



HRB Statistics Series 19

Annual Report of the National Intellectual Disability Database Committee 2012

Fionnola Kelly, Caraíosa Kelly and Anne O'Donohoe



'I offer you my hand' by Billy Arnold

My name is Billy Arnold. I was born in Bunbeg County Donegal on 3 December 1937. My mother was a schoolteacher and my father was a guard. I had a very happy childhood. I moved to Ballinasloe County Galway in the early 1980s and lived with my brother Ciaran and his wife Marie. I currently live in Avalon House and attend the Rainbow Day Services with the Brothers of Charity from Monday to Friday, where I participate in many activities and trips out. I began art classes with Maura Warde four years ago and have developed my love for art under her guidance. I have participated in numerous community art exhibitions with support from her and the staff. I am so proud that my hand was chosen for the 2012 cover. Thank you all.

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HRB Statistics Series ISSN: 2009-034x

Sub-series ISSN: 1393-9904

Copies of this publication can be obtained from:

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An electronic version is available at:

www.hrb.ie/publications



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 (1965–2011)
- National Physical and Sensory Disability Database Committee Annual Reports (2004–2011)
- National Intellectual Disability Database Committee Annual Reports (1996–2011)

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.

HRB 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.

Kelly F, Kelly C and Craig S (2010) *Annual report of the National Intellectual Disability Database Committee 2009*. HRB Statistics Series 8. Dublin: Health Research Board.

Daly A and Walsh D (2010) *Activities of Irish psychiatric units and hospitals 2009*. HRB Statistics Series 9. Dublin: Health Research Board.

Doyle A, O'Donovan MA and Craig S (2009) *Annual report of the National Physical and Sensory Disability Database Committee 2008*. HRB Statistics Series 10. Dublin: Health Research Board.

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.

Kelly C (2012) *Annual report of the National Intellectual Disability Database Committee 2011*. HRB Statistics Series 17. Dublin: Health Research Board.

Daly A and Walsh D (2012) *Activities of Irish psychiatric units and hospitals 2011*. HRB Statistics Series 18. Dublin: Health Research Board.



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Acknowledgements

The National Intellectual Disability Database Committee wishes to acknowledge the continuing commitment and co-operation of the following groups who are involved in the ongoing maintenance of the National Intellectual Disability Database:

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

Particular thanks are extended to Ms Joan Moore for editing the text.



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Chairperson's statement

It gives me great pleasure to introduce the 2012 Annual Report of the National Intellectual Disability Database.

This report provides a profile of the population with intellectual disability in 2012 and provides details of the existing level of specialised health and personal social services provision for people with an intellectual disability. The report also includes an outline of the future need for specialised health services and highlights some of the issues which must be addressed in planning and delivering services.

The World Report on Disability estimated that there are more than one billion people in the world who live with some form of disability of whom 200 million experience considerable difficulties in functioning. In the years ahead, disability will be an even greater concern because its prevalence is on the rise. The Value for Money and Policy Review of Disability Services in Ireland recognises that aging and population growth will result in an upward trend in future service requirements. This is true for all health services. The implementation of the Value for Money Report requires us to consider the strategic direction we should take in relation to the information systems required to support the provision of disability services over the coming years. The Report imposes significant requirements on the disability programme in the health sector to keep and maintain detailed records relating to the provision of and the need for services.

Sincere thanks are due to all those involved in the maintenance of the database at both service provider and HSE level. The contribution of my colleagues on the National Intellectual Disability Database Committee, especially the Health Research Board, in steering the development of the database is also much appreciated.

Grainne Duffy

Chair

National Intellectual Disability Database Committee

Executive summary

Demographic profile

There were 27,622 people registered on the National Intellectual Disability Database (NIDD) at the end of December 2012. Based on 2011 census figures, this represents a prevalence rate of 6.02 per 1,000 population. The prevalence rate for mild intellectual disability was 1.99 per 1,000, and the rate for moderate, severe or profound intellectual disability was 3.51 per 1,000. There were more males than females registered with an intellectual disability in all age groups except the 55-years-and-over group, with an overall ratio of 1.37 to 1.

The total number of individuals with moderate, severe or profound intellectual disability has increased by 43% 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 48% in 2012. 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 2012

The numbers registered on the NIDD in December 2012 were as follows:

- 27,256 people with intellectual disability who were in receipt of services, representing 99% of the total population registered on the NIDD. This was the highest number of people in receipt of services since the database was established.
- 227 people (0.8% of those registered) who were without services in 2012 and who were identified as requiring appropriate services in the period 2013–2017.
- 139 people (0.5%) who were not availing of services and had no identified requirement for services during the planning period 2013–2017.



Of the 27,256 people who were in receipt of services in 2012:

- 8,098 (29.7%) were in receipt of full-time residential services, a decrease of 1% on the 2011 figure. This is the ninth 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 22 (10.3%), from 214 in 2011 to 192 in 2012.
- 27,191 (99.8%) people availed of at least one day programme in 2012. This is the highest number registered as receiving such services since NIDD data were first reported in 1996. Of this group, 8,058 were in full-time residential placements.
- 23,350 (85.7%) 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 (18,330 individuals) lived at home with parents, siblings, relatives or foster parents in 2012. More than one in four over-35s who had a moderate, severe or profound intellectual disability lived at home in 2012. 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 2012 include:

- An increase of 77% (from 2,393 in 1996 to 4,226 in 2012) in the number of people with intellectual disability living full time in community group homes.
- An 80% reduction (from 970 in 1996 to 192 in 2012) 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 substantially: 4,852 people availed of this type of service in 2012, 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 2013–2017

The 2012 data indicate that 4,522 new residential, day and residential support places will be needed to meet service requirements. The following services will be needed in the period 2013–2017 (most service needs were recorded as being immediate):

- 2,271 full-time residential placements, an increase of 23, or 1.0%, on the projected number required in 2011.
- 2,054 residential support services, an increase of 14 on the projected number required in 2012. A continuing high level of need for these services exists, even though there were almost 5,500 people availing of residential support services in 2012.
- 197 day programmes (this figure excludes multidisciplinary support services and services provided by early intervention teams). This number is in addition to the services required by 870 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.
- 109 individuals who were living in psychiatric hospitals in 2012 have been identified as needing to transfer from these locations to more appropriate accommodation.

Of those in receipt of services in 2012, 11,884 people required alternative, additional, or enhanced services in the period 2013–2017, an increase of 60, or 0.5%, since 2011. 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:

- 10,304 day places will require changes or enhancements. Health-funded services are required by 6,873 individuals (66.7%), employment services are required by 1,322 individuals (12.8%), education services are required by 1,467 individuals (14.2%) and generic services are required by 642 individuals (6.2%). Of the 1,467 service changes required within education, 982 (66.9%) are requirements for an alternative service and 485 (33.1%) are requirements for an enhancement of the individual's existing service.



- Of the 1,500 children attending an education setting in 2012, almost one third (470 individuals) require rehabilitative training, 365 (24.3%) require vocational training and 202 (13.5%) require activation programmes.
- 2,711 residential places will require changes or enhancements.
- 1,637 residential support places will require changes or enhancements.

Despite high levels of service provision in 2012, there remained a significant demand for new and enhanced multidisciplinary support services. Almost three quarters (19,945 individuals) of the population registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2013–2017. 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. Most service providers upload data to the NIDD electronically, while a small proportion supply information to their LHO and this information is subsequently recorded on the NIDD.

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 2012.

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.

2012 annual report

This is the fifteenth report of the National Intellectual Disability Database Committee. The report is based on validated data extracted from the NIDD in December 2012. In addition to this report, a summary bulletin is produced for each of the four HSE regions and 32 LHOs.

The 2012 dataset consists of information relating to 27,622 individuals. Of these registrations, 99.4% (27,466 records) were updated following the completion of the 2012 review of NIDD information; the remaining 156 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 2012 dataset, there were 852 people recorded as being of average ability and 804 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 the categories of mild, moderate, severe and profound intellectual disability.



2. Profile of the registered population

National level

Summary

There were 27,622 people registered on the NIDD at the end of 2012. As shown in Figure 2.1, there were more males (57.8%) than females (42.2%) 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 (28.4%) and in the 35–54-year age group (27.8%).



Figure 2.1 Profile of the population registered on the NIDD, 2012

During the review and update period prior to the 2012 extract of data from the NIDD, 829 people were removed from the database¹ and there were 1,127 new registrations, the largest proportion of these 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, those who had no requirement for intellectual disability services, or those who no longer wanted their information to be held on a national system were among the records 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 2012, 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 population in 2012.

Table 2.1 Number of people registered on the NIDD, by age group, gender and degree of intellectual disability, 2012

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	419	679	1098	36	57	93	28	58	86	24	20	44	4	3	7	511	817	1328
5–9	242	591	833	305	523	828	257	501	758	97	185	282	25	29	54	926	1829	2755
10–14	62	174	236	438	854	1292	365	787	1152	139	199	338	32	36	68	1036	2050	3086
15–19	8	32	40	547	908	1455	449	714	1163	129	202	331	36	27	63	1169	1883	3052
20–34	23	28	51	968	1191	2159	1220	1645	2865	374	557	931	80	100	180	2665	3521	6186
35–54	40	47	87	1074	1187	2261	1587	1811	3398	636	854	1490	195	246	441	3532	4145	7677
55 & over	18	30	48	545	493	1038	868	767	1635	334	332	666	66	85	151	1831	1707	3538
All ages	812	1581	2393	3913	5213	9126	4774	6283	11057	1733	2349	4082	438	526	964	11670	15952	27622
Prevalence rates – numbers per 1,000 of the general population for each age group³																		
0–4	2.40	3.73	3.08	0.21	0.31	0.26	0.16	0.32	0.24	0.14	0.11	0.12	0.02	0.02	0.02	2.93	4.49	3.73
5–9	1.54	3.60	2.60	1.95	3.19	2.58	1.64	3.05	2.36	0.62	1.13	0.88	0.16	0.18	0.17	5.91	11.15	8.59
10–14	0.42	1.12	0.78	2.97	5.51	4.27	2.48	5.07	3.81	0.94	1.28	1.12	0.22	0.23	0.22	7.03	13.22	10.20
15–19	0.06	0.22	0.14	3.94	6.29	5.14	3.24	4.95	4.11	0.93	1.40	1.17	0.26	0.19	0.22	8.42	13.05	10.78
20–34	0.04	0.05	0.05	1.80	2.31	2.05	2.27	3.19	2.72	0.70	1.08	0.88	0.15	0.19	0.17	4.96	6.84	5.88
35–54	0.06	0.07	0.07	1.68	1.86	1.77	2.49	2.84	2.67	1.00	1.34	1.17	0.31	0.39	0.35	5.54	6.51	6.02
55 & over	0.03	0.06	0.05	1.04	1.04	1.04	1.66	1.61	1.64	0.64	0.70	0.67	0.13	0.18	0.15	3.50	3.59	3.54
All ages	0.35	0.70	0.52	1.69	2.29	1.99	2.06	2.76	2.41	0.75	1.03	0.89	0.19	0.23	0.21	5.04	7.02	6.02

³ Prevalence rates are based on Census of Population 2011 figures (CSO 2012).

Prevalence

The 2012 prevalence rates are calculated using NIDD data for 2012 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.

The prevalence rate for mild intellectual disability in 2012 was 1.99/1000, a slight increase on the 2011 rate of 1.98/1000. 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 2012 was also slightly up, at 3.51/1000, compared to 3.47/1000 in 2011.

Gender differences

As Table 2.1 indicates, overall the number of males exceeded the number of females in all age groups except the 55-years-and-over group. The overall male to female ratio was 1.37:1. This represents a prevalence rate of 7.02/1000 males and 5.04/1000 females.

Age differences

Of the people recorded on the NIDD, 10,221 (37.0%) were aged 19 years or under, 6,186 (22.4%) were aged between 20 and 34 years, 7,677 (27.8%) were aged between 35 and 54 years, and 3,538 (12.8%) were aged 55 years or over. Figure 2.2 illustrates the proportion in each age group at each level of intellectual disability.

