



# HRB Statistics Series 8

Annual Report of the National Intellectual Disability  
Database Committee 2009

Caraíosa Kelly, Sarah Craig and Fionnola Kelly



**Ciaran Smyth**

National Intellectual Disability Database Committee Annual Report 2009 cover design competition winner.

Ciaran lives with his parents in Ashford, County Wicklow and attends Glenvale Day Centre, which is part of Sunbeam House Services, five days a week. He enjoys listening to music, horse racing, arts and crafts, gardening and watching the Late, Late Show. He also enjoys getting involved in daily activities and socialising with friends. The winning image designed by Ciaran was entitled 'Happy Fatherhood'.



*'Happy Fatherhood'*  
by Ciaran Smyth

# HRB Statistics Series 8

Annual Report of the National  
Intellectual Disability Database  
Committee 2009

Caraíosa Kelly, Sarah Craig and Fionnola Kelly

**Published by:**

Health Research Board, Dublin  
An Bord Taighde Sláinte  
Knockmaun House  
42–47 Lower Mount Street  
Dublin 2  
Ireland

© Health Research Board 2010  
HRB Statistics Series ISSN: 2009-034x  
Sub-series ISSN: 1393–9904

**Copies of this report can be obtained from:**

Disability Databases Team  
Health Research Board  
Knockmaun House  
42–47 Lower Mount Street  
Dublin 2  
Ireland

t 353 1 234 5194  
f 353 1 661 1856



# 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 (1965–2008)
- National Physical and Sensory Disability Database Committee Annual Reports (2004–2008)
- National Intellectual Disability Database Committee Annual Reports (1996–2008)

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



## **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.



# Table of contents

List of tables and figures	6
Acknowledgements	9
Members of the National Intellectual Disability Database Committee 2009	11
Chairperson's statement	13
Executive summary	15
1. The National Intellectual Disability Database	19
2. Profile of the population	23
3. Service provision in 2009	33
4. Assessment of need 2010–2014	53
5. Conclusion	86
References	88
Appendix A	89
National Intellectual Disability Database form 2009	89
Appendix B: Service categories	93
Day programmes	93
Residential circumstances	94
Day service groupings	95
Appendix C:	
Supplementary table	96
Appendix D	98
National Intellectual Disability Database publications	98





# 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, 2009	24
<b>Table 2.2</b>	Prevalence of intellectual disability, by degree (moderate, severe and profound) and by age group, 1974, 1981, 1996, 2009	27
<b>Table 2.3</b>	Number of people registered on the NIDD, by HSE region, 2009	30
<b>Table 2.4</b>	Number of people registered on the NIDD with a physical and/or sensory disability, by gender, 2009	32
<b>Table 3.1</b>	Overall service provision to those registered on the NIDD, 2009	34
<b>Table 3.2</b>	Main residential circumstances, by degree of intellectual disability and by age group, 2009	37
<b>Table 3.3</b>	Main residential circumstances and overall level of residential service provision, 2009	39
<b>Table 3.4</b>	Use of respite nights, by HSE region and by LHO area of residence, 2009	43
<b>Table 3.5</b>	Residential status of people availing of day services, by degree of intellectual disability and by age group, 2009	44
<b>Table 3.6</b>	Principal day service availed of, by degree of intellectual disability and by age group, 2009	47
<b>Table 3.7</b>	Principal day service and overall level of day service provision, by age group, 2009	49
<b>Table 3.8</b>	Overall provision of multidisciplinary support services, by age and access to an early intervention team (EIT), 2009	50
<b>Table 3.9</b>	Service provision by HSE region of registration, 2009	52
<b>Table 4.1</b>	Number of new places required to meet need 2010–2014, by HSE region of registration	55
<b>Table 4.2</b>	Future full-time residential service requirements of individuals receiving no residential service in 2009, by degree of intellectual disability	58
<b>Table 4.3</b>	Future day service requirements of individuals receiving no day service in 2009, by degree of intellectual disability	59
<b>Table 4.4</b>	Future residential support service requirements of individuals receiving no residential support services in 2009, by degree of intellectual disability	60
<b>Table 4.5</b>	Use of and requirements for respite by people living in home/independent setting, by HSE region and LHO area, 2009	62
<b>Table 4.6</b>	Category of service change required 2010–2014, by degree of intellectual disability	64





<b>Table 4.7</b>	Number of places requiring change, 2010–2014	64
<b>Table 4.8</b>	Pattern of movement of individuals from existing residential services to future residential services, 2010–2014	66
<b>Table 4.9</b>	Pattern of movement of individuals from existing day services to future day services, 2010–2014	70
<b>Table 4.10</b>	Additional residential support services required by people availing of residential support services in 2009	72
<b>Table 4.11</b>	Future day service requirements of individuals aged 16 years or over who were in an education setting in 2009, by age	74
<b>Table 4.12</b>	Future day service requirements of individuals aged 16 years or over who were in an education setting in 2009, by degree of intellectual disability	74
<b>Table 4.13</b>	Future day service requirements of individuals aged 16 years or over who were in an education setting in 2009, by year of service requirement	75
<b>Table 4.14</b>	Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2009	76
<b>Table 4.15</b>	Day service requirements of people appropriately accommodated in psychiatric hospitals in 2009	77
<b>Table 4.16</b>	Residential service requirements of people resident in psychiatric hospitals in 2009 who require transfer to the intellectual disability sector	77
<b>Table 4.17</b>	Day service requirements of people resident in psychiatric hospitals in 2009 who require transfer to the intellectual disability sector	78
<b>Table 4.18</b>	Pattern of full-time residential service provision required, 2010–2014	82
<b>Table 4.19</b>	Pattern of day service provision required, 2010–2014	85
<b>Table B1</b>	Details of main residential circumstances, degree of intellectual disability and age group	96

## Figures

<b>Figure 2.1</b>	Profile of the population registered on the NIDD, 2009	23
<b>Figure 2.2</b>	Individuals registered on the NIDD, by degree of intellectual disability and by age group, 2009	25
<b>Figure 2.3</b>	Prevalence of moderate, severe and profound intellectual disability (combined), by age group: 1974–2009	29
<b>Figure 2.4</b>	Prevalence of NIDD registrations per 1,000 of the general population, by HSE local health office area of residence, 2009	31
<b>Figure 2.5</b>	Proportion of those registered on the NIDD with a physical and/or sensory disability, by age group, 2009	32
<b>Figure 3.1</b>	Summary of service provision, by age group, 2009	33
<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, 2009	40
<b>Figure 3.3</b>	Total number of respite nights received, by HSE region of residence, 2009	42
<b>Figure 4.1</b>	Summary of the service requirements of those registered on the NIDD, 2009	54
<b>Figure 4.2</b>	Multidisciplinary support services received in 2009 and required in the period 2010–2014	80

# Acknowledgements

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

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

Particular thanks are extended to Professor Philip McCallion for peer reviewing this report, to Ms Joan Moore for editing the text and to Conor Teljeur for designing the map of the local health offices in Ireland.



# Members of the National Intellectual Disability Database Committee 2009

**Mr Colm Desmond (Chairperson)**

Office for Disability and Mental Health,  
Department of Health and Children

**Mr Harry Harris**

Office for Disability and Mental Health,  
Department of Health and Children

**Mr James O'Grady**

Office for Disability and Mental Health,  
Department of Health and Children

**Mr James Rocke**

Western Care Association  
Castlebar  
Co Mayo

*Representing the National Federation of  
Voluntary Bodies providing services to  
people with intellectual disability*

**Mr Paul Ledwidge**

St Michael's House  
Ballymun Road  
Ballymun  
Dublin 9

*Representing the National Federation of  
Voluntary Bodies providing services to  
people with intellectual disability*

**Ms Elizabeth Doherty**

Health Service Executive  
Area Disability Specialist  
HSE West

**Ms Sarah Craig**

Disability Databases Team

**Ms Fionnola Kelly**

Disability Databases Team

**Ms Mary O'Gorman**

Disability Databases Team

**Ms Caraíosa Kelly**

Disability Databases Team

Health Research Board  
An Bord Taighde Sláinte  
Knockmaun House  
42-47 Lower Mount Street  
Dublin 2



# Chairperson's statement

I am pleased to introduce this, the twelfth Annual Report of the National Intellectual Disability Database (NIDD). Compiled by the Health Research Board (HRB), the report is prepared to assist service planners with the process of making decisions about the allocation of resources for intellectual disability services. The report is based on over 26,000 registrations. This year there are a couple of welcome additions to the report:

- Greater focus on the day service needs of children/young people as they prepare to leave the education system and seek services provided in the health sector.
- Increased reporting on respite services and identification of the growing demand for these services to support the maintenance of people with intellectual disability in a home or independent setting.

In the current economic climate it is more appropriate than ever that we ensure that information which assists the planning of services is up to date, timely and accessible to those who are involved in the delivery of services. The Disability Databases Unit of the HRB analyses data at local health office (LHO) level, which can be used by the Health Service Executive (HSE) to inform planning of services at a local level.

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

The report also identifies trends in the data that have been discernible in the last number of years. It is clear that greater numbers of people with intellectual disability are now surviving into old age, which has implications for the provision of services that are appropriate to older people.

Trends in service usage and need are also being examined as part of the Value for Money and Policy Review of disability services which is currently under way, led by the Department of Health and Children in conjunction with the Health Service Executive. On behalf of the Department, I very much welcome the fact that detailed information from the NIDD has been supplied by the HRB to the Department as part of the data collection process undertaken to inform the review.

I would like to thank the NIDD Committee members for all their work on the report and their ongoing input into the Committee. I would like to add a particular thanks to those working in the Disability Databases Team of 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 26,066 people registered on the National Intellectual Disability Database (NIDD) in December 2009, representing a prevalence rate of 6.15 per 1,000 population. The administrative prevalence rate for mild intellectual disability was 2.04 per 1,000 and the prevalence rate for moderate, severe or profound intellectual disability was 3.65 per 1,000. There were more males than females at all levels of intellectual disability, with an overall ratio of 1.30 to 1. The total number with moderate, severe or profound intellectual disability has increased by 37% 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 2009. This reflects an increase in the lifespan of people with intellectual disability. This changing age profile observed in the data over the past three decades has major implications for service planning; it points 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 this sector.

## Service provision in 2009

The numbers registered on the NIDD in December 2009 were as follows:

- 25,556 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.
- 263 people (1% of those registered) who were without services in 2009 and who were identified as requiring appropriate services in the period 2010–2014.
- 247 people (1%) who were not availing of services and had no identified requirement for services during the planning period 2010–2014.

Of the 25,556 people who were in receipt of services in 2009:

- 8,251 (32.2%) were in receipt of full-time residential services, a decrease of 39 since 2008. This is the sixth 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 31 (10.1%), from 308 in 2008 to 277 in 2009.
- 25,472 (99.7%) people availed of at least one day programme in 2009. This is the highest rate of day service usage since NIDD data were first reported in 1996. Of this group, 8,188 were in full-time residential placements and 5,472 were in receipt of residential support services such as respite care.
- 21,223 (83.7%) people availed of one or more multidisciplinary support services. The services most commonly availed of by adults were social work, medical services and psychiatry. The services most commonly availed of by children were speech and language therapy, occupational therapy and social work.

Sixty-four per cent of those registered on the NIDD (16,742 individuals) lived at home with parents, siblings, relatives or foster parents in 2009. More than one in four people who had a moderate, severe or profound intellectual disability and who were aged 35 years or over in 2009 lived in a home setting. Formal supervised living arrangements will need to be provided for an increasing number of adults with intellectual disability as their carers begin to age beyond their care-giving capacity. Because people with intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years. These data highlight the importance of planning for both the cohort on the NIDD who are ageing and for their carers.

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 2009 include:

- an increase of 66% in the number of people with intellectual disability living full time in community group homes;
- a 71% 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 437%; 4,681 people availed of this type of service in 2009, allowing them to continue living with their families and in their communities;
- increased provision in almost all areas of adult day services and in the level of support services delivered as part of a package of day services to both children and adults.



## Service requirements

The 2009 data indicate that 4,622 new residential, day and/or residential support places will be needed to meet service requirements. The following services will be needed in the period 2010–2014 (most service needs were recorded as being immediate):

- 2,298 full-time residential placements, an increase of 42, or 2%, since 2009 and the highest number since the Database was established. The number of new full-time residential places required has been increasing consistently following a slight downward trend during the years 2000 to 2002. The demographic profile of people with intellectual disability in Ireland suggests that the number of new full-time residential places required is likely to continue to increase over the coming years as those with a more severe disability and those who care for them advance in age.
- 2,115 residential support services, a decrease of 14, or 1%, since 2008. This high level of need is presenting even though there were over 5,000 people availing of residential support services in 2009.
- 209 day programmes (this figure excludes multidisciplinary support services and services provided by early intervention teams). The number of new day places required has been decreasing since NIDD data were first reported in 1996 and is now at its lowest since the Database was established. This number does not include the 908 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.
- 169 individuals who were living in psychiatric hospitals in 2009 have been identified as needing to transfer from these locations to more appropriate accommodation.

Of those in receipt of services in 2009, 11,564 people required alternative, additional, or enhanced services in the period 2010–2014, a decrease of 259, or 2%, since 2008. 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:

- 9,998 day places will require changes or enhancements. Health-funded services are required by 6,934 individuals (69.3%), employment services are required by 1,279 individuals (12.8%), education services are required by 1,121 individuals (11.2%) and generic services are required by 664 individuals (6.6%). Of the 1,121

service changes required within education, 861 (76.8%) are requirements for an alternative service and 260 (23.2%) are requirements for an enhancement of the individual's existing service. A large proportion of the 1,449 individuals who were attending special schools in 2009 require adult day services within the period 2010–2014. Of this group, over one quarter (395 individuals) require rehabilitative training, 329 (22.7%) require vocational training and 158 (10.9%) require activation programmes.

- 3,055 residential places will require changes or enhancements.
- 1,625 residential support places will require changes or enhancements.

Despite high levels of service provision in 2009, there remained a significant demand for new and enhanced multidisciplinary support services. Three quarters (19,413 individuals) of the population registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2010–2014. There was substantial demand for all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy.

The service demands identified in the report outstrip the level of resources that have been put in place under the multi-annual funding package 2006–2009. In the medium term, it is expected that the increased demand for intellectual disability services will continue.

# 1. The National Intellectual Disability Database

## Background

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

The Database was established on the principle that 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 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.

## 2009 annual report

This is the twelfth report of the National Intellectual Disability Database Committee. The report is based on validated data extracted from the NIDD in December 2009. 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 2009 dataset, there were 554 people recorded as being of average ability and 688 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 2009 dataset consists of information in relation to 26,066 individuals. Of the 26,066 registrations, 97.1% (25,315 cases) were updated following the completion of the 2009 review of NIDD information; the remaining 751 registrations contain the last-known data in each case. This rate of update is lower than the 2008 figure, when 25,820 (99%) cases were updated, and highlights the continued need for commitment by HSE and service provider staff to the Database.

