be explained by the fact that the number of people in this age group with an intellectual disability increased by 12% between 2002 and 2007, despite the fact that there was a decline in the general population in this age group of 4% during the corresponding census period.

The prevalence rate for the 35–54 and 55 years and over age groups increased steadily from 2002 until 2006 but experienced a drop in prevalence in 2007. The demographic trends in the general population make interpretation of these results more complicated. The decrease in prevalence observed in the older adult age groups is considerably affected by marked demographic population changes and is masking a real increase in the number of adults with intellectual disability. Furthermore, as the primary purpose of the database is to plan services, the overall number of people affected is a more useful measure than the prevalence rate.

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 33 years (Table 2.3).

The number of those most severely affected has increased by 30.9% (3,481 individuals) since 1974, which closely matches the general population increase over the 33 year period. The total number of those with a more severe disability is 14,737 in 2007, compared to 11,256 in 1974. The current prevalence rate of 3.48 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 is confined to the two older age groups, the 35–54 years age group and the 55 years and over age group. With the exception of the 55 years and over age group in 2002, the two older age groups have shown a continued increase in numbers each year since 1996. The overall increase in numbers is influenced by a number of factors, including the general population increase in these age groups during the period, improved standards of care, and an increase in the lifespan of people with intellectual disability.

Table 2.3 Age and degree of intellectual disability (moderate, severe and profound): 1974, 1981, 1996, 2007

Age group	Numbers															
	Moderate			Severe			Profound			All levels						
	1974	1981	1996	2007	1974	1981	1996	2007	1974	1981	1996	2007	1974	1981	1996	2007
0-4	189	214	226	69	143	83	19	99	26	30	6	431	332	339	94	
5-9	809	955	736	605	617	260	260	224	99	77	50	1650	1384	1073	915	
10-14	752	1035	948	895	583	305	304	292	117	93	56	1627	1580	1346	1255	
15-19	698	1203	1072	940	445	378	276	241	154	132	53	1384	1865	1582	1269	
20-34	1498	2419	2997	2813	1017	1350	1053	441	340	460	268	2956	3888	4807	4134	
35-54	1321	1559	2626	3127	626	1183	1507	201	97	343	472	2148	2268	4152	5106	
55 & over	669	715	987	1293	307	394	548	84	24	53	123	1060	987	1434	1964	
All ages	5936	8100	9592	9742	3738	3953	3967	1582	857	1188	1028	11256	12304	14733	14737	
<i>Prevalence rates – numbers per 1,000 of the general population for each age group</i>																
0-4	0.60	0.62	0.83	0.23	0.45	0.27	0.06	0.31	0.07	0.11	0.02	1.36	0.97	1.24	0.31	
5-9	2.55	2.73	2.31	2.10	1.95	0.94	0.90	0.71	0.28	0.24	0.17	5.20	3.95	3.37	3.17	
10-14	2.52	3.08	2.72	3.27	1.95	1.27	1.11	0.98	0.35	0.27	0.20	5.45	4.70	3.86	4.58	
15-19	2.61	3.79	3.20	3.24	1.66	1.60	0.95	0.90	0.48	0.39	0.18	5.17	5.88	4.72	4.37	
20-34	2.78	3.33	3.93	2.64	1.88	1.56	0.99	0.82	0.47	0.60	0.25	5.48	5.35	6.31	3.88	
35-54	2.13	2.43	3.25	2.73	1.01	0.95	1.32	0.32	0.15	0.42	0.41	3.46	3.53	5.14	4.46	
55 & over	1.08	1.09	1.45	1.48	0.50	0.38	0.63	0.14	0.04	0.08	0.14	1.71	1.51	2.11	2.24	
All ages	1.99	2.35	2.72	2.30	1.25	0.97	0.94	0.53	0.25	0.34	0.24	3.80	3.60	4.18	3.48	

The graphical representation of the combined data for moderate, severe, and profound intellectual disability shown in Figures 2, 3 and 4 indicated a distinct changing age profile over the 33 year period, with fewer children and young adults and more older adults availing of or in need of, intellectual disability services. There are fewer children and young people, aged 0–19 years, with moderate, severe, or profound intellectual disability now 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 education that 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 years age group. The implementation of Part II of the Disability Act, 2005 on assessment of need for children under 5 years is likely to generate much needed information about this cohort.

Cohort effect

There has been a significant increase in the number of adults currently availing of, or in need of, intellectual disability services. Closer examination of recent databases suggests that the increase in the older age group almost certainly reflects a cohort effect, whereby a population bulge originating in the 1960s and lasting until the mid-1970s is moving through the services and is now 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 years age group, which translated into the peak prevalence rate in 1981 in the 15–19 years age group. The peak prevalence rate in 1996 to 2002 was observed in the 20–34 years age group. As this cohort continued to age, the peak prevalence rate each year from 2003 to 2006 was observed in the 35–54 years age group. However, in 2007, this pattern changed, the prevalence rate in this age group decreased from 4.82/1000 in 2006 to 4.46/1000 in 2007. What is of particular interest in 2007 is that for the first time the peak prevalence rate for individuals with moderate, severe or profound intellectual disability was observed in the 10–14 years age group. As mentioned early in the chapter, this change can be attributed to an increase of 12% between 2002 and 2007 in the numbers in the 10–14 years age group with moderate, severe or profound intellectual disability registered on the database, with a simultaneous decrease of 4% in this age group in the general population during the corresponding census period (Central Statistics Office, 2006).

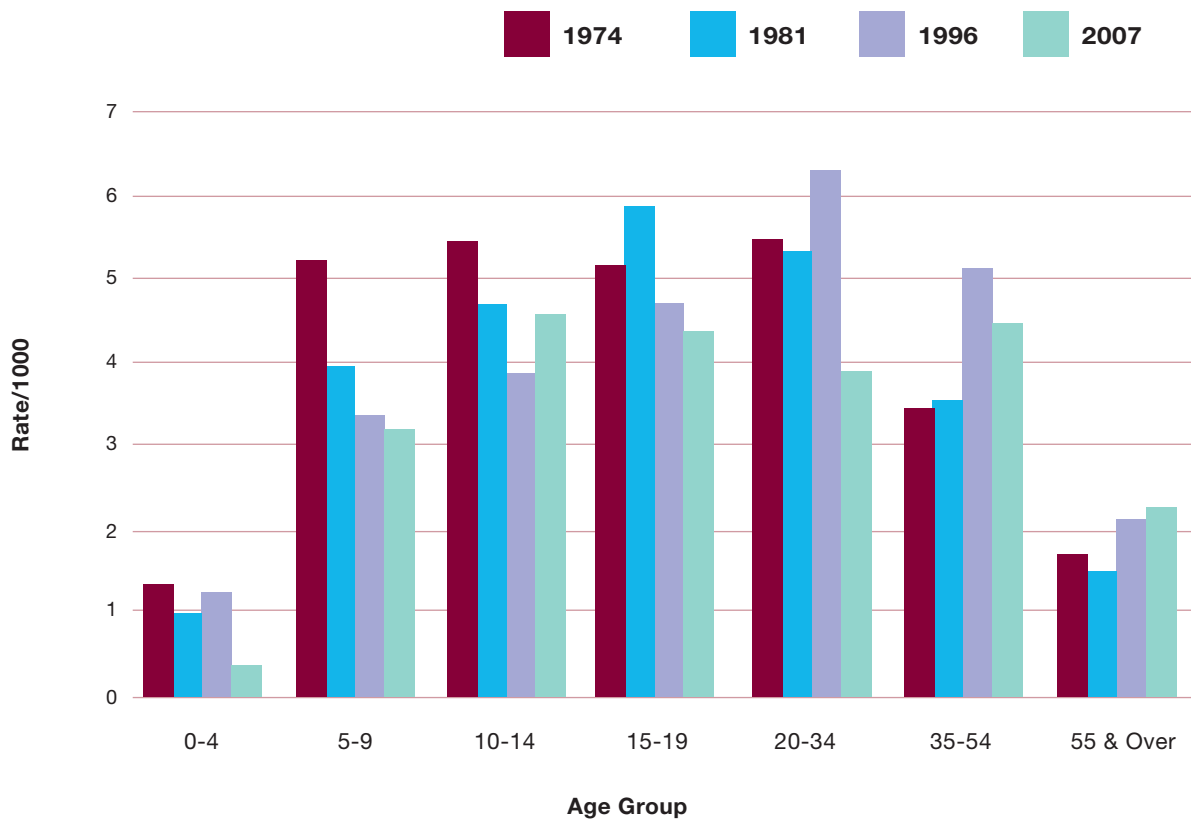


Figure 2 Prevalence of moderate, severe and profound intellectual disability (combined) by age group: 1974, 1981, 1996, 2007

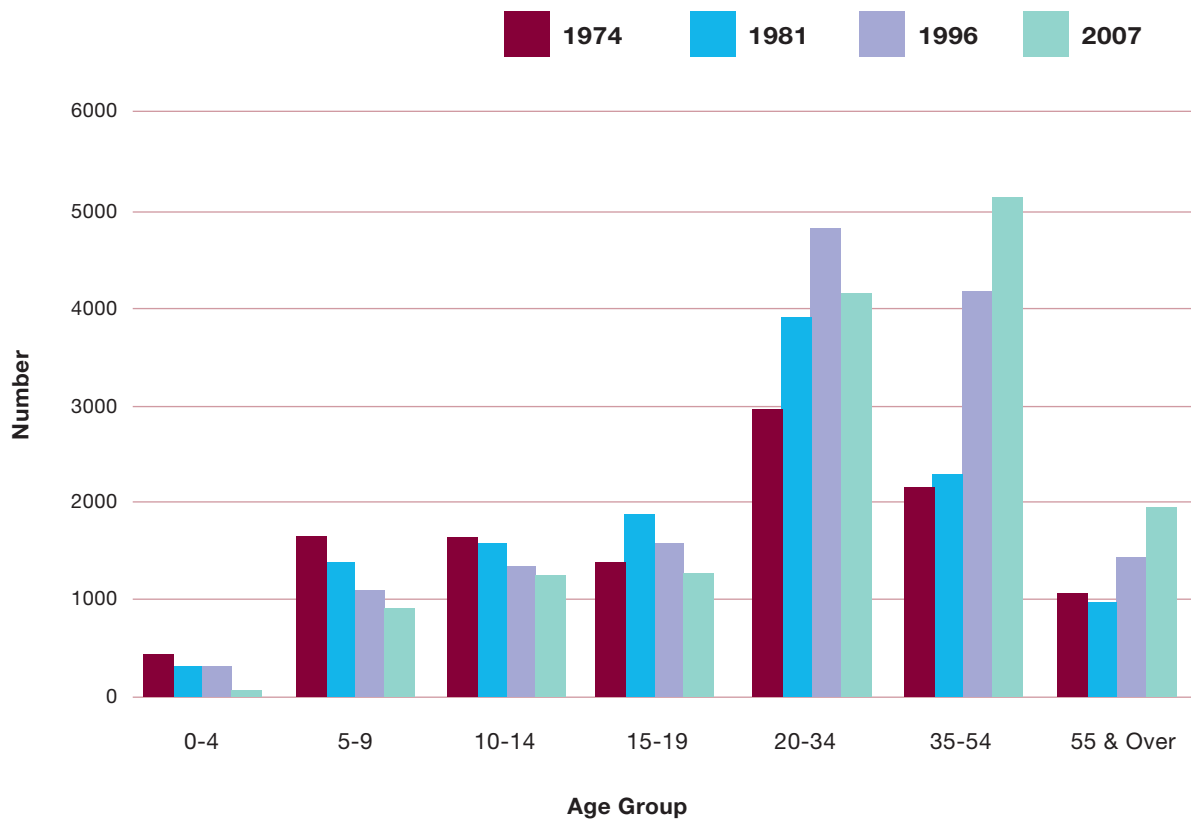


Figure 3 Numbers with moderate, severe and profound intellectual disability (combined) by age group: 1974, 1981, 1996, 2007



Ageing Population

Figure 4 provides evidence to suggest that the population of people with intellectual disability in Ireland is an ageing one. Increased longevity in this population is attributed in the research literature to improved health and well-being, the control of infectious diseases, the move to community living, improved nutrition, and the quality of health care services. By grouping people with a moderate, severe or profound intellectual disability into two groups, people aged under 35 years and people aged 35 years or over, it can be seen that 28.5% of this population 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 48.0% in the 2007 dataset. Almost half of people with a moderate, severe or profound intellectual disability are aged 35 years or over. This increase between 1996 and 2007 represents 1,484 more people with a moderate, severe or profound intellectual disability that are aged 35 years or over.

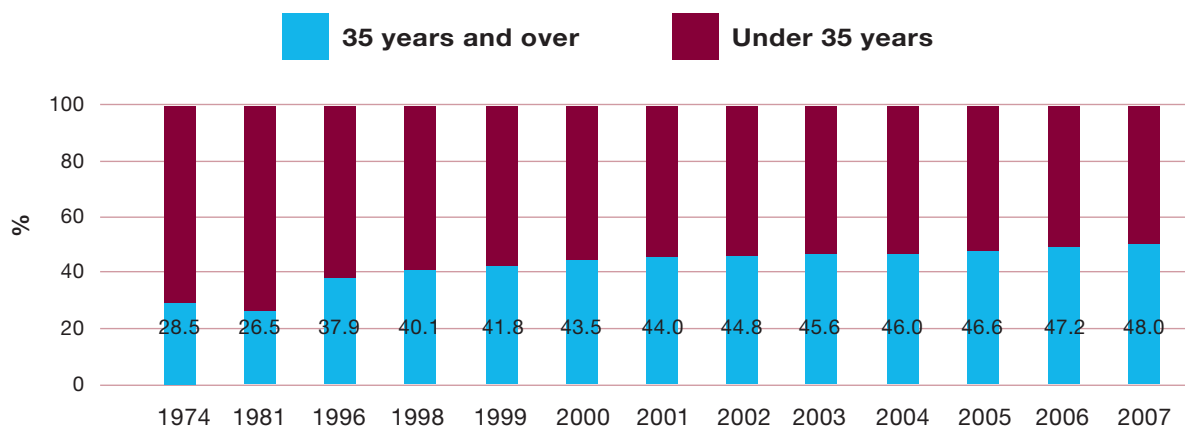


Figure 4 Proportion of people with moderate, severe and profound intellectual disability (combined) aged over 35 years: 1974, 1981, 1996, 1998–2007

Impact of observed trends

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

- Residential services are primarily used by adults with a more severe intellectual disability (see Chapter 3). As the number of individuals in this group increases, more pressure is being placed on residential services. This is reflected in the current waiting lists for full-time residential services.
- Improved life expectancy among adults with a more severe intellectual disability 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.
- The majority of adults with intellectual disability continue to live with their families (see Chapter 3). As these caregivers age beyond their care-giving capacity, residential supports are required.
- Additional therapeutic support services are also 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 – this baby-boom generation, born in the 1960s and 1970s, will begin to reach age 55 in 2015, just eight years away. Without anticipation of these needs, crisis situations often result for families and service providers. The NIDD is an invaluable resource in providing a sound evidence base for service planning and delivery. Not only does it allow us to identify specific individual service requirements arising in the next five years, but the demographic information also allows us to look further into the future and anticipate the impact of changing demographic trends.

Regional Level

Numbers on each regional database

Table 2.4 details the number of individuals registered within each Regional Health Area of the HSE. The numbers registered in each region are 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 are funded by the State but receive services outside the State. Table 2.5 details the number of individuals registered within each Local Health Office of the HSE.