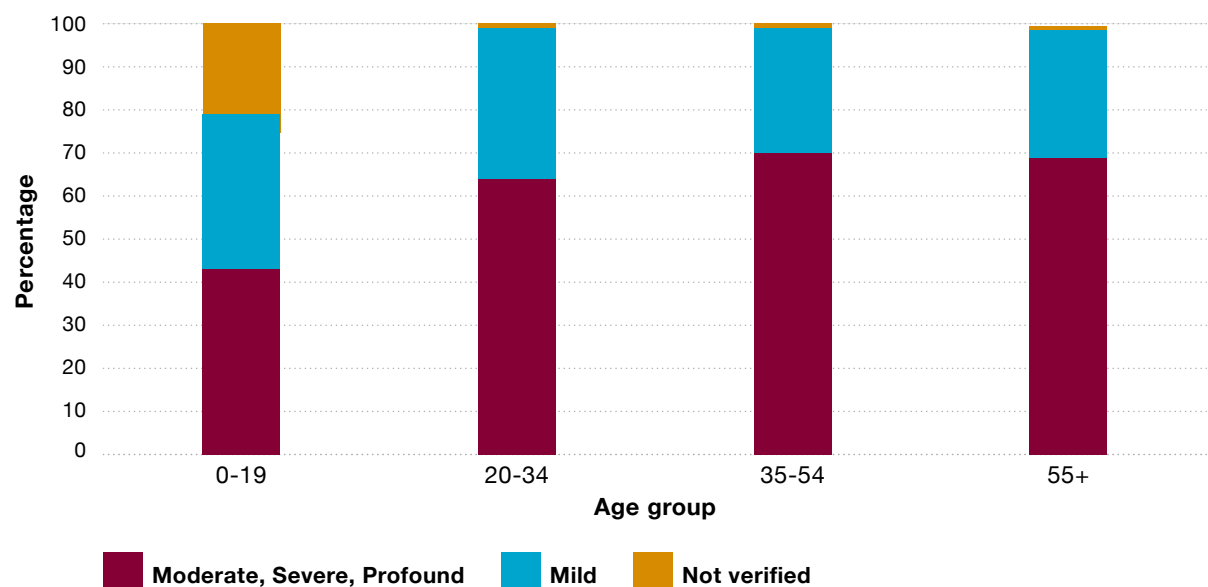


Figure 2.2 Individuals registered on the NIDD, by degree of intellectual disability and by age group, 2012

National Disability Survey 2006

In 2006 the Central Statistics Office (CSO) conducted a National Disability Survey (NDS) to establish the extent and impact of disability in Ireland. Data from the survey indicate that 50,400 people in Ireland have a diagnosed intellectual disability (CSO, 2010). This information differs greatly from what is recorded on the NIDD, for three 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 used by the two sources also differ. For inclusion on the NIDD a person is usually assessed by a multidisciplinary team, and his/her level of intellectual disability (mild, moderate, severe or profound) is established based on this assessment. In the NDS data-collection method, the response to the question pertaining to whether or not the individual had a diagnosed intellectual disability was self-interpreted in a guided interview context. Almost 14,000 individuals whose main disability was classified as dyslexia or a specific learning difficulty answered 'Yes' to this question, as did over 2,500 individuals (or their proxy) whose disability was classified as attention deficit disorder (CSO, 2010). This question was also answered positively by a large number of people who had an acquired brain injury. People diagnosed with the conditions mentioned above are not generally included on the NIDD unless they have a diagnosed intellectual disability as defined by the WHO ICD-10, where disability is estimated on a scale ranging from mild to moderate to severe to profound (WHO, 1996).
3. As a general principle, the NIDD registers data only on individuals with an intellectual disability for whom specialised health services are being provided or who, following a needs assessment, are considered to require specialised services in the next five years. Almost everyone with a moderate, severe or profound intellectual disability is expected to be included on the NIDD as they are likely to be in receipt of or require intellectual disability services. The number of people on the NIDD with a mild intellectual disability may, however, be underestimated as they are less likely to require specialised intellectual disability services. By contrast, the 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.



Trends over time

Recent trends

Prevalence rates for moderate, severe and profound intellectual disability for the years 2002, 2007 and 2012 are shown in Table 2.2. The 2002 prevalence rates are calculated using NIDD and Census of Population data for 2002. The 2007 prevalence rates are calculated using NIDD data for 2007 and Census of Population data for 2006. The 2012 prevalence rates are calculated using NIDD data for 2012 and Census of Population data for 2011.

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 2012 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 five-year period, rising from 4.37/1000 in 2007 to 5.50/1000 in 2012. 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 2002–2012; however, the number of individuals registered in the 5–9-year age group has increased by 140 (14.7%), and the number in the 55-years-and-over age group has increased by 786 (47.2%). 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 2.2 Prevalence of intellectual disability, by degree (moderate, severe and profound) and by age group, 2002, 2007 and 2012

Age group	Moderate			Severe			Profound			All levels		
	2002	2007	2012	2002	2007	2012	2002	2007	2012	2002	2007	2012
0–4	145	69	86	57	19	44	17	6	7	219	94	137
5–9	645	605	758	257	260	282	52	50	54	954	915	1094
10–14	806	895	1152	271	304	338	48	56	68	1125	1255	1558
15–19	947	940	1163	287	276	331	75	53	63	1309	1269	1557
20–34	2912	2813	2865	1158	1053	931	353	268	180	4423	4134	3976
35–54	2936	3127	3398	1500	1507	1490	425	472	441	4861	5106	5329
55 & over	1104	1293	1635	474	548	666	88	123	151	1666	1964	2452
All ages	11497	9742	11057	4004	3967	4082	1058	1028	964	14557	14737	16103
Prevalence rates – numbers per 1,000 of the general population for each age group												
0–4	0.52	0.23	0.24	0.21	0.06	0.12	0.06	0.02	0.02	0.79	0.31	0.38
5–9	2.44	2.1	2.36	0.97	0.9	0.88	0.20	0.17	0.17	3.61	3.17	3.41
10–14	2.82	3.27	3.81	0.95	1.11	1.12	0.17	0.2	0.22	3.94	4.58	5.15
15–19	3.02	3.24	4.11	0.92	0.95	1.17	0.24	0.18	0.22	4.18	4.37	5.50
20–34	3.08	2.64	2.72	1.22	0.99	0.88	0.37	0.25	0.17	4.68	3.88	3.78
35–54	2.81	2.73	2.67	1.44	1.32	1.17	0.41	0.41	0.35	4.66	4.46	4.18
55 & over	1.40	1.48	1.64	0.60	0.63	0.67	0.11	0.14	0.15	2.12	2.24	2.46
All ages	2.94	2.3	2.41	1.02	0.94	0.89	0.27	0.24	0.21	3.72	3.48	3.51

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 2012 allows us to monitor trends in the population with an intellectual disability over the past 38 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.



Table 2.3 Prevalence of intellectual disability, by degree (moderate, severe and profound) and by age group, 1974, 1981, 1996, 2012

Age group	Moderate				Severe				Profound				All levels			
	1974	1981	1996	2012	1974	1981	1996	2012	1974	1981	1996	2012	1974	1981	1996	2012
0–4	189	214	226	86	143	92	83	44	99	26	30	7	431	332	339	137
5–9	809	955	736	758	617	330	260	282	224	99	77	54	1650	1384	1073	1094
10–14	752	1035	948	1152	583	428	305	338	292	117	93	68	1627	1580	1346	1558
15–19	698	1203	1072	1163	445	508	378	331	241	154	132	63	1384	1865	1582	1557
20–34	1498	2419	2997	2865	1017	1129	1350	931	441	340	460	180	2956	3888	4807	3976
35–54	1321	1559	2626	3398	626	612	1183	1490	201	97	343	441	2148	2268	4152	5329
55 & over	669	715	987	1635	307	248	394	666	84	24	53	151	1060	987	1434	2452
All ages	5936	8100	9592	11057	3738	3347	3953	4082	1582	857	1188	964	11256	12304	14733	16103
Prevalence rates – numbers per 1,000 of the general population for each age group																
0–4	0.6	0.62	0.83	0.24	0.45	0.27	0.3	0.12	0.31	0.07	0.11	0.02	1.36	0.97	1.24	0.38
5–9	2.55	2.73	2.31	2.36	1.95	0.94	0.82	0.88	0.71	0.28	0.24	0.17	5.2	3.95	3.37	3.41
10–14	2.52	3.08	2.72	3.81	1.95	1.27	0.88	1.12	0.98	0.35	0.27	0.22	5.45	4.7	3.86	5.15
15–19	2.61	3.79	3.2	4.11	1.66	1.6	1.13	1.17	0.9	0.48	0.39	0.22	5.17	5.88	4.72	5.50
20–34	2.78	3.33	3.93	2.72	1.88	1.56	1.77	0.88	0.82	0.47	0.6	0.17	5.48	5.35	6.31	3.78
35–54	2.13	2.43	3.25	2.67	1.01	0.95	1.46	1.17	0.32	0.15	0.42	0.35	3.46	3.53	5.14	4.18
55 & over	1.08	1.09	1.45	1.64	0.5	0.38	0.58	0.67	0.14	0.04	0.08	0.15	1.71	1.51	2.11	2.46
All ages	1.99	2.35	2.72	2.41	1.25	0.97	1.12	0.89	0.53	0.25	0.34	0.21	3.8	3.6	4.18	3.51

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 in 2011 (0.4%) and again in 2012 (0.2%).

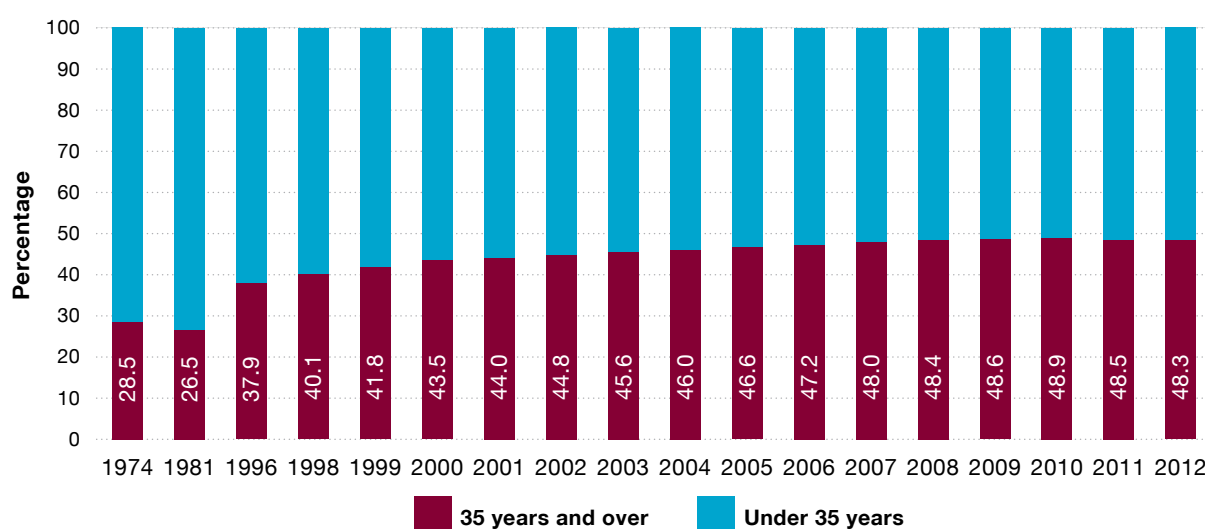


Figure 2.3 Proportion of people with moderate, severe or profound intellectual disability (combined), by age group, 1974–2012

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 these 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 2012 by HSE region. The highest number of registrations was in the HSE South Region and the lowest number in the HSE Dublin/North-East Region. The numbers registered in each region were broadly in line with 2011 figures.

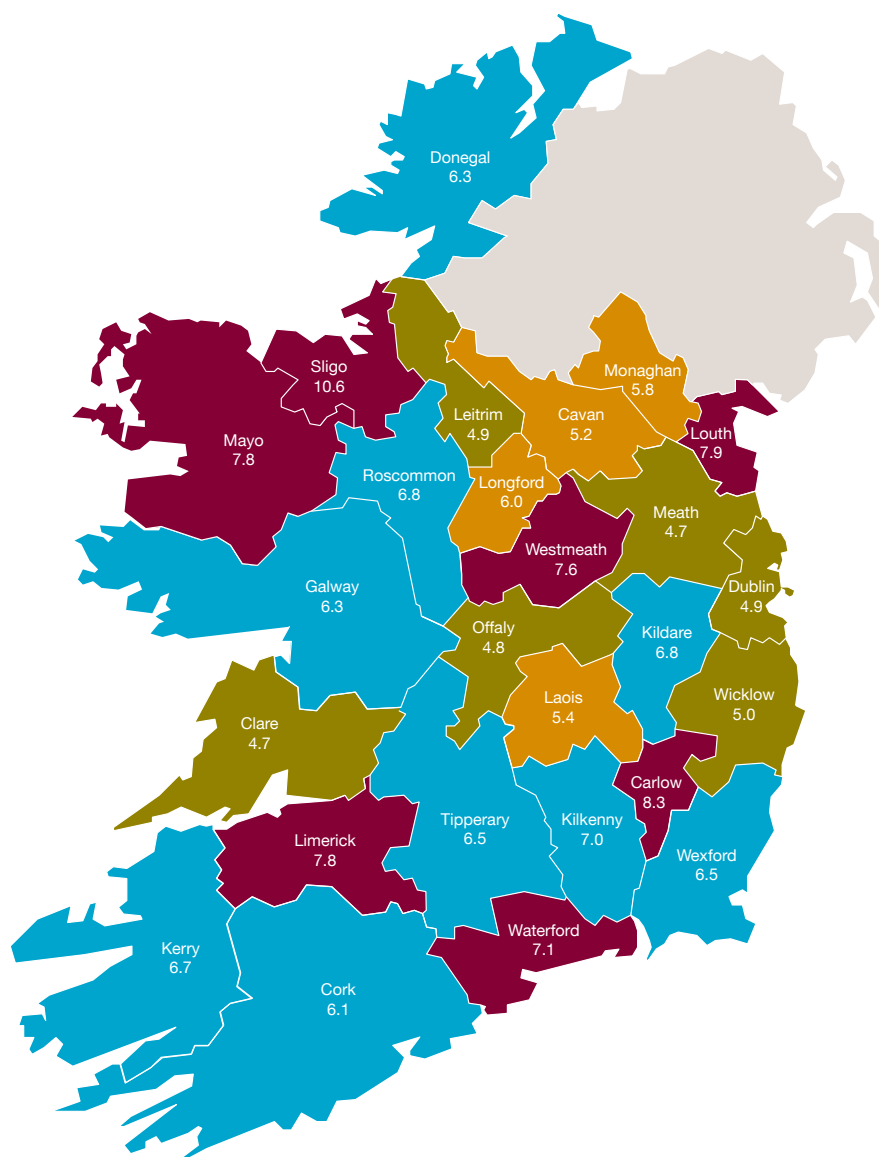
Table 2.4 Number of people registered on the NIDD, by HSE region, 2012

HSE Region	n	% of NIDD
Dublin/Mid-Leinster*	7004	25.4
South†	7832	28.4
West‡	7185	26.0
Dublin/North-East	5601	20.3
Total	27622	100.0

* One individual received services in the HSE Dublin/Mid-Leinster Region but has not been included in the overall figures as he/she did not consent to having their information included on the national system.

