



# HRB Statistics Series 13

Annual Report of the National Intellectual Disability  
Database Committee 2010

Fionnola Kelly and Caraíosa Kelly



**Rita McAuley**

National Intellectual Disability Database Committee Annual Report 2010 cover design competition winner.

Rita is a service member of the Sonas programme in Malta Services Drogheda and has been attending the service for the past thirty years. Rita enjoys art, pottery, literacy and numeracy and going out for meals and outings with her friends. Rita painted her winning picture at her weekly art class in the James Carroll Centre, Donore Road, Drogheda. Her picture was painted in poster paints using a brush and sponge.



*'I'm Here!'*  
by Rita McAuley

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Intellectual Disability Database  
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# About the HRB

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

## Our information systems

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

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

- Activities of Irish Psychiatric Units and Hospitals (1965–2010)
- National Physical and Sensory Disability Database Committee Annual Reports (2004–2009)
- National Intellectual Disability Database Committee Annual Reports (1996–2009)

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



## **Statistics Series publications to date**

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

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

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

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

Daly A, Walsh D and Moran R (2009) *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 C, Kelly F 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) *National Physical and Sensory Disability Database Committee Annual Report 2008*. HRB Statistics Series 10. Dublin: Health Research Board.

O'Donovan MA, Doyle A and Craig S (2010) *National Physical and Sensory Disability Database Committee Annual Report 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.



# Table of contents

Acknowledgements	9
Members of the National Intellectual Disability Database Committee 2010	10
Chairperson's statement	11
Executive summary	12
1. The National Intellectual Disability Database	15
2. Profile of the population	19
3. Service provision in 2010	28
4. Assessment of need 2011–2015	45
5. Conclusion	78
References	80
Appendix A	81
2010 National Intellectual Disability Database form	81
Appendix B: Service categories	85
Day programmes	85
Residential circumstances	86
Day service groupings	87
Appendix C	88
Supplementary table	88
Appendix D	90
National Intellectual Disability Database publications	90



# List of tables and figures

## Tables

<b>Table 2.1</b>	Number of people registered on the NIDD, by age, gender and degree of intellectual disability, 2010	20
<b>Table 2.2</b>	Prevalence of intellectual disability, by degree (moderate, severe and profound) and by age group, 1974, 1981, 1996, 2010	23
<b>Table 2.3</b>	Number of people registered on the NIDD, by HSE region, 2010	25
<b>Table 2.4</b>	Number of people registered on the NIDD with a physical and/or sensory disability, by gender, 2010	27
<b>Table 3.1</b>	Overall service provision to those registered on the NIDD, 2010	29
<b>Table 3.2</b>	Main residential circumstances, by degree of intellectual disability and by age group, 2010	32
<b>Table 3.3</b>	Main residential circumstances and overall level of residential service provision, 2010	33
<b>Table 3.4</b>	Use of respite nights, by HSE region and by LHO area of residence, 2010	36
<b>Table 3.5</b>	Residential status of people availing of day services, by degree of intellectual disability and by age group, 2010	37
<b>Table 3.6</b>	Principal day service availed of, by degree of intellectual disability and by age group, 2010	39
<b>Table 3.7</b>	Principal day service and overall level of day service provision, by age group, 2010	41
<b>Table 3.8</b>	Overall provision of multidisciplinary support services, by age and access to an early intervention team (EIT), 2010	43
<b>Table 3.9</b>	Service provision by HSE region of registration, 2010	44
<b>Table 4.1</b>	Number of new places required to meet need 2011–2015, by HSE region of registration, 2010	47
<b>Table 4.2</b>	Future full-time residential service requirements of individuals receiving no residential service in 2010, by degree of intellectual disability	49
<b>Table 4.3</b>	Future day service requirements of individuals receiving no day service in 2010, by degree of intellectual disability	50
<b>Table 4.4</b>	Future residential support service requirements of individuals receiving no residential support services in 2010, by degree of intellectual disability	51
<b>Table 4.5</b>	Use of and requirements for respite by people living in home/independent setting, by HSE region and LHO area, 2010	53





<b>Table 4.6</b>	Category of service change required 2011–2015, by degree of intellectual disability	55
<b>Table 4.7</b>	Number of places requiring change, 2011–2015	55
<b>Table 4.8</b>	Pattern of movement of individuals from existing residential services to future residential services, 2011–2015	57
<b>Table 4.9</b>	Pattern of movement of individuals from existing day services to future day services, 2011–2015	61
<b>Table 4.10</b>	Additional residential support services required by people availing of residential support services in 2010	64
<b>Table 4.11</b>	Future day service requirements of individuals aged 16 years or over who were in an education setting in 2010, by age	66
<b>Table 4.12</b>	Future day service requirements of individuals aged 16 years or over who were in an education setting in 2010, by degree of intellectual disability	66
<b>Table 4.13</b>	Future day service requirements of individuals aged 16 years or over who were in an education setting in 2010, by year of service requirement	67
<b>Table 4.14</b>	Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2010, by HSE region of registration	68
<b>Table 4.15</b>	Day service requirements of people appropriately accommodated in psychiatric hospitals in 2010	69
<b>Table 4.16</b>	Residential service requirements of people resident in psychiatric hospitals in 2010 who require transfer to the intellectual disability sector	69
<b>Table 4.17</b>	Day service requirements of people resident in psychiatric hospitals in 2010 who require transfer to the intellectual disability sector	70
<b>Table 4.18</b>	Pattern of full-time residential service provision required, 2011–2015	74
<b>Table 4.19</b>	Pattern of day service provision required, 2011–2015	77
<b>Table C1</b>	Details of main residential circumstances, degree of intellectual disability and age group	88

## Figures

<b>Figure 2.1</b>	Profile of the population registered on the NIDD, 2010	19
<b>Figure 2.2</b>	Individuals registered on the NIDD, by degree of intellectual disability and by age group, 2010	21
<b>Figure 2.3</b>	Proportion of people with moderate, severe or profound intellectual disability (combined), by age group: 1974–2010	24
<b>Figure 2.4</b>	Prevalence of NIDD registrations per 1,000 of the general population, by HSE LHO area of residence, 2010	26
<b>Figure 3.1</b>	Summary of service provision, by age group, 2010	28
<b>Figure 3.2</b>	Number of people in receipt of respite nights and median number of respite nights received, by degree of intellectual disability, 2010	34
<b>Figure 3.3</b>	Total number and median number of respite nights received, by HSE region of residence, 2010	35
<b>Figure 4.1</b>	Summary of the service requirements of those registered on the NIDD, 2010	46
<b>Figure 4.2</b>	Multidisciplinary support services received in 2010 and required in the period 2011–2015	72

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- the parents and families of people with an intellectual disability and their representative bodies; and
- all those in intellectual disability services throughout Ireland.

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# Chairperson's statement

I am pleased to introduce the 2010 Annual Report of the National Intellectual Disability Database (NIDD). The database has almost 26,500 registrations and this year the focus continues on areas that have particular relevance to service planners and providers, namely: the transition from youth to adulthood and the service needs required as a result, and the growing provision and demand for respite services to support people with intellectual disability and their families to remain at home.

This year we will spend in the region of €1.5bn of taxpayers' money on specialist health services for people with a disability, approximately 10% of the health budget. While the government has initiated a comprehensive spending review across all departments, the disability sector is already the subject of a detailed value for money (VFM) and policy review. The review will assess how well current services for people with disabilities are meeting their objectives. The evaluation will also explore the way forward for services. I expect that the review will be completed by the end of 2011. The data in this report have proved extremely useful for the work of the VFM review.

This year's report, similar to those in previous years, identifies trends in the data that have been discernible in the last number of years. These trends include increased provision of services, an increase in the reported needs of people with an intellectual disability, the move to community group homes, the move from psychiatric hospitals, and greater numbers of individuals surviving into old age. All of these trends have implications for the planning and provision of services into the future.

In this context, an Expert Reference Group on Disability Policy was established to look specifically at existing disability policy, and to propose how it might better meet the expectations and objectives of people with disabilities. People with disabilities and their families are looking, above all, for more choice in the services they receive and more control over how they access them. The government published a summary of the proposals emerging from the Expert Reference Group in December 2010. The report proposes a very significant reframing of disability services towards a model of individualised supports, underpinned by mainstreaming of all public services.

I would like to thank the NIDD Committee members for all their work on the report and their ongoing input into the National Committee. I would like to add a particular thanks to those working in the Disability Databases Team at the HRB for their efforts in preparing and completing this report on behalf of the Committee.

**Colm Desmond**

Chairperson

National Intellectual Disability Database Committee

# Executive summary

## Demographic profile

There were 26,484 people registered on the National Intellectual Disability Database (NIDD) in December 2010, representing a prevalence rate of 6.25 per 1,000 population. The prevalence rate for mild intellectual disability was 2.09 per 1,000 and the prevalence rate for moderate, severe or profound intellectual disability was 3.69 per 1,000. There were more males than females at all levels of intellectual disability, with an overall ratio of 1.32 to 1. The total number with moderate, severe or profound intellectual disability has increased by 39% 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. Of the people with moderate, severe or profound intellectual disability, the proportion who were aged 35 years or over increased from 29% in 1974 to 38% in 1996, and to 49% in 2010. This reflects an increase in the lifespan of people with intellectual disability. This changing age profile observed in the data over the past three decades gives rise to an ongoing high level of demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability. This helps to explain the ongoing demand for additional resources for people with intellectual disability.

## Service provision in 2010

The numbers registered on the NIDD in December 2010 were as follows:

- 25,936 people with intellectual disability who were in receipt of services, representing 98% of the total population registered on the NIDD. This was the highest number of people in receipt of services since the database was established.
- 287 people (1% of those registered) who were without services in 2010 and who were identified as requiring appropriate services in the period 2011–2015.
- 261 people (1%) who were not availing of services and had no identified requirement for services during the planning period 2011–2015.

Of the 25,936 people who were in receipt of services in 2010:

- 8,213 (31.2%) were in receipt of full-time residential services, a decrease of 38 since 2009. This is the seventh 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 39 (14.1%), from 277 in 2009 to 238 in 2010.
- 25,857 (99.7%) people availed of at least one day programme in 2010. This is the highest rate of day service usage since NIDD data were first reported in 1996. Of this group, 8,152 were in full-time residential placements.
- 21,803 (84.1%) 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-five per cent of those registered on the NIDD (17,112 individuals) lived at home with parents, siblings, relatives or foster parents in 2010. More than one in four people who had a moderate, severe or profound intellectual disability and who were aged 35 years or over in 2010 lived at home. 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.

Since the first report from the NIDD in 1996, there has been significant growth in the level of provision of full-time residential services, residential support services, and day services. Key developments during the period 1996 to 2010 include:

- an increase of 71% in the number of people with intellectual disability living full time in community group homes;
- a 75% reduction in the number of people with intellectual disability accommodated in psychiatric hospitals;
- a continued expansion in the availability of residential support services, particularly planned or emergency centre-based respite services, which have grown by a substantial 468%; 4,951 people availed of this type of service in 2010, allowing them to continue living with their families and in their communities; and
- increased provision in almost all areas of adult day services and in the level of support services delivered as part of a package of day services to both children and adults.

## **Service requirements**

The 2010 data indicate that 4,539 new residential, day and/or residential support places will be needed to meet service requirements. The following services will be needed in the period 2011–2015 (most service needs were recorded as being immediate):

- 2,269 full-time residential placements, a decrease of 29, or 1%, since 2009.
- 2,045 residential support services, a decrease of 70, or 3.3%, since 2009. This high level of need is presenting even though there were over 5,500 people availing of residential support services in 2010.
- 225 day programmes (this figure excludes multidisciplinary support services and services provided by early intervention teams). This number does not include the 841 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.
- 162 individuals who were living in psychiatric hospitals in 2010 have been identified as needing to transfer from these locations to more appropriate accommodation. Further analysis and review of this cohort will be undertaken in 2011.

Of those in receipt of services in 2010, 11,505 people required alternative, additional, or enhanced services in the period 2011–2015, a decrease of 59, or 0.5%, since 2009. 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:

- 9,873 day places will require changes or enhancements. Health-funded services are required by 6,808 individuals (69.0%), employment services are required by 1,243 individuals (12.6%), education services are required by 1,186 individuals (12.0%) and generic services are required by 636 individuals (6.4%). Of the 1,186 service changes required within education, 926 (78.1%) are requirements for an alternative service and 260 (21.9%) are requirements for an enhancement of the individual's existing service. A large proportion of the 1,343 individuals who were attending special schools in 2010 require adult day services within the period 2011–2015. Of this group, almost one quarter (328 individuals) require rehabilitative training, 282 (21.0%) require vocational training and 150 (11.2%) require activation programmes.
- 2,869 residential places will require changes or enhancements.
- 1,701 residential support places will require changes or enhancements.

Despite high levels of service provision in 2010, there remained a significant demand for new and enhanced multidisciplinary support services. Three quarters (19,466 individuals) of the population registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2011–2015. 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. The principal aim of the NIDD is to ensure that information is available to enable the Department of Health, the Health Service Executive (HSE) and the non-statutory agencies in Ireland to provide appropriate services designed to meet the changing needs of people with intellectual disability and their families. The database is intended to provide a comprehensive and accurate information base for decision making in relation to the planning, funding and management of services for people with an intellectual disability.

The database was established on the principle that minimal information with maximal accuracy was preferred; hence, it incorporates only three basic elements of information: demographic details, current service provision and future service requirements. Information is generally collected on day, residential and multidisciplinary support service usage and future service need (the form used to collect information, and details of the service categories that are included on the NIDD are presented in Appendices A and B). The objective is to obtain this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service. Information pertaining to diagnosis is specifically excluded, as the database is not designed as a medical, epidemiological tool. The data held on any individual represent the information available for that individual at a specified point in time only. The record is updated whenever there are changes in the person's circumstances or during the annual review process when service provider agencies assess ongoing and future needs.

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

## Structure

The HSE is responsible for the administration of the database. This includes the implementation and maintenance of structures for the identification of individuals and the collection, review and updating of data. The initial step in the generation of the national dataset is the completion of a data form for each identified individual (Appendix A). Responsibility for providing this information to the HSE lies primarily with the service providers, local health office (LHO) personnel and school principals. The designated data providers supply this information to their LHO and a local database is compiled. Data from the local databases enable more sophisticated service planning at local level and promote effective co-ordination of services within the area.

Information (excluding personal details such as name and address) is extracted from the NIDD at the end of the annual review and update period. This information forms the national dataset for that year.

## Data quality

The Health Research Board (HRB) oversees a system of ongoing validation which aims to identify and correct gaps and inconsistencies in the data. The database guidelines and protocols are revised and refined in response to issues highlighted by the HRB, HSE regions and service providers. The HRB also 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 enable routine data validation to be carried out by service providers and HSE regions. There are ongoing efforts to ensure continued improvement of data quality at local, regional and national levels. As part of these efforts a national audit of the NIDD was undertaken in 2007; some of the recommendations of that audit have since been implemented.

## 2010 annual report

This is the thirteenth report of the National Intellectual Disability Database Committee. The report is based on validated data extracted from the NIDD in December 2010. In addition to this report, a summary bulletin and a complete set of tables are produced for each HSE LHO.

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

The nature of service provision in the intellectual disability area in Ireland ensures that an almost complete capture of 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 2010 dataset, there were 646 people recorded as being of average ability and 710 people in the borderline intellectual disability category. The HSE regions are involved in an ongoing appraisal of the appropriateness of such registrations on the database. The disability category described as 'not verified' has been included in the analyses as members of this group have an intellectual disability but the level of disability has not been confirmed. Accordingly, the data presented include the 'not verified' category in addition to those with a mild, moderate, severe or profound intellectual disability.

The 2010 dataset consists of information in relation to 26,484 individuals. Of the 26,484 registrations, 98.5% (26,091 cases) were updated following the completion of the 2010 review of NIDD information; the remaining 393 registrations contain the last-known data in each case.

