



HRB Statistics Series 17

Annual Report of the National Intellectual Disability
Database Committee 2011

Caraíosa Kelly



Pamela Kavanagh

My name is Pamela Kavanagh and I live with my mum and two brothers in Clondalkin.

I started taking an interest in art when I moved to Stewarts Care Ltd. at the age of 16. I would like to give a special thanks to the art teachers in Stewarts for supporting and guiding me in the field of art.

Art has become a great love of mine. In 2009 I had a solo exhibition entitled "Flora and Fauna", in Stewarts Clarkeville Art Gallery in Palmerstown.

This special art award means a lot to me and gives me the confidence to continue in my artwork which I thoroughly enjoy.



'Butterfly'
by Pamela Kavanagh

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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 these systems. 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.

The **HRB Statistics series** compiles data on problem alcohol and drug use, disability and mental health from a single point or period in time. Previous reports associated with this series are:

- Activities of Irish psychiatric units and hospitals (1965–2010)
- National Physical and Sensory Disability Database Committee annual reports (2004–2011)
- National Intellectual Disability Database Committee annual reports (1996–2010)

The **Disability Databases Team** manages two national service-planning databases for people with disabilities on behalf of the Department of Health: 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.

Statistics series publications to date

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

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

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

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

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

Kelly F, Kelly C and Craig S (2009) *Annual report of the National Intellectual Disability Database Committee 2008*. HRB Statistics Series 6. Dublin: Health Research Board.

Daly A and Walsh D (2009) *Activities of Irish psychiatric units and hospitals 2008*. HRB Statistics Series 7. Dublin: Health Research Board.

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O'Donovan MA, Doyle A and Craig S (2010) *Annual report of the National Physical and Sensory Disability Database Committee 2009*. HRB Statistics Series 11. Dublin: Health Research Board.

Daly A and Walsh D (2011) *Irish psychiatric units and hospitals census 2010*. HRB Statistics Series 12. Dublin: Health Research Board.

Kelly F and Kelly C (2011) *Annual report of the National Intellectual Disability Database Committee 2010*. HRB Statistics Series 13. Dublin: Health Research Board.

O'Donovan MA, (2011) *Annual report of the National Physical and Sensory Disability Database Committee 2010*. HRB Statistics Series 14. Dublin: Health Research Board.

Daly A and Walsh D (2011) *Activities of Irish psychiatric units and hospitals 2010 executive summary*. HRB Statistics Series 15. Dublin: Health Research Board.

Doyle A (2012) *Annual report of the National Physical and Sensory Disability Database Committee 2011*. HRB Statistics Series 16. Dublin: Health Research Board.



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- the National Federation of Voluntary Bodies providing services to people with intellectual disability;
- the parents and families of people with an intellectual disability and their representative bodies; and
- all those in intellectual disability services throughout Ireland.

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Chairperson's statement

This is the fourteenth annual report of the National Intellectual Disability Database (NIDD) Committee, compiled by the Health Research Board (HRB). The report is based on up-to-date data on over 27,000 people registered on the database.

As is the case with previous annual reports, this publication provides an update of information on the demographic profile of those who are registered on the NIDD, on their current usage of day and residential services, and on the range of multidisciplinary supports availed of by them. It also presents information on the needs of people with intellectual disability for such services in the next five years.

This year the report continues to focus on areas that have particular relevance to service planners and providers, including:

- the transition from school into health and employment services; and
- the growing demand for services to support the maintenance of people with intellectual disability in a home or independent setting.

The Irish health system will undergo comprehensive reform in the coming years. A total transformation is planned which will see changes to how citizens will access healthcare and how it is financed and managed. A new model of care incorporating an overhaul of health system governance, where the money follows the patient, is envisaged. Where disability services are concerned, a value-for-money (VFM) review of the efficiency and effectiveness of disability services in Ireland will be completed this year. It will establish to the greatest degree possible how and where we spend the €1.5 billion in the health sector for services for people with disabilities, and will also focus on the question of whether the current objectives of public policy in this area are being delivered. The process of completing the VFM review has reinforced the importance of data availability and quality. This is one of the areas that will be addressed specifically in the final VFM report, and will have implications for the nature of the disability databases in the future. Informing the deliberations of the VFM review group, a comprehensive review of disability policy was published in 2011. That review sets out a vision for the future of disability services. It recommends a major policy shift to a model of care based on individualised supports and individualised budgeting. This is a hugely significant change, which values citizenship and self-determination as key principles.

I would like to thank the NIDD Committee members for all their work on the report and their ongoing input to the Committee. I would like to add a particular thanks to those working in the Disability Databases Team at the Health Research Board for their ongoing efforts in preparing and completing this report, and for the data which they supplied to the VFM Review Project Team, which was invaluable in informing their review.

Colm Desmond

Chairperson

National Intellectual Disability Database Committee

June 2012



Executive summary

Demographic profile

There were 27,324 people registered on the National Intellectual Disability Database (NIDD) at the end of December 2011. Based on 2011 census figures, this represents a prevalence rate of 5.96 per 1,000 population. The prevalence rate for mild intellectual disability was 1.98 per 1,000, and the rate for moderate, severe or profound intellectual disability was 3.47 per 1,000. There were more males than females at all levels of intellectual disability, with an overall ratio of 1.35 to 1.

The total number of individuals with moderate, severe or profound intellectual disability has increased by 41% since the first Census of Mental Handicap in the Republic of Ireland was carried out in 1974. One of the factors contributing to this increase in numbers is the growth in the general population over the period. The birth rate has increased in recent years, which may result in a rise in demand for intellectual disability services for children and young people, though some of this need could be met by mainstream services. Of the people with moderate, severe or profound intellectual disability, the proportion aged 35 years or over increased from 29% in 1974 to 38% in 1996, and to 49% in 2011. This reflects an increase in the lifespan of people with intellectual disability. This changing age profile, observed in the data over the past four decades, has major implications for service planning; it points to an enduring high level of demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability. This helps to explain the ongoing demand for additional resources for people with intellectual disability.

Service provision in 2011

The numbers registered on the NIDD in December 2011 were as follows:

- 26,831 people with intellectual disability who were in receipt of services, representing 98% of the total population registered on the NIDD. This was the highest number of people in receipt of services since the database was established.
- 271 people (1% of those registered) who were without services in 2011 and who were identified as requiring appropriate services in the period 2012–2016.
- 222 people (1%) who were not availing of services and had no identified requirement for services during the planning period 2012–2016.

Of the 26,831 people who were in receipt of services in 2011:

- 8,214 (30.1%) were in receipt of full-time residential services, almost the same number as 2010 (8,213). This is the eighth consecutive year in which the data indicate that more people live in community group homes than in residential centres.
- The number of people with intellectual disability accommodated in psychiatric hospitals decreased by 24 (10.1%), from 238 in 2010 to 214 in 2011.
- 26,744 (99.7%) people availed of at least one day programme in 2011. This is the highest number registered as receiving such services since NIDD data were first reported in 1996. Of this group, 8,153 were in full-time residential placements.
- 22,969 (85.6%) people availed of one or more multidisciplinary support services. The services most commonly availed of by adults were social work, medical services and psychiatry. The services most commonly availed of by children were speech and language therapy, occupational therapy and social work.

Sixty-six per cent of those registered on the NIDD (17,916 individuals) lived at home with parents, siblings, relatives or foster parents in 2011. More than one in four over-35s who had a moderate, severe or profound intellectual disability lived at home in 2011. Because people with intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years, which has implications for service planning.

There has been significant growth in the level of provision of full-time residential services, residential support services, and day services since the first NIDD report in 1996. Key developments during the period 1996 to 2011 include:

- An increase of 72% (from 2,393 in 1996 to 4,127 in 2011) in the number of people with intellectual disability living full time in community group homes.
- A 78% reduction (from 970 in 1996 to 214 in 2011) in the number of people with intellectual disability accommodated in psychiatric hospitals.
- A continued expansion in the availability of residential support services, which allow people to continue living with their families and in their communities. Planned or emergency centre-based respite services have grown by a substantial 470%; 4,963 people availed of this type of service in 2011, compared with 871 in 1996.
- 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 2012–2016

The 2011 data indicate that 4,505 new residential, day and/or residential support places will be needed to meet service requirements. The following services will be needed in the period 2012–2016 (most service needs were recorded as being immediate):

- 2,248 full-time residential placements, a decrease of 21, or 0.9%, on the projected number required in 2010.
- 2,040 residential support services, a decrease of five on the projected number required in 2010. A continuing high level of need for these services exists, even though there were over 5,500 people availing of residential support services in 2011.
- 217 day programmes (this figure excludes multidisciplinary support services and services provided by early intervention teams). This number is in addition to the 913 young adults who, as they approach the age of 18, are preparing to leave the education system to take up a range of training and supported/sheltered employment opportunities, which traditionally have been funded by the health sector.
- 123 individuals who were living in psychiatric hospitals in 2011 have been identified as needing to transfer from these locations to more appropriate accommodation.

Of those in receipt of services in 2011, 11,824 people required alternative, additional, or enhanced services in the period 2012–2016, an increase of 319, or 2.8%, since 2010. This group included people who required an increased level of service provision, increased support within their existing services, transfer to more appropriate placements, or a service change to coincide with transition periods in their lives, for example movement from child to adult services, or from education to training and/or employment placements. To address the required service changes over the next five years:

- 10,153 day places will require changes or enhancements. Health-funded services are required by 6,881 individuals (67.8%), employment services are required by 1,320 individuals (13.0%), education services are required by 1,284 individuals (12.6%) and generic services are required by 668 individuals (6.6%). Of the 1,284 service changes required within education, 945 (73.6%) are requirements for an alternative service and 339 (26.4%) are requirements for an enhancement of the individual's existing service.

- 1,472 individuals who were attending special schools in 2011 have recorded a requirement for adult day services within the period 2012–2016. Of this group, over one quarter (385 individuals) require rehabilitative training, 315 (21.4%) require vocational training and 158 (10.7%) require activation programmes.
- 2,865 residential places will require changes or enhancements.
- 1,701 residential support places will require changes or enhancements.

Despite high levels of service provision in 2011, there remained a significant demand for new and enhanced multidisciplinary support services. Almost three quarters (19,813 individuals) of the population registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2012–2016. There was substantial demand for all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy.

1. The National Intellectual Disability Database

Background

The National Intellectual Disability Database (NIDD) was established in 1995 in the Republic of Ireland with the aim of providing 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. This information is made available to the Department of Health (DoH), the Health Service Executive (HSE) and the non-statutory agencies to enable the provision of appropriate services designed to meet the changing needs of people with intellectual disability and their families.

Based on a policy of recording only essential data with maximal accuracy, the information collected by the NIDD is limited to three key elements: demographic details, current service provision and future service requirements. The objective is to record 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. Consent is obtained prior to the registration of individuals on the database. Diagnostic information is specifically excluded as the database is not intended to act as a medical or epidemiological tool.

Information is generally collected on day, residential and multidisciplinary support service usage and future service need. Each individual's record is updated whenever there are changes in his/her circumstances or during the annual review process when service provider agencies assess current and future needs.

The information available from the NIDD provides a sound basis for decision-making since priorities can be set based on the requirements of people with intellectual disability, leading to the delivery of services appropriate to these needs. The commitment of all services and agencies involved in the maintenance of the database is significant and their continuing co-operation is crucial in the provision of relevant and accurate information.

NIDD structure and management

The NIDD is owned by the DoH and managed by the Health Research Board (HRB). The HSE is responsible for the collection of the data, including the implementation and maintenance of structures for the identification of suitable individuals. Though the NIDD is a national database, access is controlled at agency, local and HSE regional level, meaning that system users only have access to the records of service users for whom they are responsible. The provision of access to local data facilitates service planning at local level and promotes effective co-ordination of services within the area.

The initial step in the data collection process is the completion of a data form (Appendix A) for each service user. Responsibility for the collection and provision of this information to the HSE lies primarily with the service providers, local health office (LHO) personnel and school principals. The information is supplied to the LHO and recorded in the NIDD. Some agencies with information systems upload data to the NIDD electronically.

At the end of each year the HRB takes a snapshot of the information within the database (excluding personal details such as name and address), which forms the national dataset for that year. This report is based on the anonymised dataset for 2011.

Data quality

The HRB oversees a system of ongoing validation which aims to identify and correct gaps and inconsistencies in the NIDD data. The database guidelines and protocols are revised and refined in response to issues highlighted by the HRB, HSE regions and service providers. The HRB provides training to HSE and service provider staff which ensures greater standardisation of data collection throughout the country. In addition, the NIDD software contains a series of technical checks which validate the data as it is entered by service providers and HSE regional users.

2011 annual report

This is the fourteenth report of the National Intellectual Disability Database Committee. The report is based on validated data extracted from the NIDD in December 2011. In addition to this report, a summary bulletin is produced for each HSE region and LHO.

The 2011 dataset consists of information relating to 27,324 individuals. Of these registrations, 99.3% (27,128 records) were updated following the completion of the 2011 review of NIDD information; the remaining 196 registrations contain the last-known data in each case. Prevalence rates per thousand of population are based on up-to-date data from the 2011 Census of Population (Central Statistics Office, 2012).

The nature of service provision in the intellectual disability area in Ireland ensures that an almost complete capture of data on all individuals with a moderate, severe or profound intellectual disability is possible and expected. Inclusion of individuals with a mild level of intellectual disability is sought if they are in special classes or special schools for children with intellectual disability, or are attending an intellectual disability service as adults, or if they are considered likely to require such a service within the next five years. Some of those in the average ability and borderline intellectual disability categories are registered on the NIDD but have been excluded from the analyses presented in this report because services for this group are not usually provided within intellectual disability services. In the 2011 dataset, there were 752 people recorded as being of average ability and 761 people in the borderline intellectual disability category. The HSE regions 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.



2. Profile of the registered population

National level

Summary

There were 27,324 people registered on the NIDD at the end of 2011. As shown in Figure 2.1 there were more males (57.4%) than females (42.6%) registered on the database, with the highest proportions of both males and females diagnosed as having a moderate level of intellectual disability. Figure 2.1 also indicates that the largest percentages of people registered were in the HSE South Region (27.8%) and in the 35–54-year age group (28.1%).

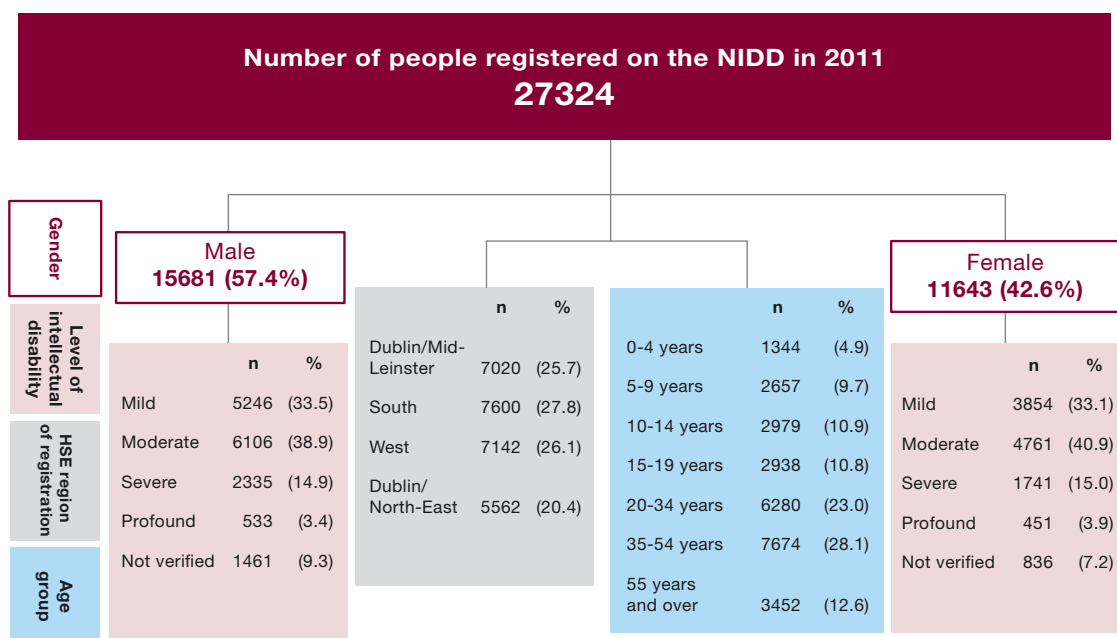


Figure 2.1 Profile of the population registered on the NIDD, 2011

During the review and update period prior to the 2011 extract of data from the NIDD, 654 people were removed from the database¹ and there were 1,422 new registrations, the largest proportion of these (33.8%) in the 0–4-year age group. The age and gender distribution by degree of intellectual disability of those registered on the database is summarised in Table 2.1 which shows the corresponding prevalence² rates per thousand of the population.

- 1 Records of those who had died, who had no requirement for intellectual disability services, or who no longer wanted their information to be held on a national system were among those removed from the database.
- 2 Prevalence is the proportion of people in a population who have a disease or condition at a specific point in time. For example, in 2011, 300 people with an intellectual disability received services in a specific LHO area with a population of 35,000. The prevalence is the total number of cases (300) divided by the population living in the LHO area (35,000) expressed per 1,000 of the population. The calculation in this case is as follows: $(300/35,000) \times 1,000$, which gives a prevalence rate of 8.6 per 1,000 of the specific LHO area population in 2011.