Table 2.4 Number of people registered within the Regional Health Areas of the Health Service Executive

	n	% of NIDD	% of total population
Dublin/Mid-Leinster	6959	27.2	28.7
South	7014	27.4	25.5
West	6691	26.1	23.9
Dublin/North-East	4946	19.3	21.9
Out of State	3	0.0	0.0
Total	25613	100.0	100.0

Table 2.5 Number of people registered within the Local Health Offices of the Health Service Executive

	n	% of NIDD
Dublin/Mid-Leinster	6959	27.2
South Dublin Area 1	645	2.5
South Dublin Area 2	334	1.3
Wicklow Area 10	750	2.9
Dublin South City Area 3	301	1.2
Dublin South West Area 4	754	2.9
Dublin West Area 5	1308	5.1
Kildare/West Wicklow Area 9	1317	5.1
Laois/Offaly	678	2.6
Longford/Westmeath	872	3.4
South	7014	27.4
Cork North Lee	1564	6.1
Cork South Lee ^a	422	1.6
North Cork	538	2.1
West Cork	390	1.5
Kerry	912	3.6
Carlow/Kilkenny	943	3.7
South Tipperary SR	643	2.5
Waterford	684	2.7
Wexford	918	3.6
West	6691	26.1
Donegal	889	3.5
Sligo/Leitrim	855	3.3
Galway	1587	6.2
Mayo	931	3.6
Roscommon	380	1.5
Limerick	902	3.5
North Tipperary	685	2.7
Clare	462	1.8
Dublin/North-East	4946	19.3
North Dublin Area 6	1124	4.4
North Dublin Area 7	537	2.1
North Dublin Area 8	1182	4.6
Cavan/Monaghan	582	2.3
Louth	972	3.8
Meath	549	2.1
Out of State	3	0.0
Total	25613	100.0

^a Cork North Lee and Cork South Lee were previously considered as one area for local administrative purposes within intellectual disability services. The process of assigning NIDD records within the two areas has recently commenced.



Table 2.6 summarises the number and proportion of people at each level of intellectual disability registered in each Regional Health Area of the HSE. Table 2.7 details the number and proportion of people at each level of intellectual disability registered within each Local Health Office of the HSE.

Table 2.6 Degree of intellectual disability by the Regional Health Areas of the Health Service Executive

	Not verified	Mild	Moderate	Severe	Profound	All levels
	n	n	n	n	n	n
	%	%	%	%	%	%
Dublin/Mid-Leinster	954	2082	2745	875	303	6959
	13.7	29.9	39.4	12.6	4.4	100.0
Southern	544	2432	2559	1115	364	7014
	7.8	34.7	36.5	15.9	5.2	100.0
Western	614	2259	2488	1129	201	6691
	9.2	33.8	37.2	16.9	3.0	100.0
Dublin/North-East	444	1544	1950	848	160	4946
	9.0	31.2	39.4	17.1	3.2	100.0
Out of State	0.0	3	0.0	0.0	0.0	3
	0.0	100.0	0.0	0.0	0.0	100.0
Total	2556	8320	9742	3967	1028	25613
	10.0	32.5	38.0	15.5	4.0	100.0

Table 2.7 Degree of intellectual disability by the Local Health Offices of the Health Service Executive

	Not verified	Mild	Moderate	Severe	Profound	All levels
	n	n	n	n	n	n
	%	%	%	%	%	%
Dublin/Mid-Leinster	954	2082	2745	875	303	6959
	13.7	29.9	39.4	12.6	4.4	100.0
South Dublin Area 1	112	204	225	86	18	645
	17.4	31.6	34.9	13.3	2.8	100.0
South Dublin Area 2	80	108	116	27	3	334
	24.0	32.3	34.7	8.1	0	100.0
Wicklow Area 10	154	332	185	74	5	750
	20.5	44.3	24.7	9.9	0	100.0
Dublin South City Area 3	36	66	165	34	0	301
	12.0	21.9	54.8	11.3	0	100.0
Dublin South West Area 4	106	195	322	102	29	754
	14.1	25.9	42.7	13.5	3.8	100.0
Dublin West Area 5	148	370	472	163	155	1308
	11.3	28.3	36.1	12.5	11.9	100.0
Kildare/West Wicklow Area 9	187	347	573	163	47	1317
	14.2	26.3	43.5	12.4	3.6	100.0
Laois/Offaly	59	213	307	81	18	678
	8.7	31.4	45.3	11.9	2.7	100.0
Longford/Westmeath	72	247	380	145	28	872
	8.3	28.3	43.6	16.6	3.2	100.0
South	544	2432	2559	1115	364	7014
	7.8	34.7	36.5	15.9	5.2	100.0
Cork North Lee	45	545	537	321	116	1564
	2.9	34.8	34.3	20.5	7.4	100.0
Cork South Lee ^a	15	145	193	48	21	422
	3.6	34.4	45.7	11.4	5.0	100.0
North Cork	15	164	254	87	18	538
	2.8	30.5	47.2	16.2	3.3	100.0
West Cork	21	195	122	35	17	390
	5.4	50.0	31.3	9.0	4.4	100.0
Kerry	139	251	360	135	27	912
	15.2	27.5	39.5	14.8	3.0	100.0
Carlow/Kilkenny	71	341	322	131	78	943
	7.5	36.2	34.1	13.9	8.3	100.0
South Tipperary	54	290	206	69	24	643
	8.4	45.1	32.0	10.7	3.7	100.0
Waterford	18	218	268	143	37	684
	2.6	31.9	39.2	20.9	5.4	100.0
Wexford	166	283	297	146	26	918
	18.1	30.8	32.4	15.9	2.8	100.0



	Not verified	Mild	Moderate	Severe	Profound	All levels
	n	n	n	n	n	n
	%	%	%	%	%	%
West	614	2259	2488	1129	201	6691
	9.2	33.8	37.2	16.9	3.0	100.0
Donegal	119	289	347	113	21	889
	13.4	32.5	39.0	12.7	2.4	100.0
Sligo/Leitrim	63	315	280	169	28	855
	7.4	36.8	32.7	19.8	3.3	100.0
Galway	108	563	548	321	47	1587
	6.8	35.5	34.5	20.2	3.0	100.0
Mayo	147	323	308	137	16	931
	15.8	34.7	33.1	14.7	1.7	100.0
Roscommon	40	142	146	45	7	380
	10.5	37.4	38.4	11.8	1.8	100.0
Limerick	55	317	333	157	40	902
	6.1	35.1	36.9	17.4	4.4	100.0
North Tipperary	46	153	312	137	37	685
	6.7	22.3	45.5	20.0	5.4	100.0
Clare	36	157	214	50	5	462
	7.8	34.0	46.3	10.8	1.1	100.0
Dublin/North-East	444	1544	1950	848	160	4946
	9.0	31.2	39.4	17.1	3.2	100.0
North Dublin Area 6	97	302	478	197	50	1124
	8.6	26.9	42.5	17.5	4.4	100.0
North Dublin Area 7	88	156	211	73	9	537
	16.4	29.1	39.3	13.6	1.7	100.0
North Dublin Area 8	126	340	452	244	20	1182
	10.7	28.8	38.2	20.6	1.7	100.0
Cavan/Monaghan	64	121	308	73	16	582
	11.0	20.8	52.9	12.5	2.7	100.0
Louth	22	385	295	216	54	972
	2.3	39.6	30.3	22.2	5.6	100.0
Meath	47	240	206	45	11	549
	8.6	43.7	37.5	8.2	2.0	100.0
Out of State	0.0	3	0.0	0.0	0.0	3
	0.0	100.0	0.0	0.0	0.0	100.0
Total	2556	8320	9742	3967	1028	25613
	10.0	32.5	38.0	15.5	4.0	100.0

^a Cork North Lee and Cork South Lee were previously considered as one area for local administrative purposes within intellectual disability services. The process of assigning NIDD records within the two areas has recently commenced.

3. Service Provision in 2007

National Level

Summary of service provision

In 2007, 24,898 people with intellectual disability are receiving services, which accounts for 97.2% of the total population registered on the NIDD. This is the highest number of people recorded as in receipt of services since the database was established in 1995. A further 715 (2.8%) people are identified as not being in receipt of services, of whom 305 (1.2%) have expressed a need for services in the period 2008–2012. A summary of the overall level of service provision in 2007 is provided in Table 3.1.

Table 3.1 Summary of service provision in 2007

	n	%
Attending services on a day basis	16604	64.8
Receiving 5- or 7-day residential services	7933	31.0
Resident in a psychiatric hospital	329	1.3
Receiving residential support services only	32	0.1
Receiving no service – on waiting list	305	1.2
No identified service requirements	410	1.6
Total	25613	100.0

Note:

5,028 day attenders and 603 full-time residents receive residential support services in addition to their principal service. 8,125 full-time residents receive a day service in addition to their full-time residential service.

Table 3.2 summarises service provision in 2007 by degree of intellectual disability and age group.

Without services

In 2007 there are 305 people (1.2%) without services and who have identified service needs in the period 2008–2012, details of which are presented in chapter 4¹. Over 60% of this group are in the 'not verified' (14.1%) and mild (46.9%) categories of intellectual disability and 39.0% have a moderate, severe, or profound level of intellectual disability. The majority (86.6%) are aged 18 years and over.

1. Seventeen require a full-time residential place and a day place, 5 require a full-time residential place only, 214 require a day place only (Table 4.1), 17 require a residential support place only (Table 4.2), and 52 require multidisciplinary support services only (Table 4.19).



Table 3.2 Summary of service provision in 2007 by degree of intellectual disability and age group

	Not verified			Mild			Moderate, Severe & 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
Attending services on a day basis	1763	450	2213	2829	3952	6781	2846	4764	7610	7438	9166	16604
Receiving 5- or 7- day residential services	14	154	168	31	1196	1227	155	6383	6538	200	7733	7933
Resident in psychiatric hospital	0	7	7	0	88	88	0	234	234	0	329	329
Receiving residential support services only	6	1	7	0	13	13	2	10	12	8	24	32
Receiving no service - on waiting list	29	14	43	5	138	143	7	112	119	41	264	305
No current service requirements	99	19	118	5	63	68	11	213	224	115	295	410
Total	1911	645	2556	2870	5450	8320	3021	11716	14737	7802	17811	25613

A further 410 people (1.6% of total registrations) are also without services but have no identified requirement for services within the five-year period 2008–2012. There are two likely explanations for this categorisation. Firstly, it is possible that some of this group are appropriately registered on the database but their service needs have not been adequately identified. Secondly, it is also likely that a proportion of this group, who have a mild degree of intellectual disability, are inappropriately registered on the database, as they are not seeking to avail of specialised health services. Of this group of 410 people with no identified service requirements:

- 160 (39.0%) have their circumstances formally reviewed annually and 148 (36.1%) have contingency service plans identified on the database.
- 295 (72.0%) are aged 18 years or over.
- 186 (45.4%) have a mild or 'not verified' level of intellectual disability and it is not unreasonable to assume that they genuinely do not require services at this time. The appropriateness of registering people with mild intellectual disability who have no identified need for specialised health services on the database is being monitored on an ongoing basis.
- 224 (54.6%) have a moderate, severe, or profound degree of intellectual disability. Within this group, 116 have their circumstances formally reviewed annually and 91 have contingency service plans identified on the database. While these people may not wish to avail of services at this time, it is essential that their needs are monitored on a regular basis so that changing circumstances can be identified and responded to in a timely manner. Failure to anticipate the needs of this group can result in emergency admissions to services that may not be tailored to the specific needs of the individual. The National Intellectual Disability Database Committee remains concerned about the circumstances of 11 children within this group who have a moderate, severe or profound intellectual disability and are not availing of services and have no identified need for services in the period 2008–2012.

Availing of services

As mentioned in Chapter 2, there is a clear relationship between level of disability, age, and the type of service availed of. As illustrated in Table 3.2, individuals attending services on a day basis tend to be younger and in the less severe range of intellectual disability, while residential services are used primarily by adults with a moderate, severe or profound level of intellectual disability.



- Of the 16,604 individuals accessing services on a day basis in 2007, 6,781 (40.8%) have a mild level of intellectual disability and 7,438 (44.8%) are under 18 years.
- There are 7,933 full-time residents in 2007, of whom 6,538 (82.4%) have a moderate, severe or profound degree of disability, and 7,733 (97.5%) are aged 18 years or over.
- All 329 individuals with an intellectual disability residing in psychiatric hospitals are aged 18 years or over, and 234 (71.1%) have a moderate, severe, or profound degree of intellectual disability.

A further 32 individuals registered on the database in 2007 are availing of residential support services only.

Residential circumstances

Table 3.3 outlines the main residential circumstances of those registered on the NIDD in 2007. The main groupings of individuals consist of

- 16,366 individuals (63.9%) living in a home setting with parents, relatives, or foster parents;
- 8,262 individuals (32.3%) living in full-time residential services, mainly in community group homes, residential centres, psychiatric hospitals, and intensive placements. This is an increase of 81 on last year's figure and is the largest number of full-time residents recorded on the database since 2001;
- 903 individuals (3.5%) living independently or semi-independently.

The most commonly availed of residential settings are community group homes. This is the third consecutive year of data that indicate that more full-time residents live in homes in the community (3,750) than in residential centres (3,178). The numbers of people accommodated in community group homes and in residential centres have increased and decreased respectively, on an almost continuous basis, since data collection commenced in 1996. This trend reflects a shift towards community living in the provision of residential services to people with an intellectual disability.

In 2007, there are 387 people with an intellectual disability residing full-time in mental health services; either in psychiatric hospitals (329 individuals, compared with 348 individuals in 2006) or in mental health community residences (58 individuals).

The 2007 data indicate that 52 of the full-time residents are occupying residential support places on a full-time basis, thereby reducing the number of residential support places available for the provision of respite care. There are thirteen individuals registered on the database who have no fixed abode. There is insufficient information on the residential circumstances of 69 people (0.3%) registered on the database, a decrease of 160 people (69.9%) since 2006. This figure highlights that progress has been made over the past number of years in reducing the numbers in this group, however the remaining people need to be further reviewed as a matter of urgency to improve the overall quality of data available from the NIDD.

Table 3.3 Main residential circumstances

	n	%
Home setting	16366	63.9
At home with both parents	11074	43.2
At home with one parent	3848	15.0
At home with sibling	885	3.5
At home with other relative	224	0.9
Living with non-relative	27	0.1
Adoption	26	0.1
Foster care and boarding-out arrangements	282	1.1
Independent setting	903	3.5
Living independently	599	2.3
Living semi-independently	304	1.2
Community group homes	3750	14.6
5-day community group home	491	1.9
7-day (48-week) community group home	629	2.5
7-day (52-week) community group home	2630	10.3
Residential centres	3178	12.4
5-day residential centre	99	0.4
7-day (48-week) residential centre	429	1.7
7-day (52-week) residential centre	2650	10.3
Other full-time services	1334	5.2
Nursing home	155	0.6
Mental health community residence	58	0.2
Psychiatric hospital	329	1.3
Intensive placement (challenging behaviour)	438	1.7
Intensive placement (profound or multiple handicap)	257	1.0
Occupying a residential support place	52	0.2
Other full-time residential service	45	0.2
No fixed abode	13	0.1
Insufficient information	69	0.3
Total	25613	100.0



Main residential circumstances: age group and degree of intellectual disability

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

Age differences

There are notable differences in the age profiles of individuals in the various categories of accommodation. The proportion of people living in a home setting decreases with age – 96.6% of individuals aged 0–19 years live in a home setting, declining to 69.8% of those aged 20–34 years, 37.5% of those aged 35–54 years, and 16.7% of those aged 55 years or over.