## **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. The preliminary results were published in October 2008. Data from the survey indicate that 50,400 people in Ireland have a diagnosed intellectual disability (CSO, 2008). This information differs greatly from what is recorded on the NIDD, for two main reasons:

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

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

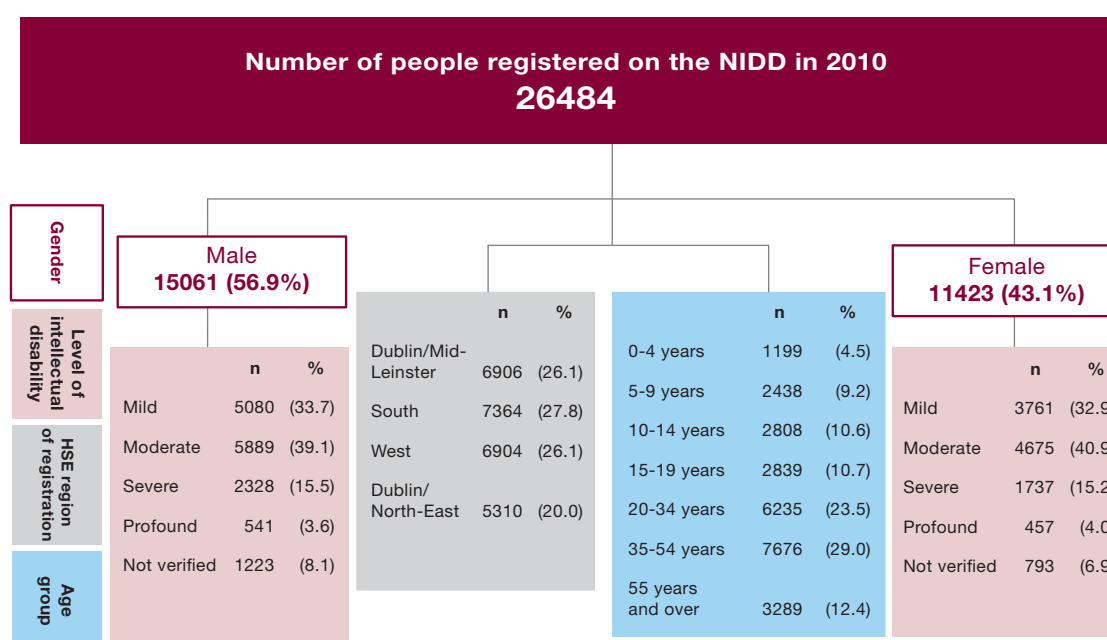
- As a general principle, the NIDD registers data only on individuals with an intellectual disability for whom specialised health services are being provided or who, following a needs assessment, are considered to require specialised services in the next five years. Almost everyone with a moderate, severe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

## 2. Profile of the population

### National level

#### Summary

Figure 2.1 shows that there were 26,484 people registered on the NIDD in 2010. There were more males (56.9%) than females (43.1%) 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 proportions of people registered were in the HSE South Region (27.8%) and in the 35–54-year age group (29.0%).



**Figure 2.1** Profile of the population registered on the NIDD, 2010

During the review and update period prior to the 2010 extract of data from the NIDD, 652 people were removed from the Database<sup>1</sup> and there were 1,070 new or reactivated registrations. Table 2.1 summarises the age and gender distribution of those registered on the Database by degree of intellectual disability and shows the corresponding prevalence<sup>2</sup> rates per thousand of the population.

- 1 Records of those who had died, who had no requirement for intellectual disability services, or who no longer wanted their information to be held on a national system were among those removed from the database.
- 2 Prevalence is the proportion of people in a population who have a disease or condition at a specific point in time. For example, in 2010, 300 people with an intellectual disability received services in a specific LHO area. The prevalence is the total number of cases (300) divided by the population living in the LHO area (35,000) expressed per 1,000 of the population. The calculation in this case is as follows:  $(300/35,000) \times 1,000$ , which gives a prevalence rate of 8.6 per 1,000 of the specific LHO area population in 2010.

**Table 2.1** Number of people registered on the NIDD, by age, gender and degree of intellectual disability, 2010

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	452	576	1028	32	63	95	21	18	39	12	18	30	3	4	7	517	682	1199
5-9	215	454	669	233	483	716	508	739	1245	93	157	250	34	30	64	806	1632	2438
10-14	22	51	73	464	860	1324	370	635	1005	138	201	339	34	33	67	1028	1780	2808
15-19	2	10	12	515	890	1405	426	638	1064	114	178	292	36	30	66	1093	1746	2839
20-34	33	34	67	964	1188	2152	1208	1621	2829	392	593	985	88	114	202	2685	3550	6235
35-54	50	53	103	1067	1156	2223	1597	1766	3363	666	871	1537	200	250	450	3580	4096	7676
55 & over	19	45	64	486	440	926	825	700	1525	322	310	632	62	80	142	1714	1575	3289
All ages	793	1223	2016	3761	5080	8841	4675	5889	10564	1737	2328	4065	457	541	998	11423	15061	26484
<b>Prevalence rates – numbers per 1,000 of the general population for each age group<sup>3</sup></b>																		
0-4	3.06	3.73	3.40	0.22	0.41	0.31	0.12	0.14	0.13	0.08	0.12	0.10	0.02	0.03	0.02	3.50	4.41	3.97
5-9	1.53	3.07	2.32	1.66	3.26	2.48	1.65	3.43	2.56	0.66	1.06	0.87	0.24	0.20	0.22	5.74	11.03	8.46
10-14	0.16	0.36	0.27	3.48	6.12	4.83	2.77	4.52	3.67	1.03	1.43	1.24	0.25	0.23	0.24	7.71	12.67	10.25
15-19	0.01	0.07	0.04	3.63	6.00	4.84	3.00	4.30	3.67	0.80	1.20	1.01	0.25	0.20	0.23	7.70	11.78	9.78
20-34	0.06	0.06	0.06	1.83	2.20	2.02	2.30	3.00	2.66	0.75	1.10	0.92	0.17	0.21	0.19	5.11	6.58	5.85
35-54	0.09	0.09	0.09	1.88	2.00	1.94	2.81	3.06	2.94	1.17	1.51	1.34	0.35	0.43	0.39	6.31	7.09	6.70
55 & over	0.04	0.11	0.07	1.05	1.07	1.06	1.78	1.70	1.74	0.70	0.75	0.72	0.13	0.19	0.16	3.71	3.82	3.76
All ages	0.37	0.58	0.48	1.78	2.39	2.09	2.21	2.78	2.49	0.82	1.10	0.96	0.22	0.26	0.24	5.39	7.10	6.25

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

## Prevalence

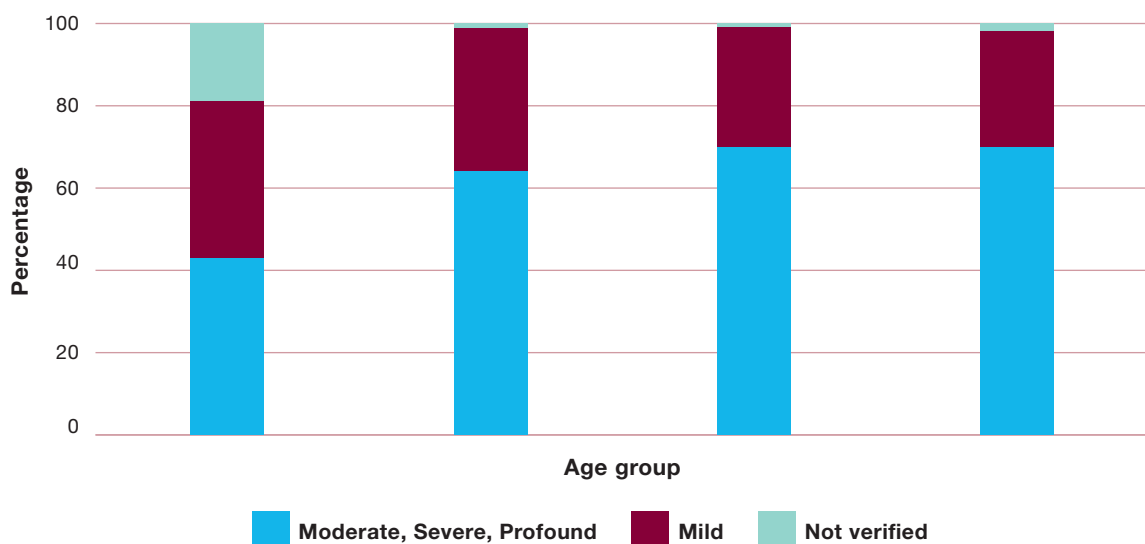
The prevalence rate for mild intellectual disability in 2010 was 2.09/1000, a slight increase on the 2009 rate of 2.04/1000. This figure is not a true reflection of the prevalence as those with a mild intellectual disability are under-represented; of this group, only those accessing or requiring intellectual disability services are included in the Database. The prevalence rate for moderate, severe and profound intellectual disability in 2010 was 3.69/1000, compared to 3.65/1000 in 2009.

## Gender differences

As Table 2.1 indicates, the number of males exceeded the number of females at all levels of intellectual disability, and in all age groups, except the 55-years-and-over group. The overall male to female ratio was 1.32:1. This represents a prevalence rate of 7.10/1000 males and 5.39/1000 females.

## Age differences

Of the persons recorded on the NIDD, 9,284 (35.1%) were aged 19 years or under, 6,235 (23.5%) were aged between 20 and 34 years, 7,676 (29.0%) were aged between 35 and 54 years, and 3,289 (12.4%) were 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, 2010

## Trends over time

### Recent trends

Prevalence rates for moderate, severe and profound intellectual disability between 1974 and 2010 are shown in Table 2.2. The 1996 prevalence rates are calculated using NIDD data from 1996 and Census of Population data from 1996. The 2010 prevalence rates are calculated using NIDD data from 2010 and Census of Population data from 2006. Compared to the 1996 data (National Intellectual Disability Database Committee, 1997), the 2010 data in Table 2.2 demonstrate the following trends:

- The prevalence rate among the 0–4-year age group has continued to decline. This can in part be attributed to an increase between the two census dates in the numbers in this age group in the general population and to the declining numbers in this age group that are registered on the NIDD. In compiling the Database each year, attempts are made to discover every child with intellectual disability at the earliest possible age, but respect is also given to situations where parents are reluctant to allow information about their young child to be recorded on the Database. Indeed, significant developmental delay is much less evident in the first two years, becoming much more noticeable by the time a child is aged three or four. Another potential reason for the fall in the number of 0–4-year-olds registered on the Database is that children in this age group are increasingly using mainstream services. In addition, the assessment of need process, which has been in place since 2007 for those aged under five years, may have had some impact on registration for this age group.
- The prevalence rate among 20–34-year-olds continues to fall, as has consistently been the case over the period 1974–2010.
- There has been an overall increase in prevalence in the 55-years-and-over age group; the prevalence rate in 2010 was 2.63 per thousand of population. The number of people in this age group registered on the Database increased by 865 (60.3%) between 1996 and 2010.



**Table 2.2** Prevalence of intellectual disability, by degree (moderate, severe and profound) and by age group, 1974, 1981, 1996, 2010

Age group	Moderate				Severe				Profound				All levels			
	1974	1981	1996	2010	1974	1981	1996	2010	1974	1981	1996	2010	1974	1981	1996	2010
-4	189	214	226	39	143	92	83	30	26	30	7	431	332	339	76	
5-9	809	955	736	739	617	330	260	250	224	99	64	1650	1384	1073	1053	
10-14	752	1035	948	1005	583	428	305	339	292	117	93	1627	1580	1346	1411	
15-19	698	1203	1072	1064	445	508	378	292	241	154	132	1384	1865	1582	1422	
20-34	1498	2419	2997	2829	1017	1129	1350	985	441	340	202	2956	3888	4807	4016	
35-54	1321	1559	2626	3363	626	612	1183	1537	201	97	343	2148	2268	4152	5350	
55 & over	669	715	987	1525	307	248	394	632	84	24	53	1060	987	1434	2299	
<b>All ages</b>	<b>5936</b>	<b>8100</b>	<b>9592</b>	<b>10564</b>	<b>3738</b>	<b>3347</b>	<b>3953</b>	<b>4065</b>	<b>1582</b>	<b>857</b>	<b>1188</b>	<b>998</b>	<b>11256</b>	<b>12304</b>	<b>14733</b>	<b>15627</b>
<b>Prevalence rates – numbers per 1,000 of the general population for each age group</b>																
0-4	0.6	0.62	0.83	0.13	0.45	0.27	0.3	0.10	0.31	0.07	0.11	0.02	1.36	0.97	1.24	0.25
5-9	2.55	2.73	2.31	2.56	1.95	0.94	0.82	0.87	0.71	0.28	0.24	0.22	5.2	3.95	3.37	3.65
10-14	2.52	3.08	2.72	3.67	1.95	1.27	0.88	1.24	0.98	0.35	0.27	0.24	5.45	4.7	3.86	5.15
15-19	2.61	3.79	3.2	3.67	1.66	1.6	1.13	1.01	0.9	0.48	0.39	0.23	5.17	5.88	4.72	4.90
20-34	2.78	3.33	3.93	2.66	1.88	1.56	1.77	0.92	0.82	0.47	0.6	0.19	5.48	5.35	6.31	3.77
35-54	2.13	2.43	3.25	2.94	1.01	0.95	1.46	1.34	0.32	0.15	0.42	0.39	3.46	3.53	5.14	4.67
55 & over	1.08	1.09	1.45	1.74	0.5	0.38	0.58	0.72	0.14	0.04	0.08	0.16	1.71	1.51	2.11	2.63
<b>All ages</b>	<b>1.99</b>	<b>2.35</b>	<b>2.72</b>	<b>2.49</b>	<b>1.25</b>	<b>0.97</b>	<b>1.12</b>	<b>0.96</b>	<b>0.53</b>	<b>0.25</b>	<b>0.34</b>	<b>0.24</b>	<b>3.80</b>	<b>3.60</b>	<b>4.18</b>	<b>3.69</b>

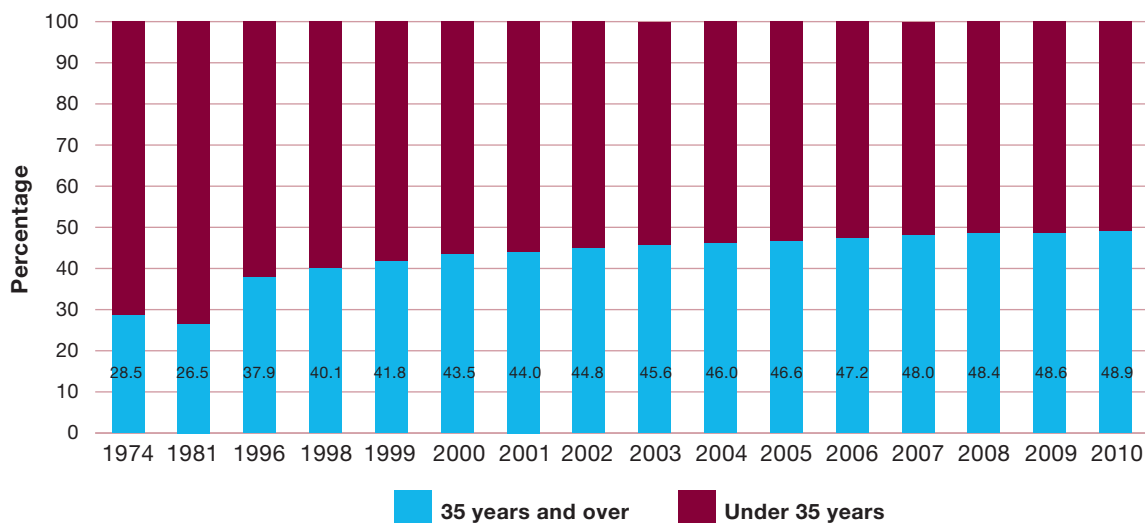
## Trends over past three decades

Data from the 1974 and 1981 Censuses of Mental Handicap, carried out by the Medico-Social Research Board (Mulcahy, 1976; Mulcahy and Ennis, 1976; Mulcahy and Reynolds, 1984), enable us to monitor trends in the population with an intellectual disability over the past 35 years (Table 2.2).

Of particular interest from a trends point of view, and most relevant to service planning, is that, as reported in previous years, the increase in numbers since 1996 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. However, in 2010 as in 2009, there was an increase in the numbers in the 10–14-year age group.

## Ageing population

Figure 2.3 shows continued growth in the proportion of over-35s among those with moderate, severe or profound intellectual disability in Ireland. Increased longevity in this population is attributed in the research literature to improved health and well-being, the control of infectious diseases, the move to community living, improved nutrition, and the quality of health care services. It can be seen that 28.5% of this population were aged 35 years or over in 1974. A steady increase in the proportion aged 35 years or over has been observed in each dataset since 1996; the proportion rose from 37.9% in 1996 to 48.9% in 2010, when almost half of those with a moderate, severe or profound intellectual disability were aged 35 years over.