† An additional 50 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 36 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.



3.0–5.0 NIDD registrations per 1,000 population

5.1–6.0 NIDD registrations per 1,000 population

6.1–7.0 NIDD registrations per 1,000 population

7.1 & over NIDD registrations per 1,000 population

Figure 2.4 NIDD registrations per 1,000 of the general population, by county of residence, 2012

Figure 2.4 presents the number of NIDD registrations by county of residence. The national prevalence rate was 6.0/1000. The counties with the highest prevalence rates were Sligo (10.6/1000), Carlow (8.3/1000) and Louth (7.9/1000), while Clare (4.7/1000) and Meath (4.7/1000) had the lowest prevalence rates.

Co-morbidity within the NIDD population

As Table 2.5 indicates, 11,601 individuals (42.0%) registered on the NIDD in 2012 had a physical and/or sensory disability in addition to an intellectual disability. This number represents an increase of 7.1% on the 2011 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, 2012

	Male		Female		Total	
	n	%	n	%	n	%
Intellectual and physical/sensory disability	6534	41.0	5067	43.4	11601	42.0
Intellectual disability only	9418	59.0	6603	56.6	16021	58.0
Total	15952	100.0	11670	100.0	27622	100.0



3. Service provision in 2012

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 2012. Day services were availed of by 98.4% of all those registered on the NIDD in 2012. 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 (2.2%) of adults were without day services, compared to their younger counterparts (0.3%). The residential circumstances for both age groups also differed. In 2012 98.3% (8,970) of those aged under 18 years lived at home, compared to 50.6% (9,360) 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, 2012

In 2012, 27,256 people with intellectual disability were receiving services, which accounted for 98.7% of the total population registered on the NIDD. Of the remaining 366 people (1.3%) who were not in receipt of services, 227 (0.8% of total registered population) expressed a need for services in the period 2013–2017. The overall level of service provision in 2012 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, 2012

	n	%
Attending services on a day basis	19133	69.3
Receiving 5- or 7-day residential services	7906	28.6
Resident in a psychiatric hospital	192	0.7
Receiving residential support services only	25	0.1
Receiving no service – on waiting list	227	0.8
No identified service requirements	139	0.5
Total	27622	100.0

Residential circumstances

Table 3.2 provides an overview of the main residential circumstances of those registered on the NIDD in 2012 by degree of intellectual disability and age group (a further breakdown is presented in Table 3.3).

The main groupings of individuals consisted of:

- 18,330 individuals (66.4%) 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.
- 8,098 individuals (29.3%) 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.
- 1,157 individuals (4.2%) who lived independently or semi-independently. This represents an increase of 47 on the 2011 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 (4,226) than in residential centres (2,561). 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 2012, 244 people with an intellectual disability resided full time in mental health facilities, either in psychiatric hospitals (192 individuals, compared with 214 individuals in 2011) or in mental health community residences (52 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 2012 decreased with age: 97.8% of individuals aged 0–19 years lived in a home setting, declining to 75.3% of those aged 20–34 years, 39.9% of those aged 35–54 years, and 17.4% 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 2012 increased with age: 2.1% of all 0–19-year-olds received full-time residential services, compared with 20.9% of 20–34-year-olds, 52.0% of 35–54-year-olds and 73.5% 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 2012. 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 1,157 individuals who lived in independent or semi-independent settings in 2012, 80.5% were aged 35 years or over and over three quarters (77.3%) had a mild intellectual disability.

Degree of intellectual disability

Variations were also noticeable 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 57.3% 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 15.5% of people with a mild intellectual disability lived in full-time residential services, but this increased to 41.3% in the case of those with a moderate, severe or profound disability.

Where individuals were in full-time residential services in 2012, the type of service varied according to the level of intellectual disability. In the past, full-time residents with a mild intellectual disability were generally 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 2012 who had a moderate, severe or profound intellectual disability, 49.2% were in community group homes, 35.0% were in residential centres, and 15.8% 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 2012, 66.1% were in community group homes, 17.4% were in other full-time residential services and 16.4% were in residential centres.

Table 3.2 Main residential circumstances, by degree of intellectual disability and by age group, 2012

	Not verified					Mild					Moderate, severe or profound					All levels				
	0–19	20–34	35–54	55+	Total	0–19	20–34	35–54	55+	Total	0–19	20–34	35–54	55+	Total	0–19	20–34	35–54	55+	Total
Home setting	2199	41	45	19	2304	3623	1759	1171	253	6806	4172	2856	1850	342	9220	9994	4656	3066	614	18330
Independent setting	0	7	30	15	52	3	182	480	229	894	0	34	101	76	211	3	223	611	320	1157
Community group home	0	3	8	8	19	29	133	443	328	933	84	527	1790	873	3274	113	663	2241	1209	4226
Residential centre	1	0	1	0	2	2	24	78	128	232	38	292	1106	891	2327	41	316	1185	1019	2561
Other full-time services*	4	0	3	6	13	8	54	86	98	246	49	260	476	267	1052	61	314	565	371	1311
No fixed abode	0	0	0	0	0	1	5	2	2	10	0	0	1	2	3	1	5	3	4	13
Insufficient information	3	0	0	0	3	2	2	1	0	5	3	7	5	1	16	8	9	6	1	24
Total	2207	51	87	48	2393	3668	2159	2261	1038	9126	4346	3976	5329	2452	16103	10221	6186	7677	3538	27622

* 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 2012 (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, where 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 16-year period between 1996 and 2012 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 in 2006. In 2012 4,852 individuals availed of respite services, which brings the total increase over the period to 3,981 individuals (457.1%).



Table 3.3 Main residential circumstances and overall level of residential service provision, 2012

	Main residential circumstances			Overall level of residential provision/circumstance		
	Under 18	18 & over	All ages	Under 18	18 & over	All ages
Home setting	8970	9360	18330	8977	9365	18342
At home with both parents	6931	5442	12373	6931	5442	12373
At home with one parent	1788	2674	4462	1788	2674	4462
At home with sibling	3	932	935	3	932	935
At home with other relative	47	153	200	47	153	200
Living with non-relative	3	26	29	3	26	29
Adoption	7	11	18	7	11	18
Foster care and boarding out arrangements	191	122	313	198	127	325
Independent setting	0	1157	1157	0	1158	1158
Living independently	0	732	732	0	733	733
Living semi-independently	0	425	425	0	425	425
Community group homes	79	4147	4226	79	4147	4226
5-day community group home	20	406	426	20	406	426
7-day (48-week) community group home	8	515	523	8	515	523
7-day (52-week) community group home	51	3226	3277	51	3226	3277
Residential setting	25	2536	2561	25	2536	2561
5-day residential centre	3	54	57	3	54	57
7-day (48-week) residential centre	7	272	279	7	272	279
7-day (52-week) residential centre	15	2210	2225	15	2210	2225

Table 3.3 Main residential circumstances and overall level of residential service provision, 2012 (*continued*)

	Main residential circumstances			Overall level of residential provision/circumstance		
	Under 18	18 & over	All ages	Under 18	18 & over	All ages
Other full-time residential services	42	1269	1311	42	1269	1311
Nursing home	0	155	155	0	155	155
Mental health community residence	0	52	52	0	52	52
Psychiatric hospital	0	192	192	0	192	192
Intensive placement (challenging behaviour)	14	482	496	14	482	496
Intensive placement (profound or multiple disability)	7	241	248	7	241	248
Occupying a full-time support place	11	61	72	11	61	72
Other full-time residential service	10	86	96	10	86	96
Residential support service	0	0	0	1476	3992	5468
Holiday residential placement	0	0	0	4	63	67
Crisis or planned respite	0	0	0	1300	3552	4852
Occasional respite with host family	0	0	0	146	191	337
Overnight respite in the home	0	0	0	6	9	15
Shared care or guardianship	0	0	0	6	12	18
Regular part-time care (2/3 days per week)	0	0	0	5	82	87
Regular part-time care (every weekend)	0	0	0	2	11	13
Regular part-time care (alternate weeks)	0	0	0	0	49	49
Other residential service	0	0	0	7	23	30
No fixed abode	0	13	13	0	13	13
Insufficient information	7	17	24	7	17	24
Total	9123	18499	27622	10606	22497	33103

Note: The total number of services received (33,103) 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.

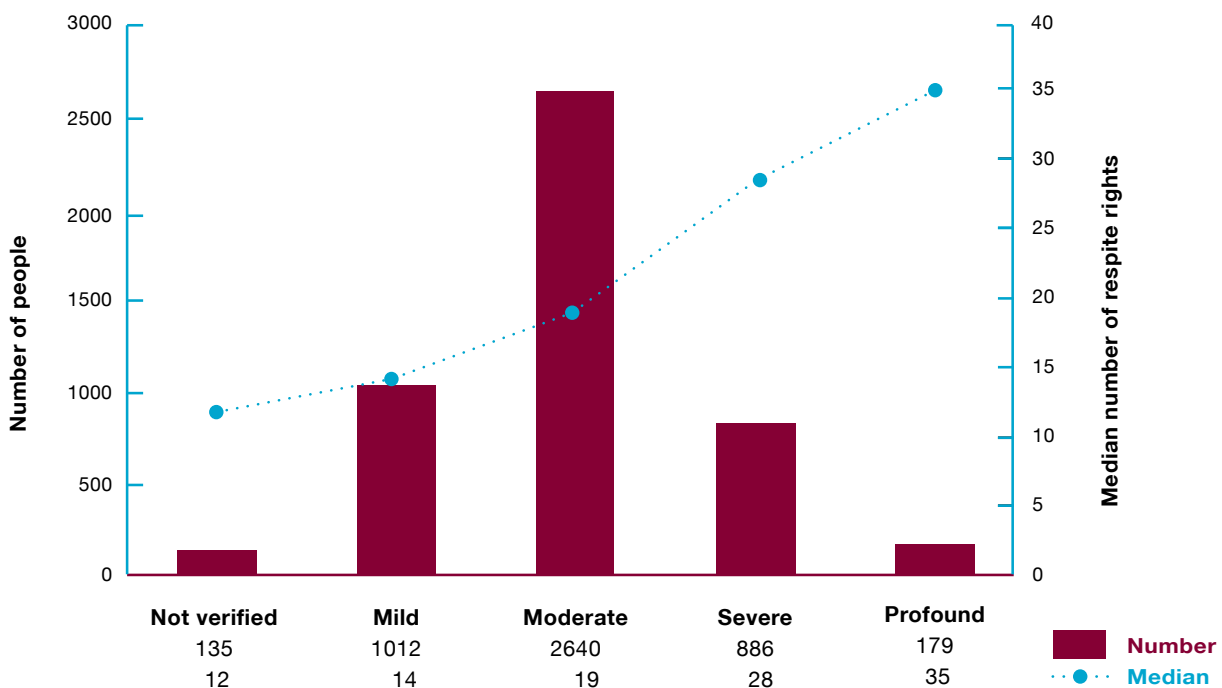


Figure 3.2 Number of people in receipt of respite nights and median number of respite nights received, by degree of intellectual disability, 2012

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.

Table 3.4 presents data on use of respite services for each of the HSE areas. The table shows that there were marked differences between regions in the total number of respite nights received in 2012, which ranged from 28,932 in the HSE Dublin/North-East Region to 39,222 nights in the HSE Dublin/Mid-Leinster Region. Chapter 4 presents data on those who require respite care.