Table 2.1 Number of people registered on the NIDD, by age group, gender and degree of intellectual disability, 2011

Age group	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
0-4	464	641	1105	42	62	104	26	48	74	27	26	53	3	5	8	562	782	1344
5-9	224	533	757	293	549	842	240	503	743	93	160	253	31	31	62	881	1776	2657
10-14	44	139	183	444	867	1311	390	693	1083	130	207	337	31	34	65	1039	1940	2979
15-19	7	20	27	513	900	1413	430	697	1127	124	184	308	37	26	63	1111	1827	2938
20-34	28	34	62	973	1221	2194	1226	1638	2864	397	573	970	84	106	190	2708	3572	6280
35-54	46	50	96	1065	1179	2244	1593	1785	3378	638	867	1505	203	248	451	3545	4129	7674
55 & over	23	44	67	524	468	992	856	742	1598	332	318	650	62	83	145	1797	1655	3452
All ages	836	1461	2297	3854	5246	9100	4761	6106	10867	1741	2335	4076	451	533	984	11643	15681	27324
Prevalence rates – numbers per 1,000 of the general population for each age group*																		
0-4	2.66	3.52	3.10	0.24	0.34	0.29	0.15	0.26	0.21	0.15	0.14	0.15	0.02	0.03	0.02	3.23	4.29	3.77
5-9	1.43	3.25	2.36	1.87	3.35	2.62	1.53	3.07	2.32	0.59	0.98	0.79	0.20	0.19	0.19	5.62	10.83	8.28
10-14	0.30	0.90	0.60	3.01	5.59	4.33	2.65	4.47	3.58	0.88	1.33	1.11	0.21	0.22	0.21	7.05	12.51	9.85
15-19	0.05	0.14	0.10	3.70	6.24	4.99	3.10	4.83	3.98	0.89	1.28	1.09	0.27	0.18	0.22	8.01	12.66	10.38
20-34	0.05	0.07	0.06	1.81	2.37	2.08	2.28	3.18	2.72	0.74	1.11	0.92	0.16	0.21	0.18	5.04	6.93	5.97
35-54	0.07	0.08	0.08	1.67	1.85	1.76	2.50	2.80	2.65	1.00	1.36	1.18	0.32	0.39	0.35	5.56	6.48	6.02
55 & over	0.04	0.09	0.07	1.00	0.98	0.99	1.64	1.56	1.60	0.63	0.67	0.65	0.12	0.17	0.15	3.43	3.48	3.46
All ages	0.36	0.64	0.50	1.66	2.31	1.98	2.06	2.69	2.37	0.75	1.03	0.89	0.19	0.23	0.21	5.03	6.90	5.96

* Prevalence rates are based on Census of Population 2011 figures (CSO, 2012).

Prevalence

The 2011 prevalence rates are calculated using NIDD and Census of Population data for 2011. Prevalence rates quoted in NIDD reports issued between 2007 and 2010 were calculated using the 2006 Census of Population data. Calculating prevalence rates using census data and NIDD data collected in the same year has allowed for realignment, given that the intervening period represented a time of great change in the size and composition of the Irish population.

The prevalence rate for mild intellectual disability in 2011 was 1.98/1000, a slight decrease on the 2010 rate of 2.09/1000. This figure is not a true reflection of the prevalence rate for mild intellectual disability since only those who are accessing or requiring intellectual disability services are included in the database. The prevalence rate for moderate, severe and profound intellectual disability in 2011 was also slightly down, at 3.47/1000, compared to 3.69/1000 in 2010.

Gender differences

As Table 2.1 indicates, over the entire NIDD population, the number of males exceeded the number of females at all levels of intellectual disability, and in all age groups except the 55-years-and-over group. The overall male to female ratio was 1.35:1. This represents a prevalence rate of 6.90/1000 males and 5.03/1000 females.

Age differences

Of the people recorded on the NIDD, 9,918 (36.3%) were aged 19 years or under, 6,280 (23.0%) were aged between 20 and 34 years, 7,674 (28.1%) were aged between 35 and 54 years, and 3,452 (12.6%) were aged 55 years or over. Figure 2.2 illustrates the proportion in each age group at each level of intellectual disability.

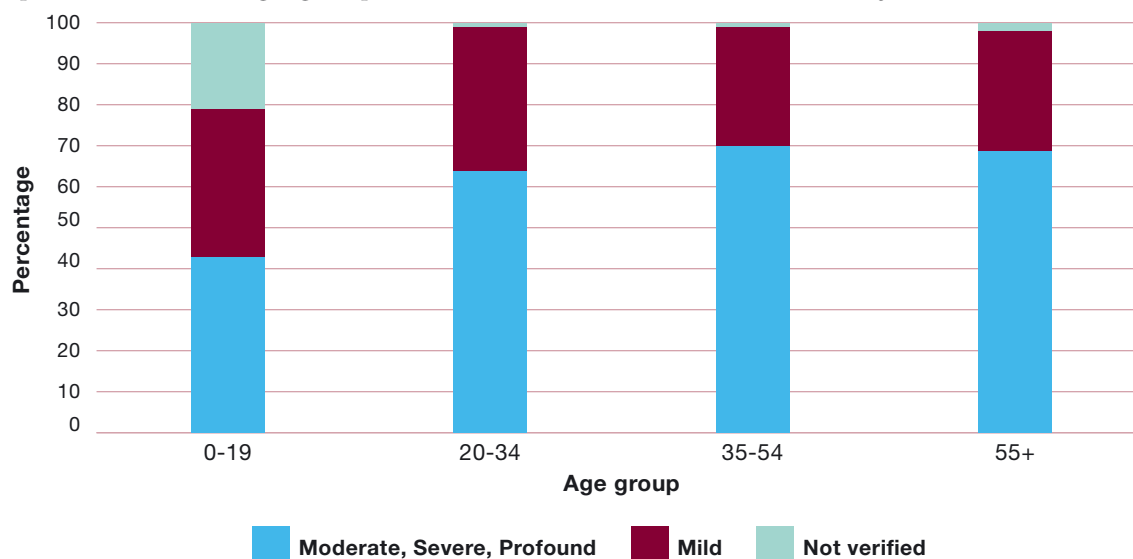


Figure 2.2 Individuals registered on the NIDD, by degree of intellectual disability and by age group, 2011



National Disability Survey 2006

In 2008 the Central Statistics Office (CSO) released results of the National Disability Survey (NDS) conducted in 2006. Data from the survey indicate that 50,400 people in Ireland have a diagnosed learning disability (CSO, 2008). This information differs greatly from the NIDD, which reported 25,518 registrations in April 2006, for two main reasons:

1. Intellectual disability is defined differently by the two data sources: the NIDD definition is based on the WHO International Classification of Diseases, Tenth Edition (ICD-10), while the NDS definition is based on the WHO International Classification of Functioning (ICF).
2. The data-collection methods differ. For inclusion on the NIDD the level of intellectual disability (mild, moderate, severe or profound) is established based on assessment by a multidisciplinary team and only those who are also accessing or require a specialised intellectual disability service are registered. The number of people on the NIDD with a mild intellectual disability may, however, be underestimated as they are less likely to require specialised services. By contrast, the NDS included all individuals who defined themselves as having an intellectual disability, regardless of whether they were in receipt of or required intellectual disability services. This number also included individuals with conditions such as attention deficit disorder or an acquired brain injury; these people are not generally included on the NIDD unless they have a diagnosed intellectual disability as defined by WHO ICD-10 (WHO, 1996).

Trends over time

Recent trends

General population

The Irish population increased by 348,404 (8.2%) between 2006 and 2011. This increase resulted from a large number of births (365,000, average 73,000 per year), lower mortality (140,000 deaths in the same period) and net inward migration of 125,000, (CSO, 2012).

Increases in numbers are reported in all except the 15–29-year age group, which was impacted by a reduced birth rate in the late 1980s/early 1990s and by outward migration in recent years of people in their twenties. The continuing high birth rate is reflected in the increase in the number of 0–4-year-olds, and the fact that people are living longer is demonstrated by the increase of 14.4% in the general population of those aged 65 years and over.

NIDD population

Prevalence rates for moderate, severe and profound intellectual disability for the years 2002, 2007 and 2011 are shown in Table 2.2. The 2002 prevalence rates are calculated using NIDD and Census of Population data for 2002, 2007 prevalence rates are calculated using NIDD data for 2007 and Census of Population data for 2006. The 2011 prevalence rates are calculated using NIDD and Census of Population data for 2011.



Table 2.2 Prevalence of intellectual disability, by degree (moderate, severe and profound) and by age group, 2002, 2007, 2011

Age group	Moderate		Severe		Profound		All levels		
	2002	2007	2011	2002	2007	2011	2002	2007	2011
0-4	145	69	74	57	19	53	17	6	8
5-9	645	605	743	257	260	253	52	50	62
10-14	806	895	1083	271	304	337	48	56	65
15-19	947	940	1127	287	276	308	75	53	63
20-34	2912	2813	2864	1158	1053	970	353	268	190
35-54	2936	3127	3378	1500	1507	1505	425	472	451
55 & over	1104	1293	1598	474	548	650	88	123	145
All ages	11497	9742	10867	4004	3967	4076	1058	1028	984
Prevalence rates – numbers per 1,000 of the general population for each age group									
0-4	0.52	0.23	0.21	0.21	0.06	0.15	0.06	0.02	0.02
5-9	2.44	2.10	2.32	0.97	0.90	0.79	0.20	0.17	0.19
10-14	2.82	3.27	3.58	0.95	1.11	1.11	0.17	0.20	0.21
15-19	3.02	3.24	3.98	0.92	0.95	1.09	0.24	0.18	0.22
20-34	3.08	2.64	2.72	1.22	0.99	0.92	0.37	0.25	0.18
35-54	2.81	2.73	2.65	1.44	1.32	1.18	0.41	0.41	0.35
55 & over	1.40	1.48	1.60	0.60	0.63	0.65	0.11	0.14	0.15
All ages	2.94	2.30	2.37	1.02	0.94	0.89	0.27	0.24	0.21
							3.72	3.48	3.47

A comparison of the data presented in Table 2.2 shows that:

- The prevalence rate in the 0–4-year age group was lower in 2007 (0.31/1000) than in 2002 (0.79/1000) but rose slightly in 2011 to 0.38/1000. Each year, efforts are made to register every eligible child as soon as possible after birth, but a number of factors can contribute to under-registration. Children may not be registered in cases where the developmental delay was not evident for some time, or where parents are reluctant to allow information about their young child to be recorded on the database. Another possible reason for the small number of 0–4-year-olds registered on the NIDD is that the needs of children in this age group are increasingly being met by mainstream rather than specialised intellectual disability services, which puts them outside the scope of the database. The assessment-of-need process, which has been in place since 2007 for those aged under five years, may have also had some impact on registration for this age group.
- The prevalence rate among 15–19-year-olds is the only one which has significantly increased in the four-year period, rising from 4.37/1000 in 2007 to 5.29/1000 in 2011. This may be due to the number of individuals becoming newly registered as they transition from education to special employment services for those with intellectual disability.
- In both the 5–9-year and 55-years-and-over age groups the prevalence rates have effectively remained unchanged in the period 2002–2011; however, the number of individuals registered in the 5–9-year age group has increased by 104 (10.9%), and the number in the 55-years-and-over age group has increased by 727 (43.6%). The smaller increase in the younger age group may again reflect the possibility that the needs of children of this age may be met by mainstream rather than specialist intellectual disability services.

Table 2.3 Prevalence of intellectual disability, by degree (moderate, severe and profound) and by age group, 1974, 1981, 1996, 2011

Age group	Moderate				Severe				Profound				All levels			
	1974	1981	1996	2011	1974	1981	1996	2011	1974	1981	1996	2011	1974	1981	1996	2011
0-4	189	214	226	74	143	92	83	53	99	26	30	8	431	332	339	135
5-9	809	955	736	743	617	330	260	253	224	99	77	62	1650	1384	1073	1058
10-14	752	1035	948	1083	583	428	305	337	292	117	93	65	1627	1580	1346	1485
15-19	698	1203	1072	1127	445	508	378	308	241	154	132	63	1384	1865	1582	1498
20-34	1498	2419	2997	2864	1017	1129	1350	970	441	340	460	190	2956	3888	4807	4024
35-54	1321	1559	2626	3378	626	612	1183	1505	201	97	343	451	2148	2268	4152	5334
55 & over	669	715	987	1598	307	248	394	650	84	24	53	145	1060	987	1434	2393
All ages	5936	8100	9592	10867	3738	3347	3953	4076	1582	857	1188	984	11256	12304	14733	15927
Prevalence rates – numbers per 1,000 of the general population for each age group																
0-4	0.60	0.62	0.83	0.21	0.45	0.27	0.30	0.15	0.31	0.07	0.11	0.02	1.36	0.97	1.24	0.38
5-9	2.55	2.73	2.31	2.32	1.95	0.94	0.82	0.79	0.71	0.28	0.24	0.19	5.20	3.95	3.37	3.30
10-14	2.52	3.08	2.72	3.58	1.95	1.27	0.88	1.11	0.98	0.35	0.27	0.21	5.45	4.70	3.86	4.91
15-19	2.61	3.79	3.20	3.98	1.66	1.60	1.13	1.09	0.90	0.48	0.39	0.22	5.17	5.88	4.72	5.29
20-34	2.78	3.33	3.93	2.72	1.88	1.56	1.77	0.92	0.82	0.47	0.60	0.18	5.48	5.35	6.31	3.82
35-54	2.13	2.43	3.25	2.65	1.01	0.95	1.46	1.18	0.32	0.15	0.42	0.35	3.46	3.53	5.14	4.18
55 & over	1.08	1.09	1.45	1.60	0.50	0.38	0.58	0.65	0.14	0.04	0.08	0.15	1.71	1.51	2.11	2.40
All ages	1.99	2.35	2.72	2.37	1.25	0.97	1.12	0.89	0.53	0.25	0.34	0.21	3.80	3.60	4.18	3.47

Trends over past four decades

The availability of data from the 1974 and 1981 Censuses of Mental Handicap carried out by the Medico-Social Research Board (Mulcahy, 1976; Mulcahy and Ennis, 1996; Mulcahy and Reynolds, 1984) along with NIDD data from 1996 and 2011 allows us to monitor trends in the population with an intellectual disability over the past 37 years (Table 2.3).

Of particular interest from a trends point of view, and most relevant to service planning, is the fact that over the period the increase in numbers registered on the NIDD is confined largely to the two older age groups, the 35–54-year age group and the 55-years-and-over age group. A number of factors contributed to this increase, 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.

Ageing population

Figure 2.3 shows that almost half of those with a moderate, severe or profound intellectual disability are aged 35 years or over. In the research literature, increased longevity in this population is attributed to improved health and well-being, the control of infectious diseases, the move to community living, better nutrition, and an improvement in the quality of health care services. It can be seen that 28.5% of this population were aged 35 years or over in 1974. A steady increase in the proportion in this age group was observed in each dataset between 1996 (37.9%) and 2010 (48.9%) with a very small drop (0.4%) in 2011.

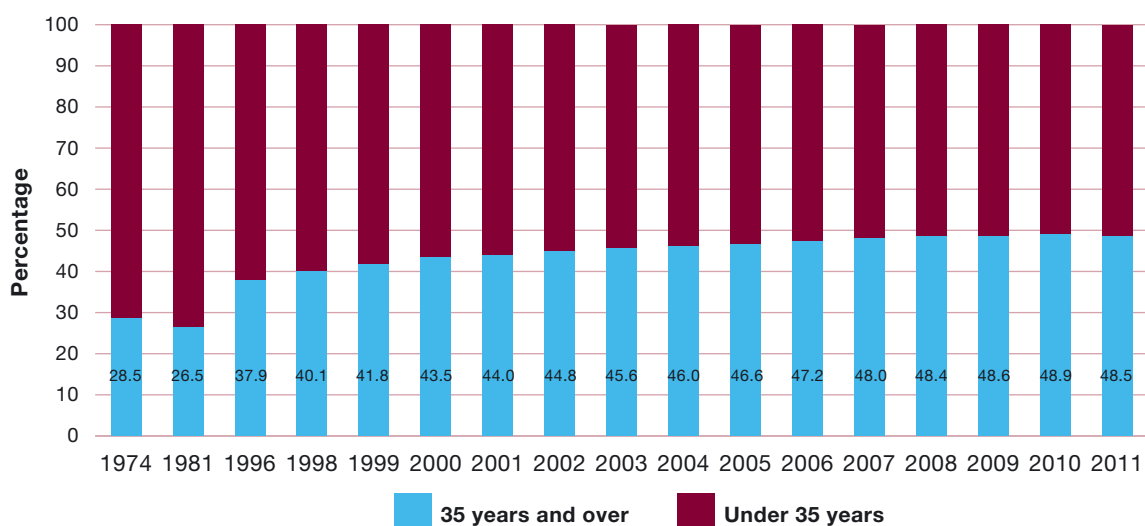


Figure 2.3 Proportion of people with moderate, severe or profound intellectual disability (combined), by age group, 1974–2011

Impact of observed trends

As previous reports from the NIDD have highlighted, the changing age profile of the population with moderate, severe or profound intellectual disability has major implications for service planning in the years ahead. Key issues include:

- Transition points such as the movement from pre-school to primary school, primary to secondary school and from school to employment are particularly important from a service planning perspective.
- Residential services are primarily used by adults with a moderate, severe or profound intellectual disability (see Chapter 3). As the number of individuals in this group increases, more pressure is being placed on 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. 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 and to live as independently as possible.