**Figure 2.3** Proportion of people with moderate, severe or profound intellectual disability (combined), by age group: 1974–2010



## 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 as this is where the demands on the health services are most acute. Key issues include:

- Residential services are primarily used by adults with a moderate, severe or profound intellectual disability (see Chapter 3). As the number of individuals in this group increases, more pressure is being placed on residential services.
- Improved life expectancy among adults with a more severe intellectual disability places an increased demand on the health services and poses new challenges to health care professionals. Fewer places are becoming free over time, a higher degree of support within day and residential services is required, and specific support services for older people are needed.
- The majority of adults with intellectual disability continue to live with their families. As these caregivers age beyond their care-giving capacity, residential supports are required. Additional therapeutic support services are also required for people who wish to continue to live with their families and to live as independently as possible.

## Regional level

### Numbers in each Health Service Executive region

Table 2.3 shows the number of individuals registered on the NIDD in 2010 by HSE region. The numbers registered in each region were broadly in line with what would be expected based on the size of the general population of the region (CSO, 2006).

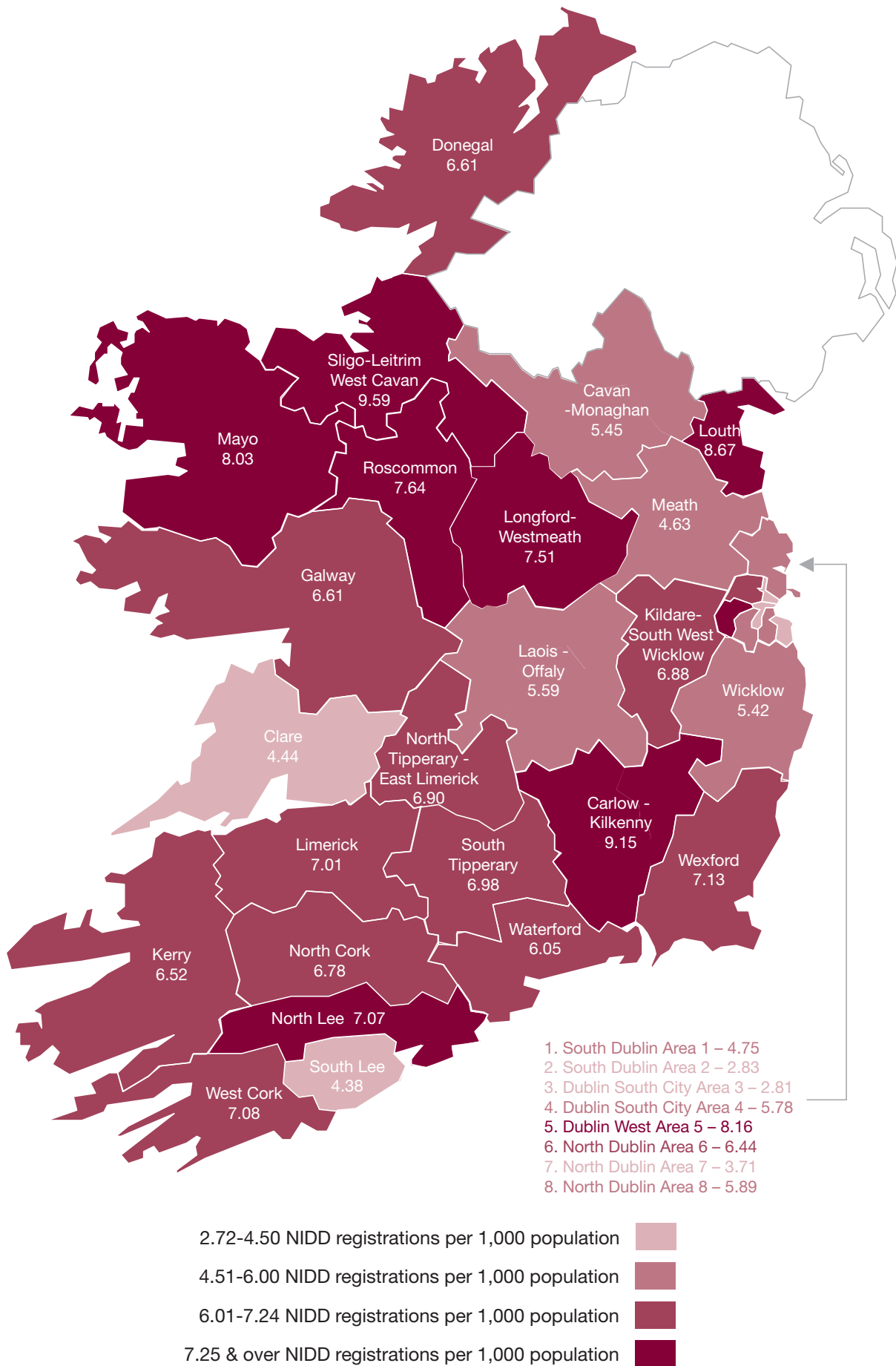
**Table 2.3** Number of people registered on the NIDD, by HSE region, 2010

HSE Region	n	% of NIDD	% of total population
Dublin/Mid-Leinster	6906	26.1	28.7
South <sup>4</sup>	7364	27.8	25.5
West <sup>5</sup>	6904	26.1	23.9
Dublin/North-East <sup>6</sup>	5310	20.0	21.9
<b>Total</b>	<b>26484</b>	<b>100.0</b>	<b>100.0</b>

4 An additional 118 individuals received services in the HSE South Region but have not been included in the overall figures as they did not consent to their information being included on the national system.

5 An additional 56 individuals received services in the HSE West Region but have not been included in the overall figures as they did not consent to their information being included on the national system.

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



**Figure 2.4** Prevalence of NIDD registrations per 1,000 of the general population, by HSE LHO area of residence, 2010



Figure 2.4 presents the number of NIDD registrations by the LHO area in which service users reside. The national prevalence rate was 6.25/1000. The Sligo/Leitrim/West Cavan LHO area had the highest prevalence rate, at 9.59/1000 of the population, while the lowest prevalence rate was in the Dublin South City LHO area, at 2.81/1000.

## Co-morbidity within the NIDD population

As Table 2.4 indicates, 9,263 individuals (35.0%) registered on the NIDD in 2010 had a physical and/or sensory disability in addition to an intellectual disability. This number represents an increase of 8.8% on the 2009 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 2.4** Number of people registered on the NIDD with a physical and/or sensory disability, by gender, 2010

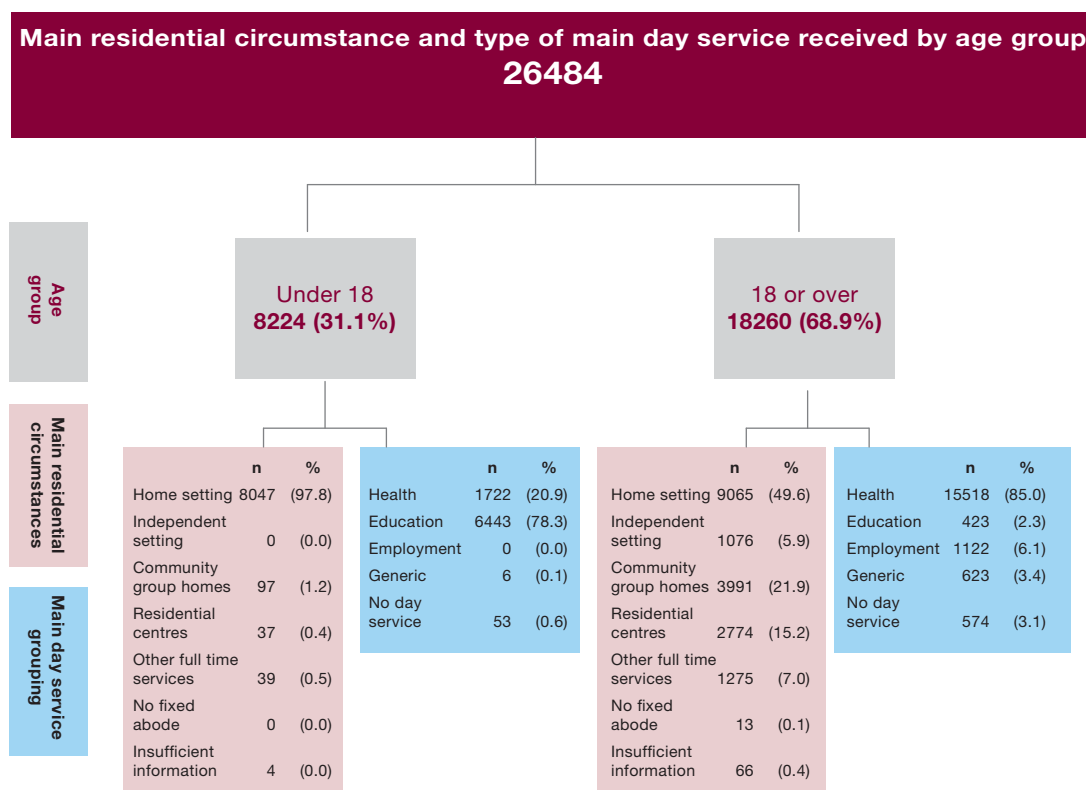
	Male		Female		Total	
	n	%	n	%	n	%
Intellectual and physical/ sensory disability	4983	33.1	4280	37.5	9263	35.0
Intellectual disability only	10051	66.7	7115	62.3	17166	64.8
Not reviewed	27	0.2	28	0.2	55	0.2
<b>Total</b>	<b>15061</b>	<b>100.0</b>	<b>11423</b>	<b>100.0</b>	<b>26484</b>	<b>100.0</b>

# 3. Service provision in 2010

## 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 2010. Day services were availed of by 97.6% of all those registered on the NIDD in 2010. The majority of services accessed by adults were health related, and the majority accessed by children were educational. Figure 3.1 also shows that a larger proportion (3.1%) of adults were without day services, compared to their younger counterparts (0.6%). The residential circumstances for both age groups also differed in 2010; 97.8% (8,047) of those aged under 18 years lived at home, compared to 49.6% (9,065) 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 represents 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, 2010

In 2010, 25,936 people with intellectual disability were receiving services, which accounted for 97.9% of the total population registered on the NIDD. Of the remaining 548 people (2.1%) who were not in receipt of services, 287 (1.1% of total registered population) had expressed a need for services in the period 2011–2015. The overall level of service provision in 2010 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, 2010**

	<b>n</b>	<b>%</b>
Attending services on a day basis	17705	66.9
Receiving 5- or 7-day residential services	7975	30.1
Resident in a psychiatric hospital	238	0.9
Receiving residential support services only	18	0.1
Receiving no service – on waiting list	287	1.1
No identified service requirements	261	1.0
<b>Total</b>	<b>26484</b>	<b>100.0</b>

## Residential circumstances

Table 3.2 provides an overview of the main residential circumstances of those registered on the NIDD in 2010 by degree of intellectual disability and age group (a further breakdown is presented in Table 3.3).

The main groupings of individuals consisted of:

- 17,112 individuals (64.6%) who lived at home with parents, relatives, or foster parents. This figure does not take account of those in the mild intellectual disability category who were living at home/independently without supports or services, and who are under-represented on the NIDD.
- 8,213 individuals (31.0%) who lived in full-time residential services, mainly in community group homes, residential centres, psychiatric hospitals, and intensive placements. This represents a decrease of 38 on the 2009 figure.
- 1,076 individuals (4.1%) who lived independently or semi-independently. This represents an increase of 84 on the 2009 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 (4,088) than in residential centres (2,811). 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 2010, 293 people with an intellectual disability resided full time in mental health services, either in psychiatric hospitals (238 individuals, compared with 277 individuals in 2009) or in mental health community residences (55 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 2010 decreased with age: 97.2% of individuals aged 0–19 years lived in a home setting, declining to 72.7% of those aged 20–34 years, 39.1% of those aged 35–54 years, and 16.8% of those aged 55 years or over.

By contrast, the proportion of people in the different age categories who lived in full-time residential services increased with age: in 2010 2.7% of all 0–19-year-olds received full-time residential services, compared with 23.3% of 20–34-year-olds, 53.0% of 35–54-year-olds, and 74.3% 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 2010. 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 1,076 individuals who lived in independent or semi-independent settings in 2010, 78.7% were aged 35 years or over, and over three quarters (77.2%) had a mild intellectual disability.

## **Degree of intellectual disability**

There were also noticeable variations between level of ability and type of residential situation (Table 3.2). Of those with a mild intellectual disability, 74.6% lived in a home setting, compared to 55.0% of those with a moderate, severe or profound intellectual disability. The proportion of people in full-time residential services increased as the level of intellectual disability increased. Only 15.8% of people with a mild intellectual disability lived in full-time residential services, but this increased to 43.3% in the case of those with a moderate, severe or profound disability.

Where individuals were in full-time residential services in 2010, the type of service varied according to the level of intellectual disability. Full-time residents with a mild intellectual disability were in the past more likely to be accommodated in community group homes, while full-time residents with a moderate, severe or profound intellectual disability were more likely to be accommodated in residential centres. However, since 2007 the number of full-time residents with a moderate, severe or profound intellectual disability living in community group homes exceeds the number living in residential centres.





- Of those in full-time residential services in 2010 who had a moderate, severe or profound intellectual disability, 46.4% were in community group homes, 37.9% were in residential centres, and 15.7% 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 2010, 66.7% were in community group homes, 16.7% were in residential centres, and 16.7% were in other full-time residential services.

Table 3.3 outlines the main residential circumstances and overall level of residential service provision of those registered on the NIDD in 2010 (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 is a combination of the main and secondary residential services provided, while the main residential circumstance is the place in which the individual resides most of the time. Of particular note is the number of residential support services available in addition to an individual's principal residential service; these include holiday residential placements, crisis or planned respite care, occasional respite with a host family, overnight respite in the home and regular part-time care.

Between 1996 and 2010 there has been considerable growth in the number of residential support places available. In particular, the data show a significant increase of 468.4% (4,080) in the number of individuals who availed of centre-based respite services, either as a planned or emergency intervention, bringing the total number of people availing of respite services in 2010 to 4,951 (Table 3.3).

**Table 3.2** Main residential circumstances, by degree of intellectual disability and by age group, 2010

	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	1778	53	61	21	1913	3477	1740	1158	226	6601	3770	2740	1781	307	8598	9025	4533	3000	554	17112
Independent setting	0	8	29	15	52	5	182	459	185	831	0	34	90	69	193	5	224	578	269	1076
Community group home	1	5	5	7	18	45	144	451	289	929	85	571	1752	733	3141	131	720	2208	1029	4088
Residential centre	0	0	2	9	11	4	28	73	127	232	48	384	1232	904	2568	52	412	1307	1040	2811
Other full-time services <sup>7</sup>	3	1	6	12	22	6	49	80	97	232	57	271	466	266	1060	66	321	552	375	1314
No fixed abode	0	0	0	0	0	0	5	2	2	9	0	0	3	1	4	0	5	5	3	13
Insufficient information	0	0	0	0	0	3	4	0	0	7	2	16	26	19	63	5	20	26	19	70
<b>Total</b>	<b>1782</b>	<b>67</b>	<b>103</b>	<b>64</b>	<b>2016</b>	<b>3540</b>	<b>2152</b>	<b>2223</b>	<b>926</b>	<b>8841</b>	<b>3962</b>	<b>4016</b>	<b>5350</b>	<b>2299</b>	<b>15627</b>	<b>9284</b>	<b>6235</b>	<b>7676</b>	<b>3289</b>	<b>26484</b>