Table 3.4 Use of respite nights, by HSE region and by LHO area of residence, 2012

	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	39222	1330	20
LHO Dublin South	4795	128	26
LHO Dublin South East	1962	63	24
LHO Dublin South City	2778	98	18
LHO Dublin South West	6764	215	21
LHO Dublin West	5260	155	21
LHO Kildare/West Wicklow	5456	249	15
LHO Wicklow	4714	114	27.5
LHO Laois/Offaly	2679	147	12
LHO Longford/Westmeath	4814	161	16
HSE South Region	31461	1240	15
LHO Carlow/Kilkenny	2743	117	12
LHO Tipperary SR	3126	149	15
LHO Waterford	1666	105	13
LHO Wexford	3075	185	14
LHO Cork North Lee	4426	161	20
LHO Cork South Lee	3724	105	26
LHO North Cork	3713	113	14
LHO West Cork	4541	129	16
LHO Kerry	4447	176	12

Table 3.4 Use of respite nights, by HSE region and by LHO area of residence, 2012 (*continued*)

	Total number of respite nights received	Number of people in receipt of respite nights	Median number of respite nights received
HSE West Region	42200	1208	25
LHO Limerick	4474	138	20
LHO Tipperary NR	3447	89	35
LHO Clare	3029	109	16
LHO Galway	13829	299	31
LHO Mayo	6680	169	32
LHO Roscommon	2224	57	30
LHO Donegal	5975	230	20
LHO Sligo/Leitrim	2542	117	13
HSE Dublin/North-East Region	28932	1074	18.5
LHO Dublin North West	6140	191	24
LHO Dublin North Central	2544	100	15
LHO Dublin North	9642	337	20
LHO Cavan/Monaghan	2579	118	15
LHO Louth	4327	152	18
LHO Meath	3700	176	16
Total	141815	4852	20

Day services

A total of 27,191 people, representing 98.4% of all those registered on the NIDD, received day services in 2012 (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 27,191 individuals who availed of day services in 2012, 8,058 (29.6%) were in full-time residential services, the majority of whom were in the moderate, severe, or profound range of intellectual disability (82.3%) and aged 18 years or over (98.2%). The remaining 19,133 (70.4%) attended services on a day basis; 39.4% were in the mild range of intellectual disability and 46.8% 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, 2012

	Not verified			Mild			Moderate, severe or profound			All levels		
	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	5	28	33	30	1363	1393	111	6521	6632	146	7912	8058
Day attendees	2186	158	2344	3125	4415	7540	3642	5607	9249	8953	10180	19133
Total	2191	186	2377	3155	5778	8933	3753	12128	15881	9099	18092	27191

Main day services by age group and degree of intellectual disability

As in 2011, the top three day activities availed of by people with an intellectual disability in 2012, 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 27,191 individuals who availed of day services in 2012, 9,099 (33.5%) were aged under 18 years, and 18,092 (66.5%) 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 18,092 adults who availed of at least one day service in 2012, most attended either activation centres (36.8%) or sheltered work centres (18.1%) as their principal day service. Smaller proportions availed of multidisciplinary support services only (9.0%), rehabilitative training (8.8%), and supported employment (4.6%).

Table 3.6 Principal day service availed of, by degree of intellectual disability and by age group, 2012

	Not verified			Mild			Moderate, severe or profound			All levels		
	Under 18	18 & over	All ages	Under 18	18 & over	All ages	Under 18	18 & over	All ages	Under 18	18 & over	All ages
Home support	61	3	64	3	63	66	8	90	98	72	156	228
Home help	0	1	1	1	10	11	0	12	12	1	23	24
Early intervention team	531	0	531	57	0	57	29	0	29	617	0	617
Special pre-school for intellectual disability	359	0	359	59	0	59	113	0	113	531	0	531
Child education and development centre	6	0	6	2	0	2	134	3	137	142	3	145
Mainstream pre-school	239	0	239	44	0	44	34	0	34	317	0	317
Mainstream school	445	3	448	860	40	900	622	27	649	1927	70	1997
Resource/visiting teacher	77	0	77	45	15	60	31	4	35	153	19	172
Special class – primary	107	0	107	200	0	200	193	0	193	500	0	500
Special class – secondary	4	0	4	92	22	114	94	20	114	190	42	232
Special school	298	0	298	1747	152	1899	2443	142	2585	4488	294	4782
Third-level education	0	1	1	0	25	25	0	7	7	0	33	33
Rehabilitative training	0	9	9	5	776	781	0	805	805	5	1590	1595
Activation centre	0	15	15	0	1373	1373	0	5272	5272	0	6660	6660
Programme for the older person	0	12	12	0	117	117	0	535	535	0	664	664
Special high-support day service	0	0	0	1	52	53	5	710	715	6	762	768
Special intensive day service	0	0	0	0	49	49	0	345	345	0	394	394
Sheltered work centre	0	21	21	0	1309	1309	0	1944	1944	0	3274	3274

Table 3.6 Principal day service availed of, by degree of intellectual disability and by age group, 2012 (*continued*)

	Not verified			Mild			Moderate, severe or profound			All levels		
	Under 18	18 & over	All ages	Under 18	18 & over	All ages	Under 18	18 & over	All ages	Under 18	18 & over	All ages
Sheltered employment centre	0	11	11	0	51	51	0	20	20	0	82	82
Multidisciplinary support services	17	22	39	12	507	519	15	1095	1110	44	1624	1668
Centre-based day respite service	4	1	5	2	9	11	0	9	9	6	19	25
Day respite in the home	3	0	3	0	1	1	1	3	4	4	4	8
Outreach programme	1	5	6	0	70	70	0	96	96	1	171	172
Other day service	37	0	37	23	182	205	30	308	338	90	490	580
Enclave within open employment	0	0	0	0	3	3	0	6	6	0	9	9
Supported employment	0	21	21	0	482	482	0	329	329	0	832	832
Open employment	0	1	1	0	116	116	0	39	39	0	156	156
Vocational training	1	9	10	2	190	192	1	82	83	4	281	285
Generic day services	1	51	52	0	164	164	0	225	225	1	440	441
Total	2191	186	2377	3155	5778	8933	3753	12128	15881	9099	18092	27191

Degree of intellectual disability

Of those who received day services in 2012 (27,191 individuals), 8,933 (32.9%) had a mild intellectual disability, 15,881 (58.4%) had a moderate, severe or profound intellectual disability and 2,377 (8.7%) 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 (3,753, 23.6%) of the population with moderate, severe or profound intellectual disability who availed of day services in 2012 were aged under 18 years, whereas more than one in three (3,155, 35.3%) of the population with mild intellectual disability who availed of day services were aged under 18 years.

Of the 9,099 under-18s who availed of day services in 2012:

- 3,155 (34.7%) 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.
- 3,753 (41.2%) 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.
- 2,191 (24.1%) had not had their degree of intellectual disability verified.

Of the 18,092 adults in receipt of day services in 2012:

- 5,778 (31.9%) 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.
- 12,128 (67.0%) 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 availing of multidisciplinary support services.
- 186 (1.0%) had not had their degree of intellectual disability verified.



Table 3.7 outlines the principal day service and overall level of day service provision for those registered on the NIDD in 2012. 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 16-year period between 1996 and 2012. 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 2012 was 409, which represents an increase of 293 places (253%) over the 16-year period. The number of high-support day places rose by 383 (95%) in the same period.
- A large increase was also observed in the number of people who attended programmes specific to the older person. This number rose from 277 people in 1996, to 400 in 2001, and to 658 in 2006. The number of people who attended these services in 2012 was 726, representing an overall increase of 449 places (162%) since 1996.

Increases were also observed over the 16-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, 2012

	Principal day service			Overall level of day service provision		
	Under 18	18 & over	Total	Under 18	18 & over	Total
Home support	72	156	228	1102	908	2010
Home help	1	23	24	75	88	163
Early intervention team	617	0	617	1967	0	1967
Special pre-school for intellectual disability	531	0	531	543	0	543
Child education and development centre	142	3	145	151	5	156
Mainstream pre-school	317	0	317	430	0	430
Mainstream school	1927	70	1997	1959	73	2032
Resource/visiting teacher	153	19	172	838	71	909
Special class – primary	500	0	500	503	0	503
Special class – secondary	190	42	232	191	42	233
Special school	4488	294	4782	4490	295	4785
Third-level education	0	33	33	0	47	47
Rehabilitative training	5	1590	1595	5	1644	1649
Activation centre	0	6660	6660	0	6958	6958
Programme for the older person	0	664	664	0	726	726
Special high-support day service	6	762	768	7	776	783
Special intensive day service	0	394	394	4	405	409
Sheltered work centre	0	3274	3274	0	3447	3447
Sheltered employment centre	0	82	82	0	84	84

Table 3.7 Principal day service and overall level of day service provision, by age group, 2012 (*continued*)

	Principal day service			Overall level of day service provision		
	Under 18	18 & over	Total	Under 18	18 & over	Total
Multidisciplinary support services	44	1624	1668	6139	15244	21383
Centre-based day respite service	6	19	25	319	402	721
Day respite in the home	4	4	8	80	90	170
Outreach programme	1	171	172	91	318	409
Other day service	90	490	580	909	786	1695
Enclave within open employment	0	9	9	0	11	11
Supported employment	0	832	832	0	1682	1682
Open employment	0	156	156	0	274	274
Vocational training	4	281	285	4	324	328
Generic day services	1	440	441	2	474	476
Total	9099	18092	27191	19809	35174	54983

Note: The total number of services received (54,983) 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, 23,350 individuals received one or more multidisciplinary support services in 2012 (including those provided by early intervention teams). This was an increase of 381 people since 2011. As in 2011, the most commonly availed of multidisciplinary support services were: social work (11,065 individuals), medical services (10,586 individuals), speech and language therapy (10,136 individuals) and psychology (8,974 individuals).
- The services most commonly availed of by those aged 18 or over were social work (7,201), medical services (7,046) and psychiatry (6,586).
- The services most commonly availed of by children were speech and language therapy (2,079 children aged six years or under and 4,508 children aged 7–17 years), occupational therapy (1,693 children aged six years or under and 2,890 children aged 7–17 years), and social work (1,240 children aged six years or under and 2,624 children aged 7–17 years).
- Early intervention teams usually provide services to children aged six years or under; 1,917 children (83.4%) in this age group received multidisciplinary support services from an early intervention team in 2012. There were also 50 children aged seven years or over who received services from an early intervention team in 2012.



Table 3.8 Overall provision of multidisciplinary support services, by age group and access to an early intervention team (EIT), 2012

	Aged 6 or under			Aged 7–17			Aged 18 or over	
	Provided by an EIT	Not provided by an EIT	Total	Provided by an EIT	Not provided by an EIT	Total	Aged 18 or over	Total
Medical services	1138	158	1296	31	2213	2244	7046	10586
Nursing	898	113	1011	16	1193	1209	6160	8380
Dietician	427	48	475	8	580	588	2757	3820
Occupational therapy	1443	250	1693	29	2861	2890	3128	7711
Physiotherapy	1440	171	1611	25	2010	2035	3465	7111
Psychiatry	41	28	69	1	644	645	6586	7300
Psychology	1073	157	1230	30	2728	2758	4986	8974
Social work	1101	139	1240	22	2602	2624	7201	11065
Speech and language therapy	1747	332	2079	37	4471	4508	3549	10136
Other	455	100	555	7	1495	1502	4602	6659
Number of people	1917	382	2299	50	5757	5807	15244	23350

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 2012 in the four HSE regions. Nationally, 27,256 individuals (98.7%) with an intellectual disability registered on the NIDD were in receipt of services in 2012.

At national level, 8,098 individuals (29.3%) registered on the NIDD in 2012 were in receipt of a full-time residential service. Regionally, this proportion varied from 26.9% in the HSE South Region to 30.6% in the HSE Dublin/Mid-Leinster Region.

At national level, 19,133 people (69.3%) attended services on a day basis, with the proportion ranging from 66.9% in the HSE West Region to 71.9% in the HSE South Region.

Nationally, a small proportion (227, 0.8%) of registrations were without services but were identified as requiring services in the five-year period 2013–2017. The HSE West Region had the highest proportion (1.4%) of people without any service and awaiting services within the next five years.



Table 3.9 Service provision by HSE region of registration, 2012

	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	4785 (68.3)	2136 (30.5)	7 (0.1)	8 (0.1)	50 (0.7)	18 (0.3)	7004
South	5630 (71.9)	2060 (26.3)	49 (0.6)	5 (0.1)	58 (0.7)	30 (0.4)	7832
West	4806 (66.9)	2178 (30.3)	9 (0.1)	10 (0.1)	103 (1.4)	79 (1.1)	7185
Dublin/North-East	3912 (69.8)	1532 (27.4)	127 (2.3)	2 (0.0)	16 (0.3)	12 (0.2)	5601
All regions	19133 (69.3)	7906 (28.6)	192 (0.7)	25 (0.1)	227 (0.8)	139 (0.5)	27662

4. Future service requirements 2013–2017

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 another formal standardised assessment. The data reported in this chapter reflect the service needs of the individual for the period 2013–2017. For ease of interpretation, four distinct categories of need are identified, as follows:

A – Unmet need: applies to people who, in 2012, 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 2013–2017. 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 2012 but will require that service to be changed or upgraded during the period 2013–2017, 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 2012: includes people who need to transfer out of psychiatric hospitals in the period 2013–2017 and people who were resident in the psychiatric services in 2012 but require an appropriate day service in the period 2013–2017. 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 2013–2017 by all individuals registered on the NIDD in 2012. 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 unmet need, service change, and people with intellectual disability within the psychiatric services. 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 4,522 new residential, day and residential support places will be needed to meet service requirements in the period 2013–2017, half of which are residential places. Of the existing places availed of in 2012, 14,652 need to be changed or upgraded, with over two thirds of the changes/upgrades required in day services. Figure 4.1 also shows that 127 people accommodated in psychiatric hospitals in 2012 require specialist services; almost 86% of this group require residential services. In 2012, 19,945 people were recorded as requiring new or enhanced multidisciplinary services, which is a slight increase on the 19,813 recorded in 2011.