## **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).

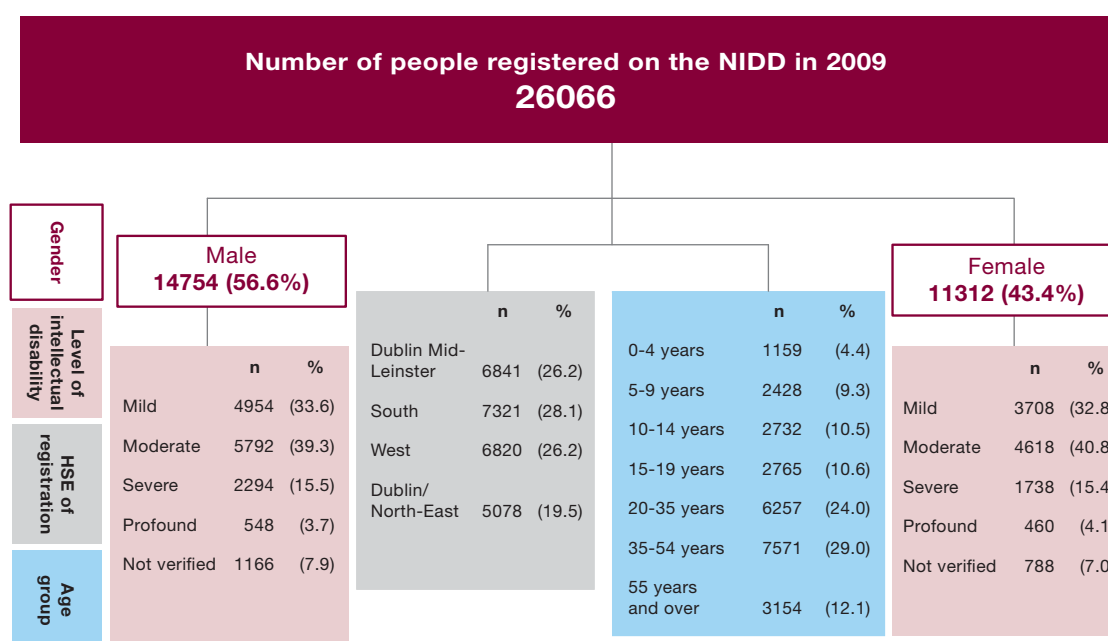
- As a general principle, the NIDD registers data only on individuals with an intellectual disability for whom specialised health services are being provided or who, following a needs assessment, are considered to require specialised services in the next five years. Almost everyone with a moderate, severe 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 26,066 people registered on the NIDD in 2009. There were more males (56.6%) than females (43.4%) registered on the Database, with the highest proportion of both males and females diagnosed as having a moderate level of intellectual disability. Figure 2.1 also indicates that the largest proportions of people registered were in the HSE South area (28.1%) and in the 35–54-year age group (29.0%).



**Figure 2.1** Profile of the population registered on the NIDD, 2009

During the review and update period prior to the 2009 extract of data from the NIDD, 671 people were removed from the Database<sup>1</sup> and there were 714 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 2009, 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 2009.

**Table 2.1** Number of people registered on the NIDD, by age, gender and degree of intellectual disability, 2009

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	428	540	968	50	52	102	21	34	55	7	20	27	3	4	7	509	650	1159
5-9	214	439	653	243	507	750	220	495	715	100	147	247	33	30	63	810	1618	2428
10-14	22	50	72	447	818	1265	378	608	986	139	201	340	36	33	69	1022	1710	2732
15-19	5	8	13	508	869	1377	412	625	1037	111	172	283	28	27	55	1064	1701	2765
20-34	41	32	73	969	1164	2133	1203	1628	2831	402	594	996	102	122	224	2717	3540	6257
35-54	58	47	105	1036	1138	2174	1575	1732	3307	672	870	1542	194	249	443	3535	4036	7571
55 & over	20	50	70	455	406	861	809	670	1479	307	290	597	64	83	147	1655	1499	3154
All ages	788	1166	1954	3708	4954	8662	4618	5792	10410	1738	2294	4032	460	548	1008	11312	14754	26066
<b>Prevalence rates – numbers per 1,000 of the general population for each age group<sup>3</sup></b>																		
0-4	2.90	3.49	3.20	0.34	0.34	0.34	0.14	0.22	0.18	0.04	0.12	0.09	0.02	0.02	0.02	3.45	4.21	3.83
5-9	1.52	2.97	2.26	1.73	3.43	2.60	1.57	3.34	2.48	0.71	0.99	0.86	0.24	0.20	0.22	5.77	10.93	8.42
10-14	0.16	0.36	0.26	3.35	5.82	4.62	2.83	4.33	3.60	1.04	1.43	1.24	0.27	0.23	0.25	7.66	12.18	9.98
15-19	0.03	0.05	0.04	3.58	5.86	4.74	2.90	4.22	3.57	0.79	1.16	0.97	0.20	0.18	0.19	7.49	11.47	9.53
20-34	0.08	0.06	0.07	1.84	2.16	2.00	2.29	3.01	2.66	0.77	1.10	0.94	0.19	0.23	0.21	5.17	6.56	5.88
35-54	0.10	0.08	0.09	1.83	1.97	1.90	2.78	3.00	2.89	1.18	1.51	1.35	0.34	0.43	0.39	6.22	6.99	6.61
55 & over	0.04	0.12	0.08	0.98	0.98	0.98	1.75	1.62	1.69	0.66	0.70	0.68	0.14	0.20	0.17	3.58	3.63	3.60
All ages	0.37	0.55	0.46	1.75	2.34	2.04	2.18	2.73	2.46	0.82	1.08	0.95	0.22	0.26	0.24	5.34	6.96	6.15

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

## Prevalence

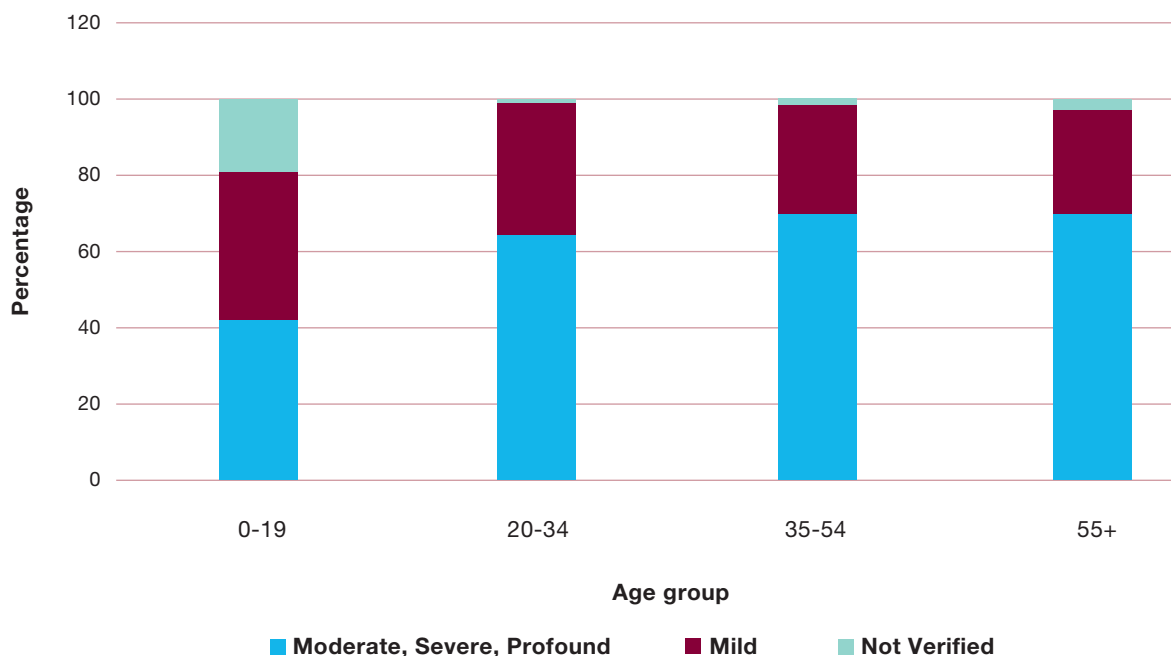
The administrative prevalence rate for mild intellectual disability in 2009 was 2.04/1000, a slight increase on the 2008 rate of 2.02/1000. This figure is not a true reflection of the prevalence as only those with mild intellectual disability accessing or requiring intellectual disability services are included in the Database. The prevalence rate for moderate, severe and profound intellectual disability in 2009 was 3.65/1000, compared to 3.61/1000 in 2008.

## 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 age group. The overall male to female ratio was 1.30:1. This represents a prevalence rate of 6.96/1000 males and 5.34/1000 females.

## Age differences

Of the persons recorded on the NIDD, 9,084 (34.8%) were aged 19 years or under, 6,257 (24.0%) were aged between 20 and 34 years, 7,571 (29.0%) were aged between 35 and 54 years, and 3,154 (12.1%) 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, 2009

## Trends over time

### Recent trends

Prevalence rates for moderate, severe and profound intellectual disability between 1974 and 2009 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 2009 prevalence rates are calculated using NIDD data from 2009 and Census of Population data from 2006. Compared to the 1996 data (National Intellectual Disability Database Committee, 1997), the 2009 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 1974–2009.
- There has been an overall increase in prevalence in the 55-years-and-over age group; the prevalence rate in 2009 was 2.54 per thousand of population. The number of people in this age group registered on the Database increased by 789 (55.0%) between 1996 and 2009.

**Table 2.2** Prevalence of intellectual disability, by degree (moderate, severe and profound) and by age group, 1974, 1981, 1996, 2009

Age group	Moderate				Severe				Profound				All levels			
	1974	1981	1996	2009	1974	1981	1996	2009	1974	1981	1996	2009	1974	1981	1996	2009
0-4	189	214	226	55	143	92	83	27	99	26	30	7	431	332	339	89
5-9	809	955	736	715	617	330	260	247	224	99	77	63	1650	1384	1073	1025
10-14	752	1035	948	986	583	428	305	340	292	117	93	69	1627	1580	1346	1395
15-19	698	1203	1072	1037	445	508	378	283	241	154	132	55	1384	1865	1582	1375
20-34	1498	2419	2997	2831	1017	1129	1350	996	441	340	460	224	2956	3888	4807	4051
35-54	1321	1559	2626	3307	626	612	1183	1542	201	97	343	443	2148	2268	4152	5292
55 & over	669	715	987	1479	307	248	394	597	84	24	53	147	1060	987	1434	2223
<b>All ages</b>	<b>5936</b>	<b>8100</b>	<b>9592</b>	<b>10410</b>	<b>3738</b>	<b>3347</b>	<b>3953</b>	<b>4032</b>	<b>1582</b>	<b>857</b>	<b>1188</b>	<b>1008</b>	<b>11256</b>	<b>12304</b>	<b>14733</b>	<b>15450</b>
<b>Prevalence rates – numbers per 1,000 of the general population for each age group</b>																
0-4	0.60	0.62	0.83	0.18	0.45	0.27	0.30	0.09	0.31	0.07	0.11	0.02	1.36	0.97	1.24	0.29
5-9	2.55	2.73	2.31	2.48	1.95	0.94	0.82	0.86	0.71	0.28	0.24	0.22	5.20	3.95	3.37	3.56
10-14	2.52	3.08	2.72	3.60	1.95	1.27	0.88	1.24	0.98	0.35	0.27	0.25	5.45	4.70	3.86	5.09
15-19	2.61	3.79	3.20	3.57	1.66	1.60	1.13	0.97	0.90	0.48	0.39	0.19	5.17	5.88	4.72	4.73
20-34	2.78	3.33	3.93	2.66	1.88	1.56	1.77	0.94	0.82	0.47	0.60	0.21	5.48	5.35	6.31	3.8
35-54	2.13	2.43	3.25	2.89	1.01	0.95	1.46	1.35	0.32	0.15	0.42	0.39	3.46	3.53	5.14	4.62
55 & over	1.08	1.09	1.45	1.69	0.50	0.38	0.58	0.68	0.14	0.04	0.08	0.17	1.71	1.51	2.11	2.54
<b>All ages</b>	<b>1.99</b>	<b>2.35</b>	<b>2.72</b>	<b>2.46</b>	<b>1.25</b>	<b>0.97</b>	<b>1.12</b>	<b>0.95</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>3.65</b>



## Trends over past three decades

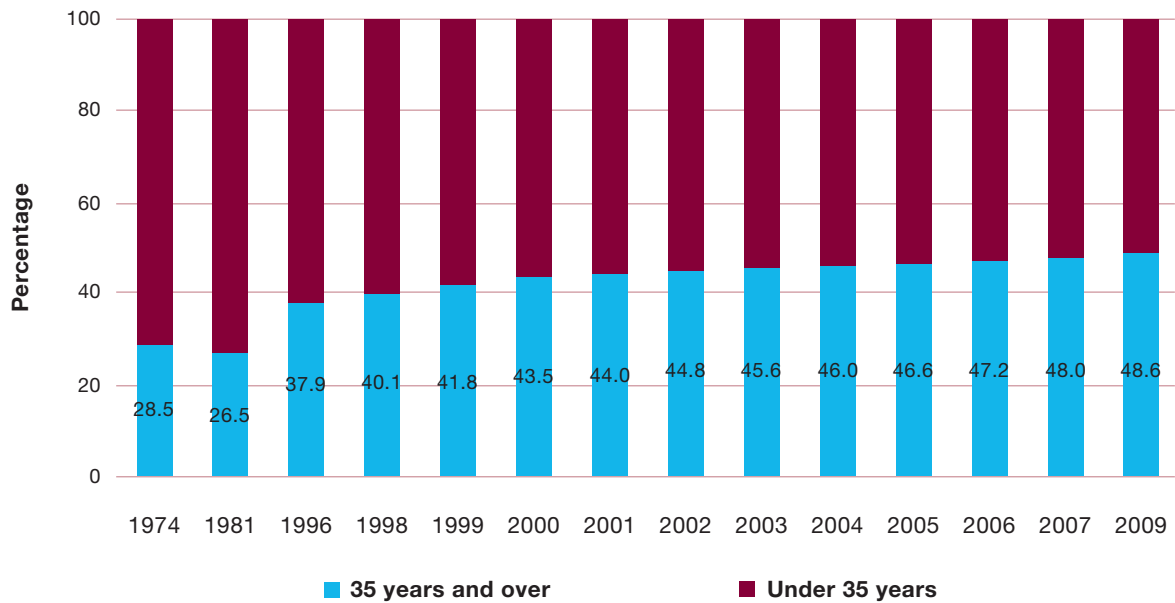
Data from the 1974 and 1981 Censuses of Mental Handicap, carried out by the Medico-Social Research Board (Mulcahy, 1976; Mulcahy and Ennis, 1976; Mulcahy and Reynolds, 1984), enable us to monitor trends in the population with an intellectual disability over the past 35 years (Table 2.2).

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 2009 there was also an increase in the numbers in the 10–14-year age group. In addition, the numbers in the 0–4-year age group continue to fall, which may reflect the decline in the birth rate in Ireland between 1980 and 1995 but also raises questions regarding the under-registration of children on the NIDD.

## 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 48.6% in 2009, when almost half of those with a moderate, severe or profound intellectual disability were aged 35 years and over.





**Figure 2.3** Prevalence of moderate, severe and profound intellectual disability (combined), by age group: 1974–2009

### 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 2009 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). The category 'Out of State' refers to individuals whose services were funded by the State but accessed outside the State.