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

**Table 3.3** Main residential circumstances and overall level of residential service provision, 2010

	Main residential circumstances			Overall level of residential provision/circumstance		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages
<b>Home setting</b>	<b>8047</b>	<b>9065</b>	<b>17112</b>	<b>8053</b>	<b>9072</b>	<b>17125</b>
At home with both parents	6230	5312	11542	6230	5312	11542
At home with one parent	1565	2539	4104	1565	2539	4104
At home with sibling	4	900	904	4	900	904
At home with other relative	52	156	208	52	156	208
Living with non-relative	4	25	29	4	25	29
Adoption	10	13	23	10	13	23
Foster care and boarding out arrangements	182	120	302	188	127	315
<b>Independent setting</b>	<b>0</b>	<b>1076</b>	<b>1076</b>	<b>0</b>	<b>1078</b>	<b>1078</b>
Living independently	0	707	707	0	708	708
Living semi-independently	0	369	369	0	370	370
<b>Community group homes</b>	<b>97</b>	<b>3991</b>	<b>4088</b>	<b>97</b>	<b>3991</b>	<b>4088</b>
5-day community group home	37	402	439	37	402	439
7-day community group home	10	529	539	10	529	539
7-day (52-week) community group home	50	3060	3110	50	3060	3110
<b>Residential setting</b>	<b>37</b>	<b>2774</b>	<b>2811</b>	<b>37</b>	<b>2774</b>	<b>2811</b>
5-day residential centre	3	58	61	3	58	61
7-day residential centre	11	333	344	11	333	344
7-day (52-week) residential centre	23	2383	2406	23	2383	2406
<b>Other full time residential services</b>	<b>39</b>	<b>1275</b>	<b>1314</b>	<b>39</b>	<b>1275</b>	<b>1314</b>
Nursing home	0	156	156	0	156	156
Mental health community residence	0	55	55	0	55	55
Psychiatric hospital	0	238	238	0	238	238
Intensive placement (challenging behaviour)	13	478	491	13	478	491
Intensive placement (profound or multiple disability)	14	242	256	14	242	256
Occupying a full-time support place	7	40	47	7	40	47
Other full-time residential service	5	66	71	5	66	71
<b>Residential support service</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1404</b>	<b>4208</b>	<b>5612</b>
Holiday residential placement	0	0	0	3	130	133
Crisis or planned respite	0	0	0	1240	3711	4951
Occasional respite with host family	0	0	0	124	183	307
Overnight respite in the home	0	0	0	7	8	15
Shared care or guardianship	0	0	0	2	9	11
Regular part-time care (2/3 days per week)	0	0	0	17	73	90
Regular part-time care (every weekend)	0	0	0	4	10	14
Regular part-time care (alternate weeks)	0	0	0	2	60	62
Other residential service	0	0	0	5	24	29
<b>No fixed abode</b>	<b>0</b>	<b>13</b>	<b>13</b>	<b>0</b>	<b>13</b>	<b>13</b>
<b>Insufficient information</b>	<b>4</b>	<b>66</b>	<b>70</b>	<b>4</b>	<b>66</b>	<b>70</b>
	<b>8224</b>	<b>18260</b>	<b>26484</b>	<b>9634</b>	<b>22477</b>	<b>32111</b>

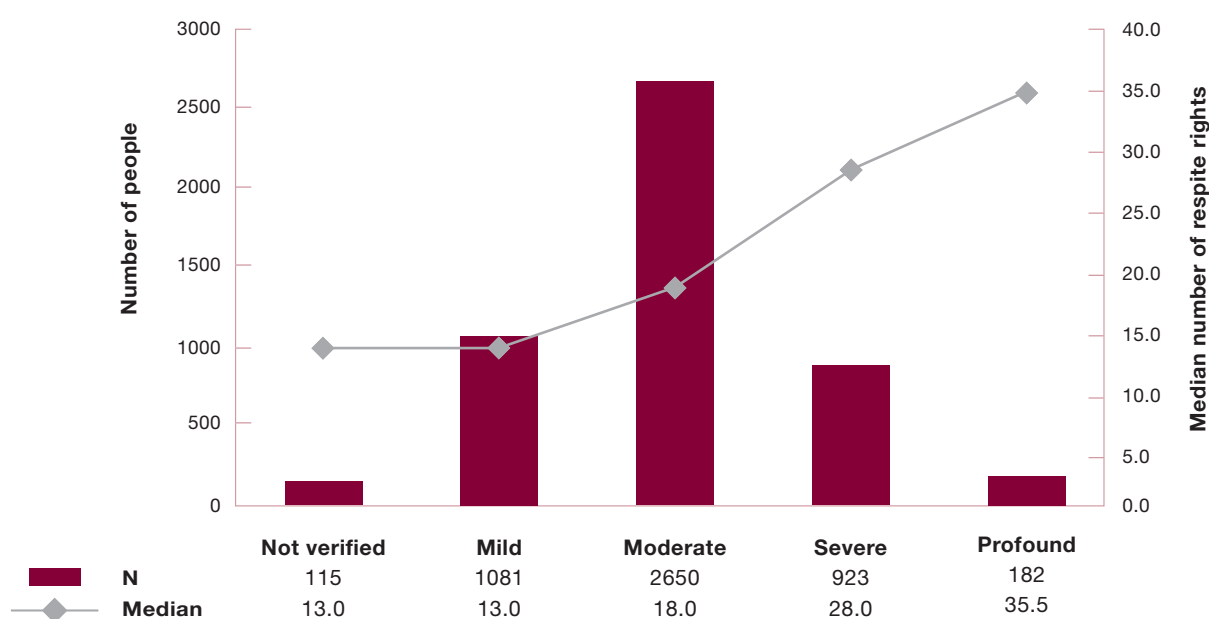
Note: The total number of services received (32,111) exceeds the actual number of people with an intellectual disability as a number of people availed of two residential services.

## 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 median<sup>8</sup> 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, 2010

### Geographical variation in respite provision

Figure 3.3 displays the total number of respite nights received in 2010 for those who were living within each of the four HSE regions. Table 3.4 presents data on respite for each of the HSE LHO areas. Both the figure and the table show that there were marked differences between regions in the total number of respite nights received in 2010, which ranged from 28,329 nights in the HSE South region to 46,645 nights in the HSE West region. Chapter 4 presents data on those who require respite care.

<sup>8</sup> The median is the value at the mid-point in a sequence of values which are ranged in ascending order. It is described as the numeric value separating the higher half of a sample from the lower half. The median can be found by arranging all the observations from lowest value to highest value and picking the middle one. For example, in the case of five clients who received 18, 19, 21, 22 and 55 nights of respite care in one year, the median (middle value) is 21 nights, whereas the mean is 27 nights. While the mean and median both describe the central value of the data, the median is more useful in this case because the mean is influenced by the one client who required a lot of respite care.



**HSE Dublin/North-East**  
 Total number of respite nights received – 29326  
 Total number of people in receipt of respite – 1126  
 Total number of people registered on NIDD – 5310  
**Median number of respite nights – 14**

**HSE Dublin/Mid-Leinster**  
 Total number of respite nights received – 39578  
 Total number of people in receipt of respite – 1375  
 Total number of people registered on NIDD – 6906  
**Median number of respite nights – 18**

**HSE West**  
 Total number of respite nights received – 46645  
 Total number of people in receipt of respite – 1275  
 Total number of people registered on NIDD – 6904  
**Median number of respite nights – 27**

**HSE South**  
 Total number of respite nights received – 28329  
 Total number of people in receipt of respite – 1175  
 Total number of people registered on NIDD – 7364  
**Median number of respite nights – 14**

**Figure 3.3** Total number and median number of respite nights received, by HSE region of residence, 2010<sup>9</sup>

9 A small number of individuals (62) remained in respite care for more than 150 nights, which may have slightly inflated the respite figures. Twenty-six of these people were resident in the West Region, 16 in the Dublin/Mid-Leinster Region, 13 in the Dublin/North-East Region and seven in the South Region.



**Table 3.4** Use of respite nights, by HSE region and by LHO area of residence, 2010

	<b>Total number of respite nights received</b>	<b>Number of people in receipt of respite nights</b>	<b>Median number of respite nights received</b>
<b>HSE Dublin/Mid-Leinster Region</b>	<b>39578</b>	<b>1375</b>	<b>18.0</b>
LHO Dublin South	4776	132	31.0
LHO Dublin South East	2475	65	21.0
LHO Dublin South City	2846	99	18.0
LHO Dublin South West	7162	235	19.0
LHO Dublin West	5062	146	23.5
LHO Kildare/West Wicklow	6148	266	14.0
LHO Wicklow	4212	108	24.5
LHO Laois/Offaly	2062	156	4.0
LHO Longford/Westmeath	4835	168	18.0
<b>HSE South Region</b>	<b>28329</b>	<b>1175</b>	<b>14.0</b>
LHO Carlow/Kilkenny	2386	123	10.0
LHO Tipperary SR	2220	128	12.0
LHO Waterford	1566	103	12.0
LHO Wexford	2848	165	14.0
LHO Cork North Lee	3948	136	17.0
LHO Cork South Lee	4437	133	25.0
LHO North Cork	3037	104	19.0
LHO West Cork	3413	88	17.0
LHO Kerry	4474	195	13.0
<b>HSE West Region</b>	<b>46645</b>	<b>1275</b>	<b>27.0</b>
LHO Limerick	4792	154	24.0
LHO Tipperary NR	4442	97	40.0
LHO Clare	3290	121	18.0
LHO Galway	15499	322	34.0
LHO Mayo	6835	182	32.5
LHO Roscommon	1967	55	27.0
LHO Donegal	6960	220	20.5
LHO Sligo/Leitrim/West Cavan	2860	124	13.0
<b>HSE Dublin/North-East Region</b>	<b>29326</b>	<b>1126</b>	<b>14.0</b>
LHO Dublin North West	5136	204	15.5
LHO Dublin North Central	2945	174	5.0
LHO Dublin North	10006	381	12.0
LHO Cavan/Monaghan	2097	100	17.5
LHO Louth	4725	107	35.0
LHO Meath	4417	160	22.5
<b>All regions</b>	<b>143878</b>	<b>4951</b>	<b>19.0</b>

## Day services

In 2010, 25,857 people, representing 97.6% of all those registered on the NIDD, received day services (Table 3.5). 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, and also by people who are receiving full-time residential services.

Of the 25,857 individuals who availed of day services in 2010, 8,152 (31.5%) were in full-time residential services, the majority of whom were in the moderate, severe, or profound range of intellectual disability (82.4%) and aged 18 years or over (97.9%). The remaining 17,705 (68.5%) attended services on a day basis, of whom 40.7% were in the mild range of intellectual disability and 45.2% 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, 2010

	Not verified			Mild			Moderate, severe or profound			Total		
	Under 18	18 or over	Total	Under 18	18 or over	Total	Under 18	18 or over	Total	Under 18	18 or over	Total
Residents	4	45	49	42	1340	1382	127	6594	6721	173	7979	8152
Day attendees	1742	180	1922	2978	4234	7212	3278	5293	8571	7998	9707	17705
<b>Total</b>	<b>1746</b>	<b>225</b>	<b>1971</b>	<b>3020</b>	<b>5574</b>	<b>8594</b>	<b>3405</b>	<b>11887</b>	<b>15292</b>	<b>8171</b>	<b>17686</b>	<b>25857</b>

## Main day services by age group and degree of intellectual disability

As in 2009, the top three day activities availed of by people with an intellectual disability in 2010, 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 25,857 individuals who availed of day services in 2010, 8,171 (31.6%) were aged under 18 years, and 17,686 (68.4%) were aged 18 years or over (Table 3.6).

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

Of the 17,686 adults who availed of at least one day service in 2010, most attended either activation centres (35.3%) or sheltered work centres (19.2%) as their principal day service. Smaller proportions availed of rehabilitative training (9.5%), multidisciplinary support services only (9.1%), and supported employment (5.3%).

## Degree of intellectual disability

Of those who received day services in 2010 (25,857 individuals), 8,594 (33.2%) had a mild intellectual disability, 15,292 (59.1%) had a moderate, severe or profound intellectual disability and 1,971 (7.6%) had not yet had their degree of intellectual disability established (Table 3.6).

The age profiles of these groups are quite different. Just over one in five (3,405, 22.3%) of the population with moderate, severe or profound intellectual disability who availed of day services in 2010 were aged under 18 years, whereas more than one in three (3,020, 35.1%) of the population with mild intellectual disability who availed of day services were aged under 18 years.

Of the 8,171 under-18s who availed of day services in 2010:

- 3,020 (37.0%) had a mild degree of intellectual disability; most of this group availed of special education services as their principal day service, with smaller numbers in mainstream schools and pre-school services.
- 3,405 (41.7%) had a moderate, severe or profound intellectual disability and, while most were receiving special education services as their principal day service, smaller numbers were in mainstream education or pre-school services and some also availed of more intensive services such as child education and development centres.
- 1,746 (21.4%) had not had their degree of intellectual disability verified.

Of the 17,686 adults in receipt of day services in 2010:

- 5,574 (31.5%) had a mild degree of intellectual disability, most of whom attended sheltered work centres, were in receipt of activation programmes, availed of rehabilitative training, or were in supported employment.
- 11,887 (67.2%) were in the moderate, severe or profound range and were most likely to be in receipt of activation programmes, with smaller numbers in sheltered work and rehabilitative training.
- 225 (1.3%) had not had their degree of intellectual disability verified.



**Table 3.6** Principal day service availed of, by degree of intellectual disability and by age group, 2010

	Not verified			Mild			Moderate, severe or profound			All levels		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home support	43	10	53	3	64	67	10	100	110	56	174	230
Home help	1	1	2	0	10	10	0	8	8	1	19	20
Early intervention team	455	0	455	25	0	25	20	0	20	500	0	500
Special pre-school for intellectual disability	366	0	366	54	0	54	100	0	100	520	0	520
Child education and development centre	3	0	3	1	0	1	140	7	147	144	7	151
Mainstream pre-school	219	0	219	68	0	68	32	0	32	319	0	319
Mainstream school	231	0	231	841	37	878	565	29	594	1637	66	1703
Resource/visiting teacher	28	0	28	55	13	68	35	7	42	118	20	138
Special class – primary	93	0	93	211	0	211	198	0	198	502	0	502
Special class – secondary	3	1	4	67	20	87	82	25	107	152	46	198
Special school	225	0	225	1637	137	1774	2172	129	2301	4034	266	4300
Third level education	0	1	1	0	24	24	0	0	0	0	25	25
Rehabilitative training	0	12	12	3	826	829	0	850	850	3	1688	1691
Activation centre	0	24	24	1	1223	1224	1	4997	4998	2	6244	6246
Programme for the older person	0	10	10	0	112	112	0	534	534	0	656	656
Special high-support day service	0	0	0	1	55	56	3	647	650	4	702	706
Special intensive day service	0	0	0	6	47	53	15	344	359	21	391	412
Sheltered work centre	0	24	24	0	1324	1324	1	2045	2046	1	3393	3394
Sheltered employment centre	0	13	13	0	57	57	0	17	17	0	87	87
Multidisciplinary support services	29	33	62	15	437	452	9	1139	1148	53	1609	1662
Centre-based day respite service	0	1	1	0	8	8	2	9	11	2	18	20
Day respite in the home	2	0	2	0	1	1	0	2	2	2	3	5
Outreach programme	1	4	5	1	46	47	1	59	60	3	109	112
Other day service	46	1	47	27	164	191	18	253	271	91	418	509
Enclave within open employment	0	0	0	0	5	5	0	7	7	0	12	12
Supported employment	0	37	37	0	535	535	0	357	357	0	929	929
Open employment	0	3	3	0	133	133	0	45	45	0	181	181
Vocational training	0	5	5	4	166	170	1	64	65	5	235	240
Generic day services	1	45	46	0	130	130	0	213	213	1	388	389
<b>Total</b>	<b>1746</b>	<b>225</b>	<b>1971</b>	<b>3020</b>	<b>5574</b>	<b>8594</b>	<b>3405</b>	<b>11887</b>	<b>15292</b>	<b>8171</b>	<b>17686</b>	<b>25857</b>

Table 3.7 outlines the main day service and overall level of day service provision for those registered on the NIDD in 2010. 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 is a combination of the main, secondary and tertiary day programmes provided. Of note is the number of support services available to people with an intellectual disability in addition to their principal day service; these include services such as home support, early intervention, education support, centre-based and home-based day respite, home help, and multidisciplinary support.

Between 1996 and 2010 there was significant growth in overall day service provision. In particular, the data show:

- Increases in the number of both high-support and intensive day places. The number of high-support day places increased by 79.5% (318 people) and the number of intensive day places increased by 267.2% (310 people). The data indicate that 718 and 426 people respectively attended high-support and intensive day services in 2010.
- An increase of 155.2% (430 people) in the number in receipt of day programmes specific to the older person. The number of people who attended such services in 2010 was 707.
- An increase of 50.3% (2,175 people) in the number who attended activation centres, bringing the total number to 6,501 in 2010.