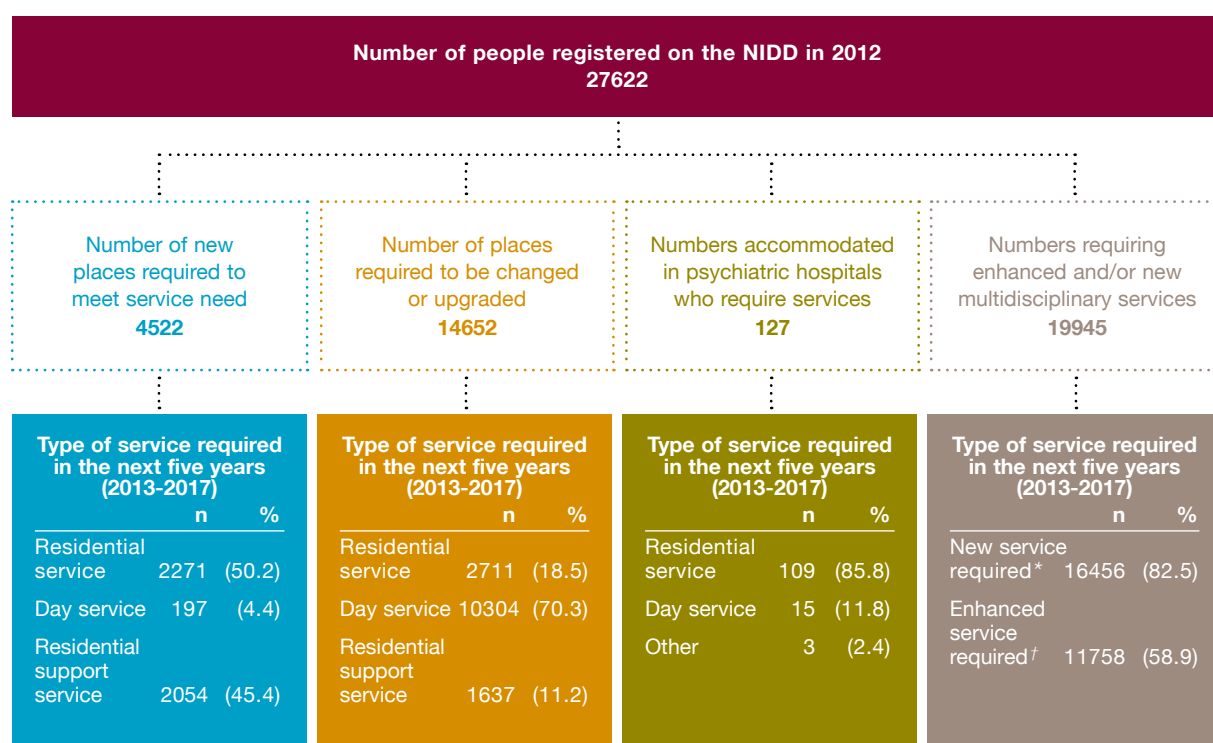


Figure 4.1 Summary of the service requirements of those registered on the NIDD, 2012

* 'New service required' refers to a new type of therapeutic input that the individual does not currently receive.

† 'Enhanced service required' refers to a change in the delivery of a therapeutic input that the individual currently receives. There are 8,269 individuals whose multidisciplinary support service change involves both a new service and an enhanced service, (Section D, this chapter), therefore, the actual number of people requiring a new and/or enhanced service is $(16,456 + 11,758) - 8,269 = 19,945$.

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 2013–2017, by HSE region of registration

	Residential	Day	Residential support	Number of NIDD registrations
Dublin/Mid-Leinster	621	50	518	7004
South	586	49	612	7832
West	508	83	577	7185
Dublin/North-East	556	15	347	5601
Total	2271	197	2054	27622

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 increased slightly since 2011, from 2,248 places in 2011 to 2,271 places in 2012. Seven out of ten of those requiring a new residential place (1,623 individuals, 71.5%) have a moderate, severe or profound intellectual disability (see Table 4.2).
- The demand for residential supports in 2012 (2,054 individuals) is a slight increase on that of 2011 (2,040 individuals). The level of need remains high despite the fact that almost 5,500 individuals availed of residential support services in 2012.

Full-time residential services

Of the 2,271 people who required full-time residential services in 2012 (Table 4.2):

- 1,623 individuals (71.5%) had a moderate, severe, or profound level of intellectual disability, of whom 1,377 required placements in community group homes, 140 required placements in a residential centre, and 98 required specialised intensive placements because of their increased dependency.

- 614 individuals (27.0%) had a mild intellectual disability, of whom 534 required placements in community group homes, 57 required placements in a residential centre, and 17 required specialised intensive placements due to their increased dependency.
- 34 individuals (1.5%) had not had their level of intellectual disability verified in 2012.

Of those who required full-time residential services in 2012, 2,258 (99.4%) were in receipt of a day service or a residential support service, 2,180 (96.0%) lived at home, and 81 (3.6%) 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 197 individuals who required day services, 178 (90.4%) lived either at home (152 individuals) or independently/semi-independently (26 individuals). A large demand came from 169 people who had no service whatsoever in 2012. Of these:

- 106 individuals (62.7%) had a mild intellectual disability and their principal service requirements were in the training and employment areas.
- 62 individuals (36.7%) 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 2,053 people (Table 4.4). Of this group, 1,818 individuals (88.5%) lived either at home (1,728 individuals) or independently/semi-independently (90 individuals); 1,786 individuals (87.0%) were in receipt of a day service; and 33 individuals (1.6%) had no day service in 2012. An additional 235 individuals (11.4%) 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 2012 (1,105 individuals), while people with mild intellectual disability accounted for 42.4% (871 individuals). The remaining 3.8% (77 individuals) had not had their degree of intellectual disability verified.
- Most of the demand in 2012 was for crisis or planned respite services (1,268 individuals, 61.8%), semi-independent and independent living arrangements (416 individuals, 20.2%), and occasional respite care with a host family (97 individuals, 4.7%).

Table 4.2 Future full-time residential service requirements of individuals receiving no residential service in 2012, by degree of intellectual disability

	No service – requires residential service				Receives residential support only – requires residential service				Receives day service – requires residential service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
5-day community group home	0	1	1	2	0	0	1	1	2	103	169	274	2	104	171	277
7-day (48-week) community group home	0	0	2	2	0	0	0	0	2	78	205	285	2	78	207	287
7-day (52-week) community group home	0	2	3	5	0	0	1	1	12	350	995	1357	12	352	999	1363
5-day residential centre	0	0	0	0	0	0	0	0	0	7	18	25	0	7	18	25
7-day (48-week) residential centre	0	0	0	0	0	1	0	1	0	10	38	48	0	11	38	49
7-day (52-week) residential centre	0	1	3	4	0	0	0	0	17	38	81	136	17	39	84	140
Nursing home	0	0	0	0	0	0	0	0	0	5	7	12	0	5	7	12
Mental health community residence	0	0	0	0	0	0	0	0	0	1	1	2	0	1	1	2
Intensive placement (challenging behaviour)	0	0	0	0	0	0	0	0	0	16	46	62	0	16	46	62
Intensive placement (profound or multiple disability)	0	0	0	0	0	0	0	0	1	1	52	54	1	1	52	54
All services	0	4	9	13	0	1	2	3	34	609	1612	2255	34	614	1623	2271

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 2012, by degree of intellectual disability

	No service – requires day service				Receives residential support only – requires day service				Receives residential service only – requires day service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Home support	0	3	5	8	0	0	0	0	0	0	0	0	0	3	5	8
Home help	0	1	0	1	0	0	0	0	0	0	1	1	0	1	1	2
Mainstream school	0	1	1	2	0	0	0	0	0	0	0	0	0	1	1	2
Resource teacher	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Special class – secondary	0	1	0	1	0	0	1	1	0	0	0	0	0	1	1	2
Special school	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	1
Third level education	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	1
Rehabilitative training	0	16	10	26	0	1	0	1	0	0	0	0	0	17	10	27
Activation centre	0	8	13	21	0	0	4	4	1	2	3	6	1	10	20	31
Programme for the older person	0	1	3	4	0	0	0	0	0	0	3	3	0	1	6	7
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	0	1	0	1	0	1
Sheltered work centre	0	8	9	17	0	1	1	2	0	2	1	3	0	11	11	22
Sheltered employment centre	0	4	1	5	0	0	0	0	0	0	0	0	0	4	1	5
Outreach programme	0	0	1	1	0	0	1	1	0	0	0	0	0	0	2	2
Other day service	0	5	2	7	0	0	0	0	0	0	1	1	0	5	3	8
Enclave within open employment	0	1	1	2	0	0	0	0	0	0	0	0	0	1	1	2
Supported employment	0	22	7	29	0	1	0	1	0	2	0	2	0	25	7	32
Open employment	1	7	0	8	0	0	0	0	0	0	0	0	1	7	0	8
Vocational training	0	26	6	32	0	0	0	0	0	1	0	1	0	27	6	33
Total	1	106	62	169	0	3	7	10	1	8	9	18	2	117	78	197

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.

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 service in 2012, by degree of intellectual disability

	No service – requires residential support				Receives day service – requires residential support				Receives residential service – requires residential support				Receives residential and day services – requires residential support				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Foster care and boarding-out	1	0	0	1	0	1	0	1	0	0	0	0	0	2	2	4	1	3	2	6
Living independently	0	2	0	2	1	42	4	47	0	1	0	1	0	7	1	8	1	52	5	58
Living semi-independently	0	9	2	11	10	214	40	264	0	0	0	0	0	47	36	83	10	270	78	358
Holiday residential placement	0	0	1	1	0	26	32	58	0	0	0	0	0	3	24	27	0	29	57	86
Crisis or planned respite	1	7	5	13	45	416	759	1220	0	0	0	0	0	10	25	35	46	433	789	1268
Occasional respite care with host family	0	2	1	3	7	37	44	88	0	0	0	0	1	2	3	6	8	41	48	97
Shared care or guardianship	0	0	0	0	0	3	8	11	0	0	0	0	0	0	5	5	0	3	13	16
Regular part-time care (2/3 days per week)	0	0	0	0	0	4	17	21	0	0	0	0	0	0	2	2	0	4	19	23
Regular part-time care (every weekend)	0	0	0	0	1	2	5	8	0	0	0	0	0	1	1	2	1	3	6	10
Regular part-time care (alternate weeks)	0	0	0	0	1	2	1	4	0	0	0	0	0	0	1	1	1	2	2	5
Other residential service	0	0	1	1	4	16	23	43	0	0	0	0	0	13	47	60	4	29	71	104
Overnight respite in the home	0	0	1	1	5	2	14	21	0	0	0	0	0	0	0	0	5	2	15	22
All services	2	20	11	33	74	765	947	1786	0	1	0	1	1	85	147	233	77	871	1105	2053

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.

Future need for centre-based respite services

As illustrated in Table 4.4, most of the demand for residential support services in 2012 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 2012, 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, 23.5% of those who were living at home or in an independent setting in 2012 received respite care, while 6.3% of the same group required respite care but did not receive it. Within the LHO areas the percentage receiving respite ranged from 14.3% in LHO Carlow/Kilkenny to 36.1% in LHO North Dublin. The percentage requiring respite ranged from 2.1% in LHO Clare and Tipperary South Riding to 11.2% in LHO Carlow/Kilkenny.

Table 4.5 Use of and requirement for respite services by people living in home/independent setting, by HSE region and LHO area of residence, 2012

	Number in receipt of crisis or planned respite in 2012		Number who do not receive respite but require it (2013–2017)		Number in home/independent setting in 2012
LHO area	n	%	n	%	n
HSE Dublin/Mid-Leinster Region	1271	25.9	274	5.6	4903
LHO Dublin South	124	30.9	16	4.0	401
LHO Dublin South East	63	26.4	7	2.9	239
LHO Dublin South City	90	32.0	19	6.8	281
LHO Dublin South West	211	31.5	35	5.2	670
LHO Dublin West	149	23.3	41	6.4	639
LHO Kildare/West Wicklow	228	23.1	51	5.2	989
LHO Wicklow	109	25.8	12	2.8	422
LHO Laois/Offaly	144	21.9	37	5.6	658
LHO Longford/Westmeath	153	25.3	56	9.3	604
HSE South Region	1131	20.4	354	6.4	5540
LHO Carlow/Kilkenny	111	14.3	87	11.2	777
LHO Tipperary SR	147	30.2	10	2.1	487
LHO Waterford	104	17.2	43	7.1	603
LHO Wexford	179	24.5	36	4.9	731
LHO Cork North Lee	147	15.6	45	4.8	941
LHO Cork South Lee	95	20.0	34	7.1	476
LHO North Cork	91	19.5	30	6.4	467
LHO West Cork	100	31.5	24	7.6	317
LHO Kerry	157	21.2	45	6.1	741

Table 4.5 Use of and requirement for respite services by people living in home/independent setting, by HSE region and LHO area of residence, 2012
(continued)

	Number in receipt of crisis or planned respite in 2012		Number who do not receive respite but require it (2013–2017)		Number in home/independent setting in 2012
LHO area	n	%	n	%	n
HSE West Region	1108	21.6	369	7.2	5125
LHO Limerick	131	14.6	70	7.8	896
LHO Tipperary NR	82	23.1	27	7.6	355
LHO Clare	95	24.6	8	2.1	386
LHO Galway	254	23.3	75	6.9	1089
LHO Mayo	162	21.9	70	9.4	741
LHO Roscommon	51	14.5	22	6.3	352
LHO Donegal	221	26.8	52	6.3	825
LHO Sligo/Leitrim/West Cavan	112	23.3	45	9.4	481
HSE Dublin/North-East Region	1063	27.1	235	6.0	3917
LHO Dublin North West	191	27.4	46	6.6	698
LHO Dublin North Central	102	27.5	22	5.9	371
LHO Dublin North	334	36.1	53	5.7	926
LHO Cavan/Monaghan	113	19.3	19	3.3	584
LHO Louth	149	22.6	21	3.2	658
LHO Meath	174	25.6	74	10.9	680
Out of state	1	50.0	1	50.0	2
All regions	4573	23.5	1233	6.3	19487

Note: The total number recorded as receiving respite in Table 4.5 (4,573 individuals) is less than that recorded in Table 3.4 (4,852 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.