Regional level

Numbers in each Health Service Executive region

Table 2.4 shows the number of individuals registered on the NIDD in 2011 by HSE region. The highest number of registrations was located in the HSE South Region and the lowest numbers registered in the HSE Dublin/North-East Region. The numbers registered in each region were broadly in line with 2010 figures.

Table 2.4 Number of people registered on the NIDD, by HSE region, 2011

HSE Region	n	% of NIDD
Dublin/Mid-Leinster	7020	25.7
South*	7600	27.8
West†	7142	26.1
Dublin/North-East‡	5562	20.4
Total	27324	100.0

* An additional 168 individuals received services in the HSE South Region but have not been included in the overall figures as they did not consent to having their information included on the national system.

† An additional 52 individuals received services in the HSE West Region but have not been included in the overall figures as they did not consent to having their information included on the national system.

‡ An additional 36 individuals received services in the HSE Dublin/North East Region but have not been included in the overall figures as they did not consent to having their information included on the national system.

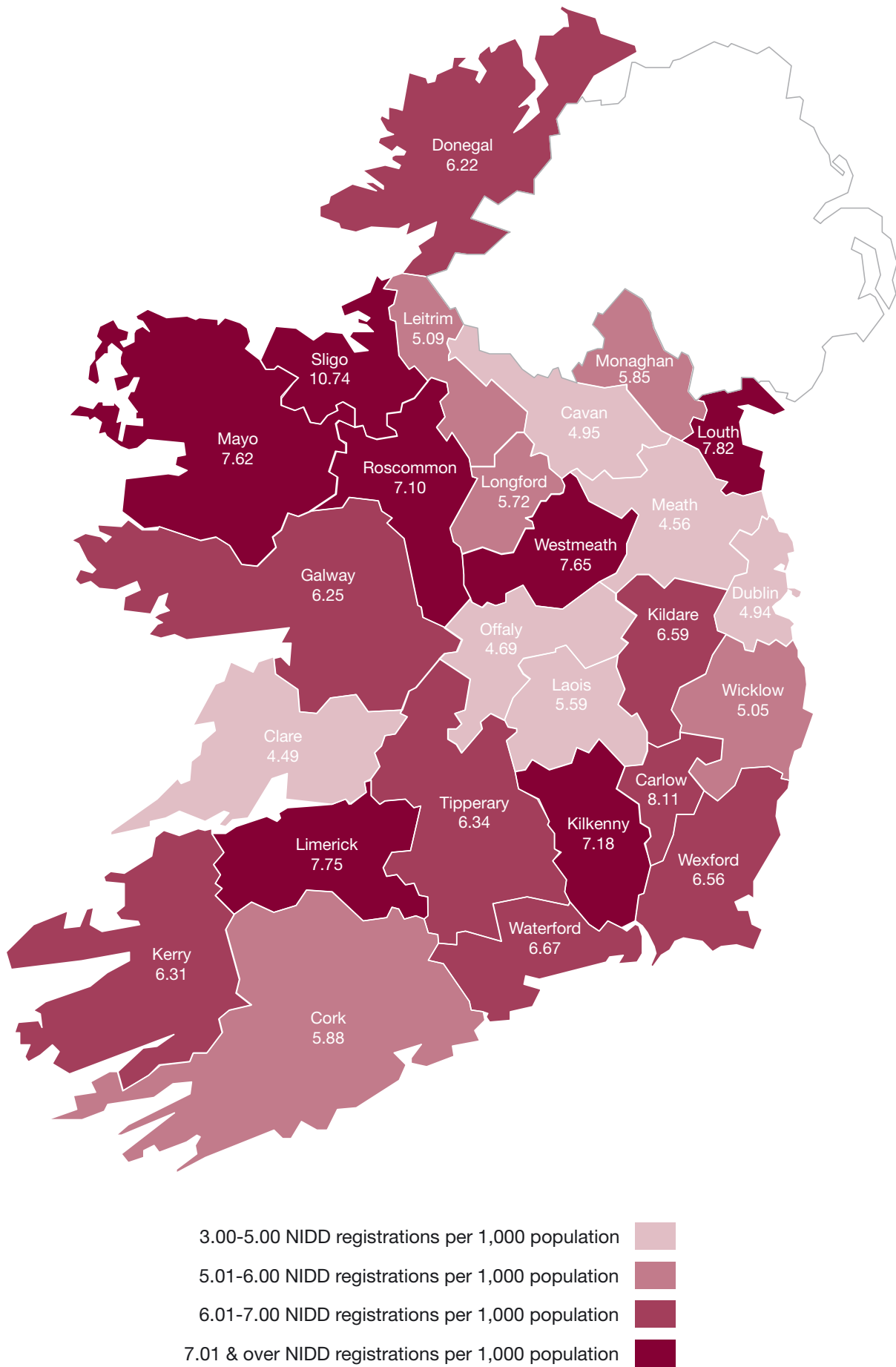


Figure 2.4 Prevalence of NIDD registrations per 1,000 of the general population, by county of residence, 2011³

³ Figure 2.4 in 2010 were calculated using Local Health Office (LHO) of residence data. This was not possible for the 2011 report as the census 2011 data for LHOs will not be released until late 2012.



Figure 2.4 presents the number of NIDD registrations by county in which service users reside. The national prevalence rate was 5.96/1000. The counties with the highest prevalence rates per 1,000 population were Sligo (10.74/1000), Carlow (8.11/1000) and Louth (7.82/1000), while Clare (4.49/1000) and Meath (4.56/1000) had the lowest prevalence rates.

Co-morbidity within the NIDD population

As Table 2.5 indicates, 10,830 individuals (39.6%) registered on the NIDD in 2011 had a physical and/or sensory disability in addition to an intellectual disability. This number represents an increase of 16.9% on the 2010 figure, reflecting an improvement in the recording of people with multiple disabilities. Individuals with multiple disabilities are likely to have more complex service needs than those with intellectual disability alone.

Table 2.5 Number of people registered on the NIDD with a physical and/or sensory disability, by gender, 2011

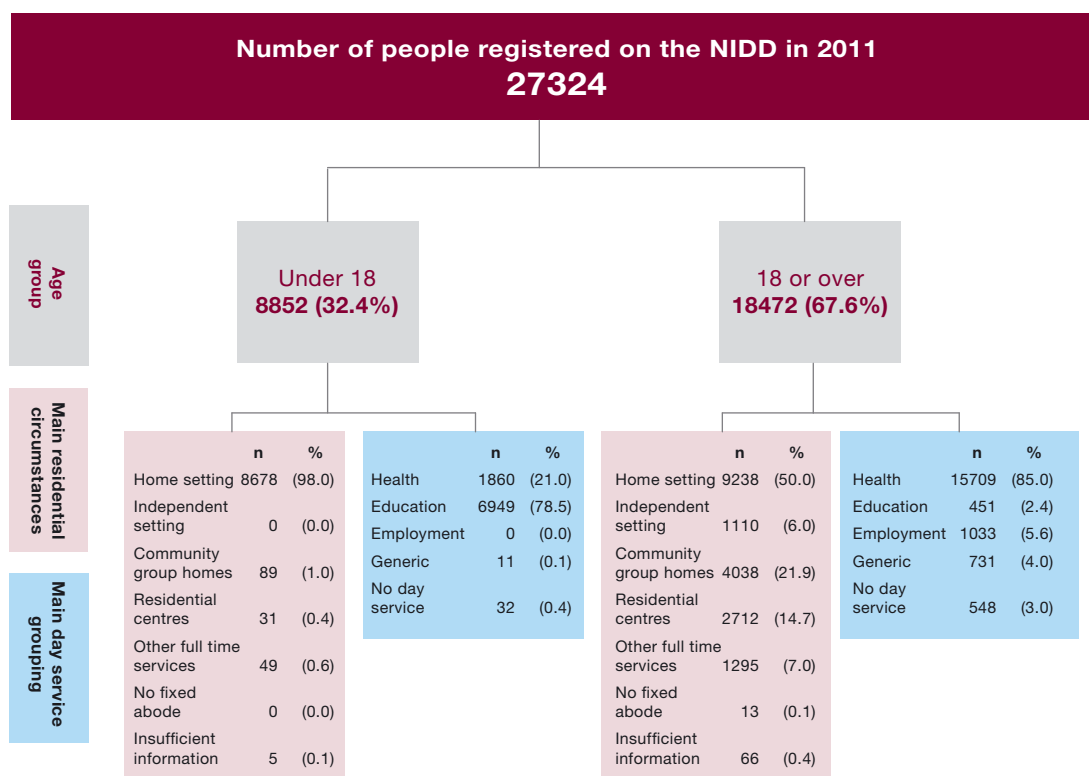
	Male		Female		Total	
	n	%	n	%	n	%
Intellectual and physical/ sensory disability	6010	38.3	4820	41.4	10830	39.6
Intellectual disability only	9646	61.5	6796	58.4	16442	60.2
Not reviewed	25	0.2	27	0.2	52	0.2
Total	15681	100.0	11643	100.0	27324	100.0

3. Service provision in 2011

National level

Summary of service provision

Figure 3.1 presents summary data for the main day and residential services provided to adults (aged 18 years and over) and children (aged under 18 years) registered on the NIDD in 2011. Day services were availed of by 97.9% of all those registered on the NIDD in 2011. The majority of services accessed by adults were health related, and the majority accessed by children were educational. Figure 3.1 also shows that a larger proportion (3.0%) of adults were without day services, compared to their younger counterparts (0.4%). The residential circumstances for both age groups also differed in 2011: 98.0% (8,678) of those aged under 18 years lived at home, compared to 50.0% (9,238) of those aged 18 years and over.



Note: The NIDD permits the recording of two different types of residential service and three different types of day service for each person on the database. The data above represent each person's main day and main residential service only. Overall service provision is detailed in Tables 3.3 and 3.7.

Figure 3.1 Summary of service provision, by age group, 2011

In 2011, 26,831 people with intellectual disability were receiving services, which accounted for 98.2% of the total population registered on the NIDD. Of the remaining 493 people (1.8%) who were not in receipt of services, 271 (1.0% of total registered population) had expressed a need for services in the period 2012–2016. The overall level of service provision in 2011 is provided in Table 3.1 (a comprehensive list of the types of service availed of is given in Appendix B).

Table 3.1 Overall service provision to those registered on the NIDD, 2011

	n	%
Attending services on a day basis	18591	68.0
Receiving 5- or 7-day residential services	8000	29.3
Resident in a psychiatric hospital	214	0.8
Receiving residential support services only	26	0.1
Receiving no service – on waiting list	271	1.0
No identified service requirements	222	0.8
Total	27324	100.0%

Residential circumstances

Table 3.2 provides an overview of the main residential circumstances of those registered on the NIDD in 2011 by degree of intellectual disability and age group (a further breakdown is presented in Table 3.3).

The main groupings of individuals consisted of:

- 17,916 individuals (65.6%) who lived at home with parents, relatives, or foster parents. This figure does not take account of those in the mild intellectual disability category living at home/independently without supports or services, and who are under-represented on the NIDD.
- 8,214 individuals (30.1%) who lived in full-time residential services, mainly in community group homes, residential centres, psychiatric hospitals, and intensive placements such as those for challenging behaviour.
- 1,110 individuals (4.1%) who lived independently or semi-independently. This represents an increase of 34 on the 2010 figure.

The most commonly availed of residential settings were community group homes. The data indicate that more full-time residents lived in homes in the community (4,127) than in residential centres (2,743). The number of people accommodated in community group homes has increased and in residential centres has decreased on an almost continuous basis since data collection commenced. This reflects an ongoing trend towards community living for people with an intellectual disability.

In 2011, 271 people with an intellectual disability resided full time in mental health facilities, either in psychiatric hospitals (214 individuals, compared with 238 individuals in 2010) or in mental health community residences (57 individuals) (Table 3.3).

Age difference

There were notable differences in the age profiles of the groups in the various categories of accommodation (Table 3.2). The proportion of people who lived in a home setting in 2011 decreased with age: 97.7% of individuals aged 0–19 years lived in a home setting, declining to 73.6% of those aged 20–34 years, 39.2% of those aged 35–54 years, and 17.3% of those aged 55 years or over.

By contrast, the proportion of people in the different age categories who lived in full-time residential services in 2011 increased with age: 2.2% of all 0–19-year-olds received full-time residential services, compared with 22.4% of 20–34-year-olds, 52.6% of 35–54-year-olds, and 73.7% of those aged 55 years or over.

The data indicate that more than one in four people aged 35 years or over with a moderate, severe or profound intellectual disability lived with their families in 2011. Because people with intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years, which has implications for service planning. Of the 1,110 individuals who lived in independent or semi-independent settings in 2011, 79.4% were aged 35 years or over and over three quarters (77.0%) had a mild intellectual disability.

Degree of intellectual disability

There were also noticeable variations between level of ability and type of residential situation (Table 3.2). Of those with a mild intellectual disability, 74.6% lived in a home setting, compared to 56.1% of those with a moderate, severe or profound intellectual disability. The proportion of people in full-time residential services increased as the level of intellectual disability increased. Only 15.8% of people with a mild intellectual disability lived in full-time residential services, but this increased to 42.2% in the case of those with a moderate, severe or profound disability.

Where individuals were in full-time residential services in 2011, the type of service varied according to the level of intellectual disability. Full-time residents with a mild intellectual disability were in the past more likely to be accommodated in community group homes, while full-time residents with a moderate, severe or profound intellectual disability were more likely to be accommodated in residential centres. However, since 2007 the number of full-time residents with a moderate, severe or profound intellectual disability living in community group homes has exceeded the number living in residential centres.

- Of those in full-time residential services in 2011 who had a moderate, severe or profound intellectual disability, 47.1% were in community group homes, 37.0% were in residential centres, and 15.9% were in other full-time residential services such as nursing homes or intensive placements.
- Of those in the mild range of intellectual disability who were in full-time residential services in 2011, 65.3% were in community group homes, 17.8% were in other full-time residential services and 16.8% were in residential centres.



Table 3.2 Main residential circumstances, by degree of intellectual disability and by age group, 2011

	Not verified				Mild				Moderate, severe or profound				All levels			
	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	
Home setting	2065	50	50	28	2193	3617	1769	1164	240	6790	4004	2805	1796	328	8933	
Independent setting	0	6	31	12	49	3	184	462	206	855	0	36	101	69	206	
Community group home	1	5	8	7	21	35	147	454	305	941	79	549	1752	785	3165	
Residential centre	2	1	1	8	12	4	27	77	134	242	38	345	1186	920	2489	
Other full-time services*	3	0	6	11	20	9	57	86	105	257	52	275	470	270	1067	
No fixed abode	0	0	0	0	0	1	5	1	2	9	0	0	3	1	4	
Insufficient information	1	0	0	1	2	1	5	0	0	6	3	14	26	20	63	
Total	2072	62	96	67	2297	3670	2194	2244	992	9100	4176	4024	5334	2393	15927	
						9918	6280	7674	3452	27324						

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

Table 3.3 outlines the main residential circumstances and overall level of residential service provision of those registered on the NIDD in 2011 (a more detailed breakdown of main residential circumstances is presented in Table C1 in Appendix C). The NIDD permits the recording of two different types of residential service for each individual registered. The overall level of residential service provision shown in Table 3.3 includes both the main and secondary residential services provided, while the main residential circumstance is the place in which the individual resides most of the time. Of particular note is the number of residential support services available in addition to an individual's principal residential service; these include holiday residential placements, crisis or planned respite care, occasional respite with a host family, overnight respite in the home and regular part-time care.

In the 15-year period between 1996 and 2011 there has been considerable growth in the number of residential support places available. This can be seen in the growing number of individuals who availed of centre-based respite services, either as a planned or emergency intervention. The number of people availing of these services rose from 871 in 1996, to 2,647 in 2001 and to 4,242 individuals in 2006. In 2011 4,963 individuals availed of respite services, which brings the total increase over the period to 4,092 individuals (469.8%).