In contrast, the proportion of people in the different age categories who are living in full-time residential services increases with age – 3.2% of all 0–19 year olds are in receipt of full-time residential services, compared to 27.1% of 20–34 year olds, 55.1% of 35–54 year olds, and 75.4% 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 continue to live with their families. Planning for the future care of these individuals and avoiding crisis situations when family carers can no longer provide care is of paramount importance.

Degree of intellectual disability

There are also noticeable variations between level of ability and type of residential situation. Of those people with a mild intellectual disability, 76.3% live in a home setting, compared to 52.5% of those with a moderate, severe or profound intellectual disability. The proportion of people in full-time residential services increases within the more severe categories of disability. Only 15.8% of people with a mild intellectual disability live in full-time residential services but this increases to 46.0% in the case of those with a moderate, severe, or profound disability.

Where individuals are in full-time residential services, the type of service varies according to level of intellectual disability. Full-time residents with a mild intellectual disability are most likely to be accommodated in community group homes, while full-time residents with a moderate, severe or profound intellectual disability are most likely to be accommodated in residential centres.



- Of those in the mild range of intellectual disability who are in full-time residential services, 64.6% are in community group homes, 18.8% are in residential centres, and 16.6% are in other full-time residential services.
- Of those in full-time residential services who have a moderate, severe or profound intellectual disability, 42.2% are in community group homes, 42.1% are in residential centres, and 15.8% are in other full-time residential services.

Table 3.4 Main residential circumstances, degree of intellectual disability and age group

	Not verified					Mild					Moderate, Severe & Profound					All levels				
	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total
Home setting	1922	156	159	45	2282	3362	1766	1050	173	6351	3302	2614	1559	258	7733	8586	4536	2768	476	16366
Independent setting	0	14	51	29	94	4	135	376	124	639	3	31	88	48	170	7	180	515	201	903
Community group home	3	9	24	9	45	34	171	411	234	850	92	627	1565	571	2855	129	807	2000	814	3750
Residential centre	5	9	22	47	83	6	38	93	110	247	84	541	1415	808	2848	95	588	1530	965	3178
Other full-time services	9	3	10	25	47	3	52	81	82	218	50	311	449	259	1069	62	366	540	366	1334
No fixed abode	0	1	0	1	2	0	2	4	1	7	0	1	2	1	4	0	4	6	3	13
Insufficient information	3	0	0	0	3	2	6	0	0	8	2	9	28	19	58	7	15	28	19	69
Total	1942	192	266	156	2556	3411	2170	2015	724	8320	3533	4134	5106	1964	14737	8886	6496	7387	2844	25613

Day services

In 2007, 24,729 people, representing 96.5% of all those registered on the NIDD, are availing of day services. This represents the highest number of NIDD registrations availing of day services 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 by people who are also receiving full-time residential services. Table 3.5 summarises the level of disability and age group of people availing of day services according to their residential status.

Table 3.5 Residential status of people availing of day services by degree of intellectual disability and age group

	Not verified			Mild			Moderate, Severe & 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
Residents	13	159	172	30	1255	1285	154	6514	6668	197	7928	8125
Day attenders	1763	450	2213	2829	3952	6781	2846	4764	7610	7438	9166	16604
Total	1776	609	2385	2859	5207	8066	3000	11278	14278	7635	17094	24729

Of the 24,729 individuals availing of day services, 8,125 (32.9%) are also in full-time residential services, the majority of whom are in the moderate, severe, or profound range of intellectual disability (82.1%) and aged 18 years or over (97.6%). The remaining 16,604 (67.1%) attend services on a day basis, of whom 40.8% are in the mild range of intellectual disability and 44.8% are under 18 years.

The 2007 data indicate that 137 full-time residents have no formal day programme. The day service needs of this group, where identified, are documented in Chapter 4 of this report.

Details of the principal day services provided in 2007 both to residents and to those who attend services on a day basis can be seen in Table 3.6.



Table 3.6 Principal day service by category of persons availing of day services

	Residents	Day attenders	Total
Home support	3	212	215
Home help	1	27	28
Early intervention team	1	492	493
Mainstream pre-school	0	300	300
Special pre-school for intellectual disability	1	557	558
Child education and development centre	30	291	321
Mainstream school	3	1243	1246
Resource/visiting teacher	1	282	283
Special class – primary level	6	523	529
Special class – secondary level	1	196	197
Special school	208	4092	4300
Rehabilitative training	245	1282	1527
Activation centre	3123	1961	5084
Programme for the older person	511	100	611
Special high-support day service	429	136	565
Special intensive day service	259	88	347
Sheltered work centre – includes long-term training schemes	1817	2498	4315
Sheltered employment centre	24	100	124
Multidisciplinary support services	1012	557	1569
Centre-based day respite service	3	16	19
Day respite in the home	2	8	10
Other day service	140	239	379
Enclave within open employment	2	10	12
Supported employment	134	823	957
Open employment	14	131	145
Vocational training	66	302	368
Generic day services	89	138	227
Total	8125	16604	24729

As in 2006, the top three day activities availed of by people with an intellectual disability in 2007, and accounting for more than half of principal day service provision, are: activation programmes, sheltered work, and special schools. People who attend services on a day basis are availing mainly of training, work programmes and education, reflecting both the higher level of ability and younger age profile of people in this category. Those in full-time residential services are much more likely to avail of services such as activation programmes, sheltered work, multidisciplinary support services, specific programmes for older people, and special high-support programmes.

Main day services by age group and degree of intellectual disability

Table 3.7 provides details of the principal day services availed of in 2007, categorised by age group and degree of intellectual disability.

Age differences

Of those availing of day services in 2007 (24,729 individuals), 7,635 (30.9%) are under 18 years, and 17,094 (69.1%) are aged 18 years or over (see Table 3.7).

In 2007 there are 7,635 individuals under 18 years accessing day services. The majority are in mainstream or special education services at primary and secondary level, availing of early intervention, attending both mainstream and specialised pre-school services, or are attending child education and development centres.

There are 17,094 adults availing of day services in 2007. Most adults attend either activation centres (29.7%) or sheltered work centres (25.2%). The next largest groups are concentrated in the areas of multidisciplinary support services only (8.9%), rehabilitative training (8.9%), and supported employment (5.6%).

Degree of intellectual disability

Of those receiving day services in 2007 (24,729 individuals), 8,066 (32.6%) have a mild intellectual disability, 14,278 (57.7%) have a moderate, severe or profound intellectual disability, 2,385 (9.6%) have not yet had their degree of intellectual disability established (see Table 3.7).

The age profiles of these groups are quite different. Just over one in five (21.0%) of the population with moderate, severe or profound intellectual disability who are availing of day services is aged under 18 years, whereas more than one in three (35.4%) of the population with mild intellectual disability who are availing of day services is aged under 18 years.



The higher number of children with mild intellectual disability in receipt of services reflects the number of children in special education, a proportion of whom do not transfer to the adult intellectual disability services upon leaving school.

Of the 7,635 children availing of day services in 2007:

- 2,859 (37.4%) have a mild degree of intellectual disability, most of whom avail of special education services, with smaller numbers in mainstream schools and pre-school services.
- 3,000 (39.3%) have a moderate, severe or profound intellectual disability and, while most are receiving special education services, smaller numbers are in mainstream education or pre-school services; some also avail of more intensive services such as child education and development centres.
- 1,776 (23.3%) have not as yet had their degree of intellectual disability verified.

Of the 17,094 adults in receipt of day services in 2007:

- 5,207 (30.5%) have a mild degree of intellectual disability, most of whom attend sheltered work centres, are in receipt of activation programmes, avail of rehabilitative training, or are in supported employment.
- 11,278 (66.0%) are in the moderate, severe or profound range and are most likely to be in receipt of activation programmes, followed by sheltered work, multidisciplinary support services only, and rehabilitative training.
- 609 (3.6%) have not had their degree of intellectual disability established.

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

	Not verified			Mild			Moderate, Severe & 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	51	25	76	8	42	50	18	71	89	77	138	215
Home help	6	2	8	0	9	9	3	8	11	9	19	28
Early intervention team	434	0	434	30	0	30	29	0	29	493	0	493
Mainstream pre-school	188	0	188	73	0	73	39	0	39	300	0	300
Special pre-school for intellectual disability	348	0	348	71	0	71	139	0	139	558	0	558
Child education and development centre	22	2	24	0	1	1	234	62	296	256	65	321
Mainstream school	169	1	170	674	49	723	341	12	353	1184	62	1246
Resource/visiting teacher	86	0	86	116	23	139	52	6	58	254	29	283
Special class – primary level	192	0	192	151	23	174	153	10	163	496	33	529
Special class – secondary level	11	2	13	64	45	109	46	29	75	121	76	197
Special school	217	11	228	1634	333	1967	1873	232	2105	3724	576	4300
Rehabilitative training	0	71	71	11	653	664	0	792	792	11	1516	1527
Activation centre	0	126	126	0	673	673	1	4284	4285	1	5083	5084
Programme for the older person	0	21	21	0	102	102	0	488	488	0	611	611
Special high-support day service	0	1	1	0	33	33	7	524	531	7	558	565
Special intensive day service	3	2	5	3	33	36	18	288	306	24	323	347
Sheltered work centre	0	108	108	0	1686	1686	0	2521	2521	0	4315	4315
Sheltered employment centre	0	10	10	0	72	72	0	42	42	0	124	124
Multidisciplinary support services	22	103	125	6	339	345	18	1081	1099	46	1523	1569
Centre-based day respite service	2	1	3	0	7	7	0	9	9	2	17	19
Day respite in the home	4	1	5	1	1	2	0	3	3	5	5	10
Other day service	20	5	25	11	113	124	27	203	230	58	321	379
Enclave within open employment	0	0	0	0	2	2	0	10	10	0	12	12
Supported employment	0	50	50	0	557	557	0	350	350	0	957	957
Open employment	0	5	5	0	113	113	0	27	27	0	145	145
Vocational training	0	15	15	5	235	240	2	111	113	7	361	368
Generic day services	1	47	48	1	63	64	0	115	115	2	225	227
Total	1776	609	2385	2859	5207	8066	3000	11278	14278	7635	17094	24729

Overall level of service provision in 2007

Background

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 analyses of existing levels of service provision in Table 3.8 and Table 3.9 are a combination of the main and secondary residential services and the main, secondary and tertiary day programmes respectively, and are representative of the overall level of service provision. The total numbers presented in both tables exceed the actual number of people with an intellectual disability in each of the service categories, as a number of people avail of two different types of residential service and two or three different types of day service.

The 2007 dataset is the eleventh in a series that commenced in 1996, and was continued in each of the nine years from 1998 to 2006. The first and fourth datasets, from 1996 (National Intellectual Disability Database Committee, 1997) and 2000 (Mulvany, 2001), have been selected for comparison with the 2007 data. The 1996 dataset is selected because it is the first in the series and the 2000 dataset is selected as a benchmark at the beginning of the significant investment programme in intellectual disability services over the period 2000–2002. The development within services over the three datasets is illustrated in Figure 5 and Figure 6.

Table 3.8 details the overall number of residential services provided to people with intellectual disability in 2007. In addition to the principal residential circumstances reported in Table 3.3, there exists a wide range of residential support services which are designed to assist people with intellectual disability to continue living with their families and in their communities. These residential supports range from holiday breaks with host families and service-based respite breaks, to the provision of regular part-time care and supported living arrangements.

Trends in residential service provision: 1996 to 2007

Figure 5 illustrates the growth in full-time residential services and residential support services during the period 1996–2007.

Key developments in the provision of full-time residential services in the period 1996–2007 include:

- an increase of 56.7% (1,357) in the number of people with intellectual disability living in community group homes. Community group homes are now the most commonly availed of full-time residential placements.

- an increase of 100.3% (347) in the number of intensive placements specially designed to meet the needs of people with challenging behaviour or multiple disabilities.
- a reduction of 66.0% (641) in the number of people with intellectual disability accommodated in psychiatric hospitals during the period 1996 to 2007.

Between 1996 and 2007 there has been significant growth in the number of residential support places available. In particular, the data show an increase of 414.4% (3,609) in the number of individuals availing of centre-based respite services either as a planned or emergency intervention, bringing the total number availing of respite services in 2007 to 4,480. The vast majority of respite services are planned.

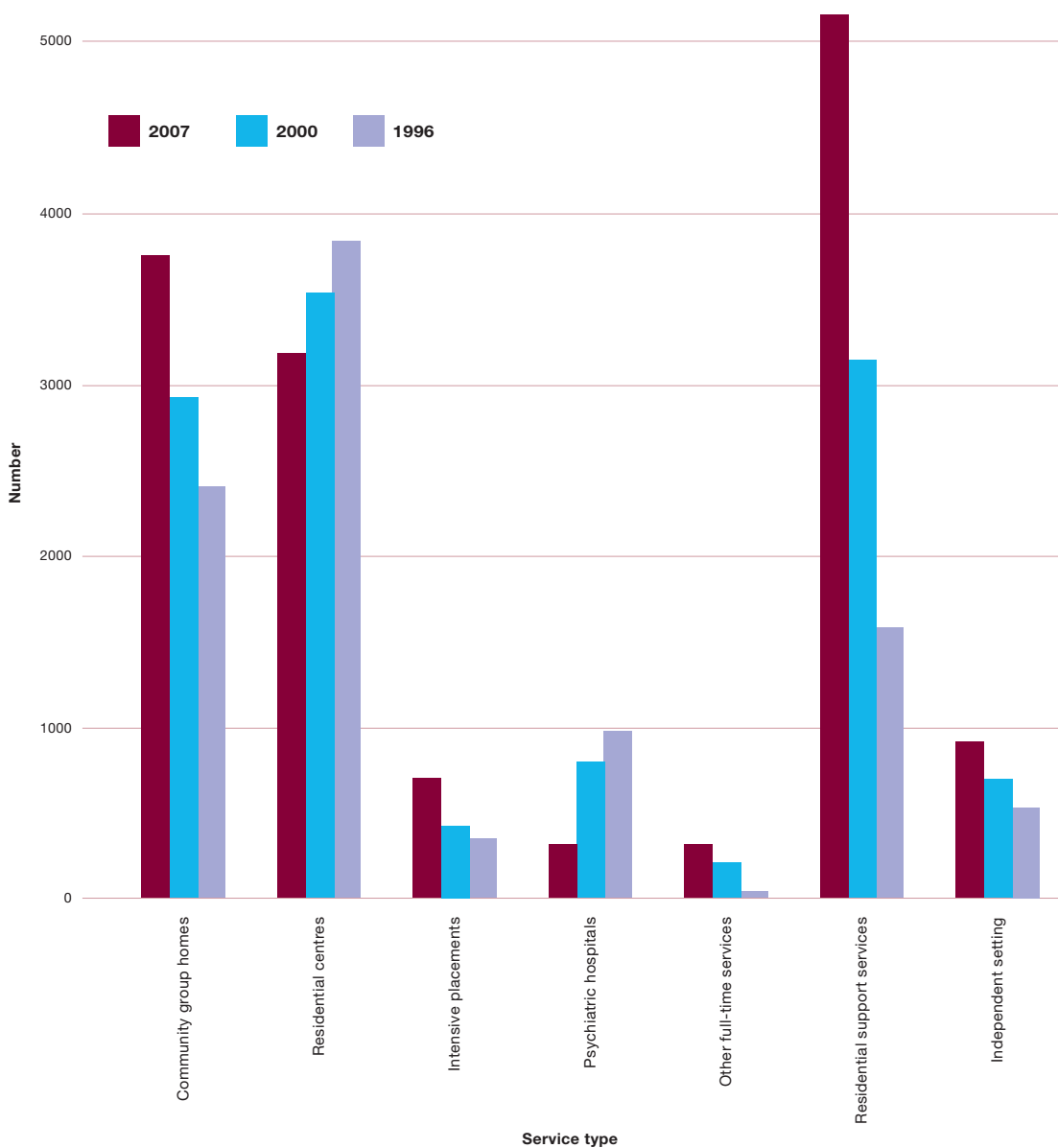


Figure 5 Changes in overall level of residential service provision: 1996, 2000, 2007