**Table 2.3** Number of people registered on the NIDD, by HSE region, 2009

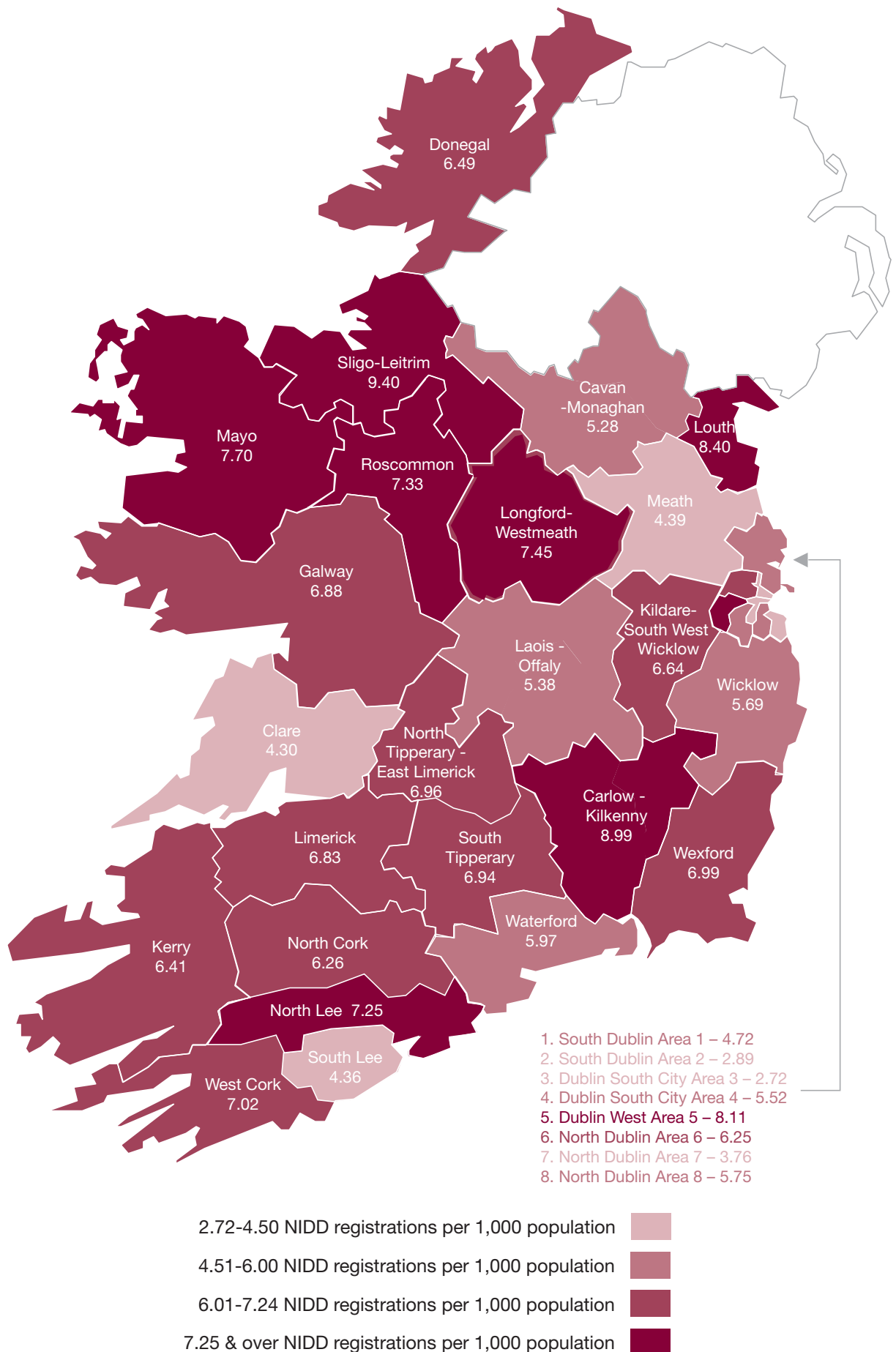
HSE Region	n	% of NIDD	% of total population
Dublin/Mid-Leinster	6841	26.2	28.7
South <sup>4</sup>	7321	28.1	25.5
West <sup>5</sup>	6820	26.2	23.9
Dublin/North-East <sup>6</sup>	5078	19.5	21.9
Out of State	6	-	-
<b>Total</b>	<b>26066</b>	<b>100.0</b>	<b>100.0</b>

Figure 2.4 presents the number of NIDD registrations by the local health office (LHO) area in which the client resides. The national prevalence rate was 6.15/1000. The Sligo/Leitrim LHO area had the highest prevalence rate, at 9.40/1000 of the population, while the lowest prevalence rate was in the Dublin South City LHO area, at 2.72/1000.

4 An additional 104 individuals received services in the HSE South region but have not been included in the overall figures as they did not give consent for their information to be included on the national system.

5 An additional 81 individuals received services in the HSE West region but have not been included in the overall figures as they did not give consent for their information to be included on the national system.

6 An additional 33 individuals received services in the HSE Dublin/North East region but have not been included in the overall figures as they did not give consent for their information to be included on the national system.



**Figure 2.4** Prevalence of NIDD registrations per 1,000 of the general population, by HSE local health office area of residence, 2009

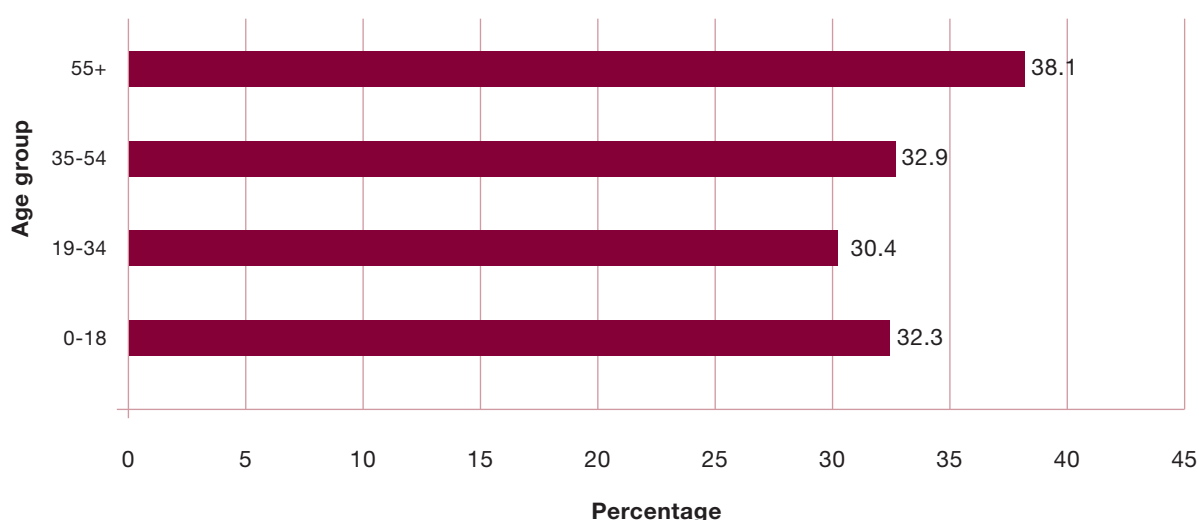


## Co-morbidity within the NIDD population

As Table 2.4 indicates, 8,513 individuals (32.7%) registered on the NIDD in 2009 had a physical and/or sensory disability in addition to an intellectual disability. This number represents an increase of 15.4% on the 2008 figure, reflecting an improvement in the recording of people with multiple disabilities. In 2009, almost one third (32.3%) of those aged 0–18 years were recorded on the NIDD as having a physical/sensory disability, while 38.1% of those aged 55 years or over recorded a physical/sensory disability (Figure 2.5). Individuals with multiple disabilities are likely to have more complex service needs than those with intellectual disability alone. In order to plan effective interventions for this group into the future, services need to reflect the changing needs of this cohort, particularly as they age, so that appropriate services and treatments are made available to meet their specific requirements.

**Table 2.4** Number of people registered on the NIDD with a physical and/or sensory disability, by gender, 2009

	Male		Female		Total	
	n	%	n	%	n	%
Intellectual and physical/sensory disability	4494	30.5	4019	35.5	8,513	32.7
Intellectual disability only	10231	69.3	7265	64.2	17496	67.1
Not reviewed	29	0.2	28	0.2	57	0.2
<b>Total</b>	<b>14754</b>	<b>100.0</b>	<b>11312</b>	<b>100.0</b>	<b>26066</b>	<b>100.0</b>



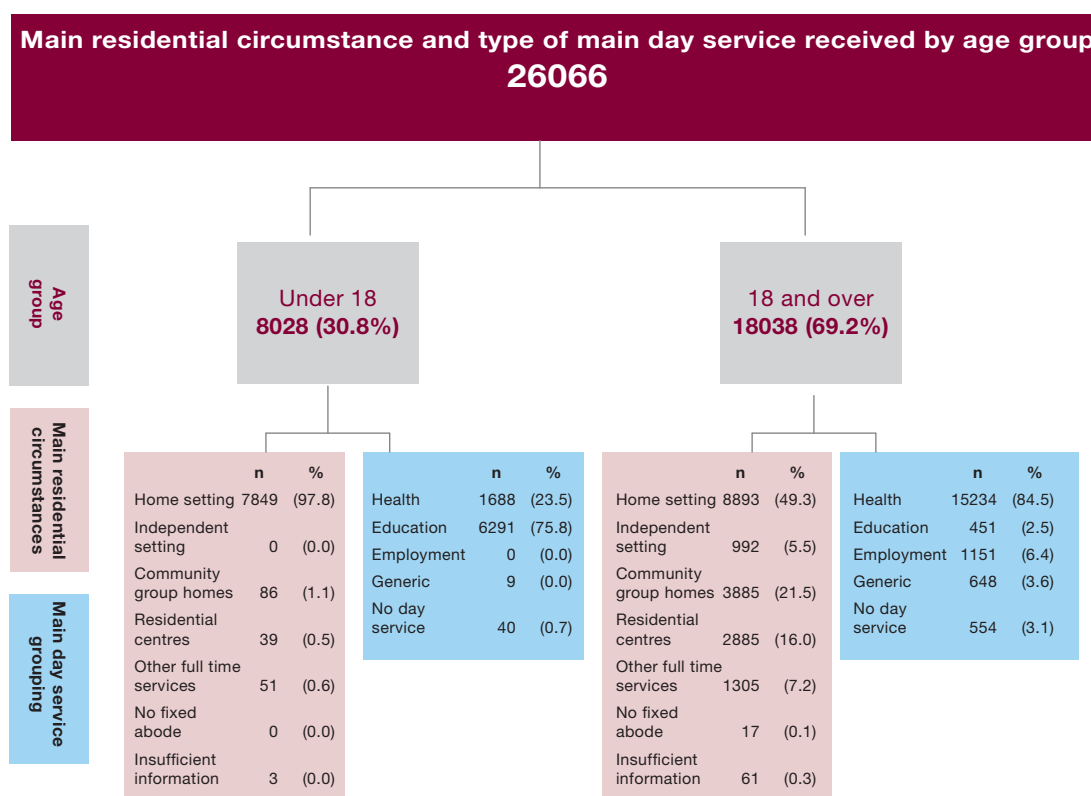
**Figure 2.5** Proportion of those registered on the NIDD with a physical and/or sensory disability, by age group, 2009

# 3. Service provision in 2009

## 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 2009. Day services were availed of by 97.7% of all those registered on the NIDD in 2009. The majority of services accessed by adults were health-related and the majority accessed by children were education. Figure 3.1 also shows that a larger proportion (3.1%) of adults were without day services compared to their younger counterparts (0.7%). The residential circumstances for both age groups also differed in 2009; 97.8% (7,849) of those aged under 18 years lived at home, compared to 49.3% (8,893) 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, 2009

In 2009, 25,556 people with an intellectual disability were receiving services, which accounted for 98.0% of the total population registered on the NIDD. This was the highest number of people recorded as being in receipt of services since the Database was established. Of the remaining 510 people (2.0%) who were not in receipt of services, 263 (1.0% of total registered population) had expressed a need for services in the period 2010–2014. The overall level of service provision in 2009 is provided in Table 3.1 (a comprehensive list of the types of service availed of are outlined in Appendix B).

**Table 3.1 Overall service provision to those registered on the NIDD, 2009**

	<b>n</b>	<b>%</b>
Attending services on a day basis	17284	66.3
Receiving 5- or 7-day residential services	7974	30.6
Resident in a psychiatric hospital	277	1.1
Receiving residential support services only	21	0.1
Receiving no service – on waiting list	263	1.0
No identified service requirements	247	0.9
<b>Total</b>	<b>26066</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 2009 by degree of intellectual disability and age group (a further breakdown is presented in Table 3.3).

The main groupings of individuals consisted of:

- 16,742 individuals (64.2%) who lived at home with parents, relatives, or foster parents. This figure does not take account of those in the mild intellectual disability category who were living at home/independently without supports or services, and who are under-represented on the NIDD. The proportion living at home is similar to that in previous years and in line with that of other European countries.
- 8,251 individuals (31.7%) who lived in full-time residential services, mainly in community group homes, residential centres, psychiatric hospitals, and intensive placements. This represents a decrease of 39 on the 2008 figure.
- 992 individuals (3.8%) who lived independently or semi-independently.



The most commonly availed of residential settings were community group homes. The year 2009 was the sixth consecutive year in which the data indicated that more full-time residents lived in homes in the community (3,971) than in residential centres (2,924). The numbers of people accommodated in community group homes have increased and in residential centres have decreased on an almost continuous basis since data collection commenced. This trend reflects a shift towards community living in the provision of residential services to people with an intellectual disability.

In 2009, 330 people with an intellectual disability resided full time in mental health service facilities, either in psychiatric hospitals (277 individuals, compared with 308 individuals in 2008) or in mental health community residences (53 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 2009 decreased with age – 97.0% of individuals aged 0–19 years lived in a home setting, declining to 71.7% of those aged 20–34 years, 38.6% of those aged 35–54 years, and 16.6% 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 2009 2.9% of all 0–19-year-olds received full-time residential services, compared with 24.8% of 20–34-year-olds, 53.7% of 35–54-year-olds, and 75.3% 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 2009. Formal supervised living arrangements will need to be provided for an increasing number of adults with an intellectual disability as their carers begin to age beyond their care-giving capacity. Because people with an intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years. These data highlight the importance of planning for an ageing population and the needs that are likely to arise as a result. Of the 992 individuals who lived in independent or semi-independent settings in 2009, 79.5% were aged 35 years or over and over three-quarters (76.1%) had a mild intellectual disability.



## Degree of intellectual disability

There were also noticeable variations between level of ability and type of residential situation (Table 3.2). Of those with a mild intellectual disability, 75.0% lived in a home setting, compared to 54.4% of those with a moderate, severe or profound intellectual disability. The proportion of people in full-time residential services increased within the more severe categories of disability. Only 16.1% of people with a mild intellectual disability lived in full-time residential services, but this increased to 44.0% in the case of those with a moderate, severe or profound disability.

Where individuals were in full-time residential services in 2009, the type of service varied according to level of intellectual disability. Full-time residents with a mild intellectual disability were in the past more likely to be accommodated in community group homes, while full-time residents with a moderate, severe or profound intellectual disability were more likely to be accommodated in residential centres. However, since 2007 the number of full-time residents with a moderate, severe or profound intellectual disability living in community group homes exceeds the number living in residential centres.

- Of those in full-time residential services in 2009 who had a moderate, severe or profound intellectual disability, 44.7% were in community group homes, 39.3% were in residential centres, and 16.0% 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 2009, 65.8% were in community group homes, 17.0% were in residential centres, and 17.2% were in other full-time residential services.

**Table 3.2** Main residential circumstances, by degree of intellectual disability and by age group, 2009

	Not verified				Mild				Moderate, severe or profound				All levels							
	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total	0-19	20-34	35-54	55+	Total					
Home setting	1694	61	60	26	1841	3432	1723	1135	209	6499	3690	2700	1724	288	8402	8816	4484	2919	523	16742
Independent setting	0	7	34	15	56	2	160	436	157	755	0	34	85	62	181	2	201	555	234	992
Community group home	3	4	3	6	16	45	163	432	276	916	82	594	1687	676	3039	130	761	2122	958	3971
Residential centre	0	0	2	10	12	4	26	84	122	236	54	429	1290	903	2676	58	455	1376	1035	2924
Other full-time services <sup>7</sup>	9	1	6	13	29	9	53	84	94	240	56	279	476	276	1087	74	333	566	383	1356
No fixed abode	0	0	0	0	0	1	5	3	3	12	0	1	2	2	5	1	6	5	5	17
Insufficient information	0	0	0	0	0	1	3	0	0	4	2	14	28	16	60	3	17	28	16	64
<b>Total</b>	<b>1706</b>	<b>73</b>	<b>105</b>	<b>70</b>	<b>1954</b>	<b>3494</b>	<b>2133</b>	<b>2174</b>	<b>861</b>	<b>8662</b>	<b>3884</b>	<b>4051</b>	<b>5292</b>	<b>2223</b>	<b>15450</b>	<b>9084</b>	<b>6257</b>	<b>7571</b>	<b>3154</b>	<b>26066</b>

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

Table 3.3 outlines the main residential circumstances and overall level of residential service provision of those registered on the NIDD in 2009 (a more detailed breakdown of main residential circumstance is presented in Table B1 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 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 2009 there has been significant growth in the number of residential support places available. In particular, the data show a significant increase of 437.4% (3,810) in the number of individuals who availed of centre-based respite services, either as a planned or emergency intervention, bringing the total number of respite services availed of in 2009 to 4,681 (Table 3.3).