Table 3.3 Main residential circumstances and overall level of residential service provision, 2011

	Main residential circumstances			Overall level of residential provision/circumstance		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home setting	8678	9238	17916	8686	9246	17932
At home with both parents	6731	5378	12109	6731	5378	12109
At home with one parent	1695	2649	4344	1695	2649	4344
At home with sibling	3	911	914	3	911	914
At home with other relative	44	159	203	44	159	203
Living with non-relative	4	24	28	4	24	28
Adoption	7	14	21	7	14	21
Foster care and boarding out arrangements	194	103	297	202	111	313
Independent setting	0	1110	1110	0	1112	1112
Living independently	0	707	707	0	708	708
Living semi-independently	0	403	403	0	404	404
Community group homes	89	4038	4127	89	4038	4127
5-day community group home	27	421	448	27	421	448
7-day (48-week) community group home	7	531	538	7	531	538
7-day (52-week) community group home	55	3086	3141	55	3086	3141
Residential setting	31	2712	2743	31	2712	2743
5-day residential centre	3	63	66	3	63	66
7-day (48-week) residential centre	9	318	327	9	318	327
7-day (52-week) residential centre	19	2331	2350	19	2331	2350
Other full-time residential services	49	1295	1344	49	1295	1344
Nursing home	0	157	157	0	157	157
Mental health community residence	1	56	57	1	56	57
Psychiatric hospital	0	214	214	0	214	214
Intensive placement (challenging behaviour)	20	482	502	20	482	502
Intensive placement (profound or multiple handicap)	11	242	253	11	242	253
Occupying a full-time support place	8	70	78	8	70	78
Other full-time residential service	9	74	83	9	74	83
Residential support service	0	0	0	1455	4153	5608
Holiday residential placement	0	0	0	4	122	126
Crisis or planned respite	0	0	0	1295	3668	4963
Occasional respite with host family	0	0	0	129	192	321
Overnight respite in the home	0	0	0	6	7	13
Shared care or guardianship	0	0	0	1	11	12
Regular part-time care (2/3 days per week)	0	0	0	12	72	84
Regular part-time care (every weekend)	0	0	0	2	7	9
Regular part-time care (alternate weeks)	0	0	0	1	54	55
Other residential service	0	0	0	5	20	25
No fixed abode	0	13	13	0	13	13
Insufficient information	5	66	71	5	66	71
	8852	18472	27324	10315	22635	32950

Note: The total number of services received (32,950) exceeds the actual number of people with an intellectual disability as a number of people availed of two residential services.

Respite services

As illustrated in Table 3.3, the majority of residential support services are service-based respite breaks. The NIDD allows for the recording of each person's need for respite services.

Degree of intellectual disability

Figure 3.2 highlights a clear relationship between level of disability and the median⁴ number of nights availed of. As would be expected, people with moderate, severe or profound levels of intellectual disability required more respite nights than those with a mild level of intellectual disability.

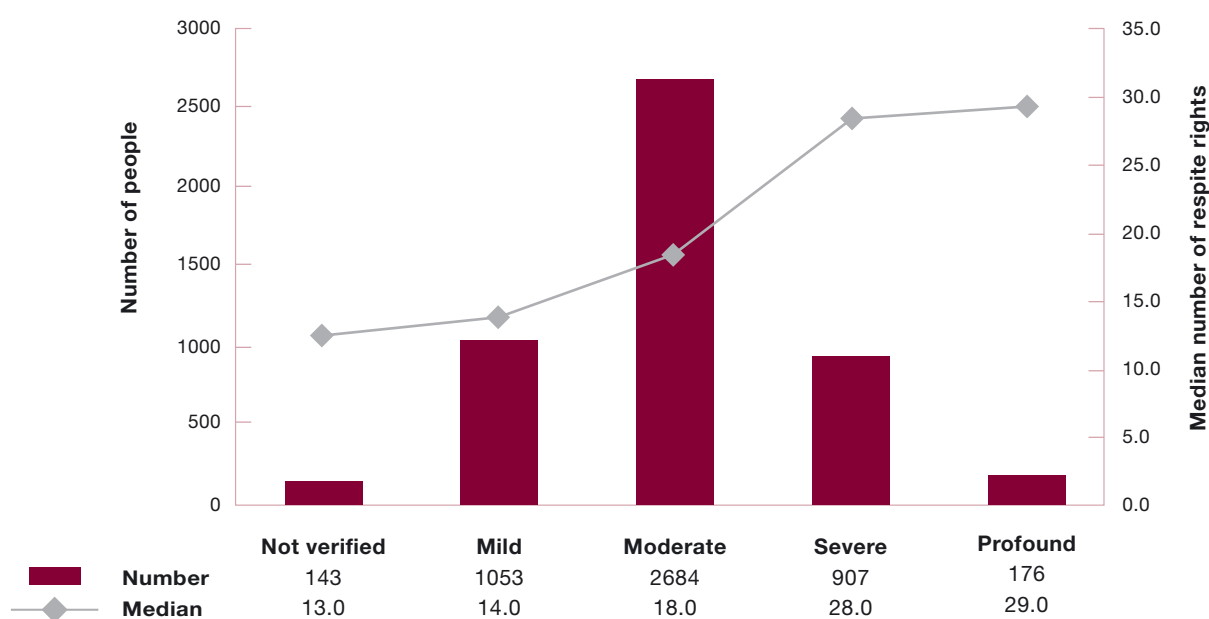


Figure 3.2 Number of people in receipt of respite nights and median number of respite nights received, by degree of intellectual disability, 2011

Geographical variation in respite provision

Figure 3.3 displays the total number of respite nights received in 2011 by HSE region. Table 3.4 presents data on respite for each of the HSE local health office (LHO) areas. Both the figure and the table show that there were marked differences between regions in the total number of respite nights received in 2011, which ranged from 24,241 nights in the HSE South Region to 47,187 nights in the HSE West Region. Chapter 4 presents data on those who require respite care.

⁴ The median is the value at the mid-point in a sequence of values which are ranged in ascending order. It is described as the numeric value separating the higher half of a sample from the lower half. The median can be found by arranging all the observations from lowest value to highest value and picking the middle one. For example, in the case of five clients who received 18, 19, 21, 22 and 55 nights of respite care in one year, the median (middle value) is 21 nights, whereas the mean is 27 nights. While the mean and median both describe the central value of the data, the median is more useful in this case because the mean is influenced by the one client who required a lot of respite care.



HSE Dublin/North-East
 Total number of respite nights received – 28888
 Total number of people in receipt of respite – 1212
 Total number of people registered on NIDD – 5562
Median number of respite nights – 16

HSE Dublin/Mid-Leinster
 Total number of respite nights received – 40645
 Total number of people in receipt of respite – 1359
 Total number of people registered on NIDD – 7020
Median number of respite nights – 19

HSE West
 Total number of respite nights received – 47187
 Total number of people in receipt of respite – 1270
 Total number of people registered on NIDD – 7142
Median number of respite nights – 27

HSE South
 Total number of respite nights received – 24241
 Total number of people in receipt of respite – 1122
 Total number of people registered on NIDD – 7600
Median number of respite nights – 14

Figure 3.3 Total number and median number of respite nights received, by HSE region of residence, 2011⁵

5 A small number of individuals (68) remained in respite care for more than 150 nights, which may have slightly inflated the respite figures. Thirty-one of these people were resident in the West Region, 22 in the Dublin/Mid-Leinster Region, 10 in the Dublin/North-East Region and 5 in the South Region.



Table 3.4 Use of respite nights, by HSE region and by LHO area of residence, 2011

	Total number of respite nights received	Number of people in receipt of respite nights	Median number of respite nights received
HSE Dublin/Mid-Leinster Region	40645	1359	19.0
LHO Dublin South	4838	131	28.0
LHO Dublin South East	2062	68	21.0
LHO Dublin South City	2913	106	16.0
LHO Dublin South West	7978	235	20.0
LHO Dublin West	5966	155	24.0
LHO Kildare/West Wicklow	5476	254	12.5
LHO Wicklow	3927	99	28.0
LHO Laois/Offaly	2403	147	8.0
LHO Longford/Westmeath	5082	164	18.0
HSE South Region	24241	1122	14.0
LHO Carlow/Kilkenny	2816	122	12.0
LHO Tipperary SR	2618	140	13.5
LHO Waterford	1557	103	12.0
LHO Wexford	2758	173	14.0
LHO Cork North Lee	2212	105	12.0
LHO Cork South Lee	2204	101	14.0
LHO North Cork	1782	75	15.0
LHO West Cork	3961	110	16.0
LHO Kerry	4333	193	15.0
HSE West Region	47187	1270	27.0
LHO Limerick	5385	145	28.0
LHO Tipperary NR	3492	90	36.0
LHO Clare	3261	105	24.0
LHO Galway	16351	344	31.5
LHO Mayo	6846	181	31.0
LHO Roscommon	1758	52	27.0
LHO Donegal	6073	221	20.0
LHO Sligo/Leitrim/West Cavan	4021	132	14.0
HSE Dublin/North-East Region	28888	1212	16.0
LHO Dublin North West	5661	224	17.0
LHO Dublin North Central	2746	169	6.0
LHO Dublin North	9730	408	14.0
LHO Cavan/Monaghan	2359	114	15.0
LHO Louth	4524	119	32.0
LHO Meath	3868	178	18.0
All regions	140961	4963	18.0

Day services

In 2011, 26,744 people, representing 97.9% of all those registered on the NIDD, received day services (Table 3.6). This is the highest number registered as receiving such 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, in addition to people who are receiving full-time residential services.

Of the 26,744 individuals who availed of day services in 2011, 8,153 (30.5%) were in full-time residential services, the majority of whom were in the moderate, severe, or profound range of intellectual disability (81.8%) and aged 18 years or over (97.9%). The remaining 18,591 (69.5%) attended services on a day basis, of whom 40.1% were in the mild range of intellectual disability and 46.5% were aged under 18 years (Table 3.5).

Table 3.5 Residential status of people availing of day services, by degree of intellectual disability and by age group, 2011

	Not verified			Mild			Moderate, severe or profound			Total		
	Under 18	18 or over	Total	Under 18	18 or over	Total	Under 18	18 or over	Total	Under 18	18 or over	Total
Residents	6	46	52	38	1390	1428	125	6548	6673	169	7984	8153
Day attendees	2037	178	2215	3157	4289	7446	3457	5473	8930	8651	9940	18591
Total	2043	224	2267	3195	5679	8874	3582	12021	15603	8820	17924	26744

Main day services by age group and degree of intellectual disability

As in 2010, the top three day activities availed of by people with an intellectual disability in 2011, and accounting for more than half of principal day service provision, were activation programmes, special schools, and sheltered work (Table 3.6).

Age difference

Of the 26,744 individuals who availed of day services in 2011, 8,820 (33.0%) were aged under 18 years, and 17,924 (67.0%) were aged 18 years or over (Table 3.6).

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

Of the 17,924 adults who availed of at least one day service in 2011, most attended either activation centres (35.9%) or sheltered work centres (18.2%) as their principal day service. Smaller proportions availed of rehabilitative training (9.5%), multidisciplinary support services only (9.2%), and supported employment (4.8%).

Degree of intellectual disability

Of those who received day services in 2011 (26,744 individuals), 8,874 (33.2%) had a mild intellectual disability, 15,603 (58.3%) had a moderate, severe or profound intellectual disability and 2,267 (8.5%) had not yet had their degree of intellectual disability established (Table 3.6).

The age profiles of these groups are quite different. Just less than one in four (3,582, 23.0%) of the population with moderate, severe or profound intellectual disability who availed of day services in 2011 were aged under 18 years, whereas more than one in three (3,195, 36.0%) of the population with mild intellectual disability who availed of day services were aged under 18 years.

Of the 8,820 under-18s who availed of day services in 2011:

- 3,195 (36.0%) had a mild degree of intellectual disability; most of this group availed of special education services as their principal day service, with smaller numbers in mainstream schools and pre-school services.
- 3,582 (40.6%) had a moderate, severe or profound intellectual disability and, while most were receiving special education services as their principal day service, smaller numbers were in mainstream education or pre-school services and some also availed of more intensive services such as child education and development centres.
- 2,043 (23.2%) had not had their degree of intellectual disability verified.

Of the 17,924 adults in receipt of day services in 2011:

- 5,679 (31.7%) had a mild degree of intellectual disability, most of whom were in receipt of activation programmes, attended sheltered work centres, availed of rehabilitative training, or were in supported employment.
- 12,021 (67.1%) were in the moderate, severe or profound range and were most likely to be in receipt of activation programmes, with smaller numbers in sheltered work and rehabilitative training.
- 224 (1.2%) had not had their degree of intellectual disability verified.



Table 3.6 Principal day service availed of, by degree of intellectual disability and by age group, 2011

	Not verified			Mild			Moderate, severe or profound			All levels		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home support	51	5	56	6	64	70	7	96	103	64	165	229
Home help	2	1	3	0	9	9	0	11	11	2	21	23
Early intervention team	496	0	496	61	0	61	46	0	46	603	0	603
Special pre-school for intellectual disability	384	0	384	52	0	52	111	0	111	547	0	547
Child education and development centre	8	0	8	3	0	3	136	10	146	147	10	157
Mainstream pre-school	230	0	230	58	0	58	29	0	29	317	0	317
Mainstream school	375	3	378	911	41	952	611	29	640	1897	73	1970
Resource/visiting teacher	33	0	33	52	13	65	36	5	41	121	18	139
Special class – primary	99	0	99	198	0	198	203	0	203	500	0	500
Special class – secondary	5	1	6	80	19	99	86	32	118	171	52	223
Special school	271	1	272	1723	151	1874	2260	121	2381	4254	273	4527
Third-level education	0	1	1	1	22	23	0	6	6	1	29	30
Rehabilitative training	0	11	11	2	803	805	1	887	888	3	1701	1704
Activation centre	0	27	27	2	1302	1304	1	5110	5111	3	6439	6442
Programme for the older person	0	12	12	0	113	113	0	526	526	0	651	651
Special high-support day service	0	0	0	1	56	57	6	707	713	7	763	770
Special intensive day service	0	0	0	2	45	47	11	321	332	13	366	379
Sheltered work centre	0	23	23	0	1288	1288	0	1960	1960	0	3271	3271
Sheltered employment centre	0	13	13	2	59	61	0	24	24	2	96	98
Multidisciplinary support services	36	32	68	15	483	498	15	1134	1149	66	1649	1715
Centre-based day respite service	1	1	2	0	10	10	0	9	9	1	20	21
Day respite in the home	2	0	2	0	1	1	1	2	3	3	3	6
Outreach programme	1	1	2	0	52	52	0	71	71	1	124	125
Other day service	48	1	49	16	166	182	22	277	299	86	444	530
Enclave within open employment	0	0	0	0	3	3	0	6	6	0	9	9
Supported employment	0	23	23	0	515	515	0	322	322	0	860	860
Open employment	0	2	2	0	112	112	0	42	42	0	156	156
Vocational training	0	11	11	10	201	211	0	90	90	10	302	312
Generic day services	1	55	56	0	151	151	0	223	223	1	429	430
Total	2043	224	2267	3195	5679	8874	3582	12021	15603	8820	17924	26744

Table 3.7 outlines the main day service and overall level of day service provision for those registered on the NIDD in 2011. The NIDD records up to three different types of day service for each person registered. The overall level of day service provision shown in Table 3.7 includes the main, secondary and tertiary day programmes provided. Of note is the number of support services available in addition to the principal day service; these include services such as home support, education support, centre-based and home-based day respite, home help, and multidisciplinary support.

There has been a steady increase in overall day service provision in the 15-year period between 1996 and 2011. In particular, the data show:

- The number of both intensive and high-support day places has significantly increased. The number of intensive day places rose from 116 in 1996, to 178 in 2001, to 313 in 2006. The number of people attending these services in 2011 was 395, which represents an increase of 279 places (240%) over the 15-year period. The number of high-support day places rose by 384 (96%) in the same period.
- A large increase was also observed in the number of people who attended programmes specific to the older person. This rose from 277 in 1996, to 400 in 2001, to 658 people in 2006. The number of people who attended these services in 2011 was 709, representing an overall increase of 432 places (156%) since 1996.

Increases were also observed over the 15-year period in the numbers of individuals who availed of mainstream schooling, resource teachers, activation centres and vocational training.



Table 3.7 Principal day service and overall level of day service provision, by age group, 2011

	Principal day service			Overall level of day service provision		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home support	64	165	229	1140	918	2058
Home help	2	21	23	79	78	157
Early intervention team	603	0	603	1921	0	1921
Special pre-school for intellectual disability	547	0	547	558	0	558
Child education and development centre	147	10	157	157	11	168
Mainstream pre-school	317	0	317	427	0	427
Mainstream school	1897	73	1970	1926	73	1999
Resource/visiting teacher	121	18	139	777	72	849
Special class – primary	500	0	500	504	0	504
Special class – secondary	171	52	223	172	52	224
Special school	4254	273	4527	4262	275	4537
Third-level education	1	29	30	1	42	43
Rehabilitative training	3	1701	1704	3	1765	1768
Activation centre	3	6439	6442	3	6710	6713
Programme for the older person	0	651	651	0	709	709
Special high-support day service	7	763	770	10	774	784
Special intensive day service	13	366	379	15	380	395
Sheltered work centre	0	3271	3271	0	3458	3458
Sheltered employment centre	2	96	98	2	99	101
Multidisciplinary support services	66	1649	1715	6014	15034	21048
Centre-based day respite service	1	20	21	305	414	719
Day respite in the home	3	3	6	77	70	147
Outreach programme	1	124	125	85	261	346
Other day service	86	444	530	805	711	1516
Enclave within open employment	0	9	9	0	12	12
Supported employment	0	860	860	0	1771	1771
Open employment	0	156	156	0	297	297
Vocational training	10	302	312	10	335	345
Generic day services	1	429	430	3	466	469
Total	8820	17924	26744	19256	34787	54043

Note: The total number of services received (54,043) exceeds the actual number of people with an intellectual disability as a number of people availed of two or more day services.