Table 3.8 Overall level of residential service provision in 2007, degree of intellectual disability and age group

	Not verified			Mild			Moderate, Severe & 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
5-day community group home	1	10	11	12	108	120	16	344	360	29	462	491
7-day (48-week) community group home	0	4	4	1	117	118	11	496	507	12	617	629
7-day (52-week) community group home	2	28	30	12	600	612	33	1955	1988	47	2583	2630
5-day residential centre	0	0	0	1	8	9	12	78	90	13	86	99
7-day (48-week) residential centre	0	3	3	0	42	42	21	363	384	21	408	429
7-day (52-week) residential centre	5	75	80	4	192	196	28	2346	2374	37	2613	2650
Nursing home	0	26	26	0	32	32	0	97	97	0	155	155
Mental health community residence	0	1	1	0	22	22	0	35	35	0	58	58
Psychiatric hospital	0	7	7	0	88	88	0	234	234	0	329	329
Intensive placement (challenging behaviour)	2	2	4	0	51	51	9	374	383	11	427	438
Intensive placement (profound or multiple disability)	4	2	6	0	6	6	15	230	245	19	238	257
Other full-time residential place	0	2	2	1	9	10	2	31	33	3	42	45
Occupying a residential support place	0	1	1	0	9	9	8	34	42	8	44	52
Holiday residential placement	0	4	4	4	40	44	6	94	100	10	138	148
Crisis or planned respite	117	80	197	192	725	917	920	2446	3366	1229	3251	4480
Occasional respite with host family	12	1	13	28	42	70	48	112	160	88	155	243
Overnight respite in the home	1	0	1	1	0	1	4	3	7	6	3	9
Shared care or guardianship	0	0	0	1	2	3	1	3	4	2	5	7
Regular part-time care (2/3 days per week)	0	1	1	1	11	12	12	66	78	13	78	91
Regular part-time care (every weekend)	0	0	0	2	0	2	2	10	12	4	10	14
Regular part-time care (alternate weeks)	0	0	0	0	1	1	4	50	54	4	51	55
Other residential service	4	0	4	1	13	14	5	77	82	10	90	100
Foster care and boarding-out arrangements	23	4	27	107	56	163	56	49	105	186	109	295
Living semi-independently	0	15	15	1	211	212	0	80	80	1	306	307
Living independently	0	79	79	0	432	432	1	90	91	1	601	602

Overall level of day service provision in 2007

Table 3.9 provides details of the overall level of day service provision for people with an intellectual disability. Of note in this table is the number of support services available to people with an intellectual disability in addition to their principal day service reported in Table 3.6; this includes 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.

Trends in day service provision: 1996 to 2007

Figure 6 illustrates the growth in day services during the period 1996–2007. The specific services included in each category are detailed in Appendix A. Multidisciplinary support services, which were recorded on the database for the first time in 2000, are excluded from Figure 6 and are discussed separately below.

Significant growth areas in day services during the eleven-year period include:

- An increase of 410.3% (1,350 people) in the provision of supported employment. The 2007 data indicate that 1,679 people are in supported employment placements.
- Increases in both high-support and intensive day places. The number of high-support day places has increased by 47.0% (188 people) and the number of intensive day places has increased by 209.5% (243 people). The 2007 data indicate that 588 and 359 people attend high-support and intensive day services respectively.
- An increase of 139.0% (385 people) in the number in receipt of day programmes specific for the older person. The number attending such services in 2007 is 662.
- An increase of 22.8% (987 people) in the number attending activation centres, bringing the total number to 5,313 in 2007.
- An increase of 180.5% (240 people) in the number of people in open employment. Much of this increase has occurred in recent years, with the number of open employment places increasing from 164 in 2004 to 401 in 2005. The 2006 figure saw a slight downturn of people in open employment (388 people) and the current 2007 figure is less again at 373.

A noticeable trend during the 1996–2007 period is the increased number of people availing of mainstream services. Increases are observed in the numbers availing of mainstream pre-schools, mainstream schools, resource teachers and vocational training. Although the numbers availing of mainstream services are proportionately low, the growth is in a positive direction and should be specifically targeted by the HSE for consistent and sustained support in line with best international practice.



Significant reductions in day services during the eleven-year period include:

- A decrease of 15.9% (819 individuals) attending special schools. Despite this reduction, special schools are the most commonly availed of day activity for young people, with 4,317 individuals attending in 2007.
- A decrease of 16.4% (311 people) in the number attending rehabilitative training, from 1,895 in 1996 to 1,584 in 2007.
- A decrease of 53.9% (394 individuals) in the number of children attending child education and development centres. The number attending such centres is 337 in 2007.

The 2007 dataset also demonstrates significant growth in the provision of support services which are delivered as part of a package of day services.

- Increases can be seen in the numbers of individuals availing of home support, home help, resource or visiting teacher, and centre-based and home-based day respite.
- Multidisciplinary support services, including those delivered by early intervention teams, have shown very substantial increases in recent years. In 2007, there are 18,169 individuals reported as receiving one or more multidisciplinary support service and 1,630 children receiving these services from an early intervention team.

The large difference in numbers receiving multidisciplinary support services (including services delivered by early intervention teams) between Table 3.7 (principal day service provision) and Table 3.9 (overall day service provision) arises because early services and multidisciplinary support services are only recorded as a principal day service if they are the only day service that an individual receives. The majority of people who are in receipt of multidisciplinary support services or services from an early intervention team also receive another service as their principal day service. Table 3.10 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, 19,799 individuals receive one or more multidisciplinary support service (including those provided by early intervention teams). This represents an increase of 647 people since 2006. As in 2006 the most commonly availed of multidisciplinary support services are social work (9,461 individuals), medical services (8,453 individuals), psychology (7,966 individuals), and speech and language therapy (6,707 individuals).

- The most common services availed of by adults are medical services (6,217 adults), social work (6,180 adults), and psychiatry (5,630 adults).
- The most common services availed of by children are speech and language therapy (1,571 children aged 6 years and under and 3,342 children aged 7 to 17 years), social work (1,174 children aged 6 years or under and 2,107 children aged 7 to 17 years), and psychology (1,154 children aged 6 years or under and 2,222 children aged 7 to 17 years).
- Early intervention teams usually provide services to children aged 6 years or under and 1,567 children (81.6%) of this age group receiving multidisciplinary support services have access to an early intervention team. There are also 63 children aged 7 years or over who receive services from an early intervention team.

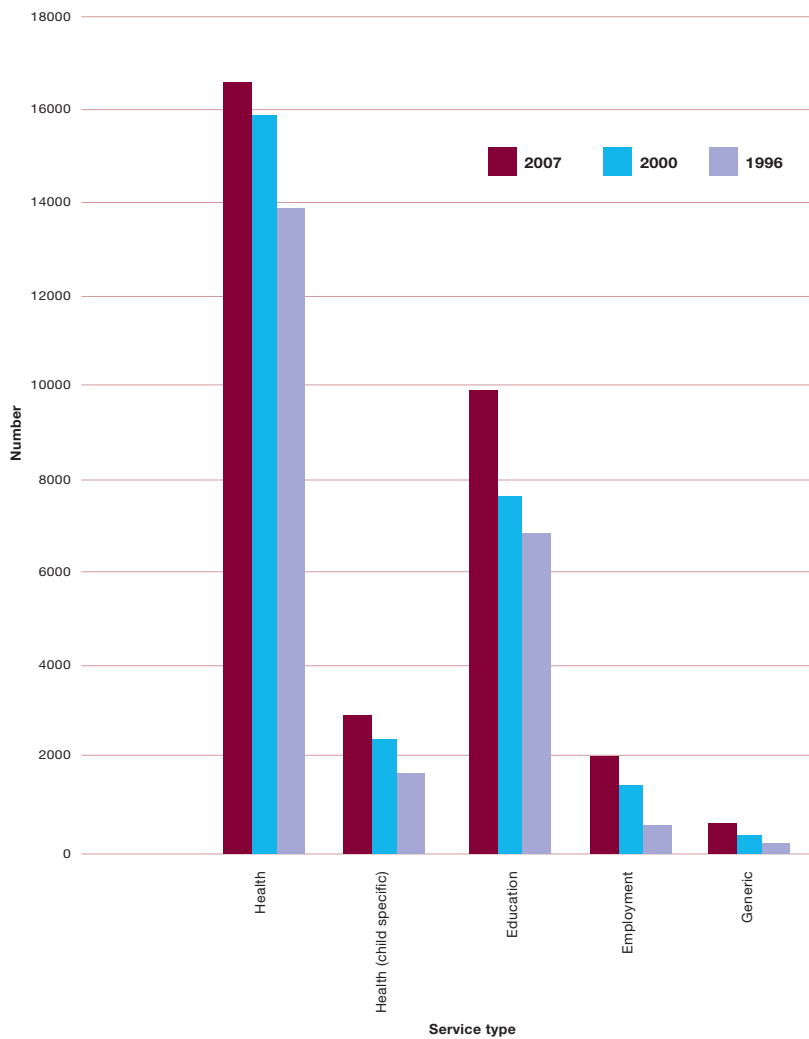


Figure 6 Changes in overall level of day service provision: 1996, 2000, 2007



Table 3.9 Overall level of day service provision in 2007, degree of intellectual disability and age group

	Not verified			Mild			Moderate, Severe & 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	228	43	271	278	200	478	616	517	1133	1122	760	1882
Home help	27	6	33	18	30	48	40	33	73	85	69	154
Early intervention team	1099	0	1099	238	0	238	293	0	293	1630	0	1630
Mainstream pre-school	269	0	269	113	0	113	81	0	81	463	0	463
Special pre-school	359	0	359	72	0	72	141	0	141	572	0	572
Child education and development centre	23	2	25	0	1	1	247	64	311	270	67	337
Mainstream school	170	1	171	686	49	735	366	15	381	1222	65	1287
Resource/visiting teacher	149	0	149	295	47	342	168	36	204	612	83	695
Special class - primary	194	0	194	151	23	174	155	11	166	500	34	534
Special class - secondary	11	2	13	64	45	109	46	29	75	121	76	197
Special school	219	11	230	1634	334	1968	1886	233	2119	3739	578	4317
Rehabilitative training	0	74	74	11	683	694	0	816	816	11	1573	1584
Activation centre	0	131	131	0	769	769	1	4412	4413	1	5312	5313
Programme for the older person	0	22	22	0	113	113	0	527	527	0	662	662
High-support day service	0	1	1	0	37	37	13	537	550	13	575	588
Intensive day service	3	3	6	3	37	40	18	295	313	24	335	359
Sheltered work	0	111	111	0	1783	1783	0	2631	2631	0	4525	4525
Sheltered employment	0	10	10	0	73	73	0	42	42	0	125	125
Multidisciplinary support services	543	346	889	1824	3459	5283	2428	9569	12024	4795	13374	18169
Centre-based day respite programme	36	2	38	128	70	198	295	325	620	459	397	856
Day respite in the home	13	1	14	4	2	6	20	8	28	37	11	48
Other day service	65	9	74	87	177	264	132	303	435	284	489	773
Enclave within open employment	0	0	0	0	5	5	0	14	14	0	19	19
Supported employment	0	58	58	0	922	922	0	699	699	0	1679	1679
Open employment	0	7	7	0	211	211	0	155	155	0	373	373
Vocational training	0	16	16	25	280	305	2	124	126	26	420	447
Generic day services	1	47	48	5	81	86	2	129	131	8	257	265

Table 3.10 Overall provision of multidisciplinary support services by age and access to early intervention teams (EIT)

	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	886	95	981	28	1227	1255	6217	8453
Nursing	726	100	826	19	987	1006	4720	6552
Nutrition	270	66	336	10	414	424	2177	2937
Occupational therapy	972	217	1189	37	1674	1711	2227	5127
Physiotherapy	1086	161	1247	28	1374	1402	2696	5345
Psychiatry	58	18	76	3	421	424	5630	6130
Psychology	981	173	1154	44	2178	2222	4590	7966
Social work	1039	135	1174	37	2070	2107	6180	9461
Speech and language therapy	1271	300	1571	52	3290	3342	1794	6707
Other	554	76	630	20	1147	1167	3622	5419
Number of people	1567	353	1920	63	4442	4505	13374	19799

Note:

Therapeutic inputs are only recorded if the individual has received, or will receive, at least four inputs of that service in a 12-month period. The number of therapeutic inputs received exceeds the number of people as many people receive more than one input.

Regional Level

Table 3.11 provides summary details of the level of service provision in 2007 within each Regional Health Area of the Health Service Executive. Table 3.12 provides details of the level of service provision in 2007 within each Local Health Office of the Health Service Executive.

Nationally, 24,898 individuals (97.2%) with an intellectual disability registered on the NIDD are in receipt of services in 2007. The highest level of service provision is in the Southern Regional Health Area, where 98.3% of the population registered on the database are receiving services. Dublin/Mid-Leinster Regional Health Area has the lowest level of service provision, where 96.5% of the population registered on the database are in receipt of services.



Nationally, 8,262 individuals (32.3%) registered on the NIDD in 2007 are in receipt of a full-time residential service. Regionally, this proportion varies from 30.8% in the Southern Regional Health Area to 33.0% in the Dublin/North-East Regional Health Area.

At national level, 16,604 (64.8% of the database population) are attending services on a day basis and this proportion ranges from 63.6% in the Western Regional Health Area to 67.5% in the Southern Regional Health Area.

Nationally, 305 (1.2%) registrations are without services but are identified as requiring services in the five-year period 2008–2012. The HSE Western Regional Health Area has the highest proportion of people without any service and awaiting services within the next five years (2.0%) and the remaining three Regional Health Areas are below the national average.

Although significantly reduced when compared with datasets from earlier years, there remains a considerable number of people registered on the database in 2007 (410, 1.6%) who are not availing of services and have no identified need for service within the five-year period 2008–2012. As mentioned earlier in this chapter, there are two likely explanations for this categorisation. Firstly, it is possible that some of this group are appropriately registered on the database but their service needs have not been adequately identified. Secondly, it is also likely that a proportion of this group, who have a mild degree of intellectual disability, are inappropriately registered on the database, as they are not seeking to avail of specialised health services. The number of people identified in this category varies between Regional Health Areas. The Southern Regional Health Area has the lowest recorded proportion of registrations with no service requirements, at 0.9%, and the Dublin/Mid-Leinster Regional Health Area has the highest proportion of individuals in this category, at 2.4% of the region's registered population. Given that the Dublin/Mid-Leinster Regional Health Area also exhibits the lowest level of service provision (96.5%), it is likely that a proportion of this group are appropriately registered but their service needs have not been adequately identified.

It is encouraging to note that the number of people described as having no identified service requirements in 2007 has fallen by over one third, from 649 in 2006 to 410 in 2007, which now represents just 1.6% of the total registrations. This highlights the commitment within the HSE Areas to appraise the remaining individuals to establish both their possible need for services and the appropriateness of their registration on the NIDD. The National Intellectual Disability Database Committee urges the HSE Regional Health Areas involved to continue prioritising this work to improve the overall quality of information held on the NIDD.