**Table 3.3** Main residential circumstances and overall level of residential service provision, 2009

	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>7849</b>	<b>8893</b>	<b>16742</b>	<b>7853</b>	<b>8902</b>	<b>16755</b>
At home with both parents	6059	5277	11336	6059	5277	11336
At home with one parent	1544	2429	3973	1544	2429	3973
At home with sibling	7	883	890	7	883	890
At home with other relative	53	146	199	53	146	199
Living with non-relative	2	28	30	2	28	30
Adoption	11	15	26	11	15	26
Foster care and boarding out arrangements	173	115	288	177	124	301
<b>Independent setting</b>	<b>0</b>	<b>992</b>	<b>992</b>	<b>0</b>	<b>997</b>	<b>997</b>
Living independently	0	654	654	0	656	656
Living semi-independently	0	338	338	0	341	341
<b>Community group homes</b>	<b>86</b>	<b>3885</b>	<b>3971</b>	<b>86</b>	<b>3885</b>	<b>3971</b>
5-day community group home	35	404	439	35	404	439
7-day community group home	12	566	578	12	566	578
7-day (52-week) community group home	39	2915	2954	39	2915	2954
<b>Residential setting</b>	<b>39</b>	<b>2885</b>	<b>2924</b>	<b>39</b>	<b>2885</b>	<b>2924</b>
5-day residential centre	6	63	69	6	63	69
7-day residential centre	15	352	367	15	352	367
7-day (52-week) residential centre	18	2470	2488	18	2470	2488
<b>Other full time residential services</b>	<b>51</b>	<b>1305</b>	<b>1356</b>	<b>51</b>	<b>1305</b>	<b>1356</b>
Nursing home	0	156	156	0	156	156
Mental health community residence	0	53	53	0	53	53
Psychiatric hospital	0	277	277	0	277	277
Intensive placement (challenging behaviour)	13	462	475	13	462	475
Intensive placement (profound or multiple handicap)	20	249	269	20	249	269
Occupying a full-time support place	7	49	56	7	49	56
Other full-time residential service	11	59	70	11	59	70
<b>Residential support service</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1426</b>	<b>3910</b>	<b>5336</b>
Holiday residential placement	0	0	0	4	144	148
Crisis or planned respite	0	0	0	1274	3407	4681
Occasional respite with host family	0	0	0	110	168	278
Overnight respite in the home	0	0	0	5	6	11
Shared care or guardianship	0	0	0	1	9	10
Regular part-time care (2/3 days per week)	0	0	0	16	71	87
Regular part-time care (every weekend)	0	0	0	4	10	14
Regular part-time care (alternate weeks)	0	0	0	4	63	67
Other residential support service	0	0	0	8	32	40
<b>No fixed abode</b>	<b>0</b>	<b>17</b>	<b>17</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>Insufficient information</b>	<b>3</b>	<b>61</b>	<b>64</b>	<b>0</b>	<b>0</b>	<b>0</b>
	<b>8028</b>	<b>18038</b>	<b>26066</b>	<b>9455</b>	<b>21884</b>	<b>31339</b>

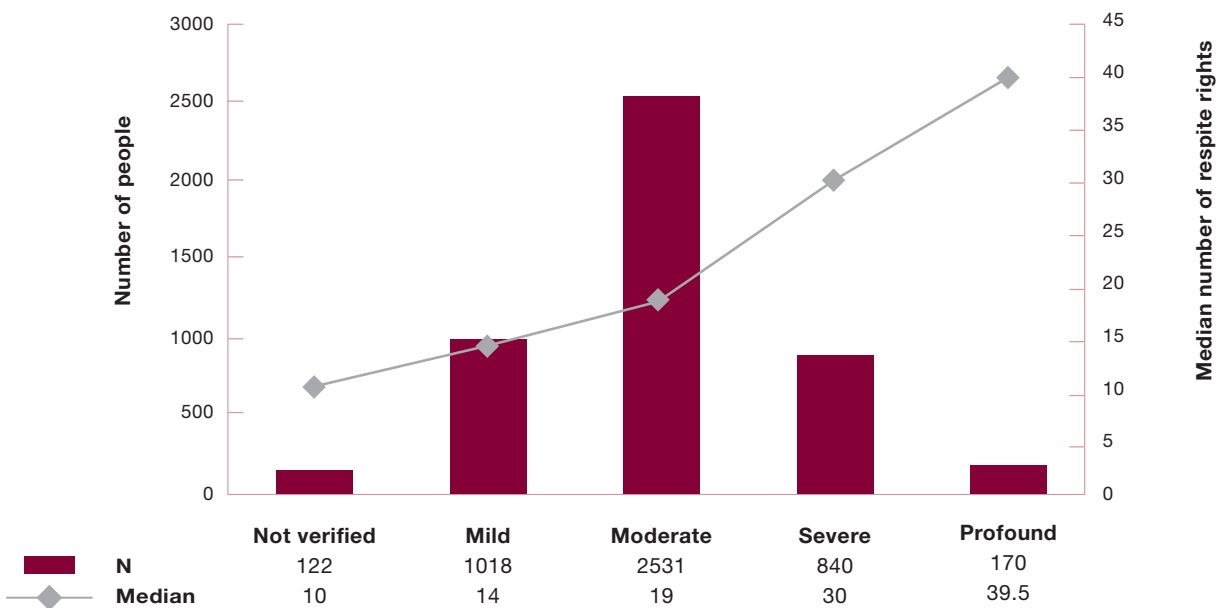
Note: The total number exceeds the actual number of people with an intellectual disability as a number of people availed of two residential services.

## 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.

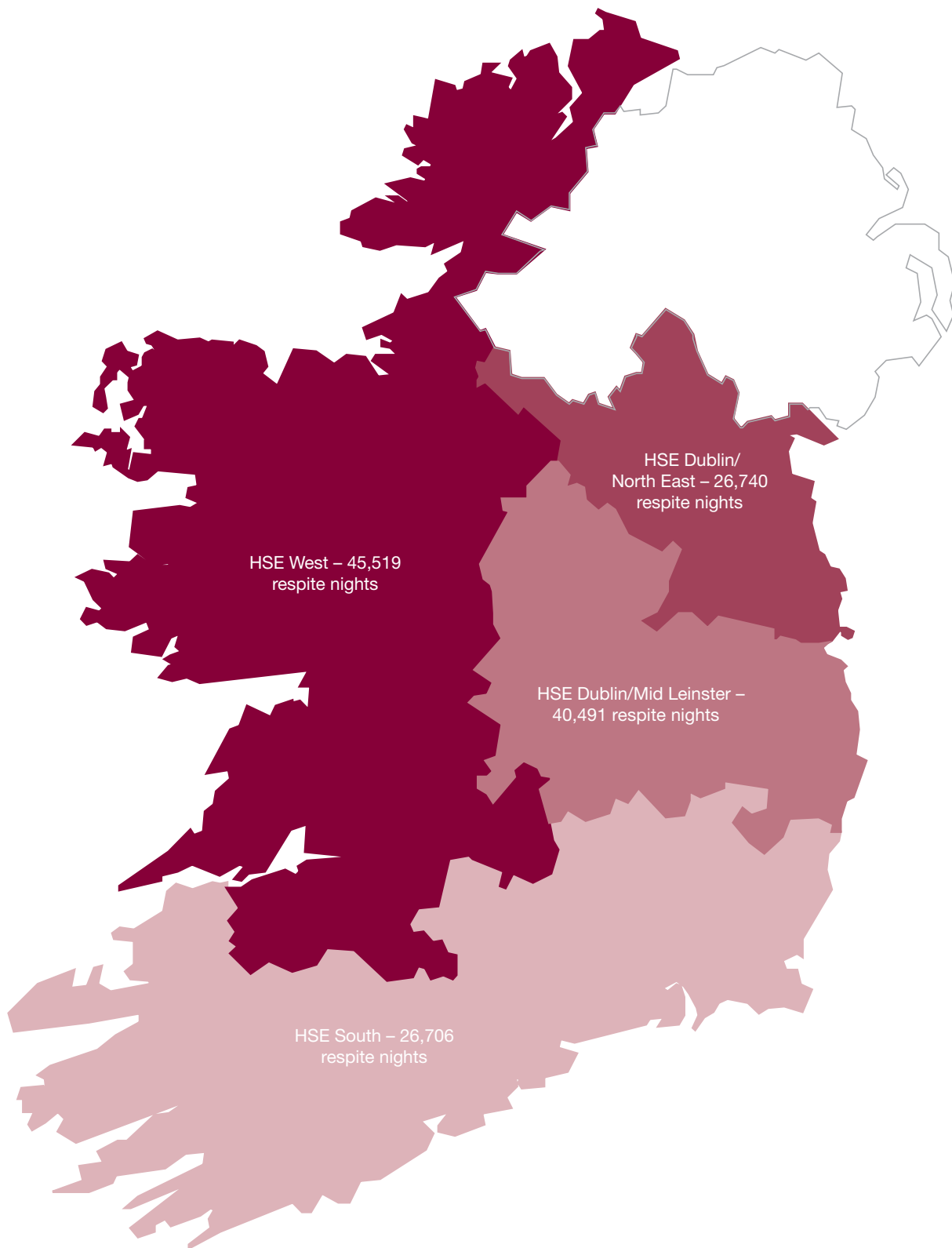


**Figure 3.2** Number of people in receipt of respite nights and median number of respite nights received, by degree of intellectual disability, 2009

<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.

## **Geographical variation in respite provision**

Figure 3.3 displays the total number of respite nights received in 2009 for those who were living within each of the four HSE regions. Table 3.4 presents data on respite for each of the HSE local health office (LHO) areas. Both the figure and the table show that there were marked differences between regions in the total number of respite nights received in 2009, which ranged from 26,706 nights in the HSE South to 45,519 nights in the HSE West. Chapter 4 presents data on those who require respite care.



**Figure 3.3** Total number of respite nights received, by HSE region of residence, 2009



**Table 3.4** Use of respite nights, by HSE region and by LHO area of residence, 2009

	Total number of respite nights received	Number of people in receipt of respite nights
<b>HSE Dublin/Mid Leinster</b>	<b>40491</b>	<b>1336</b>
LHO South Dublin area 1	4590	125
LHO South Dublin area 2	1676	65
LHO Dublin South City Area 3	2898	98
LHO Dublin South City Area 4	6738	205
LHO Dublin West Area 5	5103	143
LHO Kildare/West Wicklow	6791	248
LHO Wicklow	4595	106
LHO Laois-Offaly	2191	164
LHO Longford-Westmeath	5909	182
<b>HSE South</b>	<b>26706</b>	<b>1121</b>
LHO Carlow-Kilkenny	2700	116
LHO Tipperary SR	1850	117
LHO Waterford	1370	96
LHO Wexford	2750	160
LHO Cork North Lee	4114	136
LHO Cork South Lee	4135	132
LHO North Cork	2870	106
LHO West Cork	2542	77
LHO Kerry	4375	181
<b>HSE West</b>	<b>45519</b>	<b>1257</b>
LHO Limerick	4023	136
LHO Tipperary NR	4679	105
LHO Clare	3046	123
LHO Galway	14867	298
LHO Mayo	7502	187
LHO Roscommon	1690	52
LHO Donegal	6429	226
LHO Sligo-Leitrim	3283	130
<b>HSE Dublin/North East</b>	<b>26740</b>	<b>967</b>
LHO North Dublin Area 6	5367	171
LHO North Dublin Area 7	2472	114
LHO North Dublin Area 8	8059	340
LHO Cavan-Monaghan	2105	88
LHO Louth	4588	110
LHO Meath	4149	144
<b>All regions</b>	<b>139456</b>	<b>4681</b>

## Day services

In 2009, 25,472 people, representing 97.7% of all those registered on the NIDD, received day services (Table 3.6). This is the highest number registered as receiving such services since the Database was established.



## Residential status of people availing of day services

Day services are availed of by people who live at home or in independent living settings in the community, and also by people who are receiving full-time residential services.

Of the 25,472 individuals who availed of day services in 2009, 8,188 (32.1%) were in full-time residential services, the majority of whom were in the moderate, severe, or profound range of intellectual disability (82.5%) and aged 18 years or over (97.9%). The remaining 17,284 (67.9%) attended services on a day basis, of whom 40.9% 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, 2009

	Not verified			Mild			Moderate, severe or profound			Total		
	18		Total	18		Total	18		Total	18		Total
	Under 18	and over		Under 18	and over		Under 18	and over		Under 18	and over	
Residents	11	45	56	35	1339	1374	128	6630	6758	174	8014	8188
Day attendees	1669	203	1872	2939	4130	7069	3206	5137	8343	7814	9470	17284
<b>Total</b>	<b>1680</b>	<b>248</b>	<b>1928</b>	<b>2974</b>	<b>5469</b>	<b>8443</b>	<b>3334</b>	<b>11767</b>	<b>15101</b>	<b>7988</b>	<b>17484</b>	<b>25472</b>

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

As in 2008, the top three day activities availed of by people with an intellectual disability in 2009, 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 25,472 individuals who availed of day services in 2009, 7,988 (31.4%) were aged under 18 years, and 17,484 (68.6%) 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 17,484 adults who availed of at least one day service in 2009, most attended either activation centres (33.5%) or sheltered work centres (20.8%) as their principal day



service. Smaller proportions availed of rehabilitative training (9.6%), multidisciplinary support services only (9.1%), and supported employment (5.4%).

## **Degree of intellectual disability**

Of those who received day services in 2009 (25,472 individuals), 8,443 (33.1%) had a mild intellectual disability, 15,101 (59.3%) had a moderate, severe or profound intellectual disability and 1,928 (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 (3,334, 22.1%) of the population with moderate, severe or profound intellectual disability who availed of day services in 2009 were aged under 18 years, whereas more than one in three (2,974, 35.2%) of the population with mild intellectual disability who availed of day services were aged under 18 years.

Of the 7,988 under-18s who availed of day services in 2009:

- 2,974 (37.2%) had a mild degree of intellectual disability; most of this group availed of special education services as their principal day service, with smaller numbers in mainstream schools and pre-school services.
- 3,334 (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.
- 1,680 (21.0%) had not had their degree of intellectual disability verified.

Of the 17,484 adults in receipt of day services in 2009:

- 5,469 (31.3%) 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.
- 11,767 (67.3%) 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.
- 248 (1.4%) had not had their degree of intellectual disability established.