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



**Table 3.7** Principal day service and overall level of day service provision, by age group, 2010

	Principal day service			Overall level of day service provision		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home support	56	174	230	1125	907	2032
Home help	1	19	20	87	74	161
Early intervention team	500	0	500	1699	0	1699
Special pre-school for intellectual disability	520	0	520	536	0	536
Child education and development centre	144	7	151	158	9	167
Mainstream pre-school	319	0	319	405	0	405
Mainstream school	1637	66	1703	1665	68	1733
Resource/visiting teacher	118	20	138	748	63	811
Special class – primary	502	0	502	506	0	506
Special class – secondary	152	46	198	152	46	198
Special school	4034	266	4300	4035	267	4302
Third-level education	0	25	25	0	27	27
Rehabilitative training	3	1688	1691	3	1745	1748
Activation centre	2	6244	6246	2	6499	6501
Programme for the older person	0	656	656	0	707	707
Special high-support day service	4	702	706	7	711	718
Special intensive day service	21	391	412	23	403	426
Sheltered work centre	1	3393	3394	1	3603	3604
Sheltered employment centre	0	87	87	0	89	89
Multidisciplinary support services	53	1609	1662	5562	14542	20104
Centre-based day respite service	2	18	20	319	440	759
Day respite in the home	2	3	5	83	66	149
Outreach programme	3	109	112	50	231	281
Other day service	91	418	509	735	671	1406
Enclave within open employment	0	12	12	0	15	15
Supported employment	0	929	929	0	1855	1855
Open employment	0	181	181	0	337	337
Vocational training	5	235	240	5	276	281
Generic day services	1	388	389	3	423	426
<b>Total</b>	<b>8171</b>	<b>17686</b>	<b>25857</b>	<b>17909</b>	<b>34074</b>	<b>51983</b>

Note: The total number of services received (51,983) 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 between the principal day service provision and the overall day service provision (Table 3.7) 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.

- Overall, 21,803 individuals received one or more multidisciplinary support services in 2010 (including those provided by early intervention teams). This was an increase of 580 people since 2009. As in 2009, the most commonly availed of multidisciplinary support services were social work (10,530 individuals), medical services (9,775 individuals), speech and language therapy (8,536 individuals) and psychology (8,354 individuals).
- The services most commonly availed of by adults were social work (6,815), medical services (6,767) and psychiatry (6,259).
- The services most commonly availed of by children were speech and language therapy (1,729 children aged six years or under and 3,894 children aged 7–17 years), occupational therapy (1,415 children aged six years or under and 2,404 children aged 7–17 years), and social work (1,173 children aged six years or under and 2,542 children aged 7–17 years).
- Early intervention teams usually provide services to children aged six years or under; 1,649 children (82.3%) in this age group received multidisciplinary support services from an early intervention team in 2010. There were also 50 children aged seven years or over who received services from an early intervention team in 2010.

**Table 3.8** Overall provision of multidisciplinary support services, by age and access to an early intervention team (EIT), 2010

	Aged 6 or under			Aged 7–17			Aged 18 or over	Total
	Provided by an EIT	Not provided by an EIT	Total	Provided by an EIT	Not provided by an EIT	Total		
Medical services	1050	119	1169	21	1818	1839	6767	9775
Nursing	835	110	945	19	1191	1210	5895	8050
Nutrition	352	45	397	7	512	519	2575	3491
Occupational therapy	1182	233	1415	33	2371	2404	2762	6581
Physiotherapy	1194	168	1362	30	1693	1723	3178	6263
Psychiatry	56	21	77	2	513	515	6259	6851
Psychology	860	164	1024	27	2410	2437	4893	8354
Social work	1021	152	1173	32	2510	2542	6815	10530
Speech and language therapy	1434	295	1729	39	3855	3894	2913	8536
Other	441	72	513	12	1342	1354	4234	6101
<b>Number of people</b>	<b>1649</b>	<b>354</b>	<b>2003</b>	<b>50</b>	<b>5208</b>	<b>5258</b>	<b>14542</b>	<b>21803</b>

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 2010 within the four HSE regions. Nationally, 25,936 individuals (97.9%) with an intellectual disability registered on the NIDD were in receipt of services in 2010.

At national level, 8,213 individuals (31.0%) registered on the NIDD in 2010 were in receipt of a full-time residential service. Regionally, this proportion varied from 29.1% in the HSE South Region to 32.0% in the HSE West Region.

At national level, 17,705 (66.9%) attended services on a day basis, with the proportion ranging from 65.0% in the HSE West Region to 69.4% in the HSE South Region.

Nationally, a small proportion (287, 1.1%) of registrations were without services but were identified as requiring services in the five-year period 2011–2015. The HSE West Region had the highest proportion (1.8%) of people without any service and awaiting services within the next five years.

**Table 3.9** Service provision by HSE region of registration, 2010

	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	4592 (66.5)	2171 (31.4)	15 (0.2)	7 (0.1)	54 (0.8)	67 (1.0)	6906
South	5108 (69.4)	2087 (28.3)	58 (0.8)	5 (0.1)	63 (0.9)	43 (0.6)	7364
West	4491(65.0)	2191 (31.7)	23 (0.3)	3 (0.0)	121 (1.8)	75 (1.1)	6904
Dublin/North-East	3514 (66.2)	1526 (28.7)	142 (2.7)	3 (0.1)	49 (0.9)	76 (1.4)	5310
<b>All regions</b>	<b>17705 (66.9)</b>	<b>7975 (30.1)</b>	<b>238 (0.9)</b>	<b>18 (0.1)</b>	<b>287 (1.1)</b>	<b>261 (1.0)</b>	<b>26484</b>

## 4. Assessment of need 2011–2015

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

**A – Unmet need:** applies to people who, in 2010, 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 2011–2015. 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 2010 but will require that service to be changed or upgraded during the period 2011–2015, 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).

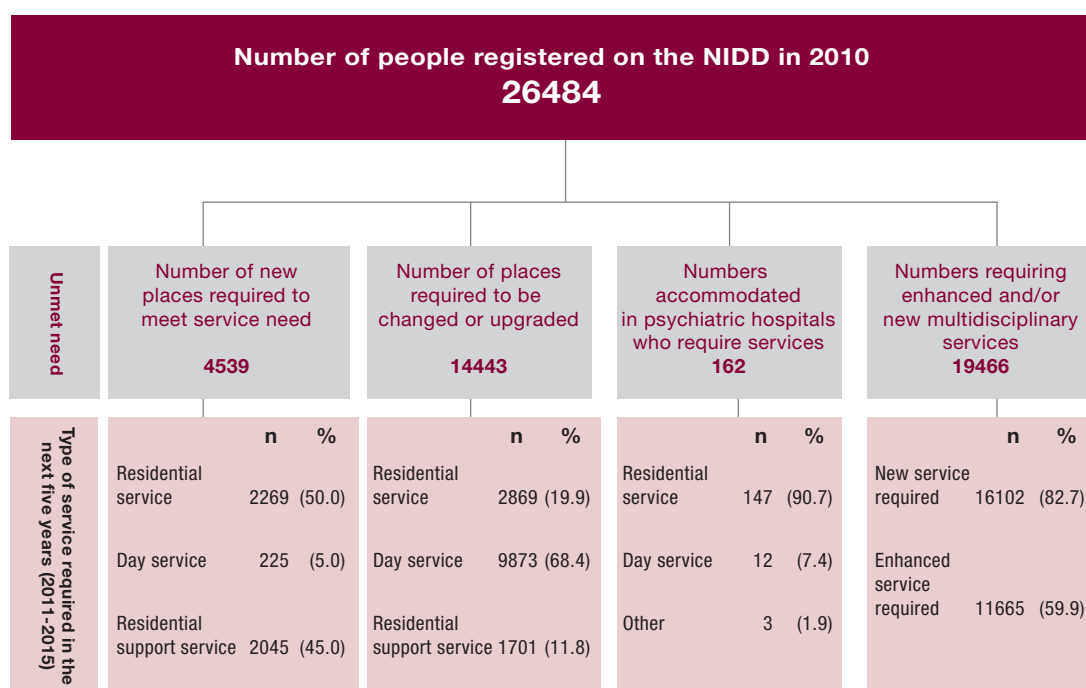
**C – People with intellectual disability who were accommodated in psychiatric hospitals in 2010:** includes people who need to transfer out of psychiatric hospitals in the period 2011–2015 and people who were resident in the psychiatric services in 2010 but require an appropriate day service in the period 2011–2015. 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 2011–2015 by all individuals registered on the NIDD in 2010. This category includes the multidisciplinary support service requirements of the unmet need and service change groups as well as those of people with an intellectual disability within the psychiatric services.

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

## Summary

Figure 4.1 indicates that 4,539 new residential, day and/or residential support places will be needed to meet service requirements in the period 2011–2015, half of which are residential places. Of the existing places available in 2010, 14,443 need to be changed or upgraded, with just over two-thirds of the changes/upgrades required in day services. Figure 4.1 also shows that 162 people accommodated in psychiatric hospitals in 2010 require specialist services; 90% of this group require residential services. In 2010, 19,466 people were recorded as requiring new or enhanced multidisciplinary services, which is a slight increase on the number recorded in 2009.



Note: '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 8,301 individuals whose multidisciplinary support service change involves both a new service and an enhanced service, therefore, the actual number of people requiring a new and/or enhanced service is  $(16,102 + 11,665) - 8,301 = 19,466$ .

**Figure 4.1** Summary of the service requirements of those registered on the NIDD, 2010

## 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 2011–2015, by HSE region of registration, 2010

	<b>Residential</b>	<b>Day</b>	<b>Residential support</b>	<b>% of total NIDD registrations</b>
Dublin/Mid-Leinster	623	52	476	26.1
South	559	44	666	27.8
West	502	97	566	26.1
Dublin/North-East	585	32	337	20.0
<b>Total</b>	<b>2269</b>	<b>225</b>	<b>2045</b>	<b>100</b>

The key figures and trends are summarised as follows:

- The number of new day places required has been falling steadily since 1996. However, the 2010 figure of 225 is a slight increase on the 2009 figure of 209. 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 in Section B below.
- The number of new residential places required has decreased slightly since 2009, from 2,298 places in 2009 to 2,269 places in 2010. Seven out of ten of those requiring a new residential place (1,613 individuals, 71.1%) have a moderate, severe or profound intellectual disability.
- The demand for residential supports has decreased slightly since 2009. The 2010 figure of 2,045 represents a small decrease of 70 (3.3%) since 2009. This high level of need is presenting even though there were over 5,000 people availing of residential support services in 2010.

### **Full-time residential services**

Of the 2,269 people who required full-time residential services in 2010 (Table 4.2):

- 1,613 individuals (71.1%) had a moderate, severe, or profound level of intellectual disability, of whom 1,358 required placements in community group homes, 145 required placements in a residential centre, and 103 required specialised intensive placements because of their increased dependency.
- 611 (26.9%) individuals had a mild intellectual disability, of whom 540 required placements in community group homes, 49 required placements in a residential centre, and 20 required specialised intensive placements due to their increased dependency.

- 45 (2.0%) had not had their level of intellectual disability verified in 2010. Of those who required full-time residential services in 2010, 2,251 (99.2%) were in receipt of a day service or a residential support service, 2,185 (96.3%) lived at home, and 74 (3.3%) lived independently or semi-independently.

### **Day services**

As in previous years, demand for day services among those reported as not being in receipt of such services was confined almost exclusively to adult services (Table 4.3). Of the 225 individuals who required day services, 206 (91.6%) lived either at home (187 individuals) or independently/semi-independently (19 individuals). The largest demand came from 203 people who had no service whatsoever in 2010. Of the 203 people who had no service:

- 135 individuals (66.5%) had a mild intellectual disability and their principal service requirements were in the training and employment areas.
- 62 individuals (30.5%) 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 2,045 people (Table 4.4). Of this group, 1,768 individuals (86.5%) lived either at home (1,692 individuals) or independently/semi-independently (76 individuals); 1,737 individuals (85.9%) were in receipt of a day service; and 32 individuals (1.6%) had no day service in 2010. An additional 276 individuals (13.5%) 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 2010 (1,091 individuals), while people with mild intellectual disability accounted for 42.5% (869 individuals). The remaining 4.2% (85 individuals) had not had their degree of intellectual disability verified in 2010.
- Most of the demand in 2010 was for crisis or planned respite services (1,244 individuals, 60.8%), semi-independent and independent living arrangements (395 individuals, 19.3%), and holiday residential placements (142 individuals, 6.9%).



**Table 4.2** Future full-time residential service requirements of individuals receiving no residential service in 2010, 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	0	1	1	4	109	166	279	4	110	168	282
7-day (48-week) community group home	0	0	2	2	0	0	0	0	0	1	87	211	299	1	87	213	301
7-day (52-week) community group home	0	4	2	6	0	0	0	0	13	339	975	1327	13	343	977	1333	
5-day residential centre	0	1	0	1	0	0	0	0	0	0	2	17	19	0	3	17	20
7-day (48-week) residential centre	0	0	0	0	0	1	0	1	0	11	35	46	0	12	35	47	
7-day (52-week) residential centre	0	1	4	5	0	0	0	0	23	33	89	145	23	34	93	150	
Nursing home	0	0	0	0	0	0	0	0	0	2	6	8	0	2	6	8	
Mental health community residence	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	1	
Intensive placement (challenging behaviour)	0	0	0	0	0	0	0	0	0	18	49	67	0	18	49	67	
Intensive placement (profound or multiple disability)	0	0	2	2	0	0	0	0	4	2	52	58	4	2	54	60	
<b>All services</b>	<b>0</b>	<b>7</b>	<b>11</b>	<b>18</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>2</b>	<b>45</b>	<b>603</b>	<b>1601</b>	<b>2249</b>	<b>45</b>	<b>611</b>	<b>1613</b>	<b>2269</b>	

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 2010, by degree of intellectual disability

	No service – requires day service					Receives residential support only – requires day service					Receives residential service only – requires day service					Overall need			
	NV	Mild	MSP	All		NV	Mild	MSP	All		NV	Mild	MSP	All		NV	Mild	MSP	All
Home support	1	1	5	7	0	0	0	0	0	0	0	0	0	0	0	1	1	5	7
Home help	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Mainstream pre-school	2	0	0	2	0	0	0	0	0	0	0	0	0	0	2	0	0	0	2
Mainstream school	1	0	1	2	0	0	0	0	0	0	0	0	0	0	1	0	0	1	2
Special class – secondary	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Special school	2	2	0	4	0	0	0	0	0	0	0	0	0	0	2	2	2	0	4
Third level education	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0
Rehabilitative training	0	32	8	40	0	0	0	0	0	0	0	0	1	1	0	32	9	41	
Activation centre	0	7	13	20	0	2	2	2	1	0	8	9	1	7	23	31			
Programme for the older person	0	2	2	4	0	0	0	0	0	0	1	1	0	2	3	5			
Special high support day service	0	0	4	4	0	0	0	0	0	0	0	0	0	4	4				
Special intensive day service	0	0	1	1	0	0	0	0	0	1	0	1	0	1	2				
Sheltered work centre	0	14	14	28	2	0	2	0	1	1	2	0	17	15	32				
Sheltered employment centre	0	1	1	2	0	0	0	0	0	0	0	0	1	1	2				
Other day service	0	4	0	4	0	0	0	0	0	1	1	0	4	1	5				
Enclave within open employment	0	1	0	1	0	0	0	0	0	0	0	0	1	0	1				
Supported employment	0	26	5	31	0	0	0	0	2	0	2	0	28	5	33				
Open employment	0	8	0	8	0	0	0	0	0	0	0	0	8	0	8				
Vocational training	0	35	7	42	0	0	0	0	0	1	1	0	35	8	43				
<b>All services</b>	<b>6</b>	<b>135</b>	<b>62</b>	<b>203</b>	<b>2</b>	<b>2</b>	<b>4</b>	<b>4</b>	<b>1</b>	<b>4</b>	<b>13</b>	<b>18</b>	<b>77</b>	<b>225</b>					

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

**Table 4.4** Future residential support service requirements of individuals receiving no residential support services in 2010, 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				
Foster care and boarding-out	0	0	0	0	0	1	0	1	0	0	0	0	0	0	1	2	0	2	1	3
Living independently	0	4	0	4	2	40	5	47	0	1	0	1	0	5	1	6	2	49	6	58
Living semi-independently	0	7	0	7	8	196	39	243	0	0	0	0	1	52	35	88	9	255	74	338
Holiday residential placement	0	0	1	1	0	39	31	70	0	0	0	0	0	7	64	71	0	46	96	142
Crisis or planned respite	2	12	6	20	54	420	723	1197	0	0	0	0	1	4	22	27	57	436	751	1244
Occasional respite care with host family	0	0	0	0	12	32	38	82	0	0	0	0	0	0	1	1	12	32	39	83
Shared care or guardianship	0	0	0	0	0	4	5	9	0	0	0	0	0	0	4	4	0	4	9	13
Regular part-time care (2/3 days per week)	0	0	0	0	0	5	10	15	0	0	0	0	0	0	0	0	0	5	10	15
Regular part-time care (every weekend)	0	0	0	0	1	1	4	6	0	0	0	0	0	1	0	1	1	2	4	7
Regular part-time care (alternate weeks)	0	0	0	0	0	2	5	7	0	0	0	0	0	0	1	1	0	2	6	8
Other residential service	0	0	1	1	2	15	20	37	0	0	0	0	0	15	58	73	2	30	79	111
Overnight respite in the home	0	0	0	0	2	5	16	23	0	0	0	0	0	0	0	0	2	5	16	23
<b>All services</b>	<b>2</b>	<b>23</b>	<b>8</b>	<b>33</b>	<b>81</b>	<b>760</b>	<b>896</b>	<b>1737</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>85</b>	<b>187</b>	<b>274</b>	<b>85</b>	<b>868</b>	<b>1091</b>	<b>2045</b>

## **Future need for centre-based respite services**

As illustrated in Table 4.5, most of the demand for residential support services in 2010 was for crisis or planned respite services. Table 4.5 presents the respite use and requirements of those registered, by LHO area. It also presents the total number who were living in a home or independent setting in 2010, and who may be in need of respite services in the future. The table presents data on each of the LHO areas and shows a marked difference in the number of people receiving and requiring the service. Overall, 25% of those who were living at home or in an independent setting in 2010 received respite care, while 7% of the same group required respite care. Within the LHO areas the percentage receiving respite ranged from 13.2% in LHO Roscommon to 37.8% in LHO North Dublin. Similarly, the percentage requiring respite ranged from 2.8% in LHO Dublin South-East to 12.0% in LHO Carlow/Kilkenny.