Table 3.11 Service provision in 2007 by the Regional Health Areas of the Health Service Executive

	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 2007	Total
	n	n	n	n	n	n	n
	%	%	%	%	%	%	%
Dublin/Mid-Leinster	4442	2240	13	16	78	167	6959
	63.8	32.2	0.2	0.2	1.1	2.4	100.0
South	4732	2053	104	5	55	65	7014
	67.5	29.3	1.5	0.1	0.8	0.9	100.0
West	4254	2182	39	8	132	76	6691
	63.6	32.6	0.6	0.1	2.0	1.1	100.0
Dublin/North-East	3174	1457	173	3	40	99	4946
	64.2	29.5	3.5	0.1	0.8	2.0	100.0
Out of State	2	1	0.0	0.0	0.0	0.0	3
	66.7	33.3	0.0	0.0	0.0	0.0	100.0
All areas	16604	7933	329	32	305	410	25613
	64.8	31.0	1.3	0.1	1.2	1.6	100.0

Table 3.12 Service provision in 2007 by the Local Health Offices of the Health Service Executive

	Receiving day services	Receiving 5-or 7- day residential services	Resident in psychiatric hospital	Receiving residential support services only	Receiving no service - on waiting list	No current service requirement	Total
	n	n	n	n	n	n	n
	%	%	%	%	%	%	%
Dublin/Mid-Leinster	4442	2240	13	16	78	170	6959
	63.8	32.2	0.2	0.2	1.1	2.4	100.0
South Dublin Area 1	418	212	1	1	4	9	645
	64.8	32.9	0.2	0.2	0.6	1.4	100.0
South Dublin Area 2	192	129	0.0	3	5	5	334
	57.5	38.6	0.0	0.9	1.5	1.5	100.0
Wicklow Area 10	553	147	2	3	3	42	750
	73.7	19.6	0.3	0.4	0.4	5.6	100.0
Dublin South City Area 3	161	122	1	1	0.0	16	301
	53.5	40.5	0.3	0.3	0.0	5.3	100.0
Dublin South West Area 4	526	198	0.0	4	8	18	754
	69.8	26.3	0.0	0.5	1.1	2.4	100.0

	Receiving day services	Receiving 5-or 7- day residential services	Resident in psychiatric hospital	Receiving residential support services only	Receiving no service - on waiting list	No current service requirement	Total
	n	n	n	n	n	n	n
	%	%	%	%	%	%	%
Dublin West Area 5	777	466	0	0	9	56	1308
	59.4	35.6	0.0	0.0	0.7	4.3	100.0
Kildare/West Wicklow Area 9	742	514	0.0	1	37	23	1317
	56.3	39.0	0.0	0.1	2.8	1.7	100.0
Laois/Offaly	523	140	4	2	8	1	678
	77.1	20.6	0.6	0.3	1.2	0.1	100.0
Longford/Westmeath	550	312	5	1	4	0	872
	63.1	35.8	0.6	0.1	0.5	0.0	100.0
South	4732	2053	104	5	55	65	7014
	67.5	29.3	1.5	0.1	0.8	0.9	100.0
Cork North Lee ^a	881	660	0.0	1	6	16	1564
	56.3	42.2	0.0	0.1	0.4	1.0	100.0
Cork South Lee	329	84	0.0	1	5	3	422
	78.0	19.9	0.0	0.2	1.2	0.7	100.0
North Cork	389	106	14	0	17	12	538
	72.3	19.7	2.6	0.0	3.2	2.2	100.0
West Cork	276	97	2	1	6	8	390
	70.8	24.9	0.5	0.3	1.5	2.1	100.0
Kerry	667	221	9	1	3	11	912
	73.1	24.2	1.0	0.1	0.3	1.2	100.0
Carlow/Kilkenny	591	305	24	1	11	11	943
	62.7	32.3	2.5	0.1	1.2	1.2	100.0
South Tipperary	483	135	21	0.0	3	1	643
	75.1	21.0	3.3	0.0	0.5	0.2	100.0
Waterford	430	247	2	0.0	3	2	684
	62.9	36.1	0.3	0.0	0.4	0.3	100.0
Wexford	686	198	32	0.0	1	1	918
	74.7	21.6	3.5	0.0	0.1	0.1	100.0

Table 3.12 Service provision in 2007 by the Local Health Offices of the Health Service Executive (continued)

	Receiving day services	Receiving 5-or 7- day residential services	Resident in psychiatric hospital	Receiving residential support services only	Receiving no service - on waiting list	No current service requirement	Total
	n	n	n	n	n	n	n
	%	%	%	%	%	%	%
West	4254	2182	39	8	132	76	6691
	63.6	32.6	0.6	0.1	2.0	1.1	100.0
Donegal	660	185	0	1	22	21	889
	74.2	20.8	0.0	0.1	2.5	2.4	100.0
Sligo/Leitrim	453	390	0	1	11	0	855
	53.0	45.6	0.0	0.1	1.3	0.0	100.0
Galway	1044	474	13	1	48	7	1587
	65.8	29.9	0.8	0.1	3.0	0.4	100.0
Mayo	604	282	5	0	16	24	931
	64.9	30.3	0.5	0.0	1.7	2.6	100.0
Roscommon	291	84	0	0	2	3	380
	76.6	22.1	0.0	0.0	0.5	0.8	100.0
Limerick	528	329	18	2	18	7	902
	58.5	36.5	2.0	0.2	2.0	0.8	100.0
North Tipperary	351	307	0	2	12	13	685
	51.2	44.8	0.0	0.3	1.8	1.9	100.0
Clare	323	131	3	1	3	1	462
	69.9	28.4	0.6	0.2	0.6	0.2	100.0
Dublin/North-East	3174	1457	173	3	40	99	4946
	64.2	29.5	3.5	0.1	0.8	2.0	100.0
North Dublin Area 6	597	471	0	1	13	42	1124
	53.1	41.9	0.0	0.1	1.2	3.7	100.0
North Dublin Area 7	435	83	0	0	4	15	537
	81.0	15.5	0.0	0.0	0.7	2.8	100.0
North Dublin Area 8	641	332	170	1	10	28	1182
	54.2	28.1	14.4	0.1	0.8	2.4	100.0
Cavan/Monaghan	441	122	0	1	7	11	582
	75.8	21.0	0.0	0.2	1.2	1.9	100.0
Louth	617	352	1	0	2	0	972
	63.5	36.2	0.1	0.0	0.2	0.0	100.0
Meath	443	97	2	0	4	3	549
	80.7	17.7	0.4	0.0	0.7	0.5	100.0
Out of State	2	1	0	0	0	0	3
	66.7	33.3	0.0	0.0	0.0	0.0	100.0
Total	16604	7933	329	32	305	410	25613
	64.8	31.0	1.3	0.1	1.2	1.6	100.0

^a Cork North Lee and Cork South Lee were previously considered as one area for local administrative purposes within intellectual disability services. The process of assigning NIDD records within the two areas has recently commenced.

4. Assessment of Need 2008-2012

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

A - Unmet need: describes people who are without a major element of service such as day or residential, or who are without residential support services, or who may be without any service and require these services in the period 2008 to 2012. It excludes those whose only requirement is for multidisciplinary support services (including those to be delivered by an early intervention team) as these are dealt with in category D below.

B - Service change: describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2008 to 2012, and includes children who will require access to health-funded services in the period. It excludes those whose only service change requirement is for multidisciplinary support services (including those to be delivered by an early intervention team) as these are dealt with in category D below.

C - Persons with intellectual disability who are accommodated in psychiatric hospitals: includes people who need to transfer out of psychiatric hospitals in the period 2008 to 2012 and people who are resident in the psychiatric services but require an appropriate day service within the same time period. For completeness, multidisciplinary support service requirements, where applicable, are noted in the tables.

D - Multidisciplinary support services: documents the multidisciplinary support services (including those to be delivered by early intervention teams) that are required in the period 2008 to 2012 by all individuals registered on the NIDD. 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.

A - Unmet need

Full-time residential and day services

The data returned in 2007 indicate that 2,430 people will require major elements of service, either a full-time residential service or a day service, or both, in the five-year period 2008–2012 (Table 4.1), an increase of 58 since 2006. Of this group of 2,430 people:

- 2,157 (88.8%) receive a day service but require a residential service,
- 236 (9.7%) have no service and require full-time residential and/or day services,
- 25 (1.0%) receive a residential service but also require a day service,
- 12 (0.5%) receive residential support services only, and require full-time residential and/or day services.

Table 4.1 provides a breakdown of this group by level of intellectual disability. Of the 236 people who are without services in 2007, 92 (39.0%) have a moderate, severe, or profound level of intellectual disability and 115 (48.7%) have a mild level of intellectual disability. The group which receives one major element of service, day or residential, but which needs the other element (2,157 plus 25, equals 2,182 individuals), consists mainly (70.6%) of people in the moderate, severe or profound ranges of intellectual disability.

Six hundred and eighty of the individuals who have an unmet need for a full-time residential service also require an additional future residential service, of whom 97.2% require a residential support service, in the period 2008 to 2012. Thirty three of the individuals who have an unmet need for a day service also require one additional future day service in the period 2008–2012.



Table 4.1 Number of people requiring a major element of service 2008 – 2012

	No service	Receives minimal residential support only	Receives day only –requires residential	Receives residential only – requires day	Total
Not verified	29	2	89	2	122
Mild	115	5	543	8	671
Moderate, severe or profound	92	5	1525	15	1637
All levels	236 ^a	12 ^b	2157	25	2430

^a Of the 236, 17 require residential and day, 5 require residential only, and 214 require day only.

^b Of the 12, 1 requires residential and day, 1 requires residential only, and 10 require day only.

Residential support services

The 2007 data indicate that 2,049 people are without residential support services and will require these services in the period 2008 to 2012, an increase of 138 (7.2%) since 2006 (Table 4.2). In excess of 99.0% of this group are already in receipt of a major element of service. Seventeen individuals who require residential support services are without services in 2007, of whom 6 have a moderate, severe or profound level of intellectual disability, 7 have a mild intellectual disability, and the remaining 4 individuals' level of intellectual disability has not yet been verified.

One hundred and ninety five individuals who have an unmet need for a residential support service also require a second future residential service. More than three quarters of these secondary future residential service requirements are additional residential support services.

Number of places required to meet need

Table 4.2 Number of people requiring residential support services 2008–2012

	No service	Receives day only - requires residential support	Receives residential & day - requires residential support	Receives residential only-requires residential support	Total
Not verified	4	167	4	0	175
Mild	7	756	80	1	844
Moderate, severe or profound	6	864	160	0	1030
All levels	17	1787	244	1	2049

The number of additional residential, day and residential support places required over the period 2008 to 2012 to provide these people with services is identified in Table 4.3 by each Regional Health Area.

Table 4.3 Number of new places required to meet need 2008–2012 by the Regional Health Areas of the Health Service Executive

	Residential	Day	Residential support	% of total NIDD registrations
Dublin/Mid-Leinster	596	74	487	27.2
South	577	47	658	27.4
West	535	126	627	26.1
Dublin/North-East	473	20	316	19.3
Total	2181	267	2088 ^a	100.0

^a The total number of residential support places required is different to the figure in Table 4.2 (n=2,049) as 36 of the group who have no existing service and require a day service will also need a residential support service and 3 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 2,088.

The key figures and trends are summarised below.

- Following a slight downward trend during the years 2000 to 2002, the number of new residential places required has increased by over one third (548 places) over the past five years. The current figure of 2,181 is the highest since the database was established. The current figure reflects an increase of 63 places required since 2006. Seven out of ten of this group (70.6%, 1,540 individuals) have a moderate, severe or profound intellectual disability. 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 more severe disability advance in age.

- The number of new day places required has been falling steadily since 1996. The current figure of 267 is 74.3% less than that in 1996 and is the lowest since the database was established, suggesting that significant progress has been made in meeting the demand for day services.
- The demand for residential supports has increased steadily since 1998. The current figure of 2,088 represents an increase of 134 (6.9%) since 2006 and is the highest since national data collection began. This high level of need is presenting even though there are over 5,000 people currently availing of residential support services.

Table 4.4 shows the number of new places required to meet need over the next five years within each Local Health Office of the Health Service Executive. Each area's proportion of the total NIDD registrations is included to allow meaningful comparisons to be drawn between areas.

Year in which services are required

Table 4.5 identifies the year in which the service needs arise. Most of the service needs are immediate, reflecting the backlog of people awaiting services over the past number of years.

Summary of unmet service requirements

Details of the types of services required by people who are without a major element of service or without residential support services in 2007 are set out in Tables 4.6, 4.7 and 4.8.

Table 4.4 Number of new places required to meet need 2008–2012 by the Local Health Offices of the Health Service Executive

	Residential	Day	Residential support	% of NIDD
Dublin/Mid-Leinster	596	74	487	27.2
South Dublin Area 1	66	4	35	2.5
South Dublin Area 2	43	2	32	1.3
Wicklow Area 10	57	3	47	2.9
Dublin South City Area 3	27	0	26	1.2
Dublin South West Area 4	127	9	32	2.9
Dublin West Area 5	69	12	78	5.1
Kildare/West Wicklow Area 9	41	34	97	5.1
Laois/Offaly	74	7	79	2.6
Longford/Westmeath	92	3	61	3.4
South	577	47	658	27.4
Cork North Lee ^a	94	6	189	6.1
Cork South Lee ^a	65	3	26	1.6
North Cork	56	11	43	2.1
West Cork	32	6	55	1.5
Kerry	81	3	87	3.6
Carlow/Kilkenny	65	8	146	3.7
South Tipperary	59	6	24	2.5
Waterford	60	3	49	2.7
Wexford	65	1	39	3.6
West	535	126	627	26.1
Donegal	70	25	112	3.5
Sligo/Leitrim	63	9	98	3.3
Galway	136	43	127	6.2
Mayo	65	14	136	3.6
Roscommon	43	3	39	1.5
Limerick	28	16	48	3.5
North Tipperary	35	14	50	2.7
Clare	95	2	17	1.8
Dublin/North-East	473	20	316	19.3
North Dublin Area 6	97	9	30	4.4
North Dublin Area 7	69	3	49	2.1
North Dublin Area 8	143	1	71	4.6
Cavan/Monaghan	49	3	26	2.3
Louth	66	2	46	3.8
Meath	49	2	94	2.1
Total	2181	267	2088^b	100.0

^a Cork North Lee and Cork South Lee were previously considered as one area for local administrative purposes within intellectual disability services. The process of assigning NIDD records within the two areas has recently commenced.

^b The total number of residential support places required is different to the figure in Table 4.2 (n=2,049) as 36 of the group who have no existing service and require a day service will also need a residential support service and 3 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 2,088.

Table 4.5 Year in which service needs arise

	2008	2009	2010	2011	2012	All years
Residential	2030	62	60	18	11	2181
Day	261	1	1	3	1	267
Residential support	2022	36	20	6	4	2088

Full-time residential services

Of the group that requires full-time residential services (2,181 individuals, see Table 4.6):

- 1,539 (70.6%) individuals have a moderate, severe, or profound level of intellectual disability. Of these 1,539 individuals, 1,220 require residential placements in community group homes, 183 require residential accommodation in a campus setting, and 128 require specialised intensive placements because of their increased dependency.
- 550 (25.2%) individuals have a mild intellectual disability. Of these 550 individuals, 467 require residential placements in community group homes, 52 require residential accommodation in a campus setting, and 27 require specialised intensive placements due to their increased dependency.
- 92 (4.2%) have not yet had their level of intellectual disability verified.