**Table 3.6** Principal day service availed of, by degree of intellectual disability and by age group, 2009

	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	66	12	78	9	60	69	18	104	122	93	176	269
Home help	1	1	2	1	11	12	3	8	11	5	20	25
Early intervention team	395	0	395	37	0	37	32	0	32	464	0	464
Special pre-school for intellectual disability	363	0	363	44	0	44	104	0	104	511	0	511
Child education and development centre	6	0	6	1	0	1	140	13	153	147	13	160
Mainstream pre-school	190	0	190	58	0	58	20	0	20	268	0	268
Mainstream school	198	1	199	816	46	862	517	19	536	1531	66	1597
Resource/visiting teacher	23	0	23	72	10	82	41	9	50	136	19	155
Special class – primary	80	0	80	204	0	204	196	0	196	480	0	480
Special class – secondary	1	0	1	65	27	92	72	30	102	138	57	195
Special school	259	1	260	1614	158	1772	2132	139	2271	4005	298	4303
Third level education	0	1	1	1	10	11	0	0	0	1	11	12
Rehabilitative training	1	21	22	4	809	813	0	854	854	5	1684	1689
Activation centre	0	25	25	0	1061	1061	0	4769	4769	0	5855	5855
Programme for the older person	0	13	13	0	109	109	0	505	505	0	627	627
Special high-support day service	0	0	0	1	55	56	3	578	581	4	633	637
Special intensive day service	0	0	0	6	40	46	20	333	353	26	373	399
Sheltered work centre	0	23	23	0	1412	1412	0	2209	2209	0	3644	3644
Sheltered employment centre	0	12	12	0	59	59	0	20	20	0	91	91
Multidisciplinary support services	37	36	73	16	397	413	10	1170	1180	63	1603	1666
Centre-based day respite service	1	2	3	2	11	13	3	9	12	6	22	28
Day respite in the home	3	9	12	0	11	11	0	5	5	3	25	28
Outreach programme	3	0	3	0	1	1	0	2	2	3	3	6
Other day service	53	0	53	17	176	193	20	289	309	90	465	555
Enclave within open employment	0	0	0	0	5	5	0	8	8	0	13	13
Supported employment	0	35	35	0	550	550	0	366	366	0	951	951
Open employment	0	5	5	0	140	140	0	42	42	0	187	187
Vocational training	0	4	4	6	184	190	3	78	81	9	266	275
Generic day services	0	47	47	0	127	127	0	208	208	0	382	382
<b>Total</b>	<b>1680</b>	<b>248</b>	<b>1928</b>	<b>2974</b>	<b>5469</b>	<b>8443</b>	<b>3334</b>	<b>11767</b>	<b>15101</b>	<b>7988</b>	<b>17484</b>	<b>25472</b>

Table 3.7 outlines the main day service and overall level of day service provision for those registered on the NIDD in 2009. The NIDD permits the recording of 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 2009 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 63.5% (254 people) and the number of intensive day places increased by 253.4% (294 people). The data indicate that 654 and 410 people attended high-support and intensive day services respectively in 2009.
- An increase of 146.2% (405 people) in the number in receipt of day programmes specific to the older person. The number of people who attended such services in 2009 was 682.
- An increase of 39.4% (1,772 people) in the number who attended activation centres, bringing the total number to 6,098 in 2009.

Increases were also observed over the 14-year period in the numbers of individuals who availed of mainstream schools, resource teachers, and vocational training. Although the numbers who availed of mainstream services were proportionately low, the growth was in a positive direction and should be continued to ensure consistent and sustained support in line with best international practice.



**Table 3.7** Principal day service and overall level of day service provision, by age group, 2009

	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	93	176	269	1174	879
Home help	5	20	25	95	66	161
Early intervention team	464	0	464	1617	0	1617
Special pre-school for intellectual disability	511	0	511	523	0	523
Child education and development centre	147	13	160	154	13	167
Mainstream pre-school	268	0	268	325	0	325
Mainstream school	1531	66	1597	1560	67	1627
Resource/visiting teacher	136	19	155	758	58	816
Special class – primary	480	0	480	482	0	482
Special class – secondary	138	57	195	139	57	196
Special school	4005	298	4303	4012	300	4312
Third-level education	1	11	12	1	11	12
Rehabilitative training	5	1684	1689	5	1747	1752
Activation centre	0	5855	5855	0	6098	6098
Programme for the older person	0	627	627	0	682	682
Special high-support day service	4	633	637	10	644	654
Special intensive day service	26	373	399	27	383	410
Sheltered work centre	0	3644	3644	0	3847	3847
Sheltered employment centre	0	91	91	0	93	93
Multidisciplinary support services	63	1603	1666	5429	14177	19606
Centre-based day respite service	6	22	28	324	419	743
Day respite in the home	3	25	28	38	14	52
Outreach programme	3	3	6	42	94	136
Other day service	90	465	555	620	674	1294
Enclave within open employment	0	13	13	0	16	16
Supported employment	0	951	951	0	1825	1825
Open employment	0	187	187	0	349	349
Vocational training	9	266	275	9	305	314
Generic day services	0	382	382	4	419	423
<b>Total</b>	<b>7988</b>	<b>17484</b>	<b>25472</b>	<b>17348</b>	<b>33237</b>	<b>50585</b>

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

## 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, 21,223 individuals received one or more multidisciplinary support services in 2009 (including those provided by early intervention teams). This was an increase of 252 people since 2008. As in 2008, the most commonly availed of multidisciplinary support services were social work (10,358 individuals), medical services (9,202 individuals), psychology (8,184 individuals), and speech and language therapy (8,073 individuals).
- The services most commonly availed of by adults were social work (6,796 adults), medical services (6,402 adults) and psychiatry (6,126 adults).
- The services most commonly availed of by children were speech and language therapy (1,652 children aged six years or under and 3,795 children aged 7–17 years), occupational therapy (1,399 children aged six years or under and 2,309 children aged 7–17 years), and social work (1,173 children aged six years or under and 2,389 children aged 7–17 years).
- Early intervention teams usually provide services to children aged six years or under; 1,587 children (80.5%) in this age group received multidisciplinary support services from an early intervention team in 2009. There were also 30 children aged seven years or over who received services from an early intervention team in 2009.

**Table 3.8** Overall provision of multidisciplinary support services, by age and access to an early intervention team (EIT), 2009

	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	991	130	1121	13	1666	1679	6402	9202
Nursing	834	113	947	15	1207	1222	5494	7663
Nutrition	300	41	341	4	507	511	2496	3348
Occupational therapy	1143	256	1399	18	2291	2309	2800	6508
Physiotherapy	1134	206	1340	12	1655	1667	3015	6022
Psychiatry	54	29	83	1	518	519	6126	6728
Psychology	846	203	1049	20	2298	2318	4817	8184
Social work	1030	143	1173	14	2375	2389	6796	10358
Speech and language therapy	1333	319	1652	24	3771	3795	2626	8073
Other	456	82	538	8	1371	1379	4095	6012
Number of people	1587	383	1970	30	5046	5076	14177	21223

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



## Regional level

Table 3.9 provides summary details of the level of service provision in 2009 within the four HSE regions.

Nationally, 25,556 individuals (98.0%) with an intellectual disability registered on the NIDD were in receipt of services in 2009. The HSE South and HSE Dublin/Mid Leinster regions had the highest levels of service provision, with just over 98% of the population registered on the Database in both regions receiving services. The HSE West region had the lowest level of service provision of the four regions, where 97.2% of the population registered on the Database were in receipt of services.

Nationally, 8,251 individuals (31.7%) registered on the NIDD in 2009 were in receipt of a full-time residential service. Regionally this proportion varied from 29.7% in the HSE South region to 32.1% in the HSE Dublin/Mid Leinster region.

At national level, 17,284 (66.3%) attended services on a day basis, with the proportion ranging from 64.7% in the HSE West region to 68.9% in the HSE South region.

Nationally, a small proportion (263, 1.0%) of registrations were without services but were identified as requiring services in the five-year period 2010–2014. The HSE West region had the highest proportion (1.8%) of people without any service and awaiting services within the next five years.

It is encouraging to note that the number of people described as having no identified service requirements fell by over one fifth, from 301 in 2008 to 247 in 2009, which represented just 0.9% of the total registrations. This highlights the impact of the multi-annual funding that has been available for disability, as well as the commitment of service providers to ensure that the needs of those registered on the Database are met.



**Table 3.9** Service provision by HSE region of registration, 2009

	Attending services on a day basis	Receiving 5- or 7-day residential services	Resident in a psychiatric hospital	Receiving residential support services only	Receiving no service	No service requirements in 2009	Total
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	N
Dublin/Mid-Leinster	4513 (66.0)	2183 (31.9)	12 (0.2)	10 (0.1)	49 (0.7)	74 (1.1)	6841
South	5042 (68.9)	2091 (28.6)	82 (1.1)	3 (0.0)	68 (0.9)	35 (0.5)	7321
West	4414 (64.7)	2182 (32.0)	28 (0.4)	5 (0.1)	122 (1.8)	69 (1.0)	6820
Dublin/North-East	3311 (65.2)	1517 (29.9)	155 (3.1)	3 (0.1)	23 (0.5)	69 (1.4)	5078
Out of state	4 (66.7)	1 (16.7)	0 (0.0)	0 (0.0)	1 (16.7)	0 (0.0)	6
<b>All areas</b>	<b>17284 (66.3)</b>	<b>7974 (30.6)</b>	<b>277 (1.1)</b>	<b>21 (0.1)</b>	<b>263 (1.0)</b>	<b>247 (0.9)</b>	<b>26066</b>

## 4. Assessment of need 2010–2014

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 2009, 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 2010–2014. 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 2009 but will require that service to be changed or upgraded during the period 2010–2014, 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).

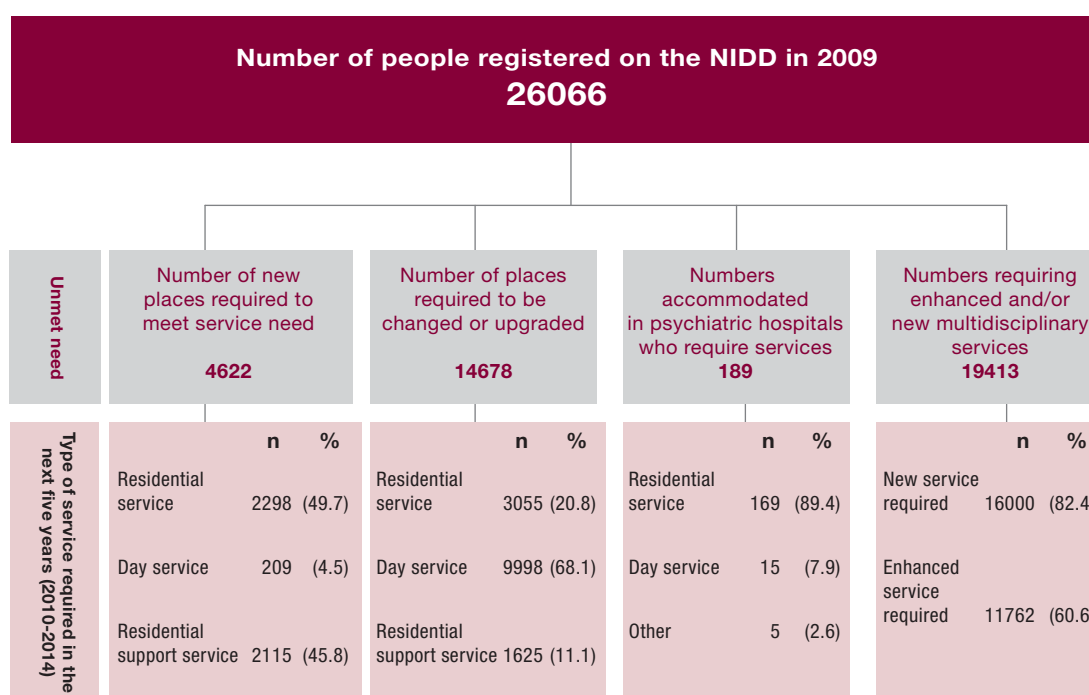
**C – People with intellectual disability who were accommodated in psychiatric hospitals in 2009:** includes people who need to transfer out of psychiatric hospitals in the period 2010 to 2014 and people who were resident in the psychiatric services in 2009 but require an appropriate day service in the period 2010–2014. 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 2010–2014 by all individuals registered on the NIDD in 2009. 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 facilitates the recording of two future residential services and two future day services for each individual. To avoid double-counting of individuals, only the first service identified is reported in the tables in this report relating to the unmet need, service change, and people with intellectual disability within the psychiatric services groups, but the level of additional need of these individuals is noted in the relevant sections of the text as well as in the multidisciplinary support services section.

## Summary

Figure 4.1 indicates that 4,622 new residential, day and/or residential support places will be needed to meet service requirements in the period 2010–2014, half of which are residential places. Of the existing places available in 2009, 14,678 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 the 189 people accommodated in psychiatric hospitals in 2009 require specialist services; almost 90% of this group require residential services. In 2009, 19,413 people were recorded as requiring new or enhanced multidisciplinary services, which is a slight decrease on the number recorded as requiring such services in 2008.



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 8,349 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  $(16,000 + 11,762) - 8,349 = 19,413$ .

**Figure 4.1** Summary of the service requirements of those registered on the NIDD, 2009

## 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 2010–2014, by HSE region of registration

	<b>Residential</b>	<b>Day</b>	<b>Residential support</b>	<b>% of total NIDD registrations</b>
Dublin/Mid-Leinster	613	48	496	26.2
South	574	50	673	28.1
West	522	96	598	26.2
Dublin/North-East	589	15	348	19.5
<b>Total</b>	<b>2298</b>	<b>209</b>	<b>2115</b>	<b>100</b>

The key figures and trends are summarised below.

- The number of new day places required has been falling steadily since 1996. The 2009 figure of 209 is the lowest since the Database was established. This figure does not, however, take account of the individuals who require a change or enhancement to their day service (see Figure 4.1), for example, those who are leaving education and require a training/employment service. This service need is considered in Section B below.
- Following a slight downward trend during the years 2000 to 2002, the number of new residential places required has increased by 41% (665 places) over the past seven years. The 2009 figure of 2,298 is the highest since the Database was established. This figure reflects an increase of 42 places required since 2008. Seven out of ten of those requiring a new residential place (1,629 individuals, 70.9%) have a moderate, severe or profound intellectual disability. Chapter 2 notes that the numbers in this group are increasing due to a cohort of people born in the 1960s and mid-1970s currently moving through the services. Chapter 3 shows that full-time residential services are more likely to be availed of by older people with a moderate, severe or profound intellectual disability. This information would suggest that the number of new full-time residential places required is likely to continue to increase over the coming years as those with a moderate, severe or profound disability advance in age. Other related factors include family members being unable or unwilling to care for their family member full time, or situations where the individual wishes to move out of the family home.
- The demand for residential supports has increased steadily since 1998. The 2009 figure of 2,115 represents a small decrease of 14 (0.7%) since 2008. This high level of need is presenting even though there were over 5,000 people availing of residential support services in 2009.

## Full-time residential services

Of the 2,298 people who required full-time residential services in 2009 (Table 4.2):

- 1,629 individuals (70.9%) had a moderate, severe, or profound level of intellectual disability, of whom 1,344 required placements in community group homes, 160 required placements in a campus setting, and 115 required specialised intensive placements because of their increased dependency.
- 627 (27.3%) individuals had a mild intellectual disability, of whom 555 required placements in community group homes, 51 required residential placements in a campus setting, and 20 required specialised intensive placements due to their increased dependency.
- 42 (1.8%) had not had their level of intellectual disability verified in 2009.

Of those who required full-time residential services in 2009, 2,277 (99.1%) were in receipt of a day service or a residential support service, 2,202 (95.8%) lived at home, and 83 (3.6%) lived independently or semi-independently.

## Day services

As in previous years, demand for day services among those reported as not being in receipt of such services is confined almost exclusively to adult services (Table 4.3). Of the 209 individuals who required day services, 192 (91.9%) lived either at home (178 individuals) or independently/semi-independently (14 individuals). The largest demand came from 186 people who had no service whatsoever in 2009. Of the 186 people who had no service:

- 113 individuals (60.8%) had a mild intellectual disability and their principal service requirements were in the training and employment areas.
- 69 individuals (37.1%) had a moderate, severe or profound intellectual disability and their principal service requirements were for activation programmes, sheltered work and rehabilitative training.

## Residential support services

Residential support services, such as respite and regular part-time care, were required by 2,115 people (Table 4.4). Of this group, 1,831 individuals (86.6%) lived either at home (1,761 individuals) or independently/semi-independently (70 individuals); 1,798 individuals (85.0%) were in receipt of a day service; and 35 individuals (1.7%) had no day service in 2009. An additional 282 individuals (13.3%) 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 2009 (1,104 individuals), while people with mild intellectual disability accounted for 42.3% (894 individuals). The remaining 5.5% (117 individuals) had not had their degree of intellectual disability verified in 2009.
- Most of the demand in 2009 was for crisis or planned respite services (1,271 individuals, 60.1%), semi-independent and independent living arrangements (413 individuals, 19.5%), and holiday residential placements (152 individuals, 7.2%).