**Table 4.5** Use of and requirements for respite by people living in home/independent setting, by HSE region and LHO area, 2010

	Number in receipt of crisis or planned respite in 2010	Number who do not receive respite but require it (2011–2015)	Number in home/independent setting in 2010
LHO area	n	n	n
<b>HSE Dublin/Mid-Leinster Region</b>	<b>1316</b>	<b>255</b>	<b>4719</b>
LHO Dublin South	128	26	402
LHO Dublin South East	65	6	212
LHO Dublin South City	92	18	288
LHO Dublin South West	228	30	667
LHO Dublin West	144	25	625
LHO Kildare/West Wicklow	243	44	889
LHO Wicklow	100	14	444
LHO Laois/Offaly	154	32	621
LHO Longford/Westmeath	162	60	571
<b>HSE South Region</b>	<b>1065</b>	<b>359</b>	<b>5060</b>
LHO Carlow/Kilkenny	116	90	749
LHO Tipperary SR	126	18	464
LHO Waterford	101	45	502
LHO Wexford	157	35	716
LHO Cork North Lee	124	37	668
LHO Cork South Lee	123	42	563
LHO North Cork	87	23	431
LHO West Cork	60	24	287
LHO Kerry	171	45	680
<b>HSE West Region</b>	<b>1171</b>	<b>372</b>	<b>4826</b>
LHO Limerick	146	57	726
LHO Tipperary NR	87	26	350
LHO Clare	109	10	350
LHO Galway	279	71	1041
LHO Mayo	176	83	712
LHO Roscommon	48	24	363
LHO Donegal	208	58	790
LHO Sligo/Leitrim/West Cavan	118	43	494
<b>HSE Dublin/North-East Region</b>	<b>955</b>	<b>230</b>	<b>3580</b>
LHO Dublin North West	187	44	689
LHO Dublin North Central	110	23	341
LHO Dublin North	303	51	802
LHO Cavan/Monaghan	99	16	520
LHO Louth	103	25	626
LHO Meath	153	71	602
<b>All regions</b>	<b>4507</b>	<b>1217</b>	<b>18188</b>

Note: The total number recorded as receiving respite in Table 4.5 (4,507 individuals) is less than that recorded in Table 3.4 (4,951 individuals) as Table 4.5 includes only those living in a home setting or living independently. A small number of people living in other residential settings also receive respite services – this group is included in Table 3.4 but is excluded from Table 4.5 above.

## **B – Service change**

The term 'service change' applies to those who already had an intellectual disability service in 2010 but who require that service to be changed or upgraded during the period 2011–2015, and includes children who availed of education services in 2010 and who will require access to health-funded services in the future. Changes in service provision relate to:

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

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

### **Categories of service change requirements**

Table 4.6 indicates that 11,505 people who were receiving services in 2010 will require a change to their existing service provision in the period 2011–2015, a decrease of 59 (0.5%) since 2009. Of the 11,505 who were recorded as requiring a service change:

- 7,778 (67.6%) were day attendees (of whom 843 also availed of residential support services).
- 2,869 (24.9%) were full-time residents (of whom 2,095 also availed of day services).
- 858 (7.5%) received residential support services only.

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

- People in the moderate, severe and profound ranges of intellectual disability accounted for 7,379 (64.1%) of the service changes required.
- People in the mild range required 3,284 (28.5%) of the service changes.
- 842 (7.3%) of the service changes were required by people whose level of intellectual disability had not been verified in 2010.





**Table 4.6** Category of service change required 2011–2015, by degree of intellectual disability

	<b>Residential and day</b>	<b>Residential only</b>	<b>Day only</b>	<b>Day and residential support</b>	<b>Residential support only</b>	<b>Total requiring service changes</b>
	<b>n</b>	<b>n</b>	<b>n</b>	<b>n</b>	<b>n</b>	<b>n</b>
Not verified	8	15	789	14	16	842
Mild	194	95	2598	208	189	3284
Moderate, severe or profound	1893	664	3548	621	653	7379
<b>All levels</b>	<b>2095</b>	<b>774</b>	<b>6935</b>	<b>843</b>	<b>858</b>	<b>11505</b>

### 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, 2011–2015

<b>Residential</b>	<b>2869</b>
<b>Day</b>	<b>9873</b>
Of which:	6808
Health services	1186
Education services	1243
Employment services	636
Generic services	
<b>Residential support</b>	<b>1701</b>

The number of places requiring change exceeds the number of people who require service changes because some people require changes in both their residential and their day services. In addition, it is important to note that, although 11,505 people were recorded in 2010 as requiring service changes, this demand does not necessitate 11,505 new places. In many instances, these individuals will be vacating their existing placement when they receive their change of service. This will free up places for other people requiring a service change and those with unmet needs. For example, when young adults move into employment from training, their training place is freed up for young adults leaving school. It is also important to note that this entire group got some level of service in 2010, so a certain level of funding is already committed to these individuals.

## Summary of service change requirements

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

### Residential service change

Table 4.8 indicates that 2,869 individuals in full-time residential services in 2010 will require an upgrading or change of accommodation within the next five years. For 60.5% of this group (1,735 individuals) changes of service type are required as follows:

- Residential placements in the community are required by 985 individuals (34.3%).
- Intensive services for either challenging behaviour or profound or multiple disability are required by 577 individuals (20.1%).
- Centre-based placements are required by 127 individuals (4.4%).
- Nursing home placements are required by 46 individuals (1.6%).

The remaining 1,134 individuals (39.5%) require an enhancement of their existing service type, as follows:

- 323 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.
- 793 individuals need an enhancement of their existing service provision (shaded areas of Table 4.8).

**Table 4.8** Pattern of movement of individuals from existing residential services to future residential services, 2011–2015

	Full-time residential service required in the period 2010–2014											Total services 2010
	5-day CGH	7-day (48-wk) CGH	7-day (52-wk) CGH	5-day RC	7-day (48-wk) RC	7-day (52-wk) RC	Nursing home	Intensive placement (CB)	Intensive placement (P/MD)			
<b>Full-time residential service in 2010</b>												
5-day community group home (CGH)	15	50	132	1	0	11	0	5	0	0	0	214
7-day (48-week) community group home	1	38	113	1	6	13	0	6	2	0	0	180
7-day (52-week) community group home	6	8	477	0	0	33	21	46	27	0	0	618
5-day residential centre (RC)	8	3	23	2	4	2	0	0	0	0	0	42
7-day (48-week) residential centre	1	57	74	0	16	22	6	19	16	0	0	211
7-day (52-week) residential centre	1	13	688	0	3	141	15	193	238	0	0	1292
Nursing home	0	0	19	0	0	3	11	2	4	0	0	39
Mental health community residence	0	0	1	0	0	0	0	0	0	0	0	1
Intensive placement (challenging behaviour) (CB)	1	1	34	1	3	45	3	51	10	0	0	149
Intensive placement (profound or multiple disability) (P/MD)	0	2	27	0	1	5	0	2	42	0	0	79
Occupying a residential support place	2	1	21	0	0	1	1	2	3	0	0	31
Other residential service	0	1	7	0	0	3	0	2	0	0	0	13
<b>Total services required</b>	<b>35</b>	<b>174</b>	<b>1616</b>	<b>5</b>	<b>33</b>	<b>279</b>	<b>57</b>	<b>328</b>	<b>342</b>	<b>0</b>	<b>0</b>	<b>2869</b>

Note: The abbreviations in the sub-column headings refer to the placement descriptions which are given more fully in column one. The shaded areas of the table represent existing services that require alteration or enhancement.

## Day service change

Within the next five years, 9,873 individuals will require a change, enhancement, or upgrading of their day service (Table 4.9).

- Health-funded services are required by 6,808 individuals (69.0%).
- Employment services are required by 1,243 individuals (12.6%).
- Education services are required by 1,186 individuals (12.0%).
- Generic services are required by 636 individuals (6.4%).

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

## Health services

Of the 6,808 service changes required within health-funded services, 4,970 (73.0%) are requirements for an alternative or additional service and 1,838 (27.0%) are requirements for an enhancement of the individual's existing service (Table 4.9). The majority of the demand for alternative or additional health-funded services arises as follows:

- 849 individuals require high-support or intensive placements, the majority of whom currently attend activation programmes (381 individuals), or receive multidisciplinary support services as their only day service (204 individuals).
- 824 individuals require activation programmes, the majority of whom currently receive multidisciplinary support services as their only day service (344 individuals), or attend special schools (150 individuals), or rehabilitative training (100 individuals).
- 745 individuals require services specific to older people, the majority of whom currently attend activation programmes (335 individuals) or receive multidisciplinary support services as their only day service (184 individuals).
- 552 individuals require rehabilitative training, the majority of whom currently attend special schools (328 individuals).

There are also 1,838 individuals who need to have their existing health-funded service enhanced (shaded area of Table 4.9). Most of these people are attending activation centres (1,001 individuals, 54.5%) or sheltered work (256 individuals, 13.9%). 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 1,243 service changes required within employment services, 1,158 (93.2%) are requirements for an alternative placement and 85 (6.8%) are requirements for an enhancement of the individual's existing placement (Table 4.9).

Most of the demand for alternative employment opportunities comes from 1,054 individuals who require supported employment, the majority of whom currently attend sheltered work (378 individuals) or activation centres (254 individuals). There are 85 individuals who require their existing employment placement to be enhanced (Table 4.9).

## Education services

Of the 1,186 service changes required within education services, 926 (78.1%) are requirements for an alternative service and 260 (21.9%) 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:

- 325 children who require special classes, mainly at secondary level. The majority of those requiring special classes at secondary level (228 children) currently attend special classes at primary level (149 children).
- 280 children who require a mainstream school placement, the majority of whom currently attend a mainstream (143 children) or specialised (67 children) pre-school.
- 235 children who require a special school placement, the majority of whom currently attend special pre-schools (126 children).

There are 260 children who require their existing education placement to be enhanced (Table 4.9), the majority of whom currently attend mainstream schools (164 children). There is also a significant demand for increased support within existing education placements.

A large proportion of the 1,343 individuals who were attending special schools in 2010 require adult day services within the period 2011–2015. Of this group, almost one quarter (328 individuals) require rehabilitative training, 282 (21.0%) require vocational training and 150 (11.2%) require activation programmes.

## **Generic services**

Of the 636 service changes required within generic services, 610 (95.9%) are requirements for an alternative service and 26 (4.1%) are requirements for an enhancement of the individual's existing service (Table 4.9).

Most of the demand for alternative generic services comes from 581 individuals who require vocational training, the majority of whom currently attend special schools (282 individuals).

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

**Table 4.9** Pattern of movement of individuals from existing day services to future day services, 2011–2015

Day service in 2010	Day service required in the period 2011–2015																			Total								
	HS	HH	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	TL	RHT	AC	POP	SHS	SI	SWC	SEC	CDR		DRH	OP	OTH	E	SE	OE	VT	GD
Home support (HS)	28	0	7	16	0	1	0	1	1	1	0	8	9	3	1	2	6	1	0	3	0	1	0	6	0	2	1	98
Home help (HH)	0	0	1	0	0	0	0	0	0	0	0	1	1	1	0	0	0	1	0	1	0	0	0	0	0	0	0	6
Early services	13	0	138	71	1	10	0	2	0	6	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	243
Mainstream pre-school (MPS)	22	0	22	7	0	143	0	6	0	22	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	222
Special pre-school (SPS)	20	0	54	44	3	67	2	30	0	126	0	0	0	0	0	0	0	0	4	0	0	3	0	0	0	0	0	353
Child education and development centre (CEDC)	20	0	0	0	4	0	0	0	0	5	0	0	24	0	1	1	0	0	2	0	0	0	0	0	0	0	0	57
Mainstream school (MS)	76	3	7	1	1	164	62	16	55	36	2	13	7	0	0	0	0	0	46	2	13	38	0	1	2	51	1	597
Resource teacher (RT)	4	0	3	0	0	9	16	0	7	3	0	9	0	0	0	0	0	0	0	0	0	0	0	0	0	25	0	76
Special class – primary (SCP)	32	2	0	0	0	19	6	5	149	16	0	1	1	0	0	0	0	0	8	1	0	6	0	0	0	0	0	246
Special class – secondary (SCS)	6	0	0	0	0	2	3	0	8	4	0	18	12	0	1	0	7	1	2	0	1	2	0	1	1	29	0	98
Special school (SS)	151	6	5	1	4	14	2	34	13	67	0	328	150	0	20	33	134	15	28	6	2	33	0	12	2	282	1	1343
Third-level education (TL)	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	1	0	0	0	1	0	8	1	3	0	16
Rehabilitative training (RHT)	17	2	0	0	0	0	0	0	0	0	1	45	100	9	4	3	267	12	7	1	17	5	0	193	9	92	15	799
Activation centre (AC)	43	5	0	0	0	2	0	0	0	0	2	74	1001	335	179	202	120	12	10	1	5	19	1	254	13	24	3	2305
Programme for the older person (POP)	6	1	0	0	0	0	0	0	0	0	0	0	15	225	6	22	6	0	0	0	3	1	1	5	0	0	1	292
Special high support day service (SHS)	4	1	1	0	0	0	0	0	0	0	0	7	48	17	113	100	11	2	1	0	19	3	0	7	0	0	0	334
Special intensive day service (SI)	4	1	0	0	0	1	1	1	1	1	3	0	1	14	1	10	76	4	0	0	1	3	2	0	8	1	0	133

**Table 4.9** Pattern of movement of individuals from existing day services to future day services, 2011–2015 (continued)

Day service required in the period 2011–2015																												
Day service in 2010	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	Total
Sheltered work centre (SWC)	16	2	0	0	0	0	0	0	0	0	1	25	68	161	19	12	256	23	5	0	26	13	4	378	29	16	4	1058
Sheltered employment centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	3	0	0	0	0	0	0	0	0	6	0	2	12
Multidisciplinary support services	13	5	2	0	1	3	0	0	1	4	0	48	344	184	75	129	31	2	3	0	0	10	2	43	12	36	1	949
Centre-based day respite service (CDR)	0	0	0	0	0	0	0	0	0	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	1	4
Day respite in the home (DRH)	0	0	2	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	1	0	0	4
Outreach programme (OP)	0	0	1	0	0	0	0	0	0	1	0	1	1	0	0	3	2	0	1	0	18	1	0	6	1	0	1	37
Other day service (OTH)	9	2	3	15	0	10	1	7	1	7	0	10	12	18	6	7	59	0	0	2	6	0	19	3	10	0	207	
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	0	1	0	1	
Supported employment (SE)	7	3	0	0	0	0	0	0	0	0	0	2	4	6	0	6	2	5	0	6	6	6	1	76	10	4	2	140
Open employment (OE)	3	1	0	0	0	0	0	0	0	0	0	1	0	1	0	1	1	1	0	1	1	1	0	11	9	3	0	34
Vocational training (VT)	1	0	0	0	0	0	0	0	0	0	1	4	4	3	1	15	5	0	0	0	0	0	1	54	7	13	0	110
Generic day services (GD)	3	0	0	0	0	1	0	0	0	0	0	1	7	4	6	5	3	0	0	0	12	1	3	40	0	0	13	99
<b>Total</b>	<b>498</b>	<b>34</b>	<b>246</b>	<b>155</b>	<b>14</b>	<b>444</b>	<b>95</b>	<b>102</b>	<b>236</b>	<b>302</b>	<b>7</b>	<b>597</b>	<b>1825</b>	<b>970</b>	<b>442</b>	<b>596</b>	<b>932</b>	<b>78</b>	<b>123</b>	<b>16</b>	<b>128</b>	<b>154</b>	<b>13</b>	<b>1130</b>	<b>100</b>	<b>594</b>	<b>42</b>	<b>9873</b>

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

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

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



## Residential support service change

The database indicates that 1,701 individuals receiving residential support services will require an additional or alternative residential support service, or will require their existing support service to be upgraded during the period 2011–2015 (Table 4.10). Additional or alternative support services are required by 466 individuals (27.4%) and 1,235 individuals (72.6%) require their existing service to be upgraded (shaded areas of Table 4.10).