Of those requiring full-time residential services, 2,159 individuals (99.0%) are 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 in 2007 is confined almost exclusively to adult services (Table 4.7). Of the 267 individuals who require day services, the largest demand comes from 231 people who have no service whatsoever at the moment. Of the 231 people with no service:

- Almost half (114 individuals, 49.4%) have a mild intellectual disability and their principal service requirements are in the training and employment fields.
- 89 individuals (38.5%) have a moderate, severe or profound intellectual disability and the principal service requirements are for activation programmes, sheltered work and rehabilitative training (Table 4.7).

Residential support services

Residential support services, such as respite and regular part-time care, are required by 2,088 people (Table 4.8), most of whom live at home and are either in receipt of a day service (1,787 individuals, 85.6%) or have no day service (53 individuals, 2.5%). An additional 248 individuals (11.9%) are full-time residents and need a residential support service either to enhance, or as an alternative to, their existing services.

- People with moderate, severe, or profound intellectual disability account for half (1,044 individuals) of the demand for residential support services, while people with mild intellectual disability account for 41.4% (865 individuals). The remaining 179 individuals (8.6%) have not yet had their degree of intellectual disability verified.
- Most of the demand is for centre-based respite services (1,255 individuals, 60.1%), semi-independent and independent living arrangements (421 individuals, 20.2%), and holiday residential placements (172 individuals, 8.2%).

Table 4.6 Future full-time residential service requirements of individuals receiving no residential service in 2007

	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	Mild	MSP	All	
5-day community group home	0	2	2	4	0	0	1	1	7	105	185	297	7	107	188	302
7-day (48-week) community group home	0	0	3	3	0	0	0	0	6	80	225	311	6	80	228	314
7-day (52-week) community group home	3	4	3	10	0	0	0	0	41	276	801	1118	44	280	804	1128
5-day residential centre	0	0	0	0	0	0	0	0	0	6	16	22	0	6	16	22
7-day (48-week) residential centre	0	0	0	0	0	0	0	0	3	8	45	56	3	8	45	56
7-day (52-week) residential centre	0	1	1	2	0	0	0	0	27	37	121	185	27	38	122	187
Nursing home	0	0	0	0	0	0	0	0	1	4	7	12	1	4	7	12
Mental health community residence	0	0	0	0	0	0	0	0	1	0	1	2	1	0	1	2
Psychiatric hospital	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Intensive placement (challenging behaviour)	0	0	1	1	0	0	0	0	3	22	54	79	3	22	55	80
Intensive placement (profound or multiple disability)	0	0	2	2	0	0	1	1	0	5	70	75	0	5	73	78
All services	3	7	12	22	0	0	2	2	89	543	1525	2157	92	550	1539	2181

Table 4.7 Future day service requirements of individuals receiving no day service in 2007

	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			
Home support	6	1	4	11	1	0	0	1	0	0	0	7	1	4	12
Home help	1	1	2	4	0	0	0	0	0	0	0	1	1	2	4
Mainstream pre-school	2	0	0	2	0	0	0	0	0	0	0	2	0	0	2
Special pre-school	6	0	0	6	0	0	0	0	0	0	0	6	0	0	6
Child education and development centre	1	0	0	1	0	0	0	0	0	0	0	1	0	0	1
Mainstream school	3	2	1	6	0	0	0	0	0	0	0	3	2	1	6
Resource/visiting teacher	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
Special class – secondary	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special school	1	1	2	4	0	0	0	0	0	0	0	1	1	2	4
Rehabilitative training	1	39	13	53	0	0	0	0	0	1	0	1	40	13	54
Activation centre	1	10	26	37	0	1	3	4	1	1	11	13	12	40	54
Programme for the older person	1	2	3	6	0	0	0	0	0	1	2	3	3	5	9
Special high-support day service	0	0	3	3	0	0	0	0	0	1	1	2	0	1	5
Special intensive day service	0	1	2	3	0	0	1	1	0	1	0	1	0	2	5
Sheltered work centre	1	16	17	34	0	0	0	0	0	0	1	1	16	18	35
Sheltered employment centre	0	3	1	4	0	0	0	0	0	0	0	0	3	1	4
Centre-based day respite service	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Day respite in the home	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other day service	1	2	0	3	0	0	0	0	1	0	0	1	2	0	4
Enclave within open employment	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Supported employment	1	13	7	21	1	3	0	4	0	2	0	2	18	7	27
Open employment	1	5	2	8	0	0	0	0	0	1	0	1	1	6	9
Vocational training	1	15	6	22	0	1	0	1	0	0	0	0	1	16	23
Generic day services	0	3	0	3	0	0	0	0	0	0	0	0	3	0	3
All services	28	114	89	231	2	5	4	11	2	8	15	25	32	108	267

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 4.8 Future residential support service requirements of individuals receiving no residential support services in 2007

	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	3	1	4	0	0	0	0	0	0	0	0	0	0	0	0	0	3	1	4
Living independently	1	3	2	6	7	64	6	77	0	1	0	1	0	9	0	9	8	77	8	93	8	84	8	93
Living semi-independently	1	7	2	10	18	173	44	235	0	1	0	1	2	58	22	82	21	239	68	328	21	239	68	328
Holiday residential placement	0	2	2	4	0	40	51	91	0	0	0	0	1	5	71	77	1	47	124	172	1	47	124	172
Crisis or planned respite	6	13	9	28	123	404	673	1200	0	1	1	2	0	3	22	25	129	421	705	1255	129	421	705	1255
Occasional respite care with host family	0	1	0	1	10	34	42	86	0	0	0	0	0	0	1	1	10	35	43	88	10	35	43	88
Overnight respite in the home	0	0	0	0	6	5	7	18	0	0	0	0	0	0	0	0	6	5	7	18	6	5	7	18
Shared care or guardianship	0	0	0	0	1	2	3	6	0	0	0	0	0	0	2	2	1	2	5	8	1	2	5	8
Regular part-time care (2/3 days per week)	0	0	0	0	0	7	11	18	0	0	0	0	0	0	1	1	0	7	12	19	0	7	12	19
Regular part-time care (every weekend)	0	0	0	0	0	3	3	6	0	0	0	0	1	1	2	3	0	4	5	9	0	4	5	9
Regular part-time care (alternate weeks)	0	0	0	0	0	7	2	9	0	0	0	0	0	0	1	1	0	7	3	10	0	7	3	10
Other residential service	0	0	4	4	2	14	21	37	0	0	0	0	1	4	38	43	3	18	63	84	3	18	63	84
All services	8	26	19	53	167	756	864	1787	0	3	1	4	4	80	160	244	179	865	1044	2088	179	865	1044	2088

B - Service change

The term 'service change' describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2008 to 2012, and includes children availing of educational services in 2007 who will require access to health-funded services in the future. Changes in service provision relate to

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

Changes in service provision exclude 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 the chapter.

There are 2,341 people included in the data presented in the section on unmet need above (Table 4.1 and Table 4.2) who are missing one element of service and require their existing element of service to be changed in some way.

- 1,181 people with an unmet need for a full-time residential place require a change in their day service.
- 10 people with an unmet need for a day service require a change in their full-time residential placement. Three people with an unmet need for a day service require a change in their residential support service.
- 1,147 people with an unmet need for a residential support service require a change in their day service.

However, to avoid double-counting of individuals, their needs in relation to service change are not included in this section of the report. It is envisaged that, when funding is made available for their unmet elements, sufficient flexibility will be incorporated within this to allow their required service change to be implemented.



Categories of service change requirements

Table 4.9 indicates that 11,928 people who are receiving services in 2007 will require a change to their existing service provision in the period 2008 to 2012, an increase of 110 (0.9%) since 2006. Of the 11,928 requiring a service change:

- 8,078 (67.7%) are day attenders (of whom 832 also avail of residential support services).
- 3,227 (27.1%) are full-time residents (of whom 2,449 also avail of day services).
- 623 (5.2%) receive residential support services only.

A breakdown of the category of service change required by level of intellectual disability is provided in Table 4.9.

- People in the moderate, severe and profound ranges of intellectual disability account for 7,349 (61.6%) of the service changes.
- People in the mild range require 3,341 (28.0%) of the service changes.
- 1,238 (10.4%) of the service changes are required by people whose level of intellectual disability has not been verified.

Table 4.9 Category of service change required 2008–2012

	Residential and day	Residential only	Day only	Day and residential support	Residential support only	Total requiring service changes
Not verified	30	29	1116	40	23	1238
Mild	231	95	2692	190	133	3341
Moderate, severe & profound	2188	654	3438	602	467	7349
All levels	2449	778	7246	832	623	11928

Number of places required to address service changes

The numbers of places involved in addressing the required service changes are summarised in Table 4.10. Day services are described under four headings: health, education, employment and generic, and the programmes included under each heading are outlined in Appendix A.

Table 4.10 Number of places requiring to be changed 2008–2012

Residential	3227
Day	10527
Of which:	
Health services	7211
Education services	1255
Employment services	1416
Generic services	645
Residential support	1455

The number of places requiring to be changed exceeds the number of people requiring service changes because some people require changes in both their residential and day services. In addition, it is important to note that, although 11,928 people require service changes, this demand does not translate into 11,928 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 the young adults leaving school. It is also important to note that this entire group gets some level of service at present, so a certain level of funding is already committed to these individuals.

Year in which service changes are required

Table 4.11 identifies the years in which the service changes are required. Again, as with the data on unmet need, most of the service changes are required immediately.

Table 4.11 Year in which service changes are required

	2008	2009	2010	2011	2012	All years
Residential	3179	21	18	5	4	3227
Day	9365	532	330	209	79	10527
Of which:						
Health services	6614	289	189	79	40	7211
Employment services	1353	37	17	9	0	1416
Educational services	1020	98	59	57	21	1255
Generic services	387	111	65	64	18	645
Residential support	1433	12	7	2	1	1455



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 4.12, 4.13 and 4.14.

Residential service change

Table 4.12 indicates that 3,227 individuals in full-time residential services in 2007 will require an upgrading or change of accommodation within the next five years. For almost two thirds of this group (2,014 individuals, 62.4%) a change of service type is required.

- Residential placements in the community are required by 1,142 individuals (35.4%).
- Intensive services for either challenging behaviour or profound or multiple disability are required by 671 individuals (20.8%).
- Centre-based placements are required by 143 individuals (4.4%).
- Nursing home placements are required by 57 individuals (1.8%).
- One individual has been identified as requiring admission to a psychiatric hospital.

The remaining 1,213 individuals (37.6%) require an enhancement in their existing service type.

- 372 individuals need their existing service upgraded to include care at weekends and holiday times.
- 20 individuals require less care and could return to their families at weekends and holiday times.
- 821 individuals need an enhancement of their existing service provision (shaded area of Table 4.12). Over two-thirds of this group need increased support in their existing placement.

Two hundred and six of the 3,227 individuals who require an upgrading or change of accommodation also require an additional future residential service, two-thirds of which are residential support services.

Table 4.12 Pattern of movement of individuals from existing residential services to future residential services 2008–2012

Full-time residential service required in the period 2008–2012											
	5-day CGH	7-day (48-wk) CGH	7-day (52-wk) CGH	5-day RC	7-day (48-wk) RC	7-day (52-wk) RC	Nursing home	Psychiatric hospital	Intensive placement (CB)	Intensive placement (P/M D)	Total services 2007
Full-time residential service in 2007											
5-day community group home (CGH)	21	66	148	1	1	19	0	0	6	3	265
7-day (48-week) community group home	0	71	116	1	3	12	2	0	15	6	226
7-day (52-week) community group home	2	14	499	0	4	34	28	0	51	43	675
5-day residential centre (RC)	8	8	38	2	6	10	0	0	4	1	77
7-day (48-week) residential centre	2	65	93	0	19	26	5	0	30	12	252
7-day (52-week) residential centre	1	14	782	0	4	109	20	0	253	222	1405
Nursing home	0	2	32	0	0	5	5	0	3	3	50
Mental health community residence	0	0	1	0	0	0	0	0	0	0	1
Intensive placement (challenging behaviour) (CB)	0	2	36	1	5	46	1	1	50	10	152
Intensive placement (profound/multiple disability) (P/M D)	0	3	30	0	1	3	0	0	3	45	85
Occupying a residential support place	4	0	21	0	2	2	0	0	4	0	33
Other full-time residential place	0	0	0	0	0	3	1	0	2	0	6
Total services required	38	245	1796	5	45	269	62	1	421	345	3227

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, 10,527 individuals will require a change, enhancement, or upgrading of their day service (Table 4.13).

- Health-funded services are required in 68.5% (7,211 individuals) of the changes or enhancements.
- Employment services are required in 13.5% (1,416 individuals) of the changes or enhancements.
- Educational services are required in 11.9% (1,255 individuals) of the changes or enhancements.
- Generic services are required in 6.1% (645 individuals) of the changes or enhancements.

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

Health services

Of the 7,211 service changes required within health-funded services, 5,367 (74.4%) are requirements for an alternative or additional service and 1,844 (25.6%) are requirements for an enhancement of the person's existing service (Table 4.13). The majority of the demand for alternative or additional health-funded services arises as follows:

- 1,034 individuals require high-support or intensive placements, the majority of whom currently attend activation programmes (421 individuals), or receive multidisciplinary support services as their only day service (243 individuals).
- 942 individuals require activation programmes, the majority of whom currently receive multidisciplinary support services as their only day service (382 individuals), attend special schools (192 individuals), or attend sheltered work (149 individuals).

- 711 individuals require rehabilitative training, the majority of whom currently attend special schools (508 individuals).
- 782 individuals require services specific to older people, the majority of whom currently attend activation programmes (341 individuals) or sheltered work (215 individuals).

There are also 1,844 individuals who need to have their existing health-funded service enhanced (shaded area of Table 4.13). Most of these people are attending activation (902 individuals, 48.9%) or attending sheltered work (427 individuals, 23.2%). 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 1,416 service changes required within employment services, 1,359 (96.0%) are requirements for an alternative placement and 57 (4.0%) are requirements for an enhancement of the person's existing placement (Table 4.13).

Most of the demand for alternative employment opportunities comes from 1,185 individuals who require supported employment, the majority of whom currently attend sheltered work (513 individuals) or rehabilitative training (237 individuals).

There are 57 individuals who require their existing employment placement to be enhanced (shaded area of Table 4.13). Fifty-two of these avail of supported employment and one third need their placement to be increased from part-time to full-time.