Category B – Service change

The term 'service change' applies to the needs of those who already had an intellectual disability service in 2012 but who require that service to be changed or upgraded during the period 2013–2017, and includes children who availed of education services in 2012 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, for example moving from residential centres to community-based residential services;
- provision of more intensive care and specialist interventions; and
- changes to existing day services, for example, moving from education to training or from training to employment.

Not included in the 'service change' category in this report are people who only require a change to their multidisciplinary support services, (including services 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 11,884 people who were receiving services in 2012 will require a change to their existing service provision in the period 2013–2017, an increase of 60 (0.5%) since 2011. Of the 11,884 people who were recorded as requiring a service change:

- 8,356 (70.3%) were day attendees (of whom 820 also availed of residential support services).
- 2,711 (22.8%) were full-time residents (of whom 1,948 also availed of day services).
- 81 (6.9%) 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 7,450 (62.7%) of the service changes required.
- 3,455 (29.1%) of the service changes were required by people in the mild range.
- 979 (8.2%) 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 2013–2017, 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
Not verified	3	5	939	15	17	979
Mild	194	100	2802	194	165	3455
Moderate, severe or profound	1751	658	3795	611	635	7450
All levels	1948	763	7536	820	817	11884

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, 2013–2017

Residential	2711
Day	10304
Of which:	
Health services	6873
Education services	1467
Employment services	1322
Generic services	642
Residential support	1637
Total	14652

The number of places requiring change (14,652) exceeds the number of people who require service changes (11,884), because some people require changes to both their residential and their day services. In addition, it is important to note that although 11,884 people were recorded in 2012 as requiring service changes, this demand does not require the provision of 11,884 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 2012, 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 2,711 individuals in full-time residential services in 2012 will require an upgrading or change of accommodation within the next five years. This number comprises 1,051 individuals (38.8%) who require an enhancement of their existing service type, and 1,660 individuals (61.2%) who require the following changes of service type:

- Residential placements in the community are required by 990 individuals (36.5%).
- Intensive services for either challenging behaviour or profound or multiple disability are required by 504 individuals (18.6%).
- Centre-based placements are required by 135 individuals (5.0%).
- Nursing home placements are required by 31 individuals (1.1%).

Of the 1,051 individuals who require an enhancement of their existing service type:

- 344 individuals need their existing service upgraded to include care at weekends and holiday times.
- 18 individuals require less care and could return to their families at weekends and holiday times.
- 689 individuals need an enhancement of their existing service (darker shaded areas of Table 4.8).



Table 4.8 Pattern of movement of individuals from existing residential services to future residential services, 2013–2017

Full-time residential service in 2012	Full-time residential service required in the period 2013–2017										Total services 2012
	5-day CGH	7-day (48-wk) CGH	7-day (52-wk) CGH	5-day RC	7-day (48-wk) RC	7-day (52-wk) RC	Nursing home	Mental health community residence	Intensive placement (CB)	Intensive placement (P/MD)	
5-day community group home (CGH)	16	57	142	0	0	13	0	0	3	1	232
7-day (48-week) community group home	0	41	112	1	4	13	0	0	6	2	179
7-day (52-week) community group home	9	5	441	1	1	33	17	0	69	25	601
5-day residential centre (RC)	5	2	21	0	3	6	0	0	0	0	37
7-day (48-week) residential centre	2	53	55	1	13	24	0	0	14	5	167
7-day (52-week) residential centre	0	8	695	0	3	95	11	0	152	203	1167
Nursing home	0	1	16	0	0	3	8	0	1	3	32
Mental health community residence	0	0	1	0	0	0	0	1	0	0	2
Intensive placement (challenging behaviour) (CB)	1	1	28	1	0	57	3	0	37	10	138
Intensive placement (profound or multiple disability) (P/MD)	0	2	41	0	1	1	0	0	4	37	86
Occupying a residential support place	2	3	39	1	0	0	0	0	4	1	50
Other residential service	0	0	14	0	0	5	0	0	1	0	20
Total services required	35	173	1605	5	25	250	39	1	291	287	2711

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, 10,304 individuals will require a change, enhancement, or upgrading of their day service (Table 4.9).

- Health-funded services are required by 6,873 individuals (66.7%).
- Employment services are required by 1,322 individuals (12.8%).
- Education services are required by 1,467 individuals (14.2%).
- Generic services are required by 642 individuals (6.2%).

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

Health services

Of the 6,873 service changes required within health-funded services, 4,978 (72.4%) are requirements for an alternative or additional service and 1,895 (27.6%) 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:

- 874 individuals require activation programmes, the majority of whom currently receive multidisciplinary support services as their only day service (315 individuals), or attend special schools (178 individuals), or rehabilitative training (120 individuals).
- 780 individuals require high-support or intensive placements, the majority of whom currently attend activation programmes (328 individuals), or receive multidisciplinary support services as their only day service (191 individuals).
- 692 individuals require services specific to older people, the majority of whom currently attend activation programmes (322 individuals) or receive multidisciplinary support services as their only day service (156 individuals).
- 645 individuals require rehabilitative training, the majority of whom currently attend special schools (422 individuals).

There are also 1,895 individuals who need to have their existing health-funded service enhanced (grey shaded areas of Table 4.9). Most of these people are attending activation centres (1,031 individuals, 54.4%), programmes specific to older people (259 individuals, 13.7%) or sheltered work centres (254 individuals, 13.4%). 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 1,322 service changes required within employment services, 1,211 (91.6%) are requirements for an alternative placement and 111 (8.4%) are requirements for an enhancement of the individual's existing placement (Table 4.9).

Most of the demand for alternative employment opportunities comes from 1,102 individuals who require supported employment, the majority of whom currently attend sheltered work (377 individuals) or activation centres (284 individuals).

Education services

Of the 1,467 service changes required within education services, 982 (66.9%) are requirements for an alternative service and 485 (33.1%) 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:

- 315 children who require a mainstream school placement, the majority of whom currently attend a mainstream (127 children) or specialised (100 children) pre-school.
- 302 children who require special classes, mainly at secondary level. The majority of those requiring special classes at secondary level (194 children) currently attend special classes at primary level (112 children).
- 233 children who require a special school placement, the majority of whom currently attend special pre-schools (126 children).

There are 485 children who require their existing education placement to be enhanced (Table 4.9), the majority of who currently attend special schools (253 children). There is also a significant demand for increased support within existing education placements.

A large proportion of the 1,603 individuals who were attending special schools in 2012 require adult day services within the period 2013–2017. Of this group, over one quarter (422 individuals) require rehabilitative training, 292 (18.2%) require vocational training and 178 (11.1%) require activation programmes.

Generic services

Of the 642 service changes required within generic services, 613 (95.5%) are requirements for an alternative service and 29 (4.5%) are requirements for an enhancement of the individual's existing service (Table 4.9).

Most of the demand for alternative generic services comes from 584 individuals who require vocational training, the majority of whom currently attend special schools (292 individuals).

Seventeen individuals attending vocational training and 12 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, 2013–2017

	Day service required in the period 2013–2017																												
Day service in 2012	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	ALL	
Home support (HS)	24	0	12	27	0	3	0	2	1	1	0	7	9	6	2	5	5	0	0	3	1	2	0	7	1	3	0	121	
Home help (HH)	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	2	
Early services	9	0	135	73	0	18	0	13	0	11	0	0	0	0	0	0	0	0	0	0	0	5	0	0	0	0	0	264	
Mainstream pre-school (MPS)	9	0	12	11	0	127	3	14	1	18	0	0	0	0	0	0	0	0	3	1	0	5	0	0	0	0	0	204	
Special pre-school (SPS)	11	1	53	50	10	100	1	33	0	126	0	0	0	0	0	0	0	0	1	1	0	4	0	0	0	0	0	391	
Child education and development centre (CEDC)	9	0	0	0	2	0	0	0	0	2	0	0	40	0	0	0	0	0	1	0	0	0	0	0	0	1	0	55	
Mainstream school (MS)	84	3	5	1	0	197	67	16	62	35	20	19	5	0	0	1	0	0	47	0	14	47	0	1	2	40	1	667	
Resource teacher (RT)	5	0	2	0	0	11	10	1	3	0	0	8	0	0	0	0	0	0	0	0	1	0	0	0	0	13	0	54	
Special class – primary (SCP)	39	1	1	1	0	18	6	11	112	21	0	1	2	0	0	1	0	0	10	1	0	2	0	0	0	0	0	227	
Special class – secondary (SCS)	17	0	0	0	0	1	2	1	13	3	1	21	18	0	1	1	1	1	2	0	1	3	0	1	0	20	0	108	
Special school (SS)	137	4	2	3	4	19	4	22	13	253	1	422	178	0	27	28	78	12	33	4	2	50	0	10	2	292	3	1603	
Third-level education (TL)	1	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	0	1	3	0	5	2	6	0	21	
Rehabilitative training (RHT)	5	2	0	0	0	0	1	0	0	1	3	38	120	4	4	6	255	17	2	1	19	18	0	181	4	91	12	784	
Activation centre (AC)	50	6	0	0	0	0	2	0	0	0	1	77	1031	322	137	191	101	14	15	3	21	28	1	284	18	25	1	2328	
Programme for the older person (POP)	4	1	0	0	0	0	0	0	0	0	0	0	20	259	5	20	5	0	0	0	1	0	0	5	0	0	1	321	
Special high support day service (SHS)	3	0	0	0	0	0	0	0	0	0	0	11	38	18	110	94	8	1	2	0	18	13	0	6	0	0	0	322	
Special intensive day service (SI)	2	1	0	0	0	0	1	0	0	1	0	2	14	3	5	59	4	0	0	0	2	2	0	8	1	0	0	105	

Table 4.9 Pattern of movement of individuals from existing day services to future day services, 2013–2017 (*continued*)

Day service in 2012	Day service required in the period 2013–2017																											
	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	ALL
Sheltered work centre (SWC)	19	1	0	0	0	0	3	0	0	0	8	9	68	151	14	9	254	16	3	0	23	17	2	377	30	16	3	1023
Sheltered employment centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	4	1	0	0	0	0	0	8	1	2	0	18
Multidisciplinary support services	14	6	1	1	0	3	1	1	0	7	1	39	315	156	58	133	27	5	4	0	2	14	1	58	16	62	2	927
Centre-based day respite service (CDR)	0	0	0	0	0	0	0	0	0	1	0	1	2	0	0	0	0	0	0	0	0	0	0	0	0	1	0	5
Day respite in the home (DRH)	0	0	0	2	0	1	0	0	0	0	0	0	2	0	0	1	0	0	0	0	0	0	0	1	0	0	0	7
Outreach programme (OP)	0	0	1	0	0	0	0	0	0	0	0	0	3	2	2	5	2	0	0	0	38	2	0	8	0	1	0	64
Other day service (OTH)	9	3	3	10	0	13	1	5	2	6	1	11	24	20	6	11	71	0	0	0	2	17	0	32	4	5	0	256
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)	7	0	0	0	0	0	0	0	0	0	0	1	5	4	1	0	6	3	1	0	7	1	1	106	14	2	4	163
Open employment (OE)	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	4	1	0	9	5	2	0	24
Vocational training (VT)	1	0	0	0	0	0	1	0	0	0	3	12	5	2	0	1	18	7	0	0	0	0	2	55	4	17	2	130
Generic day services (GD)	8	1	0	0	0	1	0	0	0	0	0	2	6	4	6	3	5	1	0	0	7	3	3	44	0	2	12	108
Total	467	32	227	179	16	512	103	119	207	486	40	683	1905	951	380	569	845	80	124	14	164	237	10	1208	104	601	41	10304

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 colour-shaded columns represent the four types of day service captured on the NIDD:

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

Residential support service change

The data indicate that 1,637 individuals receiving residential support services will require an additional or alternative residential support service in the period 2013–2017, or will require their existing support service to be upgraded (Table 4.10). Additional or alternative support services are required by 401 individuals (24.6%), and 1,236 individuals (75.5%) require their existing service to be upgraded (shaded areas of Table 4.10).