The principal residential support service changes or enhancements include:

- More frequent centre-based crisis or planned respite breaks for people already availing of this service (1,186 individuals).
- Opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (90 people).
- Occasional holiday residential placements and occasional respite care with a host family for people currently availing of crisis or planned respite (70 people).

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

**Table 4.10** Additional residential support services required by people availing of residential support services in 2010

Residential support service required 2011–2015													
Residential support service in 2010	Foster care and boarding-out	Living independently	Living semi-independently	Holiday residential placement	Crisis or planned respite	Occasional respite care (host family)	Shared care / guardianship	Regular part-time care (2/3 days per week)	Regular part-time care (every weekend)	Regular part-time care (alternate weeks)	Total		
												Overnight respite in the home	Other residential service
Foster care and boarding-out	3	1	7	2	6	3	1	1	0	1	0	1	26
Living semi-independently	0	14	21	12	5	0	0	0	0	0	0	0	52
Holiday residential placement	0	0	4	0	5	1	0	1	0	4	0	1	16
Crisis or planned respite	3	3	90	23	1186	47	21	68	18	19	2	14	1494
Occasional respite care (host family)	0	2	9	1	33	21	4	3	0	1	3	2	79
Shared care / guardianship	0	0	0	0	2	0	1	0	0	0	0	0	3
Regular part-time care (2/3 days per week)	0	0	2	0	8	0	3	0	2	0	0	0	15
Regular part-time care (alternate weeks)	0	0	1	0	3	0	0	0	0	1	0	0	5
Overnight respite in the home	0	0	0	0	1	0	0	0	0	0	1	1	3
Other residential service	0	0	2	0	4	0	0	0	0	1	0	1	8
<b>All services</b>	<b>6</b>	<b>20</b>	<b>136</b>	<b>38</b>	<b>1253</b>	<b>72</b>	<b>30</b>	<b>73</b>	<b>20</b>	<b>27</b>	<b>6</b>	<b>20</b>	<b>1701</b>

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

## Day service requirements of school leavers

Each year a proportion of those on the NIDD, as they reach the age of 18 years, 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 report focuses on the day service requirements of this specific group to examine their likely demand for services in the health sector. The next section focuses on children aged 16 years or older who were in second-level education in 2010 and who will require an adult day service in the years 2011–2015.

Over eight hundred young adults with an intellectual disability aged 16 years or over who were in an education setting in 2010 will require a range of day services within the period 2011–2015 (Table 4.11). Most of the demand is for vocational training (284 places) or rehabilitative training (227 places).

Of the 841 individuals who will require a day service (Table 4.12):

- 454 (54%) individuals had a mild intellectual disability, of whom 224 require vocational training and 123 require rehabilitative training.
- 386 (46%) individuals had a moderate, severe or profound level of intellectual disability, of whom 104 require rehabilitative training and 80 require activation programmes.
- One person had not had his/her level of intellectual disability verified in 2010 but requires vocational training.

Table 4.13 identifies the year in which the day services are required. Most of the day service requirements are immediate: 750 individuals (89%) require their day service in 2011 or 2012.

**Table 4.11** Future day service requirements of individuals aged 16 years or over who were in an education setting in 2010, by age

	16 years	17 years	18 years	19 years +	Total
Home support	14	12	8	1	35
Third-level education	0	0	1	0	1
Rehabilitative training	89	91	33	14	227
Activation centre	32	51	19	2	104
Special high-support day service	1	3	6	0	10
Special intensive day service	9	7	4	1	21
Sheltered work centre	30	35	16	4	85
Sheltered employment centre	5	4	2	2	13
Centre-based day respite service	5	7	4	1	17
Day respite in the home	2	0	0	0	2
Outreach programme	2	1	0	0	3
Other day service	6	12	5	4	27
Supported employment	0	3	4	1	8
Open employment	3	1	0	0	4
Vocational training	72	110	59	43	284
<b>Total</b>	<b>270</b>	<b>337</b>	<b>161</b>	<b>73</b>	<b>841</b>

**Table 4.12** Future day service requirements of individuals aged 16 years or over who were in an education setting in 2010, by degree of intellectual disability

	Mild	Moderate/Severe/ Profound	Total*
Home support	6	29	35
Third-level education	1	0	1
Rehabilitative training	123	104	227
Activation centre	24	80	104
Special high-support day service	0	10	10
Special intensive day service	1	20	21
Sheltered work centre	39	46	85
Sheltered employment centre	7	6	13
Centre-based day respite service	4	13	17
Day respite in the home	0	2	2
Outreach programme	1	2	3
Other day service	13	14	27
Supported employment	7	1	8
Open employment	4	0	4
Vocational training	224	59	283
<b>Total</b>	<b>454</b>	<b>386</b>	<b>840</b>

\*The total excludes one individual whose level of intellectual disability was 'not verified'.



**Table 4.13** Future day service requirements of individuals aged 16 years or over who were in an education setting in 2010, by year of service requirement

	<b>2011</b>	<b>2012</b>	<b>2013-15</b>	<b>Total*</b>
Home support	33	0	0	33
Third-level education	1	0	0	1
Rehabilitative training	119	78	30	227
Activation centre	53	38	12	103
Special high-support day service	7	2	0	9
Special intensive day service	12	7	1	20
Sheltered work centre	46	29	10	85
Sheltered employment centre	7	4	2	13
Centre-based day respite service	17	0	0	17
Day respite in the home	1	0	0	1
Outreach programme	3	0	0	3
Other day service	21	5	1	27
Supported employment	6	0	1	7
Open employment	2	1	1	4
Vocational training	181	77	23	281
<b>Total</b>	<b>509</b>	<b>241</b>	<b>81</b>	<b>831</b>

\*The total excludes ten individuals for whom year in which service was required was not recorded.

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

The data from the NIDD for 2010 identified 238 individuals with intellectual disability, all aged 20 years or over, who were accommodated in psychiatric hospitals. Table 4.14 details the overall service requirement status of this group by level of intellectual disability and by HSE region responsible.

**Table 4.14** Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2010, by HSE region of registration

Resident in psychiatric hospital in 2010	No service requirements				Has service requirements				Total
	Not verified	Mild	Moderate/ Severe/ Profound	All levels	Not verified	Mild	Moderate/ Severe/ Profound	All levels	
<b>Dublin/Mid-Leinster</b>									
With no day programme	0	0	1	1	0	0	0	0	1
With day programme	1	3	4	8	0	5	1	6	14
<b>South</b>									
With no day programme	0	0	1	1	0	1	1	2	3
With day programme	0	10	11	21	0	11	23	34	55
<b>West</b>									
With no day programme	0	0	0	0	0	0	0	0	0
With day programme	0	7	7	14	0	4	4	8	22
With residential support service and day programme	0	1	0	1	0	0	0	0	1
<b>Dublin/North-East</b>									
With no day programme	0	0	0	0	0	0	0	0	0
With day programme	0	10	20	30	0	29	83	112	142
<b>All residents</b>	<b>1</b>	<b>31</b>	<b>44</b>	<b>76</b>	<b>0</b>	<b>50</b>	<b>112</b>	<b>162</b>	<b>238</b>

Of this group, 162 individuals (68.1%) were recorded as having service requirements in the period 2011–2015, of whom:

- 147 individuals had an appropriate alternative residential facility identified for them (60 of whom also required a day service). The residential service requirements of this group are shown in Table 4.16 and their day service requirements are shown in Table 4.17. In recent years there has been considerable change in service provision for this cohort, mainly as a result of changes implemented following the report of the expert group on mental health policy, A Vision for Change. Some additional investigation of the status of this cohort and their placement within services will be undertaken in 2011 and reported on in next year's Annual Report.
- 12 individuals were recorded as appropriately placed within the psychiatric hospital but had identified day service requirements, as shown in Table 4.15.

**Table 4.15** Day service requirements of people appropriately accommodated in psychiatric hospitals in 2010

Day service in 2010	Services required 2011–2015				All services
	Activation centre	Special high-support day service	Supported employment	Other day service	
Rehabilitative training	0	0	1	0	1
Activation centre	1	1	0	0	2
Multidisciplinary support services only	7	1	0	1	9
<b>All services</b>	<b>8</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>12</b>

*Note: Four of the 12 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.*

Of the 147 people who were recorded in 2010 as needing to transfer from psychiatric to intellectual disability services for provision of their residential services, 58 individuals (39.5%) required places in residential centres, 52 individuals (35.4%) required intensive placements, and 36 individuals (24.5%) required community group home places. One individual needed to move to a mental health community centre. In all cases the need was immediate (Table 4.16).

**Table 4.16** Residential service requirements of people resident in psychiatric hospitals in 2010 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	34
7-day (48-week) residential centre	1
7-day (52-week) residential centre	57
Mental health community residence	1
Intensive placement (challenging behaviour)	41
Intensive placement (profound/multiple disability)	11
<b>All residential services</b>	<b>147</b>

Of this same group of 147 people, 60 required an appropriate day service. The greatest demand was for high-support or intensive day programmes (36 individuals, 60.0%), activation programmes (9 individuals, 15.0%) and programmes for the older person (7 individuals, 11.7%). All day services were required immediately (Table 4.17).

**Table 4.17** Day service requirements of people resident in psychiatric hospitals in 2010 who require transfer to the intellectual disability sector

	<b>Number requiring day service</b>
Rehabilitative training	3
Activation centre	9
Programme for the older person	7
Special high-support day service	28
Special intensive day service	8
Sheltered work centre	2
Sheltered employment centre	1
Generic day services	2
<b>All day services</b>	<b>60</b>

*Note: 34 of the 60 also have multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.*

The 2010 data indicate that the current day and residential programmes for 76 people with intellectual disability resident in psychiatric hospitals were appropriate and that these people had no identified service needs in the period 2011–2015 (Table 4.14). Forty-four of this group (58%) had a moderate, severe or profound intellectual disability, 31 (41%) had a mild disability and one person’s level of disability was not verified. Within this group, two people had no formal day programme.

## **D – Multidisciplinary support services**

Although the NIDD facilitates the recording of two future day services that will be required by an individual, earlier sections of this chapter detail only the first future day service so that individuals are not double-counted. Future multidisciplinary support services, including those to be delivered by early intervention teams, are only recorded as a first future day service if these support services are the only future day service required. In reality, these services are required in addition to a more substantial day service component. To avoid under-reporting the demand for these services, these requirements are excluded from the unmet need, service change, and psychiatric hospital sections above and are reported separately below in Figure 4.2. A ‘requirement’ refers to a new type of therapeutic input that the individual did not receive in 2010 and an ‘enhancement’ refers to a change in the delivery of a therapeutic input that the individual received in 2010 (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 2010 with the demand for services in the period 2011–2015.





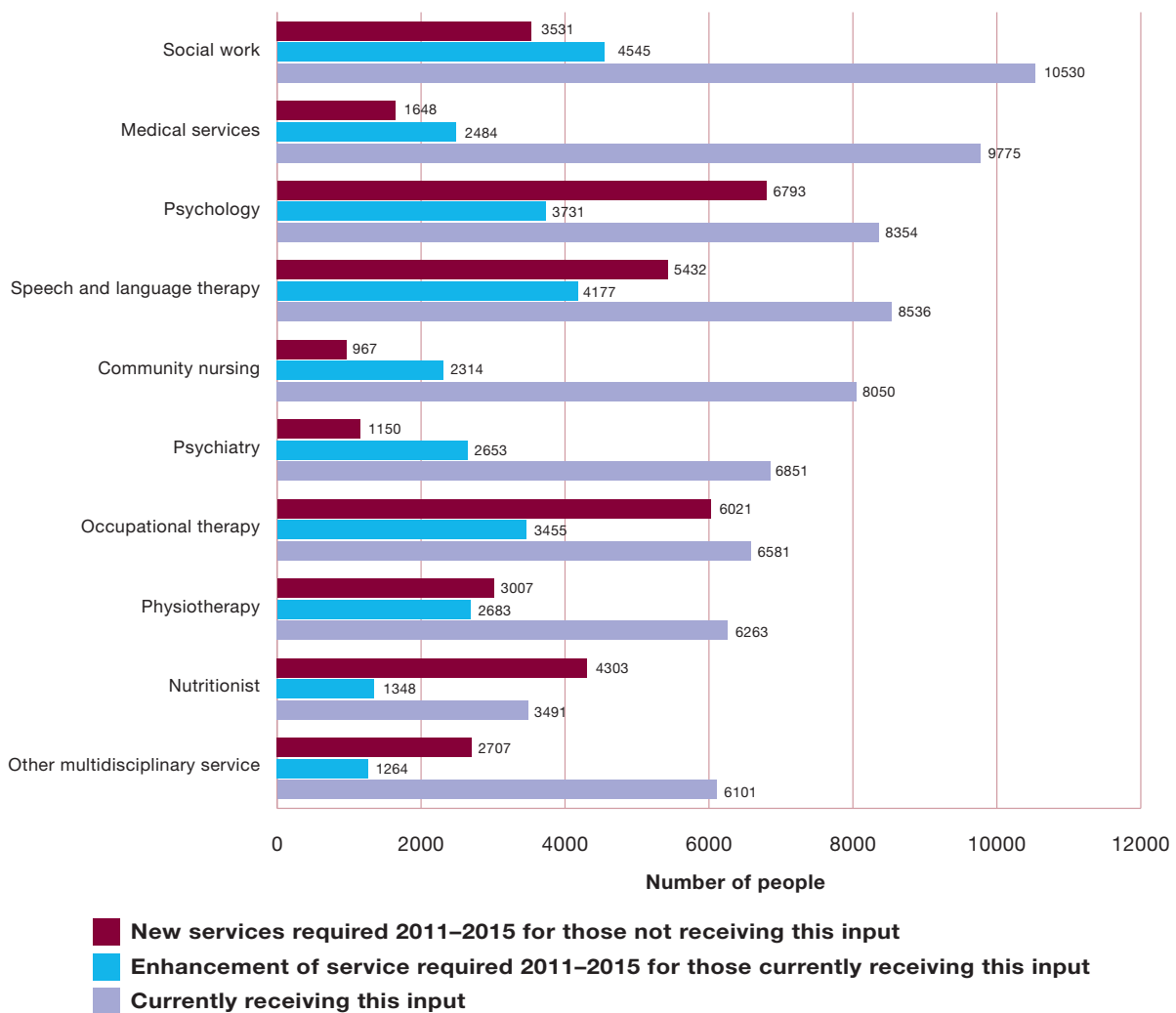
In 2010 multidisciplinary support services were availed of by 21,803 people, 16,957 of whom had further requirements for such services. A further 2,509 individuals who did not access such services in 2010 require them. There are, therefore, 19,466 (16,957 plus 2,509) individuals with a need for multidisciplinary support services; these needs involve either an enhancement of a type of service received in 2010 (3,364 individuals), a requirement for a new type of service (7,801 individuals), or both (8,301 individuals). Of the 19,466 people with future multidisciplinary support service needs, 175<sup>10</sup> received no service whatsoever in 2010. Ninety-nine per cent of those in need of multidisciplinary support services require them immediately.

Despite high levels of service provision in 2010, there was substantial demand for new services and enhanced services relating to all the therapeutic inputs, in particular, for psychology, speech and language therapy and occupational therapy. For example, 8,354 individuals received a psychology service in 2010, 3,731 of whom needed an enhancement of their service, and a further 6,793 individuals who did not receive a psychology service in 2010 require one in the period 2011–2015.