**Table 4.2** Future full-time residential service requirements of individuals receiving no residential service in 2009, 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	2	3	0	0	0	1	1	3	109	170	282	3	110	173	286
7-day (48-week) community group home	0	1	2	3	0	0	0	0	0	1	95	206	302	1	96	208	305
7-day (52-week) community group home	0	4	2	6	0	0	0	1	1	12	345	960	1317	12	349	963	1324
5-day residential centre	0	1	0	1	0	0	0	0	0	0	1	15	16	0	2	15	17
7-day (48-week) residential centre	0	0	0	0	0	1	0	1	0	13	42	55	0	14	42	56	0
7-day (52-week) residential centre	0	1	3	4	0	0	0	0	0	22	34	100	156	22	35	103	160
Nursing home	0	0	1	1	0	0	0	0	0	0	1	7	8	0	1	8	9
Mental health community residence	0	0	0	0	0	0	0	0	0	0	0	2	2	0	0	2	2
Intensive placement (challenging behaviour)	0	0	1	1	0	0	0	0	0	0	17	55	72	0	17	56	73
Intensive placement (profound or multiple disability)	0	0	2	2	0	0	0	0	0	4	3	57	64	4	3	59	66
<b>All services</b>	<b>0</b>	<b>8</b>	<b>13</b>	<b>21</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>3</b>	<b>42</b>	<b>618</b>	<b>1614</b>	<b>2274</b>	<b>42</b>	<b>627</b>	<b>1629</b>	<b>2298</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 2009, 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	NV	Mild	MSP	ALL
Home support	0	2	5	7	0	0	0	0	0	0	0	0	0	0	0	0	0	2	5	7
Home help	0	1	1	2	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	2
Special pre-school	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1
Mainstream school	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1
Special class – primary	2	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	2
Special class – secondary	0	2	1	3	0	0	0	0	0	0	0	0	0	0	0	0	0	2	1	3
Special school	1	1	1	3	0	0	0	0	0	0	0	0	0	0	0	0	1	1	1	3
Rehabilitative training	0	29	12	41	0	1	0	1	0	1	0	0	0	0	0	0	0	30	12	42
Activation centre	0	10	13	23	0	0	3	3	1	1	1	5	7	1	11	21	11	21	33	
Programme for the older person	0	2	3	5	0	0	0	0	0	0	0	1	1	0	2	4	0	2	4	6
Special high-support day service	0	0	2	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2
Special intensive day service	0	0	2	2	0	0	0	0	0	0	2	1	3	0	2	3	0	2	3	5
Sheltered work centre	0	15	15	30	0	1	0	1	0	1	0	1	2	0	17	16	0	17	16	33
Sheltered employment centre	0	3	1	4	0	0	0	0	0	0	0	0	0	0	3	1	0	3	1	4
Outreach programme	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1
Other day service	0	2	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	2
Enclave within open employment	0	1	1	2	0	0	0	0	0	0	0	0	0	0	1	1	0	1	1	2
Supported employment	1	13	4	18	0	1	0	1	0	1	0	2	0	2	4	21	1	16	4	21
Open employment	0	6	1	7	0	1	0	1	0	1	0	0	0	0	7	1	0	7	1	8
Vocational training	0	24	5	29	0	0	0	0	0	1	0	1	0	1	25	5	0	25	5	30
Generic day services	0	1	0	1	0	0	0	0	0	0	0	0	0	0	1	0	0	1	0	1
<b>All services</b>	<b>4</b>	<b>113</b>	<b>69</b>	<b>186</b>	<b>0</b>	<b>4</b>	<b>3</b>	<b>7</b>	<b>1</b>	<b>7</b>	<b>8</b>	<b>16</b>	<b>5</b>	<b>124</b>	<b>80</b>	<b>209</b>				

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



**Table 4.4** Future residential support service requirements of individuals receiving no residential support services in 2009, 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	2	0	0	0	0	0	0	0	0	0	0	0	2
Living independently	0	4	0	4	3	42	5	50	0	1	0	1	0	6	0	6	61
Living semi-independently	0	8	2	10	8	199	39	246	0	0	0	0	1	61	34	96	352
Holiday residential placement	0	1	2	3	1	39	37	77	0	0	0	0	0	8	64	72	152
Crisis or planned respite	1	10	6	17	77	425	723	1225	0	0	0	0	2	3	24	29	1271
Occasional respite care with host family	0	0	0	0	19	33	39	91	0	0	0	0	0	0	3	3	94
Shared care or guardianship	0	0	0	0	0	4	4	8	0	0	0	0	0	0	1	1	9
Regular part-time care (2/3 days per week)	0	0	0	0	0	4	12	16	0	0	0	0	0	0	0	0	16
Regular part-time care (every weekend)	0	0	0	0	1	2	5	8	0	0	0	0	0	1	1	2	10
Regular part-time care (every weekend)	0	0	0	0	0	2	5	7	0	0	0	0	0	0	1	1	8
Other residential service	0	0	1	1	1	19	23	43	0	0	0	0	0	15	56	71	115
Overnight respite in the home	0	0	0	0	3	6	16	25	0	0	0	0	0	0	0	0	25
<b>All services</b>	<b>1</b>	<b>23</b>	<b>11</b>	<b>35</b>	<b>113</b>	<b>776</b>	<b>909</b>	<b>1798</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>3</b>	<b>94</b>	<b>184</b>	<b>281</b>	<b>2115</b>

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

As illustrated in Table 4.5, most of the demand for residential support services in 2009 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 2009, 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 in a home/independent setting in 2009 received respite care, while 7% of the same group required respite care. Within the LHO areas the percentage receiving respite ranged from 17.5% in LHO North-Eastern Area Cavan-Monaghan and LHO North-Eastern Area Louth to 44.5% in LHO Northern Area 8. Similarly, the percentage requiring respite ranged from 2.6% in LHO North-Eastern Area Cavan-Monaghan to 12.8% in LHO Western Area Mayo.

**Table 4.5** Use of and requirements for respite by people living in home/independent setting, by HSE region and LHO area, 2009

	Number in receipt of crisis or planned respite in 2009	Number who do not receive respite but require it (2010–2014)	Number in home/independent setting in 2009
LHO area	n	n	n
<b>HSE Dublin/Mid Leinster</b>	<b>1285</b>	<b>275</b>	<b>4597</b>
East Coast Area 1	120	25	401
East Coast Area 2	64	7	207
South-Western Area 3	98	17	275
South-Western Area 4	204	33	629
South-Western Area 5	141	31	618
South-Western Area 9	224	55	846
East Coast Area 10	102	18	469
Midland Area Laois-Offaly	162	32	591
Midland Area Longford-Westmeath	170	57	561
<b>HSE South</b>	<b>1013</b>	<b>349</b>	<b>4950</b>
South-Eastern Area Carlow-Kilkenny	107	85	717
South-Eastern Area Tipperary SR	115	13	461
South-Eastern Area Waterford	95	55	489
South-Eastern Area Wexford	148	30	696
Southern Area Cork North Lee	124	37	694
Southern Area Cork South Lee	123	41	558
Southern Area North Cork	88	22	391
Southern Area West Cork	54	21	281
Southern Area Kerry	159	45	663
<b>HSE West</b>	<b>1156</b>	<b>380</b>	<b>4757</b>
Mid-Western Area Limerick	132	53	701
Mid-Western Area Tipperary NR	99	23	363
Mid-Western Area Clare	105	12	331
Western Area Galway	257	77	1099
Western Area Mayo	181	85	666
Western Area Roscommon	47	25	350
North-Western Area Donegal	214	58	769
North-Western Area Sligo-Leitrim	121	47	478
<b>HSE Dublin/North East</b>	<b>954</b>	<b>237</b>	<b>3428</b>
Northern Area 6	171	47	648
Northern Area 7	113	24	346
Northern Area 8	339	50	762
North-Eastern Area Cavan-Monaghan	88	13	502
North-Eastern Area Louth	105	25	600
North-Eastern Area Meath	138	78	570
<b>All regions</b>	<b>4408<sup>9</sup></b>	<b>1242</b>	<b>17734</b>

9 The total number recorded as receiving respite in Table 4.5 (4,408 individuals) is less than that recorded in Table 3.4 (4,681 individuals) as Table 4.5 only includes those living in a home setting or living independently. A small number of people living in 5 day 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 2009 but who require that service to be changed or upgraded during the period 2010–2014, and includes children who availed of education services in 2009 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 11,564 people who were receiving services in 2009 will require a change to their existing service provision in the period 2010–2014, a decrease of 259 (2.2%) since 2008. Of the 11,564 who were recorded as requiring a service change:

- 7,722 (66.8%) were day attendees (of whom 838 also availed of residential support services).
- 3,055 (26.4%) were full-time residents (of whom 2,276 also availed of day services).
- 787 (6.8%) 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 7,383 (63.8%) of the service changes required.
- People in the mild range required 3,277 (28.3%) of the service changes.
- 904 (7.8%) of the service changes were required by people whose level of intellectual disability had not been verified in 2009.

**Table 4.6** Category of service change required 2010–2014, 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	9	19	851	9	16	904
Mild	217	94	2591	208	167	3277
Moderate, severe & profound	2050	666	3442	621	604	7383
<b>All levels</b>	<b>2276</b>	<b>779</b>	<b>6884</b>	<b>838</b>	<b>787</b>	<b>11564</b>

### Number of places required to address service changes

The numbers of places involved in addressing the required service changes 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, 2010–2014

<b>Residential</b>	<b>3055</b>
<b>Day</b>	<b>9998</b>
Of which:	6934
Health services	1121
Education services	1279
Employment services	664
Generic services	
<b>Residential support</b>	<b>1625</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 day services. In addition, it is important to note that, although 11,564 people were recorded in 2009 as requiring service changes, this demand does not necessitate 11,564 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 2009, 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 3,055 individuals in full-time residential services in 2009 will require an upgrading or change of accommodation within the next five years. For 62.3% of this group (1,904 individuals) changes of service type are required as follows:

- Residential placements in the community are required by 1,113 individuals (36.4%).
- Intensive services for either challenging behaviour or profound or multiple disability are required by 610 individuals (20.0%).
- Centre-based placements are required by 132 individuals (4.3%).
- Nursing home placements are required by 49 individuals (1.6%).

The remaining 1,151 individuals (37.7%) require an enhancement in their existing service type, as follows:

- 336 individuals need their existing service upgraded to include care at weekends and holiday times.
- 15 individuals require less care and could return to their families at weekends and holiday times.
- 800 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, 2010–2014

Full-time residential service required in the period 2010–2014										
	5-day CGH	7-day (48-wk) CGH	7-day (52-wk) CGH	5-day RC	7-day (48-wk) RC	7-day (52-wk) RC	Nursing home	Intensive placement (CB)	Intensive placement (P/MD)	Total services 2009
<b>Full-time residential service in 2009</b>										
5-day community group home (CGH)	14	48	138	1	0	12	0	4	0	217
7-day (48-week) community group home	0	57	116	1	5	11	1	10	3	204
7-day (52-week) community group home	6	7	477	0	4	35	21	56	38	644
5-day residential centre (RC)	8	6	26	1	5	5	0	1	0	52
7-day (48-week) residential centre	2	61	94	0	19	24	5	17	14	236
7-day (52-week) residential centre	2	14	762	0	2	140	18	204	240	1382
Nursing home	0	1	29	0	0	4	9	1	3	47
Intensive placement (challenging behaviour) (CB)	1	2	43	1	3	44	2	42	9	147
Intensive placement (profound or multiple disability) (P/MD)	0	2	25	0	1	6	0	2	41	77
Occupying a residential support place	2	2	22	0	0	1	2	2	3	34
Other residential service	0	1	8	0	0	3	0	3	0	15
<b>Total services required</b>	<b>35</b>	<b>201</b>	<b>1740</b>	<b>4</b>	<b>39</b>	<b>285</b>	<b>58</b>	<b>342</b>	<b>351</b>	<b>3055</b>

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, 9,998 individuals will require a change, enhancement, or upgrading of their day service (Table 4.9).

- Health-funded services are required by 6,934 individuals (69.4%).
- Employment services are required by 1,279 individuals (12.8%).
- Education services are required by 1,121 individuals (11.2%).
- Generic services are required by 664 individuals (6.6%).

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

## Health services

Of the 6,934 service changes required within health-funded services, 5,156 (74.4%) are requirements for an alternative or additional service and 1,778 (25.6%) 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:

- 915 individuals require high-support or intensive placements, the majority of whom currently attend activation programmes (398 individuals), or receive multidisciplinary support services as their only day service (212 individuals).
- 838 individuals require activation programmes, the majority of whom currently receive multidisciplinary support services as their only day service (362 individuals), or attend special schools (158 individuals), or rehabilitation training (86 individuals).
- 779 individuals require services specific to older people, the majority of whom currently attend activation programmes (350 individuals) or sheltered work (182 individuals).
- 606 individuals require rehabilitative training, the majority of whom currently attend special schools (395 individuals).

There are also 1,778 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 (952 individuals, 53.5%) or sheltered work (297 individuals, 16.7%). 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 1,279 service changes required within employment services, 1,188 (92.9%) are requirements for an alternative placement and 91 (7.1%) are requirements for an enhancement of the individual's existing placement (Table 4.9).

Most of the demand for alternative employment opportunities comes from 1,078 individuals who require supported employment, the majority of whom currently attend sheltered work (403 individuals) or activation centres (232 individuals). There are 83 individuals who require their existing employment placement to be enhanced (shaded area of Table 4.9).

## Education services

Of the 1,121 service changes required within education services, 861 (76.8%) are requirements for an alternative service and 260 (23.2%) 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:

- 282 children who require special classes, mainly at secondary level. The majority of those requiring special classes at secondary level (220 children) currently attend special classes at primary level (134 children).
- 294 children who require a mainstream school placement, the majority of whom currently attend a mainstream (106 children) or specialised (80 children) pre-school.
- 215 children who require a special school placement, the majority of whom currently attend special pre-schools (112 children).

There are 360 children who require their existing education placement to be enhanced (shaded areas of Table 4.9), the majority of whom currently attend mainstream schools (152 children). There is also a significant demand for increased support within existing education placements.

A large proportion of the 1,449 children who were attending special schools in 2009 require adult services in the period 2010–2014. Of this group, over one quarter (395 individuals) require rehabilitative training, 329 (22.7%) require vocational training and 158 (10.9%) require activation programmes.



## Generic services

Of the 664 service changes required within generic services, 641 (96.5%) are requirements for an alternative service and 23 (3.5%) are requirements for an enhancement of the individual's existing service (Table 4.9).

Most of the demand for alternative generic services comes from 606 individuals who require vocational training, the majority of whom currently attend special schools (329 individuals).

Eight individuals attending vocational training and 15 individuals availing of generic day services require their existing generic service to be enhanced (shaded areas of Table 4.9).

## Residential support service change

The database indicates that 1,625 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 2010 to 2014 (Table 4.10). Additional or alternative support services are required by 439 individuals (27.0%) and 1,186 individuals (73.0%) require their existing service to be upgraded (shaded area 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 (1,132 individuals).
- Opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (81 people).
- Occasional holiday residential placements and occasional respite care with a host family for people currently availing of crisis or planned respite (60 people).