The principal residential support service changes or enhancements required include:

- More frequent centre-based crisis or planned respite breaks for people already availing of this service (1,169 individuals).
- Opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (81 individuals).
- Occasional holiday residential placements and occasional respite care with a host family for people currently availing of crisis or planned respite (53 individuals).

It is important to note that, as is the case with certain types of day service, the provision of a new residential support service to an individual may not release a residential support place for use by another person because the new service may be provided to the individual *in addition* to the existing one.



Table 4.10 Additional residential support services required by people availing of residential support services in 2012

Residential support service required 2013–2017													
Residential support service in 2012	Foster care & boarding-out	Living independently	Living semi-independently	Holiday residential placement	Crisis or planned respite	Occasional respite care (host family)	Shared care/guardianship	Regular part-time care (2/3 days per week)	Regular part-time care (every weekend)	Regular part-time care (alternate weeks)	Overnight respite in the home	Other residential service	Total
Foster care and boarding-out	7	1	5	1	10	2	0	2	0	0	0	1	29
Living semi-independently	0	11	24	3	5	0	0	0	0	0	0	1	44
Holiday residential placement	0	0	2	0	1	0	0	1	0	1	2	1	8
Crisis or planned respite	1	3	81	10	1169	43	18	53	14	19	6	16	1433
Occasional respite care (host family)	0	2	5	3	38	30	2	3	0	1	1	1	86
Shared care or guardianship	0	0	0	0	3	0	0	0	0	0	0	0	3
Regular part-time care (2/3 days per week)	0	0	4	0	6	0	2	1	1	0	0	0	14
Regular part-time care (every weekend)	0	0	0	0	1	0	0	0	0	0	0	0	1
Regular part-time care (alternate weeks)	0	0	1	1	3	0	0	0	0	2	0	0	7
Overnight respite in the home	0	0	0	0	1	0	0	0	0	0	2	1	4
Other residential service	0	0	0	0	7	0	0	0	0	0	0	1	8
All services	8	17	122	18	1244	75	22	60	15	23	11	22	1637

Day service requirements of school leavers

Each year 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 individuals aged 11 years or older who were in an education setting in 2012 and who will require an adult day service within the next five years (2013–2017).

One thousand five hundred individuals (aged 11–19 years) with an intellectual disability who were in an education setting in 2012 will require a range of day services within the period 2013–2017 (Table 4.11). Most of the demand is for rehabilitative training (470 places) or vocational training (365 places).

Of the 1,500 individuals who will require a day service (Table 4.12):

- 762 individuals (50.8%) had a mild intellectual disability, of whom 299 require vocational training and 269 require rehabilitative training.
- 716 individuals (47.7%) had a moderate, severe or profound level of intellectual disability, of whom 200 require rehabilitative training and 161 require activation programmes.
- 22 individuals (1.5%) had not had their level of intellectual disability verified, of whom 11 require third-level education.

Table 4.13 identifies the year in which the day services are required. Two thirds of the day service requirements are immediate: 1,014 individuals (67.6%) require their day service in 2013 or 2014.



Table 4.11 Future day service requirements of individuals aged 11 to 19 years who were in an education setting in 2012, by age group

	11–15 years	16–19 years	Total
Home support	112	28	140
Home help	1	0	1
Third-level education	4	18	22
Rehabilitative training	182	288	470
Activation centre	92	110	202
Special high-support day service	12	15	27
Special intensive day service	12	19	31
Sheltered work centre	21	58	79
Sheltered employment centre	4	9	13
Centre-based day respite service	27	14	41
Day respite in the home	2	0	2
Outreach programme	13	4	17
Other day service	39	31	70
Supported employment	5	7	12
Open employment	2	2	4
Vocational training	98	267	365
Generic day services	4	0	4
Total	630	870	1500

Table 4.12 Future day service requirements of individuals aged 11 to 19 years who were in an education setting in 2012, by degree of intellectual disability

	Not verified	Mild	Moderate/Severe/Profound	Total
Home support	4	45	91	140
Home help	0	0	1	1
Third-level education	11	8	3	22
Rehabilitative training	1	269	200	470
Activation centre	1	40	161	202
Special high-support day service	1	0	26	27
Special intensive day service	0	7	24	31
Sheltered work centre	0	33	46	79
Sheltered employment centre	1	6	6	13
Centre-based day respite service	0	14	27	41
Day respite in the home	0	0	2	2
Outreach programme	0	10	7	17
Other day service	3	22	45	70
Supported employment	0	4	8	12
Open employment	0	3	1	4
Vocational training	0	299	66	365
Generic day services	0	2	2	4
Total	22	762	716	1500

Table 4.13 Future day service requirements of individuals aged 11 to 19 years who were in an education setting in 2012, by year of requirement

	2013	2014	2015	2016	2017	Total
Home support	139	1	0	0	0	140
Home help	1	0	0	0	0	1
Third-level education	10	6	2	4	0	22
Rehabilitative training	180	99	72	73	46	470
Activation centre	65	39	40	40	18	202
Special high-support day service	12	5	6	3	1	27
Special intensive day service	14	5	4	4	4	31
Sheltered work centre	31	20	20	5	3	79
Sheltered employment centre	6	3	2	2	0	13
Centre-based day respite service	39	2	0	0	0	41
Day respite in the home	2	0	0	0	0	2
Outreach programme	17	0	0	0	0	17
Other day service	52	7	3	4	4	70
Supported employment	3	4	1	4	0	12
Open employment	2	0	0	1	1	4
Vocational training	157	91	53	47	17	365
Generic day services	2	0	0	2	0	4
Total	732	282	203	189	94	1500

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

The data from the NIDD for 2012 identified 192 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. Of this group, 127 individuals (66.1%) were recorded as having service requirements in the period 2013–2017, of whom:

- 109 individuals had an appropriate alternative residential facility identified for them (Table 4.16). Thirty-seven of these individuals also required a day service (Table 4.17). In recent years there has been a revised approach to 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.
- 16 individuals were recorded as appropriately placed in a psychiatric hospital but had identified day service requirements, as shown in Table 4.15.



Table 4.14 Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2012, by HSE region of registration

No service requirements					Has service requirements				
Resident in psychiatric hospital in 2012	Not verified	Mild	Moderate/Severe/ Profound	All levels	Not verified	Mild	Moderate/Severe/ Profound	All levels	Total
Dublin/Mid-Leinster									
With no day programme	0	0	1	1	0	0	0	0	1
With day programme	0	1	2	3	0	3	0	3	6
South									
With no day programme	0	0	1	1	0	0	1	1	2
With day programme	0	7	10	17	0	12	18	30	47
West									
With no day programme	0	0	0	0	0	0	0	0	0
With day programme	0	3	2	5	0	1	3	4	9
Dublin/North-East									
With no day programme	0	0	0	0	0	0	0	0	0
With day programme	0	11	27	38	0	23	66	89	127
All residents	0	22	43	65	0	39	88	127	192

Table 4.15 Day service requirements of people appropriately accommodated in psychiatric hospitals in 2012

Services required 2013–2017						
Day service in 2012	Activation centre	Special high-support day service	Sheltered work centre	Supported employment	Other day service	All services
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	1	1	0	1	10
All services	8	3	2	2	1	16

Note: Six of the 16 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.

Of the 109 people who were recorded in 2012 as needing to transfer from psychiatric to intellectual disability services for provision of their residential services, 40 individuals (36.7%) required places in community group homes, 36 individuals (33.0%) required places in residential centres and 33 individuals (30.3%) required intensive placements. In all cases the need was immediate (Table 4.16).

Table 4.16 Residential service requirements of people resident in psychiatric hospitals in 2012 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	38
7-day (48-week) residential centre	1
7-day (52-week) residential centre	35
Intensive placement (challenging behaviour)	23
Intensive placement (profound/multiple disability)	10
All residential services	109

Of this same group of 109 people, 37 required an appropriate day service (Table 4.17). The greatest demand was for high-support or intensive day programmes (21 individuals, 56.8%), activation programmes (6 individuals, 16.2%) and programmes for the older person (6 individuals, 16.2%). All day services were required immediately.

Table 4.17 Day service requirements of people resident in psychiatric hospitals in 2012 who require transfer to the intellectual disability sector

	Number requiring day service
Rehabilitative training	1
Activation centre	6
Programme for the older person	6
Special high-support day service	14
Special intensive day service	7
Sheltered employment centre	1
Generic day services	2
All day services	37

Note: Eight of the 37 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.

The 2012 data indicate that the current day and residential programmes for 65 people with intellectual disability resident in psychiatric hospitals were appropriate and that these people had no identified service needs in the period 2013–2017 (Table 4.14). Forty-three of this group (66.2%) had a moderate, severe, or profound intellectual disability and the remaining 22 (33.8%) had a mild disability. Within the group, two individuals had no formal day programme.

Category D – Multidisciplinary support services

As noted earlier, although the NIDD facilitates the recording of two future day services that will be required by an individual, the previous sections of this chapter detail only the first future day service in each case 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 are 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 2012, and an 'enhancement' refers to a change in the delivery of a therapeutic input that the individual received in 2012 (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 2012 with the demand for services in the period 2013–2017.

In 2012 multidisciplinary support services were availed of by 23,350 people, 17,658 of whom had further requirements for such services. A further 2,287 individuals who did not access such services in 2012 require them. There are, therefore, 19,945 (17,658 plus 2,287) individuals with a need for multidisciplinary support services. These needs involve either the enhancement of a service received in 2012 (3,489 individuals), a requirement for a new type of service (8,187 individuals), or a combination of both (8,269 individuals). Of the 19,945 people with future multidisciplinary support service needs, 133 received no service whatsoever in 2012.⁵ Ninety-nine per cent of those in need of multidisciplinary support services require them immediately.

Despite high levels of service provision in 2012, 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, 8,974 individuals received a psychology service in 2012, 3,994 of whom needed an enhancement of their service, and a further 6,710 individuals who did not receive a psychology service in 2012 require one in the period 2013–2017.

The data show that there was a significant shortfall in the provision of dietetics services; this was the only therapeutic input where the demand for a new service exceeded service provision in 2012. The number of individuals who were in receipt of a dietetics service in 2012 was 3,820, but 4,310 individuals who were not in receipt of this service required it in the immediate future.

⁵ 91 of the 133 also have other future service requirements that are included in the 'unmet need' section at the beginning of this chapter.



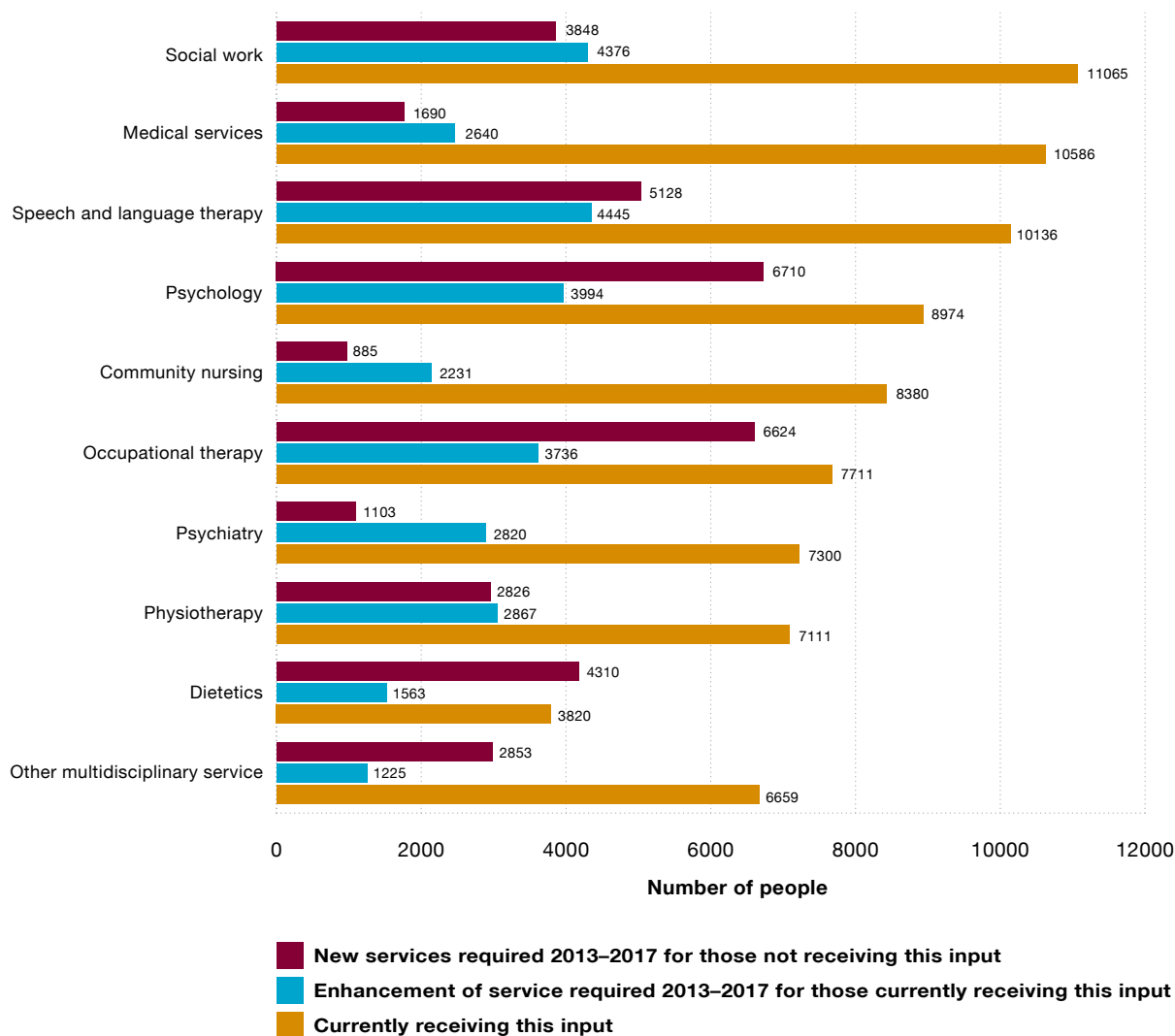


Figure 4.2 Multidisciplinary support services received in 2012, and required in the period 2013-2017

Overall service provision to people with intellectual disability and the pattern of care required in the period 2013-2017

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 2012 data indicate that there were large numbers of people who required residential services for the first time in 2012 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 implemented 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 2013–2017 comes from three distinct groups already identified in this chapter:

- 2,271 individuals who lived at home in 2012 and who were recorded as requiring full-time residential services for the first time in 2012;
- 109 individuals who resided in psychiatric hospitals in 2012 and who were recorded as requiring to transfer to the intellectual disability services; and
- 2,711 individuals who were in full-time residential services within the intellectual disability sector in 2012 and who require changes to their existing placement. Of this group, 1,660 require alternative services and 1,051 require their existing service to be enhanced. Not all of the group who require service enhancements will move to new placements. However, the needs of these individuals 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 service place may become available to another individual identified as requiring the service.