Multidisciplinary support services

In the case of multidisciplinary support services (which include services delivered by early intervention teams), the large difference shown in Table 3.7 between the principal day service and the overall day service provision arises because multidisciplinary support and early intervention services are only recorded as a principal day service if they are the sole day service that an individual receives. The majority of people who are in receipt of such services also receive another service as their principal day service.

Table 3.8 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 12-month period. The data show:

- Overall, 22,969 individuals received one or more multidisciplinary support services in 2011 (including those provided by early intervention teams). This was an increase of 1,166 people since 2010. As in 2010, the most commonly availed of multidisciplinary support services were social work (11,397 individuals), medical services (10,147 individuals), speech and language therapy (9,564 individuals) and psychology (8,820 individuals).
- The services most commonly availed of by adults were social work (7,427), medical services (6,800) and psychiatry (6,454).
- The services most commonly availed of by children were speech and language therapy (1,967 children aged six years or under and 4,278 children aged 7–17 years), occupational therapy (1,660 children aged six years or under and 2,620 children aged 7–17 years), and social work (1,220 children aged six years or under and 2,750 children aged 7–17 years).
- Early intervention teams usually provide services to children aged six years or under; 1,884 children (82.6%) in this age group received multidisciplinary support services from an early intervention team in 2011. There were also 37 children aged seven years or over who received services from an early intervention team in 2011.

Table 3.8 Overall provision of multidisciplinary support services, by age group and access to an early intervention team (EIT), 2011

	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	1116	154	1270	20	2057	2077	6800	10147
Nursing	886	125	1011	13	1215	1228	6088	8327
Dietetics	415	48	463	4	562	566	2774	3803
Occupational therapy	1400	260	1660	23	2597	2620	3023	7303
Physiotherapy	1370	189	1559	17	1866	1883	3444	6886
Psychiatry	52	23	75	3	644	647	6454	7176
Psychology	1000	158	1158	26	2658	2684	4978	8820
Social work	1073	147	1220	17	2733	2750	7427	11397
Speech and language therapy	1642	325	1967	34	4244	4278	3319	9564
Other	462	77	539	7	1407	1414	4483	6436
Number of people	1884	397	2281	37	5617	5654	15034	22969

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/service.

Regional level

Table 3.9 provides summary details of the level of service provision in 2011 in the four HSE regions. Nationally, 26,831 individuals (98.2%) with an intellectual disability registered on the NIDD were in receipt of services in 2011.

At national level, 8,214 individuals (30.1%) registered on the NIDD in 2011 were in receipt of a full-time residential service. Regionally, this proportion varied from 28.2% in the HSE South Region to 31.1% in the HSE West.

At national level, 18,591 people (68.0%) attended services on a day basis, with the proportion ranging from 66.1% in the HSE West Region to 70.4% in the HSE South Region.

Nationally, a small proportion (271, 1.0%) of registrations were without services but were identified as requiring services in the five-year period 2012–2016. The HSE West Region had the highest proportion (1.6%) of people without any service and awaiting services within the next five years.

Table 3.9 Service provision by HSE region of registration, 2011

	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 – on waiting list	No identified service requirements	Total
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	N
Dublin/Mid-Leinster	4751 (67.7)	2163 (30.8)	12 (0.2)	9 (0.1)	58 (0.8)	27 (0.4)	7020
South	5351 (70.4)	2088 (27.5)	54 (0.7)	5 (0.1)	68 (0.9)	34 (0.4)	7600
West	4724 (66.1)	2204 (30.9)	11 (0.2)	9 (0.1)	113 (1.6)	81 (1.1)	7142
Dublin/North-East	3765 (67.7)	1545 (27.8)	137 (2.5)	3 (0.1)	32 (0.6)	80 (1.4)	5562
All regions	18591 (68.0)	8000 (29.3)	214 (0.8)	26 (0.1)	271 (1.0)	222 (0.8)	27324

4. Future service requirements 2012–2016

The NIDD reports on the future service requirements of people with an intellectual disability (formally referred to as assessment of need). The requirements recorded are based on need as reported by the individual/family/key worker, and not on an assessment of need as set out in the Disability Act or other formal standardised assessment. The data reported in this chapter reflect the service needs of the individual for the period 2012–2016. For ease of interpretation, four distinct categories of need are identified, as follows:

A – Unmet need: applies to people who, in 2011, were without a major element of service such as day or residential, or who were without residential support services, or who were without any service, and will require these services in the period 2012–2016. It excludes those whose *only* requirement was for multidisciplinary support services as these are dealt with in category D below.

B – Service change: applies to those who already had an intellectual disability service in 2011 but will require that service to be changed or upgraded during the period 2012–2016, and includes children/young people who will require access to health-funded services in the period. It excludes those whose only service change requirement was for multidisciplinary support services (see category D below).

C – People with intellectual disability who were accommodated in psychiatric hospitals in 2011: includes people who need to transfer out of psychiatric hospitals in the period 2012–2016 and people who were resident in the psychiatric services in 2011 but require an appropriate day service in the period 2012–2016. For completeness, multidisciplinary support service requirements, where applicable, are noted in the tables relating to this category.

D – Multidisciplinary support services: services that will be required in the period 2012–2016 by all individuals registered on the NIDD in 2011. This category 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 records up to two future residential services and up to two future day services for each individual. To avoid double-counting of individuals, only the first service identified is reported in the tables in this report relating to the unmet need, service change, and people with intellectual disability within the psychiatric services groups, but the level of additional need of these individuals is noted in the relevant sections of the text as well as in the multidisciplinary support services section.

Summary of needs

Figure 4.1 indicates that 4,505 new residential, day and/or residential support places will be needed to meet service requirements in the period 2012–2016, half of which are residential places. Of the existing places available in 2011, 14,719 need to be changed or upgraded, with just over two thirds of the changes/upgrades required in day services. Figure 4.1 also shows that 142 people accommodated in psychiatric hospitals in 2011 require specialist services; almost 90% of this group require residential services. In 2011, 19,813 people were recorded as requiring new or enhanced multidisciplinary services, which is a slight increase on the number recorded in 2010.

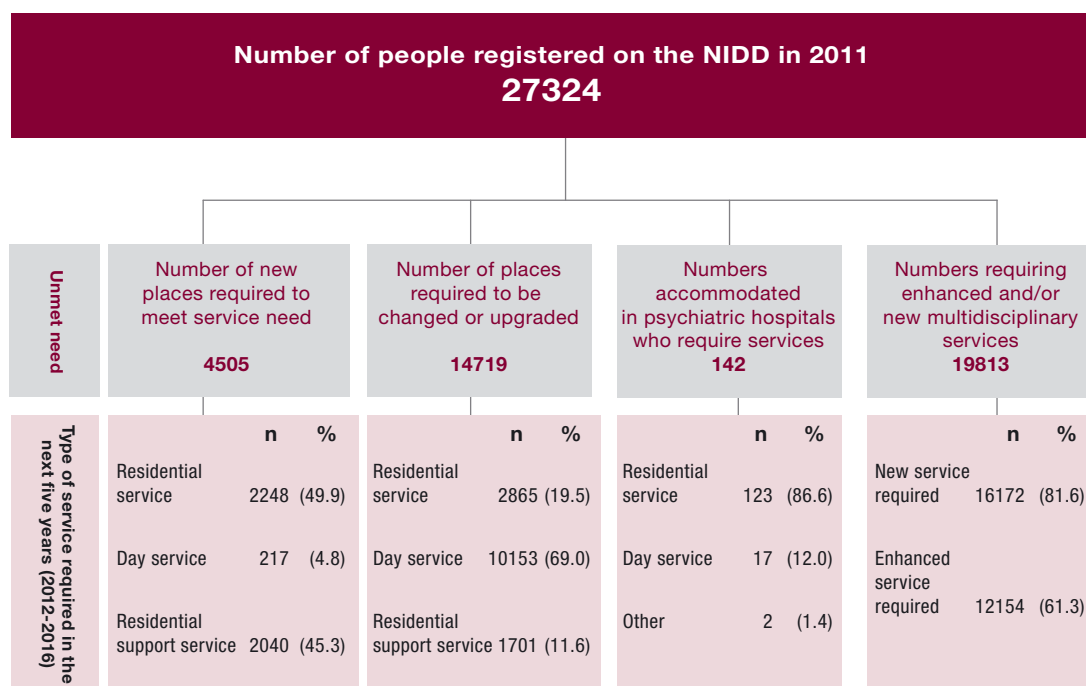


Figure 4.1 Summary of the service requirements of those registered on the NIDD, 2011

Category A – Unmet need

Number of places required to meet need

The number of new residential, day and residential support places required to meet need as assessed by service providers is shown by HSE region in Table 4.1.

Table 4.1 Number of new places required to meet need 2012–2016, by HSE region of registration

	Residential	Day	Residential support
Dublin/Mid-Leinster	632	57	512
South	576	46	648
West	492	92	550
Dublin/North-East	548	22	330
Total	2248	217	2040

The key figures and trends are summarised below.

- The number of new day places required has been falling steadily since 1996. This figure does not, however, take account of the individuals who require a change or enhancement to their day service, for example, those who are leaving education and require a training/employment service (see Figure 4.1). This service need is considered under category B below.
- The number of new residential places required has decreased slightly since 2010, from 2,269 places in 2010 to 2,248 places in 2011. Seven out of ten of those requiring a new residential place (1,601 individuals, 71.2%) have a moderate, severe or profound intellectual disability (see Table 4.2).
- The demand for residential supports in 2011 (2,040 individuals) is similar to that of 2010 (2,045 individuals). The level of need remains high despite the fact that more than 5,000 individuals availed of residential support services in 2011.

Full-time residential services

Of the 2,248 people who required full-time residential services in 2011 (Table 4.2):

- 1,601 individuals (71.2%) had a moderate, severe, or profound level of intellectual disability, of whom 1,353 required placements in community group homes, 141 required placements in a residential centre, and 100 required specialised intensive placements because of their increased dependency.
- 607 (27.0%) individuals had a mild intellectual disability, of whom 526 required placements in community group homes, 58 required placements in a residential centre, and 21 required specialised intensive placements due to their increased dependency.
- 40 (1.8%) had not had their level of intellectual disability verified in 2011.

Of those who required full-time residential services in 2011, 2,229 (99.2%) were in receipt of a day service or a residential support service, 2,163 (96.2%) lived at home, and 75 (3.3%) lived independently or semi-independently.

Day services

As in previous years, demand for day services among those reported as not being in receipt of such services was confined almost exclusively to adult services (Table 4.3). Of the 217 individuals who required day services, 198 (91.2%) lived either at home (174 individuals) or independently/semi-independently (24 individuals). The largest demand came from 190 people who had no service whatsoever in 2011. Of these:

- 118 individuals (62.1%) had a mild intellectual disability and their principal service requirements were in the training and employment areas.
- 68 individuals (35.8%) had a moderate, severe or profound intellectual disability and their principal service requirements were for sheltered work, activation programmes and rehabilitative training.

Residential support services

Residential support services, such as respite and regular part-time care, were required by 2,040 people (Table 4.4). Of this group, 1,769 individuals (86.7%) lived either at home (1,697 individuals) or independently/semi-independently (72 individuals); 1,736 individuals (85.1%) were in receipt of a day service; and 34 individuals (1.7%) had no day service in 2011. An additional 270 individuals (13.2%) were full-time residents and needed a residential support service either to enhance, or as an alternative to their existing services.

- People with moderate, severe, or profound intellectual disability accounted for more than half of the demand for residential support services in 2011 (1,096 individuals), while people with mild intellectual disability accounted for 42.1% (858 individuals). The remaining 4.2% (86 individuals) had not had their degree of intellectual disability verified.
- Most of the demand in 2011 was for crisis or planned respite services (1,246 individuals, 61.1%), semi-independent and independent living arrangements (382 individuals, 18.7%), and holiday residential placements (129 individuals, 6.3%).

Table 4.2 Future full-time residential service requirements of individuals receiving no residential service in 2011, by degree of intellectual disability

	No service – requires residential service			Receives residential support only – requires residential service			Receives day service – requires residential service			Overall need						
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All				
5-day community group home	0	0	0	0	0	0	1	1	2	101	163	266	2	101	164	267
7-day (48-week) community group home	0	0	2	2	0	0	0	0	2	80	202	284	2	80	204	286
7-day (52-week) community group home	0	4	5	9	0	0	0	0	13	341	980	1334	13	345	985	1343
5-day residential centre	0	1	1	2	0	0	0	0	0	7	18	25	0	8	19	27
7-day (48-week) residential centre	0	0	1	1	0	1	0	1	0	10	36	46	0	11	37	48
7-day (52-week) residential centre	0	1	4	5	0	0	0	0	20	38	81	139	20	39	85	144
Nursing home	0	0	0	0	0	0	0	0	0	2	6	8	0	2	6	8
Mental health community residence	0	0	0	0	0	0	0	0	0	0	1	1	0	0	1	1
Intensive placement (challenging behaviour)	0	0	0	0	0	0	0	0	0	19	49	68	0	19	49	68
Intensive placement (profound or multiple disability)	0	0	0	0	0	0	0	0	3	2	51	56	3	2	51	56
All services	0	6	13	19	0	1	1	2	40	600	1587	2227	40	607	1601	2248

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

Table 4.3 Future day service requirements of individuals receiving no day service in 2011, by degree of intellectual disability

	No service – requires day service				Receives residential support only – requires day service				Receives residential service only – requires day service				Overall need				
	NV	Mild	MSP	All	Mild	MSP	All	All	NV	Mild	MSP	All	NV	Mild	MSP	All	
Home support	0	1	6	7	0	0	0	0	0	0	0	0	0	0	1	6	7
Home help	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	1	1
Mainstream pre-school	2	0	0	2	0	0	0	0	0	0	0	0	2	0	0	2	
Mainstream school	1	0	1	2	0	0	0	0	0	0	0	0	1	0	1	2	
Resource teacher	0	1	1	2	0	0	0	0	0	0	0	0	0	0	1	2	
Special class – secondary	0	1	0	1	0	1	1	1	0	0	0	0	0	0	1	2	
Special school	0	1	0	1	0	0	0	0	0	0	0	0	0	0	1	0	1
Rehabilitative training	0	26	13	39	2	0	2	2	0	0	0	0	0	0	28	13	41
Activation centre	1	6	14	21	0	3	3	3	1	1	7	9	2	7	24	33	
Programme for the older person	0	1	3	4	0	0	0	0	0	0	2	2	0	1	5	6	
Special high-support day service	0	0	2	2	0	0	0	0	0	0	0	0	0	0	2	2	
Special intensive day service	0	0	0	0	0	0	0	0	0	1	1	2	0	1	1	2	
Sheltered work centre	0	11	13	24	1	0	1	1	0	2	1	3	0	14	14	28	
Sheltered employment centre	0	3	1	4	0	0	0	0	0	0	0	0	0	3	1	4	
Outreach programme	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1	
Other day service	0	5	1	6	0	0	0	0	0	0	1	1	0	5	2	7	
Enclave within open employment	0	1	1	2	0	0	0	0	0	0	0	0	0	1	1	2	
Supported employment	0	26	6	32	2	0	2	2	0	1	0	1	0	29	6	35	
Open employment	0	8	0	8	0	0	0	0	0	0	0	0	0	8	0	8	
Vocational training	0	27	4	31	0	0	0	0	0	0	0	0	0	27	4	31	
Total	4	118	68	190	5	4	9	9	1	5	12	18	5	128	84	217	

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

Table 4.4 Future residential support service requirements of individuals receiving no residential support services in 2011, by degree of intellectual disability

	No service-requires residential support			Receives day service-requires residential support			Receives residential service-requires residential support			Receives residential and day services-requires residential support			Overall need			
	NV	Mild	All	NV	Mild	All	NV	Mild	All	NV	Mild	All	NV	Mild	All	
Foster care and boarding-out	0	0	0	0	1	1	0	0	0	0	1	2	3	0	2	4
Living independently	0	3	3	2	42	49	0	1	0	1	7	9	9	2	53	62
Living semi-independently	0	6	8	9	187	232	0	0	0	0	53	27	80	9	246	320
Holiday residential placement	0	0	1	0	38	70	0	0	0	0	6	52	58	0	44	129
Crisis or planned respite	1	12	18	49	410	1193	0	0	0	0	8	26	35	51	430	1246
Occasional respite care with host family	0	1	2	10	33	42	0	0	0	0	2	3	6	11	36	93
Shared care or guardianship	0	0	0	0	3	7	0	0	0	0	0	5	5	0	3	12
Regular part-time care (2/3 days per week)	0	0	0	0	4	9	0	0	0	0	1	1	2	0	5	15
Regular part-time care (every weekend)	0	0	0	2	1	4	0	0	0	0	1	1	2	2	2	9
Regular part-time care (alternate weekend)	0	0	0	0	3	5	0	0	0	0	0	1	1	0	3	9
Other residential service	0	0	1	6	15	24	0	0	0	0	14	54	68	6	29	114
Overnight respite in the home	0	0	1	5	5	13	0	0	0	0	0	0	0	5	5	24
All services	1	22	11	83	742	1736	0	1	0	1	93	174	269	86	858	2040

Future need for centre-based respite services

As illustrated in Table 4.4, most of the demand for residential support services in 2011 was for crisis or planned respite services. Table 4.5 presents the respite use and requirements of those registered for each LHO area. It also shows the total number who were living in a home or independent setting in 2011, and who may be in need of respite services in the future. The table shows that there is a marked difference across the LHO areas in the number of people receiving and requiring the services. Overall, 24% of those who were living at home or in an independent setting in 2011 received respite care, while 6.4% of the same group required respite care. Within the LHO areas the percentage receiving respite ranged from 12.5% in LHO Roscommon to 40.0% in LHO North Dublin. The percentage requiring respite ranged from 2.8% in LHO Clare to 12.1% in LHO Longford/Westmeath.