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

**Table 4.9** Pattern of movement of individuals from existing day services to future day services, 2010–2014

Day service in 2009	Day service required in the period 2010–2014																	GD	ALL									
	HS	HH	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	TL	RHT	AC	POP	SHS	SI	SWC			SEC	CDR	DRH	OT	OTH	E	SE	OE	VT
Home support (HS)	24	0	14	20	0	9	2	1	2	3	0	6	10	2	2	4	6	1	1	0	2	2	0	8	0	3	1	123
Home help (HH)	0	0	1	1	0	1	2	0	0	0	0	0	0	1	0	0	0	1	0	1	1	0	1	0	0	0	0	10
Early services	24	1	149	68	0	21	0	7	0	13	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	0	0	286
Mainstream pre-school (MPS)	16	0	13	12	0	106	0	6	0	15	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	170
Special pre-school (SPS)	20	0	59	50	12	80	3	24	1	112	0	0	0	0	0	0	0	0	5	0	2	0	0	0	0	0	0	368
Child education and development centre (CEDC)	19	0	1	0	7	0	0	0	0	3	0	0	32	0	2	2	0	0	1	0	0	5	0	0	0	0	0	72
Mainstream school (MS)	75	1	6	0	0	152	49	16	59	37	3	12	5	0	0	1	3	0	57	10	0	33	0	4	2	45	2	572
Resource teacher (RT)	4	0	3	0	0	11	17	0	12	1	0	8	0	0	0	0	0	0	0	0	0	0	0	0	0	24	0	80
Special class – primary (SCP)	29	1	0	0	0	27	5	8	134	14	0	2	3	0	0	1	0	0	7	0	2	5	0	0	0	0	0	238
Special class – secondary (SCS)	6	0	0	0	0	1	2	0	9	2	0	21	10	0	0	0	3	0	2	2	0	2	0	7	2	31	0	100
Special school (SS)	152	3	5	0	4	17	1	3	9	74	0	395	158	0	20	38	131	18	32	0	6	32	0	19	2	329	1	1449
Third-level education (TL)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	1	2	0	5	
Rehabilitative training (RHT)	13	2	0	0	0	0	0	0	0	0	1	33	86	7	3	4	273	13	7	7	0	12	1	201	10	92	20	785
Activation centre (AC)	40	4	0	0	0	0	0	0	0	0	0	77	952	350	188	210	110	13	8	7	1	15	2	232	12	25	2	2248
Programme for the older person (POP)	7	0	0	0	0	0	0	0	0	0	0	0	17	188	7	37	6	1	0	1	0	3	0	2	0	0	2	271
Special high support day service (SHS)	2	1	0	0	0	0	0	0	0	0	0	6	25	13	123	99	9	1	1	5	0	4	0	7	0	0	0	296
Special intensive day service (SI)	2	1	0	0	0	0	1	1	3	9	0	1	11	1	13	67	3	0	0	8	0	3	0	9	1	0	0	134

**Table 4.9** Pattern of movement of individuals from existing day services to future day services 2010–2014 (continued)

		Day service required in the period 2010–2014																				GD	Total					
Day service in 2009	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)	13	1	0	0	0	0	0	0	0	0	1	22	85	182	23	14	297	23	3	21	0	18	6	403	28	7	4	1151
Sheltered employment centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	6	0	0	0	0	0	0	8	0	1	0	15
Multidisciplinary support services	9	5	5	4	0	4	0	0	0	2	0	35	362	183	80	132	29	3	2	0	1	9	1	51	12	28	1	958
Centre-based day respite service (CDR)	0	0	0	0	0	0	0	0	0	1	0	0	2	1	0	0	0	1	0	0	1	0	0	0	0	3	0	9
Day respite in the home (DRH)	0	0	0	0	3	0	0	0	0	0	0	1	0	1	0	1	1	0	0	0	0	0	0	1	0	1	0	9
Outreach programme (OP)	0	0	1	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	4
Other day service (OTH)	2	2	2	21	0	14	0	4	0	3	0	11	14	24	7	9	54	0	0	0	1	23	0	21	4	7	0	223
Enclave within open employment (E)	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	2	1	0	0	5
Supported employment (SE)	9	3	0	0	0	0	0	0	0	0	0	2	3	7	0	0	6	3	4	4	0	9	1	83	7	3	2	146
Open employment (OE)	2	1	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	1	1	0	0	1	0	6	8	4	0	27
Vocational training (VT)	3	0	0	0	0	0	0	0	0	0	0	4	4	3	1	1	29	7	1	0	0	4	5	63	10	8	0	143
Generic day services (GD)	4	0	0	0	0	0	0	0	0	0	0	2	7	4	9	7	3	0	0	0	0	16	1	32	0	1	15	101
<b>Total</b>	<b>475</b>	<b>26</b>	<b>259</b>	<b>178</b>	<b>23</b>	<b>446</b>	<b>82</b>	<b>70</b>	<b>229</b>	<b>289</b>	<b>5</b>	<b>639</b>	<b>1790</b>	<b>967</b>	<b>478</b>	<b>627</b>	<b>969</b>	<b>86</b>	<b>135</b>	<b>66</b>	<b>14</b>	<b>202</b>	<b>18</b>	<b>1161</b>	<b>100</b>	<b>614</b>	<b>50</b>	<b>9998</b>

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.

**Table 4.10** Additional residential support services required by people availing of residential support services in 2009

Residential support service required 2010–2014													
Residential support service in 2009	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				Total	
								part-time care (2/3 days per week)	Regular part-time care (every weekend)	Regular part-time care (alternate weeks)	Overnight respite in the home		Other residential service
Foster care and boarding-out	4	1	9	2	10	1	0	1	0	0	0	1	29
Living semi-independently	0	11	22	8	7	0	0	0	0	0	0	0	48
Holiday residential placement	0	0	4	0	7	1	0	1	0	4	0	0	19
Crisis or planned respite	2	4	81	17	1132	43	20	65	17	24	6	13	1424
Occasional respite care (host family)	0	1	6	1	30	20	4	2	0	1	1	2	68
Shared care or guardianship	0	0	0	0	1	0	0	0	0	0	0	0	1
Regular part-time care (2/3 days per week)	0	0	1	0	6	0	2	1	2	1	0	0	13
Regular part-time care (alternate weeks)	0	0	0	0	3	0	1	0	0	0	0	0	4
Overnight respite in the home	0	0	0	0	0	0	0	0	0	0	4	0	4
Other residential service	0	1	2	1	7	0	0	0	0	1	0	3	15
<b>All services</b>	<b>6</b>	<b>18</b>	<b>125</b>	<b>29</b>	<b>1203</b>	<b>65</b>	<b>27</b>	<b>70</b>	<b>19</b>	<b>31</b>	<b>11</b>	<b>21</b>	<b>1625</b>

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 year, for the first time, the NIDD annual 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 of this report focuses on children aged 16 years or older who were in second-level education in 2009 and who will require an adult day service in the years 2010–2014.

Over nine hundred young adults with an intellectual disability aged 16 years or over who were in an education setting in 2009 will require a range of day services within the period 2010–2014 (Table 4.11). Most of the demand is for vocational training (309 places) or rehabilitative training (256 places).

Of the 908 individuals who required a day service (Table 4.12):

- 505 (56%) individuals had a mild intellectual disability, of whom 253 required vocational training and 122 required rehabilitative training.
- 402 (44%) individuals had a moderate, severe or profound level of intellectual disability, of whom 133 required rehabilitative training and 56 required vocational training.
- One person had not had his/her level of intellectual disability verified in 2009 but required rehabilitative training.

Table 4.13 identifies the year in which the day services are required. Most of the day service requirements are immediate: 798 individuals (88%) require their day service in 2010 or 2011.

**Table 4.11** Future day service requirements of individuals aged 16 years or over who were in an education setting in 2009, by age

	16 years	17 years	18 years	19 years +	Total
Home support	12	10	5	2	29
Third-level education	0	1	0	1	2
Rehabilitative training	89	95	44	28	256
Activation centre	51	41	20	5	117
Special high-support day service	3	5	2	2	12
Special intensive day service	4	12	4	1	21
Sheltered work centre	25	28	16	10	79
Sheltered employment centre	3	5	3	1	12
Centre-based day respite service	11	7	1	0	19
Day respite in the home	0	1	0	0	1
Other day service	11	6	3	5	25
Supported employment	4	11	5	3	23
Open employment	1	1	0	0	2
Vocational training	105	88	86	30	309
Generic day services	0	1	0	0	1
<b>Total</b>	<b>319</b>	<b>312</b>	<b>189</b>	<b>88</b>	<b>908</b>

**Table 4.12** Future day service requirements of individuals aged 16 years or over who were in an education setting in 2009, by degree of intellectual disability

	Mild	Mod/Sev/Prof	Total*
Home support	2	27	29
Third-level education	1	1	2
Rehabilitative training	122	133	255
Activation centre	39	78	117
Special high-support day service	0	12	12
Special intensive day service	3	18	21
Sheltered work centre	39	40	79
Sheltered employment centre	7	5	12
Centre-based day respite service	5	14	19
Day respite in the home	1	0	1
Other day service	13	12	25
Supported employment	17	6	23
Open employment	2	0	2
Vocational training	253	56	309
Generic day services	1	0	1
<b>Total</b>	<b>505</b>	<b>402</b>	<b>907</b>

\*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 2009, by year of service requirement

	2010	2011	2012-14	Total*
Home support	26	0	0	26
Third-level education	1	0	1	2
Rehabilitative training	153	70	31	254
Activation centre	54	43	18	115
Special high-support day service	9	2	1	12
Special intensive day service	14	6	1	21
Sheltered work centre	46	28	5	79
Sheltered employment centre	8	2	2	12
Centre-based day respite service	18	1	0	19
Day respite in the home	1	0	0	1
Other day service	17	6	2	25
Supported employment	15	6	1	22
Open employment	1	1	0	2
Vocational training	179	90	40	309
Generic day services	1	0	0	1
<b>Total</b>	<b>543</b>	<b>255</b>	<b>102</b>	<b>900</b>

\*Excludes eight 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 2009 identified 277 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.



**Table 4.14** Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2009

Resident in psychiatric hospital in 2009	No service requirements				With service requirements				Total
	Not verified	Mild	Moderate, severe & profound	All levels	Not verified	Mild	Moderate, severe & profound	All levels	
With no day programme	0	1	1	2	0	3	2	5	7
With day programme	1	34	50	85	0	47	136	183	268
With residential support service and day programme	0	1	0	1	0	1	0	1	2
<b>All residents</b>	<b>1</b>	<b>36</b>	<b>51</b>	<b>88</b>	<b>0</b>	<b>51</b>	<b>138</b>	<b>189</b>	<b>277</b>

Of this group, 189 individuals (68.2%) were recorded as having service requirements in the period 2010–2014, of whom:

- 169 individuals had an appropriate alternative residential facility identified for them (76 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.
- 16 individuals were recorded as appropriately placed within the psychiatric hospital but had identified day service requirements, as shown in Table 4.15.
- Two people were recorded as appropriately placed within the psychiatric hospital but require residential support services.
- Two people were recorded as appropriately placed within the psychiatric hospital but require increased support.



**Table 4.15** Day service requirements of people appropriately accommodated in psychiatric hospitals in 2009

Day service in 2009	Services required 2010–2014					
	Activation centre	Programme for the older person	Special high-support day service	Supported employment	Other day service	All services
Rehabilitative training	0	0	0	1	0	1
Activation centre	1	0	0	0	1	2
Special intensive day service	0	0	1	0	0	1
Sheltered work centre	0	0	0	1	0	1
Multidisciplinary support services only	8	1	2	0	0	11
<b>All services</b>	<b>9</b>	<b>1</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>16</b>

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

Of the 169 people who were recorded in 2009 as needing to transfer from psychiatric to intellectual disability services for provision of their residential services, 66 individuals (39.1%) required places in residential centres, 63 individuals (37.3%) required intensive placements, and 39 individuals (23.1%) required community group home places. One individual needed to move to a nursing home. In all cases the need was immediate (Table 4.16).

**Table 4.16** Residential service requirements of people resident in psychiatric hospitals in 2009 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	37
7-day (48-week) residential centre	1
7-day (52-week) residential centre	65
Nursing home	1
Intensive placement (challenging behaviour)	48
Intensive placement (profound/multiple disability)	15
<b>All residential services</b>	<b>169</b>

Of this same group of 169 people, 76 required an appropriate day service. The greatest demand was for high-support or intensive day programmes (50 people, 65.8%), programmes for older people (10 people, 13.2%) and activation programmes (8 people, 10.5%). All day services were required immediately (Table 4.17).

**Table 4.17** Day service requirements of people resident in psychiatric hospitals in 2009 who require transfer to the intellectual disability sector

	Number requiring day service
Rehabilitative training	3
Activation centre	8
Programme for the older person	10
Special high-support day service	40
Special intensive day service	10
Sheltered work centre	1
Sheltered employment centre	1
Supported employment	1
Generic day services	2
<b>All day services</b>	<b>76</b>

*Note: 52 of the 76 also had multidisciplinary support service requirements. These are documented in the multidisciplinary support services section later in this chapter.*

The 2009 data indicate that the current day and residential programmes for 88 people with intellectual disability resident in psychiatric hospitals were appropriate and that these people had no identified service needs in the period 2010–2014 (Table 4.14). Fifty-one of this group (58%) had a moderate, severe, or profound intellectual disability, 36 (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 2009 and an ‘enhancement’ refers to a change in the delivery of a therapeutic input that the individual received in 2009 (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 2009 with the demand for services in the period 2010–2014.

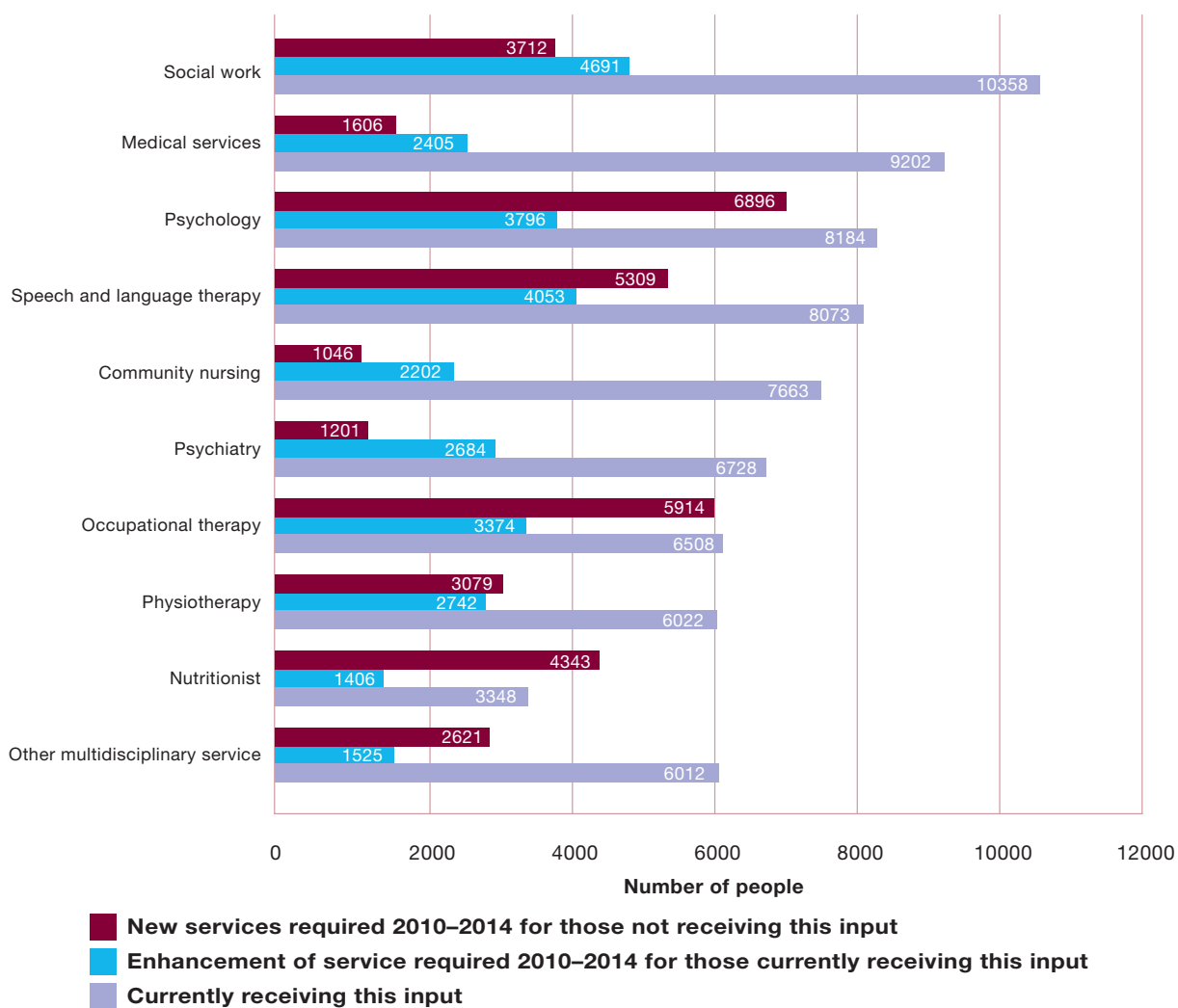
In 2009 multidisciplinary support services were availed of by 21,223 people, 16,780 of whom had further requirements for such services. A further 2,633 individuals who did not access such services in 2009 require them. There are, therefore, 19,413 (16,780 plus 2,633) individuals with a need for multidisciplinary support services; these needs involve either an enhancement of a type of service received in 2009 (3,413 individuals), a requirement for a new type of service (7,651 individuals), or both (8,349 individuals). Of the 19,413 people with future multidisciplinary support service needs, 145<sup>10</sup> received no service whatsoever in 2009. Ninety-nine per cent of those in need of multidisciplinary support services required them immediately.