Table 4.13 Pattern of movement of individuals from existing day services to future day services 2008–2012

	Day service required in the period 2008–2012																	All											
	Day service in 2007	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		
Home support (HS)	21	0	17	13	1	8	1	8	1	0	1	6	5	5	2	0	0	4	0	3	1	6	0	3	0	2	0	99	
Home help (HH)	0	0	4	3	0	1	0	0	0	0	1	1	4	1	0	0	1	1	0	0	1	0	0	0	0	0	0	17	
Early intervention team a	20	0	155	82	2	38	1	21	0	7	0	0	0	0	0	0	0	0	0	1	0	2	0	0	0	0	0	329	
Mainstream pre-school (MPS)	5	1	19	10	1	138	4	17	0	13	0	0	0	0	0	0	0	0	0	3	0	1	0	0	0	0	0	211	
Special pre-school (SPS)	17	0	68	49	9	86	4	30	0	171	0	0	0	0	0	0	0	0	0	6	0	2	0	0	0	0	0	442	
Child education & development centre (CEDC)	23	0	0	0	10	3	2	0	0	15	1	58	0	5	6	1	0	1	0	1	0	1	0	0	0	0	0	126	
Mainstream school (MS)	46	1	5	1	0	99	36	19	52	39	13	1	0	1	0	0	6	0	56	0	43	0	11	3	30	2	464		
Resource/visiting teacher (RT)	12	0	8	1	0	24	22	0	8	4	12	1	0	0	0	0	0	0	2	0	1	0	0	0	0	29	0	124	
Special class – primary (SCP)	21	0	0	0	2	10	6	10	182	12	8	2	0	1	3	0	0	0	5	1	2	0	0	0	0	4	0	269	
Special class – secondary (SCS)	3	0	0	0	0	0	1	0	9	1	20	2	0	1	0	5	0	0	0	0	2	0	2	0	16	2	29	0	91
Special school (SS)	137	3	3	0	0	8	0	1	8	109	508	192	0	39	35	137	37	45	1	16	2	27	23	23	399	0	1730		
Rehabilitative training (RHT)	8	2	0	0	0	0	0	0	0	0	38	78	8	6	5	267	9	3	0	14	1	237	9	74	13	772			
Activation centre (AC)	33	3	0	0	1	0	1	0	0	0	45	902	341	190	231	112	11	6	0	6	1	181	8	6	1	2079			
Programme for the older person (POP)	3	0	0	0	0	0	0	0	0	0	1	13	186	8	52	5	0	0	0	0	1	0	2	0	0	3	274		
Special high-support service (SHS)	3	0	0	0	0	0	0	0	0	0	5	15	9	119	102	9	0	1	0	9	0	6	0	0	0	0	278		
Special intensive service (SI)	1	1	0	0	0	0	0	0	3	8	0	10	0	17	59	1	0	0	0	0	9	0	5	0	0	0	114		
Sheltered work centre (SWC)	22	5	0	0	0	0	1	0	0	0	47	149	215	31	21	427	26	0	0	43	14	513	26	6	4	1550			
Sheltered employment centre (SEC)	1	0	0	0	0	0	0	0	0	0	0	0	0	3	0	1	0	1	0	0	0	0	23	5	1	0	36		
Multidisciplinary support services a	12	0	0	2	1	3	0	1	0	1	25	382	163	87	156	28	4	2	0	9	0	38	8	20	1	943			
Centre-based day respite service (CDR)	0	0	1	0	0	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	0	0	0	0	2	0	6		
Day respite in the home (DRH)	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	1	0	1	0	7		
Other day service (OTH)	2	1	3	14	1	3	1	1	2	2	11	9	19	5	13	32	0	1	0	10	0	18	1	2	0	151			

Table 4.13 Pattern of movement of individuals from existing day services to future day services 2008–2012 (continued)

Day service in 2007	Day service required in the period 2008–2012																	All									
	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	
Enclave with open employment (E)	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	2	1	0	0	4
Supported employment (SE)	8	1	0	0	0	0	0	0	0	0	1	4	12	1	0	10	4	3	0	29	2	2	52	12	1	0	140
Open employment (OE)	0	0	0	0	0	0	0	0	0	0	0	1	2	0	0	3	0	0	0	1	0	0	5	5	0	0	17
Vocational training (VT)	4	0	0	0	0	0	0	0	0	0	6	8	2	0	0	22	2	1	0	1	0	0	75	56	11	1	189
Generic day service (GD)	1	0	0	1	0	0	0	0	0	0	2	6	4	8	9	5	1	0	0	2	0	0	22	0	0	3	64
All services	403	18	284	177	28	421	80	100	265	389	749	1844	968	519	693	1076	94	141	7	210	20	1237	159	617	28	10527	

^a 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.

Educational services

Of the 1,255 service changes required within educational services, 1,006 (80.2%) are requirements for an alternative service and 249 (19.8%) are requirements for an enhancement of the child's existing service (Table 4.13).

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

- 346 children who require special classes, particularly at secondary level.
The majority of those requiring special classes at secondary level (256 children) currently attend special classes at primary level (182 children).
- 322 children who require a mainstream school placement, the majority of whom currently attend a mainstream (138 children) or specialised (86 children) pre-school.
- 280 children who require a special school placement, the majority of whom currently attend special pre-schools (171 children).

There are 249 children who require their existing educational placement to be enhanced (shaded area of Table 4.13), the majority of whom currently attend special schools (109 children). Almost half of the enhancements identified require the child's existing service at primary level to be carried through to secondary level. There is also a significant demand for increased support within existing educational placements.

Generic services

Of the 645 service changes required within generic services, 631 (97.8%) are requirements for an alternative service and 14 (2.2%) are requirements for an enhancement of the person's existing service (Table 4.13).

Most of the demand for alternative generic services comes from 606 individuals who require vocational training, the majority of whom currently attend special schools (399 individuals).

Eleven individuals attending vocational training and three individuals availing of generic day services require their existing generic service to be enhanced (shaded area of Table 4.13).

Pattern of movement within day services

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

The data in relation to certain day services² are reported and interpreted on the assumption that

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

Table 4.13 maps the pattern of movement of individuals from their existing day service to their future day service. The main day service and the first future day service recorded on the NIDD are used to indicate the existing and future day services.

Residential support service change

The database indicates that 1,455 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 2008 to 2012 (Table 4.14). Additional or alternative support services are required by 445 individuals (30.6%), and 1,010 individuals (69.4%) require their existing service to be upgraded (shaded area of Table 4.14).

2. 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.

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. Of these 973 individuals, 927 (95.3%) currently receive planned respite and require an enhanced service, 8 (0.8%) receive crisis respite and require their support to be planned, and 38 (3.9%) are in receipt of both planned and crisis respite and require increased planned respite.
- more regular part-time care arrangements for people already accessing crisis or planned respite services (87 people).
- occasional holiday residential placements and occasional respite care with a host family for people currently availing of crisis or planned respite (59 people).
- opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (74 people).

Two hundred and six individuals of the 1,455 who are receiving residential support services and require that service to be changed also require an additional future residential service. More than two-thirds of these additional future residential services are residential support services.

As with certain types of day service, it is important to note that existing residential support services may be retained by the individual when his/her 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 4.14 Additional residential support services required by people availing of residential support services in 2007

Residential support service in 2007	Residential support service required 2008–2012												
	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	0	0	10	3	16	1	0	1	0	0	0	2	33
Living semi-independently	0	12	18	8	2	0	0	0	0	0	0	1	41
Holiday residential placement	0	0	5	0	22	1	0	2	0	5	0	2	37
Crisis or planned respite	3	7	74	29	973	30	18	48	11	28	3	17	1241
Occasional respite care (host family)	0	0	1	1	33	10	4	1	0	3	2	3	58
Shared care or guardianship	0	0	0	0	2	0	1	1	0	0	0	0	4
Regular part-time care (2/3 days per week)	0	0	0	1	7	0	1	2	3	2	0	0	16
Regular part-time care (every weekend)	0	0	0	0	2	0	0	0	1	0	0	0	3
Regular part-time care (alternate weeks)	0	0	0	0	3	0	0	1	0	2	0	0	6
Overnight respite in the home	0	0	0	0	2	1	0	0	0	0	1	2	6
Other residential service	0	0	4	1	2	1	0	0	0	0	0	2	10
All services	3	19	112	43	1064	44	24	56	15	40	6	29	1455

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 2007 identify 329 individuals with intellectual disability, all aged 20 years or over, accommodated in psychiatric hospitals. Table 4.15 details the overall service requirement status of people resident in psychiatric hospitals by level of intellectual disability.

Table 4.15 Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2007

	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	11	11	1	8	34	43	54
Resident in a psychiatric hospital, with day programme	3	29	54	86	3	50	135	188	274
Resident in a psychiatric hospital, with residential support service and day programme	0	1	0	1	0	0	0	0	1
All residents	3	30	65	98	4	58	169	231	329

Of this group, 231 (70.2%) individuals have service requirements in the period 2008 to 2012, of whom:

- 207 have an appropriate alternative residential facility identified for them (104 of whom will also require a day service). The residential service requirements of this group are shown in Table 4.17 and their day service requirements are shown in Table 4.18.
- 20 are recorded as appropriately placed within the psychiatric hospital but have identified day service requirements (two of whom also require a residential support service and two of whom also require increased support within the psychiatric hospital). The day service requirements of these 20 people are shown in Table 4.16.
- two are recorded as appropriately placed within the psychiatric hospital but require residential support services.

- four are recorded as appropriately placed within the psychiatric hospital but require increased support within a psychiatric hospital.

Table 4.16 Day service requirements of people appropriately accommodated in psychiatric hospitals

Day service in 2007	Services required 2008–2012							
	Vocational training	Activation centre	Programme for the older person	Special high-support day service	Special intensive day service	Supported employment	Other day service	All services
No day programme	0	1	0	0	0	0	0	1
Special intensive day service	0	0	0	1	0	0	0	1
Activation centre	1	3	0	0	0	0	1	5
Sheltered work centre	0	1	0	0	0	1	0	2
Multidisciplinary support services only	0	3	1	2	1	0	0	7
Other day programme	0	3	1	0	0	0	0	4
All services	1	11	2	3	1	1	1	20

Note

7 of the 20 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.

Of the 207 people who need to transfer from psychiatric to intellectual disability services for provision of their residential services, 76 individuals (36.7%) will require places in residential centres, 72 individuals (34.8%) will require intensive placements, and 58 individuals (28.0%) will require community group home places. One individual needs to move to a nursing home. Almost all of the need arises immediately (Table 4.17).

Table 4.17 Residential service requirements of people resident in psychiatric hospitals who require to be transferred to the intellectual disability sector

	Year in which residential service is required		
	2008	2009	2008–2012
7-day (48-week) community group home	2	0	2
7-day (52-week) community group home	55	1	56
7-day (48-week) residential centre	1	0	1
7-day (52-week) residential centre	75	0	75
Nursing home	1	0	1
Intensive placement (challenging behaviour)	55	0	55
Intensive placement (profound/multiple disability)	17	0	17
All residential services	206	1	207

Of this same group of 207 people, 104 will also require an appropriate day service. The greatest demand is for high-support or intensive day programmes (55.8%, 58 people), activation programmes (21.2%, 22 people), and programmes for older people (10.6%, 11 people). All day services are required immediately (Table 4.18).

Table 4.18 Day service requirements of people resident in psychiatric hospitals who require to be transferred to the intellectual disability sector

	Year in which day service is required
	2008
Rehabilitative training	4
Activation centre	22
Programme for the older person	11
Special high-support day service	47
Special intensive day service	11
Sheltered work centre	4
Sheltered employment centre	2
Supported employment	1
Generic day services	2
All day services	104

Note

39 of the 104 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.

The 2007 data suggest that the current day and residential programmes for 98 people with intellectual disability resident in psychiatric hospitals are appropriate and these people have no identified service needs in the period 2008 to 2012 (Table 4.15). Two-thirds (65 people) of this group have a moderate, severe, or profound intellectual disability, almost one third (30 people) have a mild disability and three individuals' levels of disability are not yet verified. Within this group there are 11 people who have no formal day programme. The day service needs of this group need to be reviewed.

Multidisciplinary support services

Although the NIDD facilitates the recording of two future day services, 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 Table 4.19. A 'requirement' refers to a new type of therapeutic input that the individual does not currently receive and an 'enhancement' refers to a change in the delivery of a therapeutic input that the individual currently receives (e.g. an increase in the provision of the specific service or a change in service provider). Data from Table 3.10 are reproduced in Table 4.19 to compare current service provision with the demand for future services.

Multidisciplinary support services are currently availed of by 19,799 people, 15,853 of whom have further requirements for such services. A further 2,745 individuals who do not currently access such services require them. Therefore, there are 18,598 (15,853 plus 2,745) individuals with a need for multidisciplinary support services whose needs involve either an enhancement of a type of service currently received (3,068 individuals), a requirement for a new type of service (6,828 individuals), or both (8,702 individuals). Of this 18,598 people with future multidisciplinary support service needs, 161³ receive no service whatsoever at present. Ninety-nine per cent of the demand is immediate.

3. 109 of the 161 also have other future service requirements that are included in the 'unmet need' section at the beginning of this chapter.

Despite high levels of current provision, there is substantial demand for new services and enhanced services relating to all the therapeutic inputs, in particular, psychology, social work, and speech and language therapy. For example, 7,966 individuals currently receive a psychology service, 4,246 of whom need an enhancement of their service, and a further 7,171 individuals who do not receive a psychology service require one.

The data suggest that there is a significant shortfall of occupational therapy and nutrition services as these are the only therapeutic inputs where the demand for new services exceeds current service provision. For example, 5,127 individuals are currently in receipt of occupational therapy, 2,979 of whom need an enhancement of their service, and a further 6,126 individuals who are not in receipt of occupational therapy require it.



Table 4.19 Current and future multidisciplinary support services by age and access to early intervention teams (EIT)

	Currently receiving service				Enhancement of service required 2008-2012 by people currently receiving this input				New service required 2008-2012 by people not currently receiving this input							
	Aged 6 or under		Aged 7-17		Aged 18 or over		Total		Aged 6 or under		Aged 7-17		Aged 18 or over		Total	
	EIT	Not EIT	EIT	Not EIT	EIT	Not EIT	EIT	Not EIT	EIT	Not EIT	EIT	Not EIT	EIT	Not EIT	EIT	Not EIT
Medical services	886	95	1255	6217	8453	243	69	374	2110	2796	106	44	534	1068	1752	
Nursing	726	100	1006	4720	6552	259	60	375	1542	2236	52	15	217	966	1250	
Nutrition	270	66	424	2177	2937	68	51	164	816	1099	143	45	533	3506	4227	
Occupational therapy	972	217	1711	2227	5127	454	165	947	1413	2979	333	104	1241	4448	6126	
Physiotherapy	1086	161	1402	2696	5345	453	144	697	1528	2822	92	35	526	2121	2774	
Psychiatry	58	18	424	5630	6130	29	6	183	2869	3087	43	19	307	983	1352	
Psychology	981	173	2222	4590	7966	418	143	1156	2529	4246	293	100	1434	5344	7171	
Social work	1039	135	2107	6180	9461	425	125	1113	3340	5003	93	41	692	2986	3812	
Speech & language therapy	1271	300	3342	1794	6707	599	231	1830	991	3651	215	77	966	3859	5117	
Other	554	76	1167	3622	5419	58	29	198	1016	1301	158	42	489	2073	2762	
Number of people	1567	353	4505	13374	19799	836	292	2691	7951	11770^a	764	242	3122	11402	15530^a	

^a 'Enhancement of service required' refers to a change in the delivery of a therapeutic input that the individual currently receives. 'New service required' refers to a new type of therapeutic input that the individual does not currently receive. There are 8,702 individuals whose multidisciplinary support service change involves both a requirement and an enhancement. Therefore, the actual number of people represented in this table as requiring enhanced and/or additional services is 11,770 + 15,530 - 8,702 = 18,598. 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 or required exceeds the number of people as many people receive or require more than one input.

Overall service provision to people with intellectual disability and the pattern of care required in the period 2008 to 2012

The data presented in this chapter in relation to unmet need for services and demand for service changes need to be considered together to enable the future pattern of care to be forecast. The database indicates that there are large numbers of people who require residential services for the first time and also that there are significant numbers who require 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 the existing placement. Where the enhancement involves a move to a new placement, the freed-up place may become available to others who have an identified need for such a placement. The existing placements occupied by these individuals are secure until their new places become available. Such movement is part of the ongoing development of services and is tangible evidence of the ability of the database to match needs with service provision.