Table 4.5 Use of and requirements for respite services by people living in home/independent setting, by HSE region and LHO area, 2011

	Number in receipt of crisis or planned respite in 2011	Number who do not receive respite but require it (2012–2016)	Number in home/independent setting in 2011
LHO area	n	n	n
HSE Dublin/Mid-Leinster Region	1297	280	4850
LHO Dublin South	127	22	401
LHO Dublin South East	68	7	217
LHO Dublin South City	98	18	290
LHO Dublin South West	231	30	682
LHO Dublin West	145	22	646
LHO Kildare/West Wicklow	232	53	937
LHO Wicklow	96	15	435
LHO Laois/Offaly	145	42	657
LHO Longford/Westmeath	155	71	585
HSE South Region	1044	359	5294
LHO Carlow/Kilkenny	115	90	777
LHO Tipperary SR	137	14	465
LHO Waterford	102	43	547
LHO Wexford	167	35	728
LHO Cork North Lee	101	40	749
LHO Cork South Lee	97	40	581
LHO North Cork	69	26	476
LHO West Cork	87	27	295
LHO Kerry	169	44	676
HSE West Region	1163	345	5064
LHO Limerick	136	64	881
LHO Tipperary NR	81	29	348
LHO Clare	95	10	361
LHO Galway	291	57	1078
LHO Mayo	175	72	714
LHO Roscommon	46	21	367
LHO Donegal	212	51	815
LHO Sligo/Leitrim/West Cavan	127	41	500
HSE Dublin/North-East Region	1071	226	3816
LHO Dublin North West	204	39	705
LHO Dublin North Central	116	22	363
LHO Dublin North	353	42	882
LHO Cavan/Monaghan	112	18	561
LHO Louth	113	31	641
LHO Meath	173	74	664
Out of state	0	1	2
All regions	4575	1211	19026

Note: The total number recorded as receiving respite in Table 4.5 (4,575 individuals) is less than that recorded in Table 3.4 (4,963 individuals) as Table 4.5 includes only those living in a home setting or living independently. A small number of people living in other residential settings also receive respite services – this group is included in Table 3.4 but is excluded from Table 4.5 above.

Category B – Service change

The term 'service change' applies to the needs of those who already had an intellectual disability service in 2011 but who require that service to be changed or upgraded during the period 2012–2016, and includes children who availed of education services in 2011 and who will require access to health-funded services in the future. Changes in service provision relate to:

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

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

Categories of service change requirements

Table 4.6 indicates that 11,824 people who were receiving services in 2011 will require a change to their existing service provision in the period 2012–2016, an increase of 319 (2.8%) since 2010. Of the 11,824 people who were recorded as requiring a service change:

- 8,077 (68.3%) were day attendees (of whom 819 also availed of residential support services).
- 2,865 (24.2%) were full-time residents (of whom 2,076 also availed of day services).
- 882 (7.5%) received residential support services only.

A breakdown of the category of service change required by level of intellectual disability is provided in Table 4.6.

- People in the moderate, severe and profound ranges of intellectual disability accounted for 7,466 (63.1%) of the service changes required.
- People in the mild range required 3,445 (29.1%) of the service changes.
- 913 (7.7%) of the service changes were required by people whose level of intellectual disability had not been verified.



Table 4.6 Category of service change required 2012–2016, by degree of intellectual disability

	Residential and day	Residential only	Day only	Day and residential support	Residential support only	Total number of individuals requiring service changes
	n	n	n	n	n	n
Not verified	8	13	864	14	14	913
Mild	204	106	2750	196	189	3445
Moderate, severe or profound	1864	670	3644	609	679	7466
All levels	2076	789	7258	819	882	11824

Number of places required to address service changes

The numbers and types of places needed to meet the service change requirements are summarised in Table 4.7. Four types of day service are listed: health, education, employment and generic. The programmes included under each heading are outlined in Appendix B.

Table 4.7 Number of places requiring change, 2012–2016

Residential	2865
Day	10153
Of which:	
Health services	6881
Education services	1284
Employment services	1320
Generic services	668
Residential support	1701
Total	14719

The number of places requiring change exceeds the number of people who require service changes, (11,824), because some people require changes to both their residential and their day services. In addition, it is important to note that, although 11,824 people were recorded in 2011 as requiring service changes, this demand does not require the provision of 11,824 new places. In many instances, these individuals will be vacating their existing placement as part of the service change process, and their places will then become available for those with unmet needs and others requiring a service change. For example, when young adults move into employment from training, their training places become available to those leaving school. It is also important to note that this entire group received a certain level of service in 2011, so some funding is already committed to these individuals.

Summary of service change requirements

Details of the types of service change required by people who need alternative or enhanced full-time residential, day and residential support services are set out in Tables 4.8, 4.9 and 4.10.

Residential service change

Table 4.8 indicates that 2,865 individuals in full-time residential services in 2011 will require an upgrading or change of accommodation within the next five years; 1,079 individuals (37.7%) require an enhancement of their existing service type, and 1,786 individuals (62.3%) require the following changes of service type:

- Residential placements in the community are required by 1,057 individuals (36.9%).
- Intensive services for either challenging behaviour or profound or multiple disability are required by 548 individuals (19.1%).
- Centre-based placements are required by 137 individuals (4.8%).
- Nursing home placements are required by 44 individuals (1.5%).

Of the 1,079 individuals who require an enhancement of their existing service type:

- 339 individuals need their existing service upgraded to include care at weekends and holiday times.
- 19 individuals require less care and could return to their families at weekends and holiday times.
- 721 individuals need an enhancement of their existing service provision (darker shaded areas of Table 4.8).
- One individual needs an enhancement to their existing mental health community residence service.

Table 4.8 Pattern of movement of individuals from existing residential services to future residential services, 2012–2016

Full-time residential service required in the period 2012–2016											
	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	Mental health community residences	Intensive placement (CB)	Intensive placement (P/MD)	Total services 2011
Full-time residential service in 2011											
5-day community group home (CGH)	17	55	142	1	0	11	0	0	4	1	231
7-day (48-week) community group home	1	35	117	1	5	14	0	0	5	3	181
7-day (52-week) community group home	6	8	455	0	1	30	18	0	49	26	593
5-day residential centre (RC)	7	2	26	1	4	3	0	0	0	0	43
7-day (48-week) residential centre	1	56	68	0	15	18	4	0	21	17	200
7-day (52-week) residential centre	1	7	730	0	4	109	17	0	184	218	1270
Nursing home	0	0	17	0	0	3	9	0	1	3	33
Mental health community residence	0	0	1	0	0	0	0	1	0	0	2
Intensive placement (challenging behaviour) (CB)	1	2	38	2	3	55	4	0	40	10	155
Intensive placement (profound or multiple disability) (P/MD)	0	2	47	0	1	1	0	0	2	39	92
Occupying a residential support place	2	5	35	1	0	3	1	0	2	0	49
Other residential service	0	1	8	0	0	5	0	0	2	0	16
Total services required	36	173	1684	6	33	252	53	1	310	317	2865

Note: The abbreviations in the sub-column headings refer to the placement descriptions which are provided 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, 10,153 individuals will require a change, enhancement, or upgrading of their day service (Table 4.9).

- Health-funded services are required by 6,881 individuals (67.8%).
- Employment services are required by 1,320 individuals (13.0%).
- Education services are required by 1,284 individuals (12.6%).
- Generic services are required by 688 individuals (6.8%).

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

Health services

Of the 6,881 service changes required within health-funded services, 5,054 (75.6%) are requirements for an alternative or additional service and 1,827 (26.6%) are requirements for an enhancement of the individual's existing service (grey shaded area in Table 4.9). The majority of the demand for alternative or additional health-funded services arises as follows:

- 837 individuals require activation programmes, the majority of whom currently receive multidisciplinary support services as their only day service (377 individuals), or attend special schools (158 individuals), or rehabilitation training (89 individuals).
- 834 individuals require high-support or intensive placements, the majority of whom currently attend activation programmes (367 individuals), or receive multidisciplinary support services as their only day service (196 individuals).
- 718 individuals require services specific to older people, the majority of whom currently attend activation programmes (334 individuals) or receive multidisciplinary support services as their only day service (177 individuals).
- 676 individuals require placement in sheltered work centres, the majority of whom currently attend rehabilitative training (266 individuals).

There are also 1,827 individuals who need to have their existing health-funded service enhanced (grey shaded area of Table 4.9). Most of these people are attending activation centres (1,004 individuals, 55.0%) or programmes specific to older people (246 individuals, 13.5%). 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 1,320 service changes required within employment services, 1,235 (93.6%) are requirements for an alternative placement and 85 (6.4%) are requirements for an enhancement of the individual's existing placement (Table 4.9).

Most of the demand for alternative employment opportunities comes from 1,116 individuals who require supported employment, the majority of whom currently attend sheltered work (376 individuals) or activation centres (273 individuals). There are 85 individuals who require their existing employment placement to be enhanced (Table 4.9).

Education services

Of the 1,284 service changes required within education services, 945 (73.6%) are requirements for an alternative service and 339 (26.4%) are requirements for an enhancement of the child's existing service (Table 4.9).

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

- 292 children who require a mainstream school placement, the majority of whom currently attend a mainstream (139 children) or specialised (77 children) pre-school.
- 325 children who require special classes, mainly at secondary level. The majority of those requiring special classes at secondary level (218 children) currently attend special classes at primary level (107 children).
- 224 children who require a special school placement, the majority of whom currently attend special pre-schools (114 children).

There are 339 children who require their existing education placement to be enhanced (Table 4.9), the majority of whom currently attend mainstream schools (213 children). There is also a significant demand for increased support within existing education placements.

A large proportion of the 1,472 individuals who were attending special schools in 2011 require adult day services within the period 2012–2016. Of this group, over one quarter (385 individuals) require rehabilitative training, 315 (21.4%) require vocational training and 158 (10.7%) require activation programmes.

Generic services

Of the 668 service changes required within generic services, 637(95.4%) are requirements for an alternative service and 31(4.6%) are requirements for an enhancement of the individual's existing service (Table 4.9).

Most of the demand for alternative generic services comes from 610 individuals who require vocational training, the majority of whom currently attend special schools (315 individuals).

Eighteen individuals attending vocational training and 13 individuals availing of generic day services require their existing generic service to be enhanced (Table 4.9).

Table 4.9 Pattern of movement of individuals from existing day services to future day services, 2012–2016

Day service in 2011	Day service required in the period 2012–2016																				ALL								
	HS	HH	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	TL	RHT	AC	POP	SHS	SI	SWC	SEC	CDR	DRH		OP	OTH	E	SE	OE	VT	GD	
Home support (HS)	17	0	9	17	0	2	0	0	2	2	0	9	11	5	2	3	8	0	0	3	0	2	0	5	0	4	0	101	
Home help (HH)	1	0	0	1	0	0	0	0	0	0	0	1	1	1	0	0	0	1	0	0	0	0	0	0	0	0	0	6	
Early services	9	0	128	73	2	20	0	12	0	5	0	0	0	0	0	0	0	0	0	1	0	3	0	0	0	0	0	253	
Mainstream pre-school (MPS)	12	0	18	11	0	139	1	7	0	26	0	0	0	0	0	0	0	0	5	0	0	2	0	0	0	0	0	221	
Special pre-school (SPS)	17	1	61	41	11	77	2	38	1	114	0	0	0	0	0	0	0	0	6	0	5	0	0	0	0	0	0	374	
Child education and development centre (CEDC)	8	0	0	0	3	0	0	0	0	3	0	0	47	0	0	1	0	0	0	0	0	1	0	0	0	0	1	0	64
Mainstream school (MS)	86	3	3	0	0	213	63	16	57	44	12	14	5	0	0	1	1	0	48	2	15	43	0	2	2	52	1	683	
Resource teacher (RT)	4	0	2	0	0	8	14	1	6	0	0	6	0	0	0	0	0	0	0	0	0	0	0	0	0	22	0	63	
Special class – primary (SCP)	31	2	0	0	0	12	3	8	136	19	0	0	3	0	0	0	0	0	10	1	0	6	0	0	0	0	0	231	
Special class – secondary (SCS)	16	0	0	0	0	3	1	0	10	4	1	21	16	0	0	2	5	1	2	0	1	4	0	1	1	20	0	109	
Special school (SS)	150	6	2	1	5	15	4	24	14	94	0	385	158	0	30	35	121	16	30	5	2	44	0	12	3	315	1	1472	
Third-level education (TL)	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	0	1	0	8	2	4	1	18	
Rehabilitative training (RHT)	12	3	0	0	0	0	0	0	0	0	1	33	89	7	7	4	266	9	7	1	26	6	0	206	7	81	17	782	
Activation centre (AC)	47	5	0	0	0	0	2	0	0	0	1	77	1004	334	168	199	113	14	9	3	9	21	1	273	18	23	0	2321	
Programme for the older person (POP)	4	1	0	0	0	0	0	0	0	0	0	0	18	246	3	23	6	0	0	0	1	1	1	6	0	0	1	311	
Special high support day service (SHS)	2	1	0	0	0	0	0	0	0	0	0	16	42	18	116	96	8	1	2	0	18	6	0	6	0	0	0	332	
Special intensive day service (SI)	7	1	0	0	0	0	1	1	1	1	0	2	12	3	5	68	2	0	0	0	2	1	0	8	1	1	0	117	

Table 4.9 Pattern of movement of individuals from existing day services to future day services, 2012–2016 (continued)

Day service in 2011	Day service required in the period 2012–2016																				ALL							
	HS	HH	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	TL	RHT	AC	POP	SHS	SI	SWC	SEC	CDR	DRH		OP	OTH	E	SE	OE	VT	GD
Sheltered work centre (SWC)	19	1	0	0	0	0	0	0	0	0	6	18	66	142	15	12	239	23	4	0	24	15	3	376	35	21	1	1020
Sheltered employment centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	0	1	2	0	6	0	0	0	0	1	0	8	1	3	0	22
Multidisciplinary support services	13	5	4	2	0	3	0	0	0	1	1	43	337	177	71	125	28	4	3	0	0	15	1	54	14	45	2	948
Centre-based day respite service (CDR)	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	1	0	3
Day respite in the home (DRH)	0	0	1	1	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	1	0	0	0	4
Outreach programme (OP)	0	0	1	0	0	0	0	0	0	0	0	0	2	0	1	4	3	1	2	0	29	0	0	9	1	2	0	55
Other day service (OTH)	13	3	7	10	0	12	1	8	1	5	1	7	12	16	6	8	79	0	0	0	1	13	0	19	5	8	0	235
Enclave within open employment (E)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	2
Supported employment (SE)	6	2	0	0	0	0	0	0	0	0	0	0	5	5	0	0	6	3	1	0	5	3	1	80	14	4	3	138
Open employment (OE)	1	2	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	1	1	0	1	0	0	11	5	2	0	26
Vocational training (VT)	2	0	0	0	0	0	1	0	0	0	2	4	3	3	0	1	19	6	2	0	1	1	1	62	4	18	0	130
Generic day services (GD)	9	0	0	0	0	1	0	0	0	0	0	2	8	4	6	4	4	0	0	0	8	2	3	47	0	1	13	112
Total	486	36	236	157	21	505	93	115	228	318	25	640	1841	964	432	586	915	80	132	16	143	196	11	1196	113	628	40	10153

Notes: 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 provided in column one.

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

The following colour shaded areas represent the four types of day service captured on the NIDD:

green = health services; orange = education services; yellow = employment services; blue = generic services

Residential support service change

The data indicate that 1,701 individuals receiving residential support services will require an additional or alternative residential support service in the period 2012–2016, or will require their existing support service to be upgraded (Table 4.10). Additional or alternative support services are required by 430 individuals (25.3%) and 1,271 individuals (74.7%) require their existing service to be upgraded (shaded areas of Table 4.10).

The principal residential support service changes or enhancements include:

- More frequent centre-based crisis or planned respite breaks for people already availing of this service (1,213 individuals).
- Opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (88 individuals).
- Occasional holiday residential placements and occasional respite care with a host family for people currently availing of crisis or planned respite (62 individuals).