The data show that there was a significant shortfall in the provision of nutritionist services; this was the only therapeutic input where the demand for a new service exceeded service provision in 2010. For example, 3,491 individuals were in receipt of the services of a nutritionist in 2010, 1,348 of whom needed an enhancement of their service, and a further 4,303 individuals who were not in receipt of this service in 2010 require it in the immediate future.

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<sup>10</sup> 108 of the 175 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 2010 and required in the period 2011–2015

### Overall service provision to people with intellectual disability and the pattern of care required in the period 2011–2015

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 2010 data indicate that there were large numbers of people who required residential services for the first time in 2010 and also that there were significant numbers who required changes to, or enhancements of, their existing residential or day placements (or both). Not all service changes will require the individual to move to a new placement as many changes involve enhancements, such as increased support, which can be made available in the existing placement. Where the enhancement involves a move to a new placement, the freed-up place may become available to others who have an identified need for such a placement. The existing placements occupied by these individuals are secure until their new places become available.



## Pattern of care required in full-time residential services

As indicated in Table 4.18, demand for full-time residential services in the period 2011–2015 comes from three distinct groups already identified in this chapter:

- 2,269 individuals who lived at home in 2010 and who were recorded as requiring full-time residential services for the first time in 2010;
- 147 individuals who resided in psychiatric hospitals in 2010 and who were recorded as requiring to transfer to the intellectual disability services; and
- 2,869 individuals who were in full-time residential services within the intellectual disability sector in 2010 and who require changes to their existing placement. Of this group, 1,735 require alternative services and 1,134 require their existing service to be enhanced. Not all of the group who require service enhancements will move to new placements. However, they have been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading their services. Where the change involves a move to a new placement, the freed-up place may be available to others who are identified as requiring this service.

Table 4.18 outlines the pattern of full-time residential service provision that will be required in the period 2011–2015 to meet this demand. A total of 2,447 residential places will be required, a decrease of 54 since 2009.

- As expected, there is significant demand for community-based placements, both from people who will be coming into residential services for the first time and from people in existing residential placements. In total, 2,765 community-based placements will be required during the period, a decrease of 100 placements (3.5%) since 2009.
- There will also be a shortfall of 621 intensive residential placements, a decrease of 50 placements (7.5%) on the shortfall recorded in 2010. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

**Table 4.18** Pattern of full-time residential service provision required, 2011–2015

	<b>New services required by people living at home</b>	<b>New services required by people transferring from psychiatric hospitals</b>	<b>Service changes required by people in existing full-time residential places</b>	<b>Places vacated by people in full-time residential places</b>	<b>Shortfall (-)/ Excess of places arising from demand</b>
5-day community group home	282	0	35	214	-103
7-day (48-week) community group home	301	2	174	180	-297
7-day (52-week) community group home	1333	34	1616	618	-2365
5-day residential centre	20	0	5	42	17
7-day (48-week) residential centre	47	1	33	211	130
7-day (52-week) residential centre	150	57	279	1292	806
Nursing home	8	0	57	39	-26
Mental health community residence	1	1	0	1	-1
Psychiatric hospital	0	0	0	0	0
Intensive placement (challenging behaviour)	67	41	328	149	-287
Intensive placement (profound or multiple disability)	60	11	342	79	-334
Other/unspecified intellectual disability service	0	0	0	13	13
Designated residential support placement	0	0	0	31*	0
<b>Total</b>	<b>2269</b>	<b>147</b>	<b>2869</b>	<b>2838</b>	<b>-2447</b>

\* 31 designated residential support places being blocked by full-time residents will be freed up, but they have not been deducted from the total number of full-time residential places required as they should not be made available for full-time use.

## Pattern of care required in day services

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

- 225 individuals who were without day services in 2010;
- 60 individuals who were resident in psychiatric hospitals in 2010 and who will require an appropriate day service when they transfer to intellectual disability services;
- 12 individuals appropriately placed in psychiatric hospitals in 2010 who will require a day programme within that setting between 2011 and 2015; and
- 9,873 individuals who were in day services within the intellectual disability sector in 2010 and who will require changes to, or enhancements of, their placement. Of this group, 7,664 require alternative or additional services and 2,209 require their service to be enhanced. The majority (6,808) of these changes involve services provided by the health sector. Many of the changes are required to address transitional needs, such as moving from child to adult services or moving from training into employment. Not all of the group who require service enhancements will move to new placements. However, the entire group has been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading services for these individuals. Where the change involves a move to a new placement, the freed-up place may be available to others who are identified as requiring this service.

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

The data in relation to certain day services<sup>11</sup> are reported and interpreted on the assumption that:

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

Table 4.19 outlines the pattern of day service provision that will be required in the period 2011–2015 to meet demand. The data in the table have been adjusted to reflect the fact that not all existing services will be freed up.

A total of 1,677 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 2011–2015 will be as follows:

- A reduction of approximately 10% may be expected in the number of children requiring places in special schools; the number decreased from 1,157 children in 2009 to 1,037 in 2010. Although the numbers are small, there is a demand within this group for mainstream services.
- There is likely to be a shortfall of training and employment opportunities. In the next five years, 1,024 supported employment opportunities, 527 vocational training placements, and 74 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; 690 such places will be needed over the next five years in addition to current provision.
- As with residential services, there is significant demand for high-support and intensive day placements. Over the next five years, 142 high-support day placements and 473 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.

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11 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, 2011–2015

	New services required by people without day services	New services required by people transferring from psychiatric hospitals	New services required by people within psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Shortfall (-)/ Excess of places arising from demand
Home support	7	0	0	0	498	0	-505
Home help	1	0	0	0	34	0	-35
Mainstream pre-school	2	0	0	0	246	222	-26
Special pre-school	0	0	0	0	155	353	198
Child education and development centre	0	0	0	0	14	57	43
Mainstream school	2	0	0	0	444	597	151
Resource/visiting teacher	0	0	0	0	95	0	-95
Special class – primary	0	0	0	0	102	246	144
Special class – secondary	1	0	0	0	236	98	-139
Special school	4	0	0	0	302	1343	1037
Third-level education	1	0	0	0	7	16	8
Rehabilitative training	41	3	0	0	597	799	158
Activation centre	31	9	8	8	1825	2305	432
Programme for the older person	5	7	0	0	970	292	-690
Special high-support day service	4	28	2	2	442	334	-142
Special intensive day service	2	8	0	0	596	133	-473
Sheltered work centre	32	2	0	0	932	1058	92
Sheltered employment centre	2	1	0	0	78	12	-69
Centre-based day respite service	0	0	0	0	123	0	-123
Day respite in the home	0	0	0	0	16	0	-16
Other day service	5	0	1	1	154	207	47
Outreach programme	0	0	0	0	128	37	-91
Enclave within open employment	1	0	0	0	13	1	-13
Supported employment	33	0	1	1	1130	140	-1024
Open employment	8	0	0	0	100	34	-74
Vocational training	43	0	0	0	594	110	-527
Generic day services	0	2	0	0	42	99	55
<b>All services</b>	<b>225</b>	<b>60</b>	<b>12</b>	<b>9873</b>	<b>8493</b>	<b>-1677</b>	

## 5. Conclusion

As a national health information system on intellectual disability, the NIDD continues to be relevant to health service managers and policy makers as a tool for planning services in this area. This annual report from the NIDD, based on information from almost 26,500 people who were registered on the database at the end of December 2010, represents the cumulative specialised health service needs of this group of people.

The 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 1996–2010, and further information is reported for the past three decades, which allows an opportunity to look back at changes over time and estimate what the consequence of these changes may be for future provision.

Overall, the 2010 data show that, in line with previous years, there has been a significant increase in the levels of day service and respite service provision; however, there has been a small decrease in the number of people living in full-time residential services. Alongside this, however, this report highlights the fact that the changing age profile of individuals with intellectual disability continues to contribute to high levels of demand for residential services, support services for ageing caregivers and services designed specifically to meet the needs of older people with intellectual disability.

This report also shows that the proportion of those registered who are in receipt of day services is the highest since the database was established. 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.

The report highlights that school leavers require significant service interventions as they leave the education system and require day services that are funded by the HSE in the areas of training and employment.

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; for the seventh year in a row the data show that the number of full-time residential placements in the community exceeds that of centre-based settings. The data on respite services also show high levels of provision in 2010, albeit with varying degrees of coverage across the country.



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

The majority of those registered on the NIDD in 2010 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 the services most commonly availed of by children. This pattern of multidisciplinary support usage is similar to that indicated by 2009 data. Despite the high levels of service provision in 2010, there remains a substantial demand for new services and enhanced services relating to all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy, in the five-year period 2011–2015.

Despite increasing levels of service provision, there are still high levels of unmet need among a critical number of individuals who are registered on the NIDD. Although the data in recent years highlight growth in services, demographic factors are contributing to the increasing need for these services. The number of people with an intellectual disability is growing and the proportion who are in the older age groups is increasing. This changing age profile observed in the data has major implications for service planning; it points to an ongoing demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability. The challenge for all will be to set priorities and deliver and plan quality services within a national policy and tight budgetary framework.

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# Appendix A

## 2010 National Intellectual Disability Database form



### National Intellectual Disability Database Data Form

#### PERSONAL DETAILS

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

#### Next of Kin details

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

**CURRENT SERVICE PROVISION**

**Day Services**

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

**Residential Services**

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

**MULTIDISCIPLINARY SUPPORT SERVICES**

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

Multidisciplinary Service	Current		Future		
	Currently Receiving √	Agency Providing Current Service	Not Receiving but Requiring √	Receiving but needing an enhancement √	Reason for Duplication between Received and Enhanced
Medical services	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Nursing	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Nutrition	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Occupational therapy	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Physiotherapy	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Psychiatry	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Psychology	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Social work	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Speech & language therapy	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _
Other	<input type="radio"/>	_ _ _ _ _ _ _ _	<input type="radio"/>	<input type="radio"/>	_ _

**Specify**

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

58. Will future services be provided by an early intervention team?  1=yes 2=no 3=n/a

## FUTURE SERVICE REQUIREMENTS

### REQUIRED DAY SERVICES

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

### CONTINGENCY DAY SERVICES

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

### RESIDENTIAL SERVICES

71. Type of residential service (1) required
72. Level of support required in residential service (1) A. B. C. D. E. Z.
73. Year in which residential service (1) is required
74. Primary reason for duplication on current and future residential service (1)
75. Type of residential service (2) required
76. Level of support required in residential service (2) A. B. C. D. E. Z.
77. Year in which residential service (2) is required
78. Primary reason for duplication on current and future residential service (2)

### CONTINGENCY RESIDENTIAL SERVICES

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

83. HSE area responsible for funding future services

#### DAY SUPPORT LEVEL CODES

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

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

#### RESIDENTIAL SUPPORT LEVEL CODES

Coding for questions 47, 51, 72, 76 & 80

- A: MINIMUM (no sleep-in)
- B: LOW (staff on duty most of the time plus sleep-in)
- C: MODERATE (two staff on duty plus sleep-in)
- D: HIGH (two staff on duty plus on-duty night staff)
- E: INTENSIVE (one to one)
- 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**

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

	Not verified				Mild				Moderate-Severe-Profound				All levels							
	0-19	20-34	35-54	55+ All ages	0-19	20-34	35-54	55+ All ages	0-19	20-34	35-54	55+ All ages	0-19	20-34	35-54	55+ All ages				
<b>Residential circumstances</b>																				
<b>Home Setting</b>	<b>1778</b>	<b>53</b>	<b>61</b>	<b>21</b>	<b>1913</b>	<b>3477</b>	<b>1740</b>	<b>1158</b>	<b>226</b>	<b>6601</b>	<b>3770</b>	<b>2740</b>	<b>1781</b>	<b>307</b>	<b>8598</b>	<b>9025</b>	<b>4533</b>	<b>3000</b>	<b>554</b>	<b>17112</b>
At home with both parents	1503	40	21	1	1565	2505	1222	503	12	4242	2928	2047	745	15	5735	6936	3309	1269	28	11542
At home with one parent	246	10	27	5	288	787	443	451	50	1731	750	616	672	47	2085	1783	1069	1150	102	4104
At home with sibling	0	2	11	13	26	5	12	157	125	299	3	33	330	213	579	8	47	498	351	904
At home with other relative	4	0	1	2	7	43	22	31	30	126	19	11	22	23	75	66	33	54	55	208
Lives with non-relative	2	0	0	0	2	3	3	9	3	18	1	2	3	3	9	6	5	12	6	29
Adoption	0	0	0	0	0	5	8	0	0	13	5	4	1	0	10	10	12	1	0	23
Foster care and boarding out arrangements	23	1	1	0	25	129	30	7	6	172	64	27	8	6	105	216	58	16	12	302
<b>Independent/Semi-independent Setting</b>	<b>0</b>	<b>8</b>	<b>29</b>	<b>15</b>	<b>52</b>	<b>5</b>	<b>182</b>	<b>459</b>	<b>185</b>	<b>831</b>	<b>0</b>	<b>34</b>	<b>90</b>	<b>69</b>	<b>193</b>	<b>5</b>	<b>224</b>	<b>578</b>	<b>269</b>	<b>1076</b>
Lives independently	0	4	19	14	37	5	121	298	134	558	0	23	47	42	112	5	148	364	190	707
Living semi-independently	0	4	10	1	15	0	61	161	51	273	0	11	43	27	81	0	76	214	79	369
<b>Community Group Homes</b>	<b>1</b>	<b>5</b>	<b>5</b>	<b>7</b>	<b>18</b>	<b>45</b>	<b>144</b>	<b>451</b>	<b>289</b>	<b>929</b>	<b>85</b>	<b>571</b>	<b>1752</b>	<b>733</b>	<b>3141</b>	<b>131</b>	<b>720</b>	<b>2208</b>	<b>1029</b>	<b>4088</b>
5-day community group home	0	1	1	2	4	28	24	51	12	115	17	94	199	10	320	45	119	251	24	439
7-day (48 week) community group home	0	0	0	0	0	3	20	70	20	113	12	77	288	49	426	15	97	358	69	539
7-day (52 week) community group home	1	4	4	5	14	14	100	330	257	701	56	400	1265	674	2395	71	504	1599	936	3110
<b>Residential centres</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>9</b>	<b>11</b>	<b>4</b>	<b>28</b>	<b>73</b>	<b>127</b>	<b>232</b>	<b>48</b>	<b>384</b>	<b>1232</b>	<b>904</b>	<b>2568</b>	<b>52</b>	<b>412</b>	<b>1307</b>	<b>1040</b>	<b>2811</b>
5-day (48 week) residential centre	0	0	0	0	0	1	1	2	2	6	5	17	30	3	55	6	18	32	5	61
7-day (48 week) residential centre	0	0	1	0	1	0	7	11	12	30	16	91	140	66	313	16	98	152	78	344
7-day (52 week) residential centre	0	0	1	9	10	3	20	60	113	196	27	276	1062	835	2200	30	296	1123	957	2406

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

	Not verified					Mild					Moderate-Severe-Profound					All levels				
	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages	0-19	20-34	35-54	55+	All ages
<b>Residential circumstances</b>	3	1	6	12	22	6	49	80	97	232	57	271	466	266	1060	66	321	552	375	1314
<b>Other full-time services</b>	0	0	3	10	13	0	0	4	32	36	0	2	29	76	107	0	2	36	118	156
Nursing home	0	0	0	0	0	0	2	9	13	24	0	0	6	25	31	0	2	15	38	55
Mental health community residence	0	0	0	0	0	0	2	9	13	24	0	0	6	25	31	0	2	15	38	55
Psychiatric hospital	0	0	0	1	1	1	8	32	40	81	0	12	59	85	156	1	20	91	126	238
Intensive placement (Challenging Behaviour)	0	0	1	0	1	1	24	29	4	58	25	154	210	43	432	26	178	240	47	491
Intensive placement (Profound or Multiple disability)	1	0	0	0	1	0	3	4	1	8	17	85	127	18	247	18	88	131	19	256
Full time 'other' residential service	1	0	2	1	4	4	10	2	4	20	5	8	20	14	47	10	18	24	19	71
Full time resident in residential support place	1	1	0	0	2	0	2	0	3	5	10	10	15	5	40	11	13	15	8	47
<b>No fixed abode</b>	0	0	0	0	0	0	5	2	2	9	0	0	3	1	4	0	5	5	3	13
<b>Insufficient Information</b>	0	0	0	0	0	3	4	0	0	7	2	16	26	19	63	5	20	26	19	70
	1782	67	103	64	2016	3540	2152	2223	926	8841	3962	4016	5350	2299	15627	9284	6235	7676	3289	26484

# Appendix D

## National Intellectual Disability Database publications

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

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