Pattern of care required in full-time residential services

As is indicated in Table 4.20, demand for full-time residential services in the period 2008–2012 will come from three distinct groups already identified in this chapter:

- 2,181 individuals living at home who require full-time residential services for the first time,
- 207 individuals resident in psychiatric hospitals who require to transfer to the intellectual disability services, and
- 3,227 individuals in full-time residential services within the intellectual disability sector who require changes to their existing placement. Of this group, 2,014 require alternative services and 1,213 require their existing service to be enhanced. Not all of the group who require 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 4.20 outlines the pattern of full-time residential service provision that will be required in the period 2008–2012 to meet this demand. A total of 2,421 residential places will be required – an increase of 38 since 2006.

- 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, 2,715 community-based placements will be required during the period, an increase of 129 placements (5.0%) since 2006.
- There will also be a shortfall of 759 intensive residential placements, a decrease of 44 placements (5.5%) since 2006. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

Table 4.20 Pattern of full-time residential service provision required 2008–2012

	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	302	0	38	265	-75
7-day (48-week) community group home	314	2	245	226	-335
7-day (52-week) community group home	1128	56	1796	675	-2305
5-day residential centre	22	0	5	77	50
7-day (48-week) residential centre	56	1	45	252	150
7-day (52-week) residential centre	187	75	269	1405	874
Nursing home	12	1	62	50	-25
Mental health community residence	2	0	0	1	-1
Psychiatric hospital	0	0	1	0	-1
Intensive placement (challenging behaviour)	80	55	421	152	-404
Intensive placement (profound or multiple disability)	78	17	345	85	-355
Other/unspecified intellectual disability service	0	0	0	6	6
Designated residential support placement	0	0	0	[33a]	0
Total	2181	207	3227	3194	-2421

^a33 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 4.21, demand for day services over the next five years comes from four distinct groups:

- 267 individuals who are without day services,
- 104 individuals resident in psychiatric hospitals who will require an appropriate day service when they transfer to intellectual disability services,
- 20 individuals appropriately placed in psychiatric hospitals but requiring a day programme within that setting, and
- 10,527 individuals in existing day services within the intellectual disability sector who require changes to, or enhancements of, their existing placement. Of this group, 8,363 require alternative or additional services and 2,164 require their existing service to be enhanced. The majority (7,211) of these service changes are within the health sector. Many of the changes are required to address transitional needs such as moving from child to adult services or moving from training into employment. Not all of the group who require service enhancements will move to new placements. Again, as is seen with the requirement for enhancement of residential placements, 1,487 out of the 2,163 identified individuals (68.7%) require increased support in their existing placements. However, the entire group has been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading 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. However, unlike the situation with full-time residential services, not all existing places will become available. As previously explained in this chapter, people who are accessing, or who require, home support, early services, resource or visiting teachers, multidisciplinary supports, centre- and home-based day respite or home help services will not be freeing up existing services when their future needs are met.

Table 4.21 outlines the pattern of day service provision that will be required in the period 2008–2012 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 1,917 day places will be required – an increase of 51 places on the corresponding 2006 figure. The table shows that there is less demand for young children requiring certain services and a considerable demand for the full spectrum



of adult services. The data indicate that over the next five years there will be:

- A significant reduction in the number of children requiring special schools (1,337 children). However, there is a small demand within this group for mainstream pre-school services (75 children), special classes at secondary level (174 children), and resource or visiting teachers (80 children). This demand is likely to be greater than the data indicate due to the probable under-estimation of young children on the database discussed in Chapter 2.
- A shortfall of training and employment opportunities. In the period 2008 to 2012, 452 vocational training placements and 35 rehabilitative training placements need to be developed to meet the demand that exists for those services. There will be a shortfall of 1,126 supported employment opportunities and 151 placements in open employment during this time.
- The ageing population with intellectual disability discussed in Chapter 2 is resulting in increased demand for specific programmes for the older person and there will be a shortfall of 716 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, 296 high-support day placements and 596 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 4.21 Pattern of day service provision required 2008–2012

	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	12	0	0	403	0	-415
Home help	4	0	0	18	0	-22
Mainstream pre-school	2	0	0	284	211	-75
Special pre-school	6	0	0	177	442	259
Child education and development centre	1	0	0	28	126	97
Mainstream school	6	0	0	421	464	37
Resource/visiting teacher	0	0	0	80	0	-80
Special class – primary	0	0	0	100	269	169
Special class – secondary	0	0	0	265	91	-174
Special school	4	0	0	389	1730	1337
Rehabilitative training	54	4	0	749	772	-35
Activation centre	54	22	11	1844	2079	148
Programme for the older person	9	11	2	968	274	-716
Special high-support day service	5	47	3	519	278	-296
Special intensive day service	5	11	1	693	114	-596
Sheltered work centre	35	4	0	1076	1550	435
Sheltered employment centre	4	2	0	94	36	-64
Centre-based day respite service	0	0	0	141	0	-141
Day respite in the home	0	0	0	7	0	-7
Other day service	4	0	1	210	151	-64
Enclave within open employment	0	0	0	20	4	-16
Supported employment	27	1	1	1237	140	-1126
Open employment	9	0	0	159	17	-151
Vocational training	23	0	1	617	189	-452
Generic day services	3	2	0	28	64	31
All services	267	104	20	10527	9001	-1917

Conclusion

The 2007 dataset, in line with data in recent years, indicates that, despite substantial levels of service provision in day, residential, residential support and multidisciplinary support services, there is significant ongoing demand for new intellectual disability services and a growing requirement to enhance existing services.

The increased birth rate in the 1960s and 1970s has resulted in a large adult population moving through the services. 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. The number of new full-time residential and residential support places required are 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 contributing to long waiting lists for these services. While a multi-annual funding package has been put in place for the period 2006-2009, this is insufficient to address all of the service demands identified in this report. In the medium term, it is expected that the demand for intellectual disability services will continue. Failure to anticipate these service needs will result in crisis situations for families and for service providers.

The NIDD is an invaluable resource in providing a sound evidence base for service planning and delivery. Not only does it allow us to identify specific individual service requirements arising in the next five years, the demographic information also allows us to look further into the future and anticipate the impact of changing demographic trends. A National Audit of the NIDD took place in September 2007. The results of the audit will be published in early 2008 and recommendations will be made on how to ensure continued improvement of data quality at local, regional and national level.

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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 SERVICES

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

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

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



Service Categories

Day programmes

Home support

Mainstream pre-school

Special pre-school for intellectual disability

Mainstream school

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

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

Supported employment

Open employment

Other day programme

Resource teacher/visiting teacher

Early services

Generic day services

Home help

Annual review

Multidisciplinary support services for school age children or adults

Full-time resident with no formal day programme

Centre-based day respite service

Day respite in the home

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 handicap

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 B

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
Home setting	1922	156	159	45	2282	3362	1766	1050	173	6351	3302	2614	1559	258	7733	8586	4536	2768	476	16366
At home with both parents	1631	116	47	1	1795	2424	1266	418	12	4120	2615	1978	557	9	5159	6670	3360	1022	22	11074
At home with one parent	260	36	71	8	375	753	419	433	32	1637	603	570	630	33	1836	1616	1025	1134	73	3848
At home with sibling	1	2	34	30	67	6	24	153	94	277	2	29	329	181	541	9	55	516	305	885
At home with other relative	3	1	5	5	14	46	20	32	30	128	16	10	29	27	82	65	31	66	62	224
Living with non-relative	0	0	0	1	1	1	8	7	0	16	1	2	4	3	10	2	10	11	4	27
Adoption	3	0	0	0	3	9	4	1	0	14	6	2	1	0	9	18	6	2	0	26
Foster care and boarding-out arrangements	24	1	2	0	27	123	25	6	5	159	59	23	9	5	96	206	49	17	10	282
Independent/Semi-independent setting	0	14	51	29	94	4	135	376	124	639	3	31	88	48	170	7	180	515	201	903
Living independently	0	11	40	28	79	3	96	245	85	429	2	18	44	27	91	5	125	329	140	599
Living semi-independently	0	3	11	1	15	1	39	131	39	210	1	13	44	21	79	2	55	186	61	304
Community group home	3	9	24	9	45	34	171	411	234	850	92	627	1565	571	2855	129	807	2000	814	3750
5-day community group home	1	5	5	0	11	16	42	54	8	120	25	126	203	6	360	42	173	262	14	491
7-day (48-week) community group home	0	0	3	1	4	1	21	72	24	118	19	107	339	42	507	20	128	414	67	629
7-day (52-week) community group home	2	4	16	8	30	17	108	285	202	612	48	394	1023	523	1988	67	506	1324	733	2630
Residential centres	5	9	22	47	83	6	38	93	110	247	84	541	1415	808	2848	95	588	1530	965	3178
5-day residential centre	0	0	0	0	0	1	4	2	2	9	18	30	41	1	90	19	34	43	3	99
7-day (48-week) residential centre	0	2	1	0	3	0	12	22	8	42	24	130	172	58	384	24	144	195	66	429
7-day (52-week) residential centre	5	7	21	47	80	5	22	69	100	196	42	381	1202	749	2374	52	410	1292	896	2650
Other full-time services	9	3	10	25	47	3	52	81	82	218	50	311	449	259	1069	62	366	540	366	1334
Nursing home	0	0	5	21	26	0	0	10	22	32	0	3	34	60	97	0	3	49	103	155
Mental health community residence	0	1	0	0	1	0	0	9	13	22	0	0	12	23	35	0	1	21	36	58
Psychiatric hospital	0	0	4	3	7	0	15	37	36	88	0	17	104	113	234	0	32	145	152	329
Intensive placement (challenging behaviour)	3	0	1	0	4	2	28	17	4	51	18	169	162	34	383	23	197	180	38	438

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
Intensive placement (profound or multiple handicap)	6	0	0	0	6	0	0	2	1	6	21	101	109	14	245	27	104	111	15	257
Full-time resident in 'other' residential service	0	1	0	1	2	1	3	3	3	10	2	4	15	12	33	3	8	18	16	45
Full-time resident in residential support place	0	1	0	0	1	0	3	3	3	9	9	17	13	3	42	9	21	16	6	52
No fixed abode	0	1	0	1	2	0	2	4	1	7	0	1	2	1	4	0	4	6	3	13
Insufficient information	3	0	0	0	3	2	6	0	0	8	2	9	28	19	58	7	15	28	19	69
Total	1942	192	266	156	2556	3411	2170	2015	724	8320	3533	4134	5106	1964	14737	8886	6496	7387	2844	25613

Appendix C

Accessing statistical information from the Disability Databases

Access to statistical information

Aggregate level data, that is data about groups of individuals where there is no risk of an individual or a service provider being identified, can be authorised for release by the Chair of the relevant national or regional committee subject to the following conditions:

- If the general information sought is contained in a previously published report the published report, or extract thereof, or re-analysis of published data, may be released.
- If a request relates to only one service provider and is submitted by the service provider to their local HSE area, the information may be released.

In the case of all other requests:

- If the request relates to only one HSE area, the request will be referred to that HSE area which will be responsible for considering the request at their Regional Database Committee meeting and where approved, providing the data.
- If the request relates to only one service provider but is not submitted by that service provider, the request will be referred to the service provider that is the subject of the request and if approved may be released by the service provider that is the subject of the request, or if they are unable to do so, by their local HSE area.
- If the requester seeks comparative data between service providers he/she will need to obtain the prior written approval of each service provider and on receipt of this notification the HSE area or HRB may release the information, depending on whether the request pertains to only one HSE area or a number of HSE areas.
- Requests that do not conform to these agreed guidelines will be referred to the appropriate regional or national database committee for full consideration. If a request is referred to the full committee, the requester should be immediately informed of the expected timeframe within which their request will be considered.

Criteria for reviewing requests for statistical information

The following criteria will be employed by the regional and national disability database committees in assessing a request for information from the disability databases:

1. Is ethical approval required? If yes, has it been received?
2. Is the proposed use appropriate for service planning or research purposes?
3. Is the data requested appropriate to the stated purpose of the request?
4. Are there any concerns about the information subjects e.g. have they been previously targeted for other research studies?
5. Are there any concerns regarding confidentiality?
6. Do any special conditions apply?
7. Within what timeframe can the information be made available by the HSE area or HRB?

Notification of outcome of review to applicant

If the committee is satisfied that all requirements are met, they will authorise the use of the disability databases to satisfy the request for information. The Committee will make decisions regarding authorisation of requests by consensus. If one member feels they cannot agree to the request, the chairperson will contact the applicant to try and resolve the issue by, for example, requesting further information or seeking reassurance regarding the methodology of the study or the proposed use of the information.

Acknowledgement

The National Disability Databases are to be clearly and comprehensively acknowledged as the source of data in any publication or presentation in which data is used.

The relevant authorising Disability Database Committee is to be provided with advance copies of any publications that report the results of the research that uses database information at least four weeks prior to the publication date.

Procedure for requesting statistical information

Requests for statistical information from the disability databases for research purposes are always welcomed. There are certain procedures in place with regard to the release of information and advance notice of projects is required.

Data requested from the disability databases will be supplied provided that complying with the request does not conflict with obligations of confidentiality under the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003.

Requesters should note that names of individuals registered on the disability databases will never be released to researchers or organisations. In line with previous practice, if they so wish, HSE areas can contact the target group(s) giving them the opportunity to contact the researchers to participate in their project.

Any person requesting information must do so in writing, by post, fax or email, using the Request for Information Form (available to download from <http://www.hrb.ie>). Applicants are encouraged to contact the HSE area or Health Research Board to discuss their information requirements prior to completing the request form.

Requesting information from the National Intellectual Disability Database

1. Requests for information from the national dataset should be made to the National Intellectual Disability Database Committee using the official Request Form.
2. Any individual requiring information from the National Intellectual Disability Database is required to make a written submission to this Committee outlining the information required, the reason the information is required and the manner in which the information will be used, subject to the following provision:
 - a. A student of a professional discipline, seeking information from the National Intellectual Disability Database will be requested to ask their professional supervisor to make the application on their behalf.

3. On receiving a request for information, the chairperson of the National Intellectual Disability Database Committee will discuss the request with the other members of the committee at the earliest possible opportunity. The committee will satisfy itself:
 - a. that the use of the National Intellectual Disability Database is a valid one in view of the proposed use or research project; and
 - b. that there is no doubt concerning violation of client confidentiality.

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

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

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

Requesting information from Regional Intellectual Disability Databases

People requiring information pertaining to a specific HSE area should request the information from the relevant Regional Database Co-ordinator.

National Intellectual Disability Database Request for Information Form

Name of Applicant

Address

Telephone Number

Email address

Name of agency/
academic institution
(where applicable)

Date requested

Details of the type
of analysis required

Reason for request -
please be as specific as
possible in describing
why the information is
required and how the
data will be used -
general explanations
such as, 'research
purposes' should
not be used
(Continue on separate
page if necessary)

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

Signature of applicant: _____ Date: _____



Office Use Only:

Date request received

Received by

HRB

DoHC

Date considered by NIDDC

Decision of NIDDC

Any conditions which
are to be applied to
the request

Signed (on behalf of NIDDC): _____ Date: _____

Requests for additional statistical information

Further statistical information pertaining to specific regions may be requested from the Database Co-ordinator in the relevant Health Service Executive area.

Additional statistical information from the national dataset may be requested from the National Intellectual Disability Database Committee, using copies of the request form contained in Appendix C.

All queries about accessing data from the National Intellectual Disability Database should be addressed to the Disability Databases Unit, Health Research Board, Knockmaun House, 42-47 Lower Mount Street, Dublin 2.

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.