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

Table 4.10 Additional residential support services required by people availing of residential support services in 2011

Residential support service required 2012-2016												
Residential support service in 2011	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)	Total
						Occasional respite care (host family)	Shared care / guardianship					
Foster care and boarding-out	8	1	5	2	6	3	0	0	2	0	0	28
Living semi-independently	0	11	19	12	6	0	0	0	0	0	0	48
Holiday residential placement	0	0	3	1	2	0	0	0	1	0	1	9
Crisis or planned respite	3	4	88	17	1213	45	21	58	16	17	5	1502
Occasional respite care (host family)	0	2	6	1	37	26	2	3	0	0	1	80
Shared care or guardianship	0	0	0	0	2	0	0	0	0	0	0	2
Regular part-time care (2/3 days per week)	0	0	4	0	8	0	2	0	2	0	0	16
Regular part-time care (alternate weeks)	0	0	1	0	4	0	0	0	0	1	0	6
Overnight respite in the home	0	0	0	0	1	0	0	0	0	0	2	4
Other residential service	0	0	0	0	4	0	0	0	0	0	0	6
All services	11	18	126	33	1283	74	25	64	18	21	9	1701

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

Day service requirements of school leavers

Each year, as they reach the age of 18 years, a proportion of those registered on the NIDD leave the education system to take up a range of training and supported/sheltered employment opportunities, which have traditionally been funded by the health sector. The future day service requirements of this cohort are generally recorded not as new day service places but as enhancements to existing services. This section of the report focuses on the day service requirements of this specific group to examine their potential need for services in the health sector. It concentrates on children aged 16 years or older who were in second-level education in 2011 and who will require an adult day service in the years 2012–2016.

Over nine hundred young adults (aged 16 years or over) with an intellectual disability who were in an education setting in 2011 will require a range of day services within the period 2012–2016 (Table 4.11). Most of the demand is for vocational training (278 places) or rehabilitative training (272 places).

Of the 913 individuals who will require a day service (Table 4.12):

- 499 (54.7%) individuals had a mild intellectual disability, of whom 230 require vocational training and 147 require rehabilitative training.
- 403 (44.1%) individuals had a moderate, severe or profound level of intellectual disability, of whom 124 require rehabilitative training and 82 require activation programmes.
- 10 (1.1%) individuals had not had their level of intellectual disability verified, of whom nine require third-level education.

Table 4.13 identifies the year in which the day services are required. Most of the day service requirements are immediate: 805 individuals (88.2%) require their day service in 2012 or 2013.

Table 4.11 Future day service requirements of individuals aged 16 years or over who were in an education setting in 2011, by age group

	16 years	17 years	18 years	19 years +	Total
Home support	14	12	6	4	36
Home help	1	0	0	0	1
Third-level education	4	3	2	3	12
Rehabilitative training	97	111	53	11	272
Activation centre	31	40	35	4	110
Special high-support day service	7	2	2	1	12
Special intensive day service	7	11	5	4	27
Sheltered work centre	21	35	20	10	86
Sheltered employment centre	2	7	4	1	14
Centre-based day respite service	13	4	1	2	20
Day respite in the home	0	1	0	0	1
Outreach programme	4	1	1	0	6
Other day service	8	8	4	4	24
Supported employment	4	0	1	3	8
Open employment	2	3	1	0	6
Vocational training	76	106	67	29	278
Total	291	344	202	76	913

Table 4.12 Future day service requirements of individuals aged 16 years or over who were in an education setting in 2011, by degree of intellectual disability

	Not Verified	Mild	Moderate/Severe/ Profound	Total
Home support	0	13	23	36
Home Help	0	0	1	1
Third-level education	9	2	1	12
Rehabilitative training	1	147	124	272
Activation centre	0	27	83	110
Special high-support day service	0	1	11	12
Special intensive day service	0	2	25	27
Sheltered work centre	0	37	49	86
Sheltered employment centre	0	8	6	14
Centre-based day respite service	0	8	12	20
Day respite in the home	0	0	1	1
Outreach programme	0	4	2	6
Other day service	0	8	16	24
Supported employment	0	6	2	8
Open employment	0	6	0	6
Vocational training	0	230	48	278
Total	10	499	404	913



Table 4.13 Future day service requirements of individuals aged 16 years or over who were in an education setting in 2011, by time of requirement

	2012	2013–16*	Total
Home support	36	0	36
Home help	1	0	1
Third-level education	4	8	12
Rehabilitative training	139	133	272
Activation centre	69	41	110
Special high-support day service	6	6	12
Special intensive day service	18	9	27
Sheltered work centre	55	31	86
Sheltered employment centre	10	4	14
Centre-based day respite service	18	2	20
Day respite in the home	1	0	1
Outreach programme	6	0	6
Other day service	17	7	24
Supported employment	3	5	8
Open employment	2	4	6
Vocational training	168	110	278
Total	553	360	913

* The recorded future day service requirements are likely to be underestimated for the period 2014–2016.

Category C – People with intellectual disability who are accommodated in psychiatric hospitals

The data from the NIDD for 2011 identified 214 individuals with intellectual disability, all aged 20 years or over, who were accommodated in psychiatric hospitals. Table 4.14 details the overall service requirement status of this group by level of intellectual disability and by HSE region responsible.

Table 4.14 Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2011, by HSE region of registration

Resident in psychiatric hospital in 2011	No service requirements				Has service requirements				Total
	Not verified	Mild	Moderate/ Severe/ Profound	All levels	Not verified	Mild	Moderate/ Severe/ Profound	All levels	
Dublin/Mid-Leinster									
With no day programme	0	0	1	1	0	0	0	0	1
With day programme	1	3	4	8	0	3	0	3	11
South									
With no day programme	0	0	1	1	0	1	1	2	3
With day programme	0	7	11	18	0	13	20	33	51
West									
With no day programme	0	0	0	0	0	0	0	0	0
With day programme	0	3	3	6	0	2	3	5	11
Dublin/North-East									
With no day programme	0	0	0	0	0	0	0	0	0
With day programme	0	10	28	38	0	26	73	99	137
All residents	1	23	48	72	0	45	97	142	214

Of this group, 142 individuals (66.4%) were recorded as having service requirements in the period 2012–2016, of whom:

- 123 individuals had an appropriate alternative residential facility identified for them (Table 4.16). Forty five of these individuals also required a day service (Table 4.17). In recent years there has been a revised approach in service provision for this cohort, mainly as a result of alterations implemented following the report of the expert group on mental health policy, *A Vision for Change* (Department of Health, 2006). The status of this cohort and their placement within services is currently under investigation.
- 17 individuals were recorded as appropriately placed in a psychiatric hospital but had identified day service requirements, as shown in Table 4.15.

Table 4.15 Day service requirements of people appropriately accommodated in psychiatric hospitals in 2011

Day service in 2011	Services required 2012–2016					All services
	Activation centre	Special high-support day service	Sheltered work centre	Supported employment	Other day service	
Vocational training	0	0	1	0	0	1
Rehabilitative training	0	0	0	2	0	2
Activation centre	1	2	0	0	0	3
Multidisciplinary support services only	7	3	0	0	1	11
All services	8	5	1	2	1	17

Note: Five of the 17 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.

Of the 123 people who were recorded in 2011 as needing to transfer from psychiatric to intellectual disability services for provision of their residential services, 44 individuals (35.8%) required places in community group homes, 40 individuals (32.5%) required intensive placements and 39 individuals (31.7%) required places in residential centres. In all cases the need was immediate (Table 4.16).

Table 4.16 Residential service requirements of people resident in psychiatric hospitals in 2011 who require transfer to the intellectual disability sector

	Number requiring residential service
7-day (48-week) community group home	2
7-day (52-week) community group home	42
7-day (48-week) residential centre	1
7-day (52-week) residential centre	38
Intensive placement (challenging behaviour)	28
Intensive placement (profound/multiple disability)	12
All residential services	123

Of this same group of 123 people, 45 required an appropriate day service (Table 4.17). The greatest demand was for high-support or intensive day programmes (28 individuals, 62.2%), activation programmes (7 individuals, 15.6%) and programmes for the older person (6 individuals, 13.3%). All day services were required immediately.

Table 4.17 Day service requirements of people resident in psychiatric hospitals in 2011 who require transfer to the intellectual disability sector

	Number requiring day service
Rehabilitative training	1
Activation centre	7
Programme for the older person	6
Special high-support day service	21
Special intensive day service	7
Sheltered employment centre	1
Generic day services	2
All day services	45

Note: 11 of the 45 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.

The 2011 data indicate that the current day and residential programmes for 72 people with intellectual disability resident in psychiatric hospitals were appropriate and that these people had no identified service needs in the period 2012–2016 (Table 4.14). Forty-eight of this group (66.7%) had a moderate, severe, or profound intellectual disability, 23 (31.9%) had a mild disability and one person’s level of disability was not verified. Within this group, two individuals had no formal day programme.

Category D – Multidisciplinary support services

As explained earlier, although the NIDD facilitates the recording of two future day services that will be required by an individual, previous 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 reported separately and are therefore excluded from the unmet need, service change, and psychiatric hospital sections above and reported separately below in Figure 4.2. In reality, these services are usually required in addition to a more substantial day service component.

A ‘requirement’ refers to a new type of therapeutic input that the individual did not receive in 2011 and an ‘enhancement’ refers to a change in the delivery of a therapeutic input that the individual received in 2011 (e.g. an increase in the provision of the specific service or a change in service provider). Data from Table 3.9 are reproduced in Figure 4.2 to compare service provision in 2011 with the demand for services in the period 2012–2016.



In 2011 multidisciplinary support services were availed of by 22,969 people, 17,533 of whom had further requirements for such services. A further 2,280 individuals who did not access such services in 2011 require them. There are, therefore, 19,813 (17,533 plus 2,280) individuals with a need for multidisciplinary support services; these needs involve either an enhancement of a type of service received in 2011 (3,641 individuals), a requirement for a new type of service (7,659 individuals), or both (8,513 individuals). Of the 19,813 people with future multidisciplinary support service needs, 162 received no service whatsoever in 2011.⁶ Ninety-nine per cent of those in need of multidisciplinary support services require them immediately.

Despite high levels of service provision in 2011, there was substantial demand for new services and enhanced services relating to all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy. For example, 8,820 individuals received a psychology service in 2011, 3,953 of whom needed an enhancement of their service, and a further 6,735 individuals who did not receive a psychology service in 2011 require one in the period 2012–2016.

The data show that there was a significant shortfall in the provision of occupational therapy, dietetics services, speech and language therapy and psychology services; demand for new services for these therapeutic inputs exceeded service provision in 2011. For example, 7,303 individuals were in receipt of the services of an occupational therapist in 2011, 3,762 of whom needed an enhancement of their service, and a further 6,077 individuals who were not in receipt of this service in 2011 require it in the immediate future.

⁶ 104 of the 162 also have other future service requirements that are included in the 'unmet need' section at the beginning of this chapter.

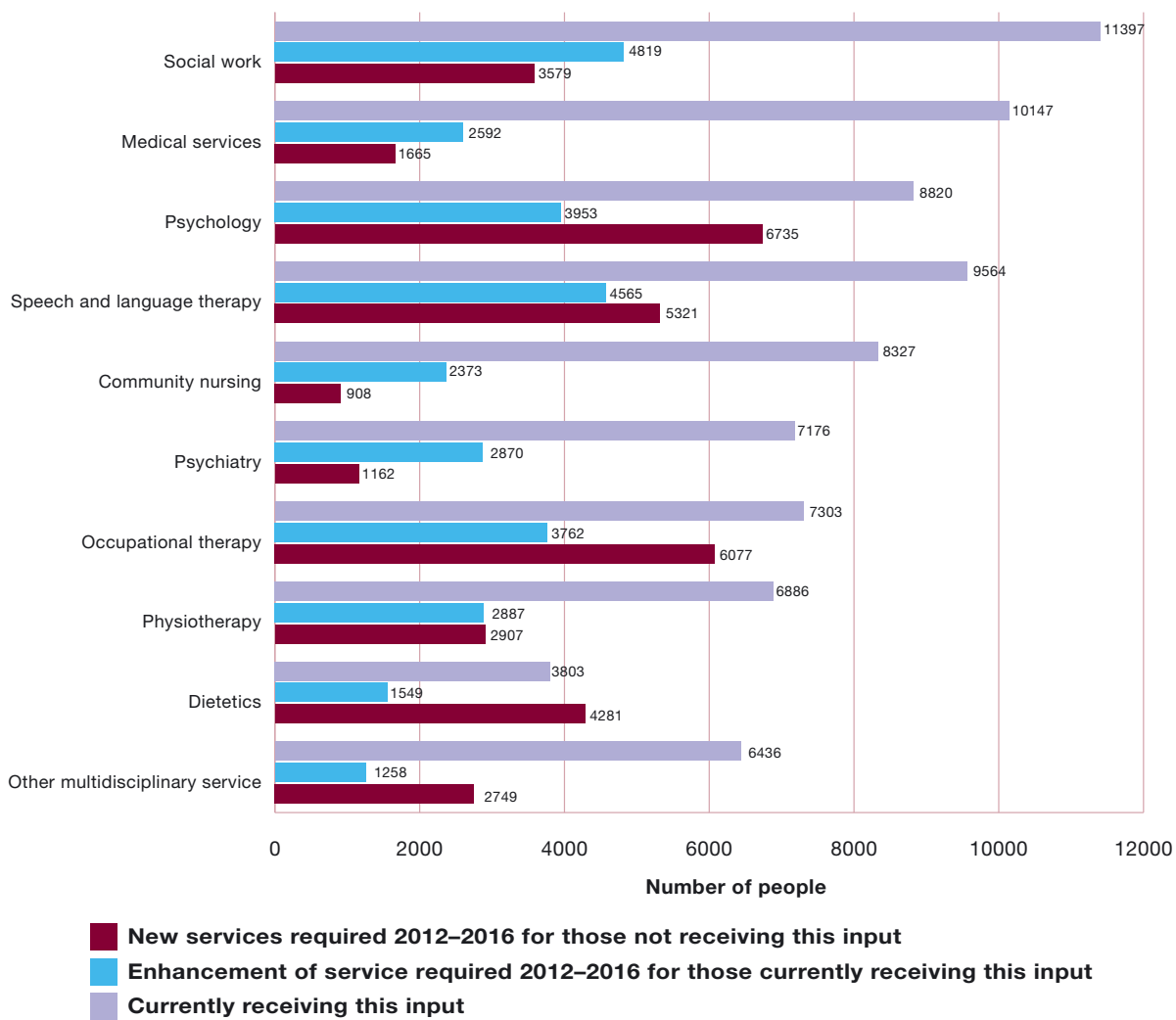


Figure 4.2 Multidisciplinary support services received in 2011, and required in the period 2012-2016

Overall service provision to people with intellectual disability and the pattern of care required in the period 2012-2016

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 2011 data indicate that there were large numbers of people who required residential services for the first time in 2011 and also that there were significant numbers who required changes to, or enhancements of, their existing residential or day placements (or both). Not all service changes will require the individual to move to a new placement as many changes involve 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 released place may become available to others who have an identified need for such a placement. The existing placements occupied by these individuals are secure until their new places become available.



Pattern of care required in full-time residential services

As indicated in Table 4.18, demand for full-time residential services in the period 2012–2016 comes from three distinct groups already identified in this chapter:

- 2,248 individuals who lived at home in 2011 and who were recorded as requiring full-time residential services for the first time in 2011;
- 123 individuals who resided in psychiatric hospitals in 2011 and who were recorded as requiring to transfer to the intellectual disability services; and
- 2,865 individuals who were in full-time residential services within the intellectual disability sector in 2011 and who require changes to their existing placement. Of this group, 1,786 require alternative services and 1,079 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 released place may be available to others who are identified as requiring this service.

Table 4.18 outlines the pattern of full-time residential service provision that will be required in the period 2012–2016 to meet this demand. A total of 2,420 residential places will be required, a decrease of 27 since 2010.

- 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, 2,828 community-based placements will be required during the period, an increase of 63 placements (2.3%) on the shortfall recorded in 2010.
- There will also be a shortfall of 544 intensive residential placements, a decrease of 77 placements (12.4%) on the shortfall recorded in 2010. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

Table 4.18 Pattern of full-time residential service provision required, 2012–2016

	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	267	0	36	231	-72
7-day (48-week) community group home	286	2	173	181	-280
7-day (52-week) community group home	1343	42	1684	593	-2476
5-day residential centre	27	0	6	43	10
7-day (48-week) residential centre	48	1	33	200	118
7-day (52-week) residential centre	144	38	252	1270	836
Nursing home	8	0	53	33	-28
Mental health community residence	1	0	1	2	0
Psychiatric hospital	0	0	0	0	0
Intensive placement (challenging behaviour)	68	28	310	155	-251
Intensive placement (profound or multiple disability)	56	12	317	92	-293
Other/unspecified intellectual disability service	0	0	0	16	16
Designated residential support placement	0	0	0	(49)*	0
Total	2248	123	2865	2816	-2420

* 49 designated residential support places which are inappropriately occupied by full-time residents will be released, but they have not been deducted from the total number of required full-time residential places as they should not be made available for full-time use.