Table 4.18 outlines the pattern of full-time residential service provision that will be required in the period 2013–2017 to meet this demand. A total of 2,430 residential places will be required, an increase of 10 over the 2011 figure.

- 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 those in existing residential placements. In total, 2,768 community-based placements will be required during the period, a decrease of 60 placements (2.1%) on the shortfall recorded in 2011.
- There will also be a shortfall of 503 intensive residential placements, a decrease of 41 placements (7.5%) on the shortfall recorded in 2011. 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, 2013–2017

	New services required by people without residential service	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	277	0	35	232	-80
7-day (48-week) community group home	287	2	173	179	-283
7-day (52-week) community group home	1363	38	1605	601	-2405
5-day residential centre	25	0	5	37	7
7-day (48-week) residential centre	49	1	25	167	92
7-day (52-week) residential centre	140	35	250	1167	742
Nursing home	12	0	39	32	-19
Mental health community residence	2	0	1	2	-1
Psychiatric hospital	0	0	0	0	0
Intensive placement (challenging behaviour)	62	23	291	138	-238
Intensive placement (profound or multiple disability)	54	10	287	86	-265
Other/unspecified intellectual disability service	0	0	0	20	20
Designated residential support placement	0	0	0	(50)*	0
Total	2271	109	2711	2661	-2430

*50 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:

- 197 individuals who were without day services in 2012;
- 37 individuals who were resident in psychiatric hospitals in 2012 and who will require an appropriate day service when they transfer to intellectual disability services;
- 16 individuals appropriately placed in psychiatric hospitals in 2012 who will require a day programme within that setting between 2013 and 2017; and
- 10,304 individuals who were in day services within the intellectual disability sector in 2012 and who will require changes to, or enhancements of, their placement. Of this group, 7,784 require alternative or additional services and 2,520 require their service to be enhanced. The majority (6,873) 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 needs of the entire group have 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 released service place may become available to another individual identified as requiring the 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 released 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 services⁶ are reported and interpreted on the assumption that:

- (a) where a service of this type already exists, it will be retained by the individual, even when another service is put in place, or
- (b) where a service of this type 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 2013–2017 to meet demand. The data in the table have been adjusted to reflect the fact that not all existing service places will be released.

A total of 1,630 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 2013–2017 will be as follows:

- A reduction of 3% in the number of places available to children requiring places in special schools.
- A shortfall in training and employment opportunities is likely. In the next five years, 1,079 supported employment opportunities, 504 vocational training placements, and 88 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; 643 such places will be needed over the next five years in addition to current provision.
- As is the case with residential services, there is significant demand for high-support and intensive day placements. Over the next five years, 77 high-support day placements and 472 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.

⁶ 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, 2013–2017

	New services required by people without day services	New services required by people transferring from psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Shortfall (-)/ Excess of places arising from demand
Home support	8	0	0	467	0	-475
Home help	2	0	0	32	0	-34
Mainstream pre-school	0	0	0	227	204	-23
Special pre-school	0	0	0	179	391	212
Child education and development centre	0	0	0	16	55	39
Mainstream school	2	0	0	512	667	153
Resource/visiting teacher	1	0	0	103	0	-104
Special class – primary	0	0	0	119	227	108
Special class – secondary	2	0	0	207	108	-101
Special school	1	0	0	486	1603	1116
Third-level education	1	0	0	40	21	-20
Rehabilitative training	27	1	0	683	784	73
Activation centre	31	6	8	1905	2328	378
Programme for the older person	7	6	0	951	321	-643
Special high-support day service	2	14	3	380	322	-77
Special intensive day service	1	7	0	569	105	-472
Sheltered work centre	22	0	2	845	1023	154

Table 4.19 Pattern of day service provision required, 2013–2017 (*continued*)

	New services required by people without day services	New services required by people transferring from psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Shortfall (-)/ Excess of places arising from demand
Sheltered employment centre	5	1	0	80	18	-68
Centre-based day respite service	0	0	0	124	0	-124
Day respite in the home	0	0	0	14	0	-14
Other day service	8	0	1	237	256	10
Outreach programme	2	0	0	164	64	-102
Enclave within open employment	2	0	0	10	2	-10
Supported employment	32	0	2	1208	163	-1079
Open employment	8	0	0	104	24	-88
Vocational training	33	0	0	601	130	-504
Generic day services	0	2	0	41	108	65
All services	197	37	16	10304	8924	-1630

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 27,500 individuals registered on the database at the end of December 2012, 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 1996–2012 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.

The 2011 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. The rising numbers in both these age groups will place further demands on service provision for people with an 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 number of health service interventions that young people 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 towards community living provision; for the ninth 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 2012, albeit with varying degrees of coverage across the country. The report highlights the fact that the changing age profile of individuals with intellectual disability continues to contribute to high levels of demand for residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability.

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 2012 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 most commonly availed of by children. This pattern of multidisciplinary support usage is similar to that indicated by 2011 data. Despite the high levels of service provision in 2012, there remains a substantial demand in the five-year period 2013–2017 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 remain high levels of unmet need among a critical number of individuals who are registered on the NIDD. Although the data in recent years highlight a 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. 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:

National Intellectual Disability Database Data Form



National Intellectual Disability Database Data Form

PERSONAL DETAILS

1. Surname _____
2. First name _____
3. Previous surname _____
4. Address _____
5. Address _____
6. Address _____
7. City / Town _____
- 7a. Phone _____
- 7b. School Roll Number (if applicable) |_|_|_|_|_|_|_|_|_|_|
8. Address (County) _____ |_|_|
9. Date of birth |_|_| - |_|_| - |_|_|_|_|
10. Year of birth (where DOB is unknown) |_|_|_|_|
11. Health Service Executive area of residence |_|_|
12. Local Health Office of residence |_|_|
13. DED |_|_| |_|_|_|
- 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	0	<input type="text"/>	0	0	<input type="text"/>
Nursing	0	<input type="text"/>	0	0	<input type="text"/>
Nutrition	0	<input type="text"/>	0	0	<input type="text"/>
Occupational therapy	0	<input type="text"/>	0	0	<input type="text"/>
Physiotherapy	0	<input type="text"/>	0	0	<input type="text"/>
Psychiatry	0	<input type="text"/>	0	0	<input type="text"/>
Psychology	0	<input type="text"/>	0	0	<input type="text"/>
Social work	0	<input type="text"/>	0	0	<input type="text"/>
Speech & language therapy	0	<input type="text"/>	0	0	<input type="text"/>
Other	0	<input type="text"/>	0	0	<input type="text"/>

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)
- Z: NOT APPLICABLE

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 and the Health Research Board.

Appendix B:

Service categories

Day programmes

- Home support (assistance provided to the family in terms of care or facilitating attendance at a social activity)
- Special pre-school for intellectual disability
- Mainstream school (includes mainstream pre-, primary and secondary schools)
- Special class – primary level
- Special class – secondary level
- Special school
- Child education and development centre (programme for children with severe or profound intellectual disability)
- Vocational training (e.g. FAS, VEC, CERT, NTDI)
- Rehabilitative training
- Activation centre/adult day centre (day centre for adults who need ongoing care, training and development)
- Programme for the older person
- Special high-support day service (e.g. relating to challenging behaviour) less than 1:1 staff ratio
- Special intensive day service (e.g. relating to challenging behaviour) 1:1 staff ratio contact or greater
- Sheltered work centre – may include long-term training schemes
- Sheltered employment centre (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 age children or adults



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

Residential circumstances

- At home, with both parents
- At home, with one parent
- At home, with sibling
- At home, with relative
- 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, by degree of intellectual disability and by age group, 2012

	Not verified					Mild					Moderate/Severe/Profound					All levels				
Residential circumstances	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages
Home setting	2199	41	45	19	2304	3623	1759	1171	253	6806	4172	2856	1850	342	9220	9994	4656	3066	614	18330
At home with both parents	1847	30	14	3	1894	2603	1219	510	15	4347	3223	2086	805	18	6132	7673	3335	1329	36	12373
At home with one parent	326	9	22	1	358	842	452	461	69	1824	857	687	680	56	2280	2025	1148	1163	126	4462
At home with sibling	0	2	7	13	22	5	14	153	139	311	3	35	325	239	602	8	51	485	391	935
At home with other relative	8	0	0	2	10	37	24	31	22	114	16	13	26	21	76	61	37	57	45	200
Lives with non-relative	0	0	1	0	1	2	6	8	2	18	1	2	4	3	10	3	8	13	5	29
Adoption	0	0	0	0	0	3	6	0	0	9	7	0	2	0	9	10	6	2	0	18
Foster care and boarding out arrangements	18	0	1	0	19	131	38	8	6	183	65	33	8	5	111	214	71	17	11	313
Independent/Semi-independent setting	0	7	30	15	52	3	182	480	229	894	0	34	101	76	211	3	223	611	320	1157
Living independently	0	5	17	15	37	2	123	292	163	580	0	16	56	43	115	2	144	365	221	732
Living semi-independently	0	2	13	0	15	1	59	188	66	314	0	18	45	33	96	1	79	246	99	425
Community group home	0	3	8	8	19	29	133	443	328	933	84	527	1790	873	3274	113	663	2241	1209	4226
5 day community group home	0	2	1	2	5	18	20	50	12	100	11	83	205	22	321	29	105	256	36	426
7 day community group home	0	0	0	0	0	2	18	64	25	109	11	62	277	64	414	13	80	341	89	523
7 day (52 week) community group home	0	1	7	6	14	9	95	329	291	724	62	382	1308	787	2539	71	478	1644	1084	3277

Table C1 Details of main residential circumstances, by degree of intellectual disability and by age group, 2012 (*continued*)

	Not verified					Mild					Moderate/Severe/Profound					All levels				
Residential circumstances	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 centre	1	0	1	0	2	2	24	78	128	232	38	292	1106	891	2327	41	316	1185	1019	2561
5 day residential centre	1	0	0	0	1	0	3	3	1	7	3	13	28	5	49	4	16	31	6	57
7 day residential centre	0	0	0	0	0	0	4	11	11	26	8	73	114	58	253	8	77	125	69	279
7 day (52 week) residential centre	0	0	1	0	1	2	17	64	116	199	27	206	964	828	2025	29	223	1029	944	2225
Other full-time service	4	0	3	6	13	8	54	86	98	246	49	260	476	267	1052	61	314	565	371	1311
Nursing home	0	0	2	6	8	0	1	5	39	45	0	2	24	76	102	0	3	31	121	155
Mental health community residence	0	0	0	0	0	1	3	10	12	26	0	0	5	21	26	1	3	15	33	52
Psychiatric hospital	0	0	0	0	0	0	5	24	32	61	0	7	48	76	131	0	12	72	108	192
Intensive placement (challenging behaviour)	0	0	0	0	0	2	23	32	6	63	15	154	219	45	433	17	177	251	51	496
Intensive placement (profound or multiple handicap)	1	0	0	0	1	0	2	2	1	5	13	65	135	29	242	14	67	137	30	248
Full time 'other' residential service	2	0	0	0	2	4	15	10	6	35	10	10	24	15	59	16	25	34	21	96
Full time resident in residential support place	1	0	1	0	2	1	5	3	2	11	11	22	21	5	59	13	27	25	7	72
No fixed abode	0	0	0	0	0	1	5	2	2	10	0	0	1	2	3	1	5	3	4	13
Insufficient information	3	0	0	0	3	2	2	1	0	5	3	7	5	1	16	8	9	6	1	24
	2207	51	87	48	2393	3668	2159	2261	1038	9126	4346	3976	5329	2452	16103	10221	6186	7677	3538	27622

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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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.

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