Pattern of care required in day services

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

- 217 individuals who were without day services in 2011;
- 45 individuals who were resident in psychiatric hospitals in 2011 and who will require an appropriate day service when they transfer to intellectual disability services;
- 17 individuals appropriately placed in psychiatric hospitals in 2011 who will require a day programme within that setting between 2012 and 2016; and
- 10,153 individuals who were in day services within the intellectual disability sector in 2011 and who will require changes to, or enhancements of, their placement. Of this group, 7,871 require alternative or additional services and 2,282 require their service to be enhanced. The majority (6,881) of these changes involve services provided by 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. However, the entire group has been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading services for these individuals. Where the change involves a move to a new placement, the freed-up place may be available to others who are identified as requiring this service.

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

The data in relation to certain day services⁷ 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 4.19 outlines the pattern of day service provision that will be required in the period 2012–2016 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 1,657 day places will be required. The table shows that there is less demand by young children for certain services and a considerable demand for the full spectrum of adult services. Trends in the NIDD data indicate that, based on current levels of service provision, the situation in relation to service requirements in the period 2012–2016 will be as follows:

- An increase of just over 10% in the number of places available to children requiring places in special schools; the number had decreased from 1,157 children in 2009 to 1,037 in 2010 but increased to 1,153 in 2011.
- There is likely to be a shortfall of training and employment opportunities. In the next five years, 1,095 supported employment opportunities, 529 vocational training placements, and 95 placements in open employment will need to be developed to meet the demand that exists for these services.
- The growth in the ageing population with intellectual disability discussed in Chapter 2 is increasing the demand for specific programmes for the older person; 665 such places will be needed over the next five years in addition to current provision.
- As with residential services, there is significant demand for high-support and intensive day placements. Over the next five years, 128 high-support day placements and 478 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.

7 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.

Table 4.19 Pattern of day service provision required, 2012–2016

	New services required by people without day services	New services required by people from psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Shortfall (-)/ Excess of places arising from demand
Home support	7	0	0	486	0	-493
Home help	1	0	0	36	0	-37
Mainstream pre-school	2	0	0	236	221	-17
Special pre-school	0	0	0	157	374	217
Child education and development centre	0	0	0	21	64	43
Mainstream school	2	0	0	505	683	176
Resource/visiting teacher	2	0	0	93	0	-95
Special class – primary	0	0	0	115	231	116
Special class – secondary	2	0	0	228	109	-121
Special school	1	0	0	318	1472	1153
Third-level education	0	0	0	25	18	-7
Rehabilitative training	41	1	0	640	782	100
Activation centre	33	7	8	1841	2321	432
Programme for the older person	6	6	0	964	311	-665
Special high-support day service	2	21	5	432	332	-128
Special intensive day service	2	7	0	586	117	-478
Sheltered work centre	28	0	1	915	1020	76
Sheltered employment centre	4	1	0	80	22	-63
Centre-based day respite service	0	0	0	132	0	-132
Day respite in the home	0	0	0	16	0	-16
Other day service	7	0	1	196	235	31
Outreach programme	1	0	0	143	55	-89
Enclave within open employment	2	0	0	11	2	-11
Supported employment	35	0	2	1196	138	-1095
Open employment	8	0	0	113	26	-95
Vocational training	31	0	0	628	130	-529
Generic day services	0	2	0	40	112	70
All services	217	45	17	10153	8775	-1657

Conclusion

As a national health information system collecting data about service provision and requirements in the intellectual disability area, the NIDD continues to be relevant to both health service managers and policy makers as a tool for planning these services. This annual report from the NIDD, based on information collected from over 27,000 individuals registered on the database at the end of December 2011, represents the cumulative service needs of this group of people.

This report highlights the need to be cognisant of trends over time in the population with intellectual disability, and of how changing circumstances can impact substantially on the type and quantity of services that are used or required by those who are registered. Trend data are presented for the period 1996–2011 and further information is reported for the past four decades, which provides the opportunity to look back at changes over time and estimate what the consequence of these changes may be for future service provision.

A national census of population was carried out in 2011 which gave the opportunity to calculate prevalence using NIDD and census information from the same year. The census has highlighted information which will impact on services for those registered on the NIDD, in particular: the continuing high birth rate, which is reflected in a 17.9% increase in the number of 0–4-year-olds since the 2006 census; and also in the same period a 14.4% increase in the general population of those aged 65 years and over, which demonstrates that people are living longer. Both of these increases will place further demands on service provision for people with an intellectual disability.

Overall, the 2011 data show that, in line with previous years, there has been a significant increase in the levels of day service and respite service provision; however there has been no change in the number of people living in full-time residential services between 2010 and 2011. This report also highlights the fact that the changing age profile of individuals with intellectual disability continues to contribute to high levels of demand for residential services, support services for ageing caregivers and services designed specifically to meet the needs of older people with intellectual disability.

This report notes that the proportion of those registered who are in receipt of day services continues to increase every year. In addition, many of those in receipt of day services are also benefiting from additional supports such as early intervention services, home support, and home help and respite services.

This report highlights the significant amount of health service interventions that school



leavers require as they leave the education system and move to day services in the areas of training and employment that are funded by the HSE.

In relation to data on residential services, this report draws attention to the continuing shift away from the more traditional institutional models of care to community living; for the eighth year in a row the data show that the number of full-time residential placements in the community exceeds that in centre-based settings. The data on respite services also show high levels of provision in 2011, albeit with varying degrees of coverage across the country.

The data on the co-existence of a physical/sensory disability and an intellectual disability indicate that this cohort has a range of additional needs, some of which do not come within the ambit of intellectual disability services but which still require to be met.

The majority of those registered on the NIDD in 2011 received multidisciplinary support services, with social work, medical services and psychiatry being the services most commonly availed of by adults, and speech and language therapy, occupational therapy and social work those most commonly availed of by children. This pattern of multidisciplinary support usage is similar to that indicated by 2010 data. Despite the high levels of service provision in 2011, there remains a substantial demand in the five-year period 2012–2016 for new services and enhanced services relating to all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy.

Even with increasing levels of service provision, there are still high levels of unmet need among a critical number of individuals who are registered on the NIDD. Although the data in recent years highlight growth in services, demographic factors are contributing to an increasing need for these services. The continuing high birth rate and the growing proportion of individuals in the older age groups will be reflected in an increase in the number of people with an intellectual disability. This changing age profile has major implications for service planning; it points to a demand for services for young children and an ongoing 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 challenge for all will be to set priorities, and to plan and deliver quality services, within a national policy and a tight budgetary framework.

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Appendix A:

2011 National Intellectual Disability Database form



National Intellectual Disability Database Data Form

PERSONAL DETAILS

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

Next of Kin details

	(A)	(B)
Next of Kin name	21a	21b
Next of Kin address	22a	22b
Next of Kin address	23a	23b
Next of Kin address	24a	24b
Next of Kin address	25a	25b
Next of Kin address (County)	26a	__ _ 26b __ _
Next of Kin telephone number	27a	27b
Next of Kin mobile number	28a	28b
Relationship of Next of Kin	29a	29b

CURRENT SERVICE PROVISION

Day Services

- 30. Agency providing main day service |_|_|_|_|_|_|_|_|
- 31. Type of main day service |_|_|
- 32. Current level of main day service support 0. 1. 2. 3. 4. 5.
- 33. Main day service: number of days received each week [0.0-7.0] |_|_|_|
- 34. LHO responsible for funding service |_|_|
- 35. Agency providing second day service |_|_|_|_|_|_|_|_|
- 36. Type of second day service |_|_|
- 37. Current level of second day service support 0. 1. 2. 3. 4. 5.
- 38. Second day service: number of days received each week [0.0-7.0] |_|_|_|
- 39. LHO responsible for funding service |_|_|
- 40. Agency providing third day service |_|_|_|_|_|_|_|_|
- 41. Type of third day service |_|_|
- 42. Current level of third day service support 0. 1. 2. 3. 4. 5.
- 43. Third day service: number of days received each week [0.0-7.0] |_|_|_|
- 44. LHO responsible for funding service |_|_|

Residential Services

- 45. Agency providing main residential service |_|_|_|_|_|_|_|_|
- 46. Type of main residential circumstance |_|_|_|
- 47. Current level of main residential service support A. B. C. D. E. Z.
- 48. LHO responsible for funding service |_|_|
- 49. Agency providing secondary residential service |_|_|_|_|_|_|_|_|
- 50. Type of secondary residential circumstance |_|_|_|
- 51. Current level of secondary residential service support A. B. C. D. E. Z.
- 52. LHO responsible for funding service |_|_|
- 53. If Planned Respite or Crisis Respite is the secondary residential service, indicate number of nights
availed of in the past 12 months: Planned|_|_|_| Crisis|_|_|_| Agency 1 |_|_|_|_|_|_|_|_|
Planned|_|_|_| Crisis|_|_|_| Agency 2 |_|_|_|_|_|_|_|_|
- Total Planned** |_|_|_| **Total Crisis** |_|_|_| **Total Nights** |_|_|_|
- 54. **HSE area responsible for funding current services** |_|_|_|

MULTIDISCIPLINARY SUPPORT SERVICES

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

Multidisciplinary Service	Current		Future		
	Currently Receiving √	Agency Providing Current Service	Not Receiving but Requiring √	Receiving but needing an enhancement √	Reason for Duplication between Received and Enhanced
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 _____

- 56. Are current services provided by an early intervention team? |_| 1=yes 2=no 3=n/a
- 57. Year in which future services are required |_|_|_|_|_|
- 58. Will future services be provided by an early intervention team? |_| 1=yes 2=no 3=n/a

FUTURE SERVICE REQUIREMENTS

REQUIRED DAY SERVICES

- 59. Type of day service (1) required |__|_|
- 60. Level of support required in day service (1) 0. 1. 2. 3. 4. 5.
- 61. Year in which day service (1) is required |__|_|_|_|
- 62. Primary reason for duplication on current and future day service (1) |__|_|

- 63. Type of day service (2) required |__|_|
- 64. Level of support required in day service (2) 0. 1. 2. 3. 4. 5.
- 65. Year in which day service (2) is required |__|_|_|_|
- 66. Primary reason for duplication on current and future day service (2) |__|_|

CONTINGENCY DAY SERVICES

- 67. Type of day service required - contingency plan |__|_|
- 68. Level of contingency plan day support required 0. 1. 2. 3. 4. 5.
- 69. Primary reason for duplication on current and contingency day service |__|_|
- 70. Primary reason for duplication on future and contingency day service |__|_|

RESIDENTIAL SERVICES

- 71. Type of residential service (1) required |__|_|_|
- 72. Level of support required in residential service (1) A. B. C. D. E. Z.
- 73. Year in which residential service (1) is required |__|_|_|_|
- 74. Primary reason for duplication on current and future residential service (1) |__|_|

- 75. Type of residential service (2) required |__|_|_|
- 76. Level of support required in residential service (2) A. B. C. D. E. Z.
- 77. Year in which residential service (2) is required |__|_|_|_|
- 78. Primary reason for duplication on current and future residential service (2) |__|_|

CONTINGENCY RESIDENTIAL SERVICES

- 79. Type of residential service required - contingency plan |__|_|_|
- 80. Level of contingency plan residential support required A. B. C. D. E. Z.
- 81. Primary reason for duplication on current and contingency residential service |__|_|
- 82. Primary reason for duplication on future and contingency residential service |__|_|

83. HSE area responsible for funding future services |__|_|

DAY SUPPORT LEVEL CODES

Coding for questions 32, 37, 42, 60, 64 & 68

- 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 questions 47, 51, 72, 76 & 80

- 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)
- E: INTENSIVE (one to one)

ADDITIONAL INFORMATION

- 84. Date of completion/review |__|_|-|__|_|-|__|_|_|_|_|
- 85. Person responsible for update of form _____ |__|_|_|_|_|_|_|_|_|_|_|_|_|
- 86. Unit/Centre of person responsible _____ |__|_|_|_|_|_|_|_|_|_|_|_|_|
- 87. Agency returning record |__|_|_|_|_|_|_|_|_|
- 88. HSE area returning record |__|_|
- 89. Local Health Office returning record |__|_|
- 90. Date consent received |__|_|_|-|__|_|_|-|__|_|_|_|_|_|
- 91. Consent Reason Awaiting Consent Received Refused

92. 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 |

93. Date of removal |__|_|_|-|__|_|_|-|__|_|_|_|_|_|

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

95. Has the Service User been involved in the completion of this form? |__|_| 1=yes 2=no

96. Has the Next of Kin been involved in the completion of this form? |__|_| 1=yes 2=no

SERVICES CODED AS "OTHER"

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

Question number/Text description

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



Appendix B: Service categories

Day programmes

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

Residential circumstances

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



Day service groupings

Health

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

Education

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

Employment

- Enclave within open employment
- Supported employment
- Open employment

Generic

- Vocational training
- Generic day services

Appendix C: Supplementary table

Table C1 Details of main residential circumstances, degree of intellectual disability and age group, 2011

	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
Residential circumstances	2065	50	50	28	2193	3617	1769	1164	240	6790	4004	2805	1796	328	8933	9686	4624	3010	596	17916
Home setting	1747	36	16	2	1801	2605	1232	491	18	4346	3099	2074	772	17	5962	7451	3342	1279	37	12109
At home with both parents	290	11	25	6	332	832	457	474	60	1823	810	651	679	49	2189	1932	1119	1178	115	4344
At home with sibling	0	2	7	17	26	4	14	155	134	307	2	31	313	235	581	6	47	475	386	914
At home with other relative	3	1	1	3	8	40	23	30	25	118	18	15	23	21	77	61	39	54	49	203
Living with non-relative	1	0	0	0	1	3	5	9	2	19	1	3	2	2	8	5	8	11	4	28
Adoption	0	0	0	0	0	4	6	0	0	10	6	4	1	0	11	10	10	1	0	21
Foster care and boarding-out arrangements	24	0	1	0	25	129	32	5	1	167	68	27	6	4	105	221	59	12	5	297
Independent/Semi-independent setting	0	6	31	12	49	3	184	462	206	855	0	36	101	69	206	3	226	594	287	1110
Living independently	0	3	19	12	34	1	125	286	149	561	0	19	54	39	112	1	147	359	200	707
Living semi-independently	0	3	12	0	15	2	59	176	57	294	0	17	47	30	94	2	79	235	87	403
Community group home	1	5	8	7	21	35	147	454	305	941	79	549	1752	785	3165	115	701	2214	1097	4127
5-day community group home	0	3	1	2	6	21	24	54	12	111	10	96	209	16	331	31	123	264	30	448
7-day community group home	0	0	0	0	0	1	20	68	23	112	10	74	280	62	426	11	94	348	85	538
7-day (52-week) community group home	1	2	7	5	15	13	103	332	270	718	59	379	1263	707	2408	73	484	1602	982	3141
Residential centres	2	1	1	8	12	4	27	77	134	242	38	345	1186	920	2489	44	373	1264	1062	2743
5-day residential centre	1	1	0	0	2	1	2	3	2	8	5	16	32	3	56	7	19	35	5	66
7-day residential centre	1	0	0	0	1	0	7	11	11	29	13	83	136	65	297	14	90	147	76	327
7-day (52-week) residential centre	0	0	1	8	9	3	18	63	121	205	20	246	1018	852	2136	23	264	1082	981	2350

	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
Residential circumstances	3	0	6	11	20	9	57	86	105	257	52	275	470	270	1067	64	332	562	386	1344
Other full-time services	0	0	3	10	13	0	1	6	36	43	0	2	21	78	101	0	3	30	124	157
Nursing home																				
Mental health community residence	0	0	0	0	0	1	3	10	14	28	0	0	5	24	29	1	3	15	38	57
Psychiatric hospital	0	0	0	1	1	0	6	26	36	68	0	9	55	81	145	0	15	81	118	214
Intensive placement (challenging behaviour)	0	0	1	0	1	4	23	30	7	64	19	158	217	43	437	23	181	248	50	502
Intensive placement (profound or multiple handicap)	1	0	0	0	1	0	3	3	1	7	16	76	131	22	245	17	79	134	23	253
Full time 'other' residential service	1	0	1	0	2	4	14	7	5	30	8	10	20	13	51	13	24	28	18	83
Full time resident in residential support place	1	0	1	0	2	0	7	4	6	17	9	20	21	9	59	10	27	26	15	78
No fixed abode	0	0	0	0	0	1	5	1	2	9	0	0	3	1	4	1	5	4	3	13
Insufficient information	1	0	0	1	2	1	5	0	0	6	3	14	26	20	63	5	19	26	21	71
	2072	62	96	67	2297	3670	2194	2244	992	9100	4176	4024	5334	2393	15927	9918	6280	7674	3452	27324

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.

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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.

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

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

Kelly F, Craig S and Kelly C (2009) *Trends in demand for services among children aged 0–5 years with an intellectual disability, 2003–2007*. HRB Trends Series 3. Dublin: Health Research Board.

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



Kelly F, Kelly C and Craig S (2009) *Annual report of the National Intellectual Disability Database Committee 2008*. HRB Statistics Series 6. Dublin: Health Research Board.

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Kelly F and Kelly C (2011) *Annual report of the National Intellectual Disability Database Committee 2010*. HRB Statistics Series 13. Dublin: Health Research Board.