Despite high levels of service provision in 2009, 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, 8,184 individuals received a psychology service in 2009, 3,796 of whom needed an enhancement of their service, and a further 6,896 individuals who did not receive a psychology service in 2009 require one in the period 2010–2014.

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 2009. For example, 3,348 individuals were in receipt of the services of a nutritionist in 2009, 1,406 of whom needed an enhancement of their service, and a further 4,343 individuals who were not in receipt of this service in 2009 require it in the immediate future.

---

10 88 of the 145 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 2009 and required in the period 2010-2014

### Overall service provision to people with intellectual disability and the pattern of care required in the period 2010-2014

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 2009 data indicate that there were large numbers of people who required residential services for the first time in 2009 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 2010–2014 comes from three distinct groups already identified in this chapter:

- 2,298 individuals who lived at home in 2009 and who were recorded as requiring full-time residential services for the first time in 2009;
- 169 individuals who resided in psychiatric hospitals in 2009 and who were recorded as requiring to transfer to the intellectual disability services; and
- 3,055 individuals who were in full-time residential services within the intellectual disability sector in 2009 and who require changes to their existing placement. Of this group, 1,904 required alternative services and 1,151 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 2010–2014 to meet this demand. A total of 2,501 residential places will be required, an increase of 23 since 2008.

- 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, 2,865 community-based placements will be required during the period, an increase of 92 placements (3.3%) since 2008.
- There will also be a shortfall of 671 intensive residential placements, a decrease of 32 placements (4.6%) on the shortfall recorded in 2009. 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, 2010–2014

	<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	286	0	35	217	-104
7-day (48-week) community group home	305	2	201	204	-304
7-day (52-week) community group home	1324	37	1740	644	-2457
5-day residential centre	17	0	4	52	31
7-day (48-week) residential centre	56	1	39	236	140
7-day (52-week) residential centre	160	65	285	1382	872
Nursing home	9	1	58	47	-21
Mental health community residence	2	0	0	0	-2
Psychiatric hospital	0	0	0	0	0
Intensive placement (challenging behaviour)	73	48	342	147	-316
Intensive placement (profound or multiple disability)	66	15	351	77	-355
Other/unspecified intellectual disability service	0	0	0	15	15
Designated residential support placement	0	0	0	34	0
<b>Total</b>	<b>2298</b>	<b>169</b>	<b>3055</b>	<b>3021</b>	<b>-2501</b>

*Note: 34 designated residential support places currently occupied 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:

- 209 individuals who were without day services in 2009;
- 76 individuals who were resident in psychiatric hospitals in 2009 and who will require an appropriate day service when they transfer to intellectual disability services;
- 16 individuals appropriately placed in psychiatric hospitals in 2009 who will require a day programme within that setting between 2010 and 2014; and



- 9,998 individuals who were in day services within the intellectual disability sector in 2009 and who will require changes to, or enhancements of, their placement. Of this group, 7,846 require alternative or additional services and 2,152 require their service to be enhanced. The majority (6,934) 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:

- where the service already exists, it will be retained by the individual, even when his/her new service comes on stream, or
- 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 2010–2014 to meet demand. The data in the table have been adjusted to reflect the fact that not all existing services will be freed up.

---

<sup>11</sup> 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.



A total of 1,545 day places will be required. This represents a decrease of 325 places on 2008 figures. The table shows that there is less demand by young children for certain services and a considerable demand for the full spectrum of adult services. Trends in the NIDD data indicate that, based on current levels of service provision, the situation in relation to service requirements in the period 2010–2014 will be as follows:

- A reduction of approximately 3% may be expected in the number of children requiring places in special schools; the number decreased from 1,196 children in 2008 to 1,157 in 2009. Although the numbers are small, there is a demand within this group for mainstream pre-school services, with the number increasing from 117 children in 2008 to 128 in 2009. This demand is likely to be greater than the data indicate due to the probable under-recording of young children on the Database discussed in Chapter 2.
- There is likely to be a shortfall of training and employment opportunities. In the next five years, 1,039 supported employment opportunities, 501 vocational training placements, and 81 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; 713 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, 227 high-support day placements and 508 intensive day placements will be required. These services involve a higher staff-to-client ratio and more specialist interventions to address needs arising from behavioural problems, multiple disabilities and the effects of ageing.

**Table 4.19** Pattern of day service provision required, 2010–2014

	New services					Shortfall (-)/
	New services required by people without day services	New services required by people transferring from psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Excess of places arising from demand
Home support	7	0	0	475	123	-359
Home help	2	0	0	26	10	-18
Mainstream pre-school	0	0	0	259	170	-89
Special pre-school	1	0	0	178	368	189
Child education and development centre	0	0	0	23	72	49
Mainstream school	1	0	0	446	572	125
Resource/visiting teacher	0	0	0	82	80	-2
Special class – primary	2	0	0	70	238	166
Special class – secondary	3	0	0	229	100	-132
Special school	3	0	0	289	1449	1157
Third-level education	0	0	0	5	5	0
Rehabilitative training	42	3	0	639	785	101
Activation centre	33	8	9	1790	2248	408
Programme for the older person	6	10	1	967	271	-713
Special high-support day service	2	40	3	478	296	-227
Special intensive day service	5	10	0	627	134	-508
Sheltered work centre	33	1	0	969	1151	148
Sheltered employment centre	4	1	0	86	15	-76
Centre-based day respite service	0	0	0	135	9	-126
Day respite in the home	0	0	0	66	9	-57
Other day service	2	0	1	202	223	18
Outreach programme	1	0	0	14	4	-11
Enclave within open employment	2	0	0	18	5	-15
Supported employment	21	1	2	1161	146	-1039
Open employment	8	0	0	100	27	-81
Vocational training	30	0	0	614	143	-501
Generic day services	1	2	0	50	101	48
<b>All services</b>	<b>209</b>	<b>76</b>	<b>16</b>	<b>9998</b>	<b>8754</b>	<b>-1545</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 over 26,500 people who were registered on the Database at the end of December 2009, represents the cumulative specialised health service needs of this group of people.

This report highlights the need to be cognisant of trends over time in the population with intellectual disability, and of how changing circumstances can impact substantially on the type and quantity of services that are used or required by those who are registered. Trend data are presented for the period 1996–2009, 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 2009 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, for the first year since reporting began 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 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 also highlights, for the first time, 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 highlights the continuing shift away from the more traditional institutional models of care towards community living; for the fifth 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 2009, 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 link between physical/sensory disability and age means that older age groups are more likely to have these additional needs. Service providers and planners must take this into account in any future planning.

The majority of those registered on the NIDD in 2009 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 2008 data. Despite the high levels of service provision in 2009, 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 2010–2014.

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 and historical under-funding of intellectual disability services are contributing to long waiting lists for these services, which are likely to continue into the future. In the current economic circumstances of reduced health spending it is imperative that we have reliable data on the services provided and the identified needs of those requiring specialist services. In providing these essential data, the NIDD currently serves the information needs of the HSE as service managers, and the Department of Health and Children as policy makers. The number of people with an intellectual disability is growing and the proportion who are in the older age groups is increasing. An older population has different needs. In addition, expectations of services are also rising. The challenge for all will be to set priorities and deliver and plan quality services within a national policy and tight budgetary framework.

# References

- Central Statistics Office (2003) *Census 2002: principal demographic results*. Dublin: Stationery Office.
- Central Statistics Office (2007) *Census of population, 2006: principal demographic results*. Dublin: Stationery Office.
- Central Statistics Office (2008) *National Disability Survey 2006: first results*. Dublin: Stationery Office.
- Kelly F, Kelly C and Craig S (2007) *Annual report of the National Intellectual Disability Database Committee 2007*. Dublin: Health Research Board.
- Kelly F, Craig S and Kelly C (2009) *Trends in demand for services among children aged 0–5 years with an intellectual disability, 2003–2007*. HRB Trends Series 3. Dublin: Health Research Board.
- Kelly F, Kelly C and Craig S (2009) *Annual report of the National Intellectual Disability Database Committee 2009*. Dublin: Health Research Board.
- Kelly C, Kelly F and Craig S (2009) *Trends in demand for services among those aged 50 years and over with an intellectual disability, 2003–2007*. HRB Trends Series 5. Dublin: Health Research Board.
- Mulcahy M (1976) *Census of the mentally handicapped in the Republic of Ireland 1974: non-residential*. Dublin: Medico-Social Research Board.
- Mulcahy M and Ennis B (1976) *Census of the mentally handicapped in the Republic of Ireland 1974: residential*. Dublin: Medico-Social Research Board.
- Mulcahy M and Reynolds A (1984) *Census of mental handicap in the Republic of Ireland 1981*. Dublin: Medico-Social Research Board.
- Mulvany F and Barron S (2003) *Annual report of the National Intellectual Disability Database Committee 2002*. Dublin: Health Research Board.
- National Intellectual Disability Database Committee (1997) *Annual report 1996*. Dublin: Health Research Board.
- World Health Organization (1996) *International statistical classification of diseases and related health problems*. Tenth Revision, Volume 1. Geneva: WHO.



# Appendix A

## National Intellectual Disability Database form 2009



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

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

## FUTURE SERVICE REQUIREMENTS

### REQUIRED DAY SERVICES

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

### CONTINGENCY DAY SERVICES

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

### RESIDENTIAL SERVICES

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

### CONTINGENCY RESIDENTIAL SERVICES

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

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

#### DAY SUPPORT LEVEL CODES

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

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

#### RESIDENTIAL SUPPORT LEVEL CODES

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

- A: MINIMUM (no sleep-in)
- B: LOW (staff on duty most of the time plus sleep-in)
- C: MODERATE (two staff on duty plus sleep-in)
- D: HIGH (two staff on duty plus on-duty night staff)
- E: INTENSIVE (one to one)
- Z: NOT APPLICABLE



**ADDITIONAL INFORMATION**

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

92. Reason for removal                      |\_|\_|

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

If deleted (3) please indicate:

- |  |   |
|--|---|
| <input type="radio"/> Emigrated                  | <input type="radio"/> Parents' request              |
| <input type="radio"/> Service no longer required | <input type="radio"/> Client's request              |
| <input type="radio"/> To NPSDD                   | <input type="radio"/> Duplication between HSE areas |
| <input type="radio"/> Other reason               | <input type="radio"/> Duplication within HSE area   |

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

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

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

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

**SERVICES CODED AS "OTHER"**

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

**Question number/Text description**

---



---



---



---



---



---



---



---



---



---



---



---

**Personally identifying details are not accessible to the Department of Health and Children 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 (receives pay and pays PRSI)
- Enclave within open employment (open employment where people with Intellectual Disability work for mainstream employer and receives normal rates for the job)
- Supported employment
- Open employment
- Other day programme
- Resource teacher/visiting teacher
- Early services (multidisciplinary intervention with infants and young children)
- Generic day services (person attends a social, psychiatric or similar centre away from their residence on a regular basis)
- Home help (assistance provided to the family in terms of assisting with domestic tasks)
- Multidisciplinary support services for school age children or adults
- Centre-based day respite service (respite services provided within Intellectual Disability Services)
- Day respite in a home (regular respite provided in the person's residence)

## Residential circumstances

- At home, with both parents
- At home, with one parent
- At home with sibling
- At home with relative
- 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 B1** 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>1694</b>	<b>61</b>	<b>60</b>	<b>26</b>	<b>1841</b>	<b>3432</b>	<b>1723</b>	<b>1135</b>	<b>209</b>	<b>6499</b>	<b>3690</b>	<b>2700</b>	<b>1724</b>	<b>288</b>	<b>8402</b>	<b>8816</b>	<b>4484</b>	<b>2919</b>	<b>523</b>	<b>16742</b>
Home Setting	1428	46	20	1	1495	2481	1254	476	16	4227	2866	2040	696	12	5614	6775	3340	1192	29	11336
At home with both parents	236	13	24	6	279	778	396	459	38	1671	729	594	658	42	2023	1743	1003	1141	86	3973
At home with one parent	0	1	14	16	31	8	11	152	118	289	2	29	340	199	570	10	41	506	333	890
At home with sibling	5	0	1	3	9	39	17	30	29	115	19	10	20	26	75	63	27	51	58	199
At home with other relative	1	0	0	0	1	2	7	9	2	20	2	1	3	3	9	5	8	12	5	30
Lives with non-relative	0	0	0	0	0	6	8	0	0	14	6	5	1	0	12	12	13	1	0	26
Adoption	24	1	1	0	26	118	30	9	6	163	66	21	6	6	99	208	52	16	12	288
Foster care and boarding out arrangements	0	7	34	15	56	2	160	436	157	755	0	34	85	62	181	2	201	555	234	992
<b>Independent/Semi-independent Setting</b>	<b>0</b>	<b>7</b>	<b>34</b>	<b>15</b>	<b>56</b>	<b>2</b>	<b>160</b>	<b>436</b>	<b>157</b>	<b>755</b>	<b>0</b>	<b>34</b>	<b>85</b>	<b>62</b>	<b>181</b>	<b>2</b>	<b>201</b>	<b>555</b>	<b>234</b>	<b>992</b>
Lives independently	0	2	25	14	41	2	109	280	116	507	0	24	44	38	106	2	135	349	168	654
Living semi-independently	0	5	9	1	15	0	51	156	41	248	0	10	41	24	75	0	66	206	66	338
<b>Community Group Homes</b>	<b>3</b>	<b>4</b>	<b>3</b>	<b>6</b>	<b>16</b>	<b>45</b>	<b>163</b>	<b>432</b>	<b>276</b>	<b>916</b>	<b>82</b>	<b>594</b>	<b>1687</b>	<b>676</b>	<b>3039</b>	<b>130</b>	<b>761</b>	<b>2122</b>	<b>958</b>	<b>3971</b>
5 day community group home	1	1	1	2	5	29	29	51	8	117	19	98	190	10	317	49	128	242	20	439
7 day community group home	0	0	0	0	0	1	24	69	21	115	16	86	308	53	463	17	110	377	74	578
7 day (52 week) community group home	2	3	2	4	11	15	110	312	247	684	47	410	1189	613	2259	64	523	1503	864	2954
<b>Residential centres</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>10</b>	<b>12</b>	<b>4</b>	<b>26</b>	<b>84</b>	<b>122</b>	<b>236</b>	<b>54</b>	<b>429</b>	<b>1290</b>	<b>903</b>	<b>2676</b>	<b>58</b>	<b>455</b>	<b>1376</b>	<b>1035</b>	<b>2924</b>
5 day residential centre	0	0	0	0	0	1	2	4	2	9	6	19	32	3	60	7	21	36	5	69
7 day residential centre	0	0	1	0	1	0	9	15	9	33	19	110	137	67	333	19	119	153	76	367
7 day (52 week) residential centre	0	0	1	10	11	3	15	65	111	194	29	300	1121	833	2283	32	315	1187	954	2488

**Table B1** 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>	<b>9</b>	<b>1</b>	<b>6</b>	<b>13</b>	<b>29</b>	<b>9</b>	<b>53</b>	<b>84</b>	<b>94</b>	<b>240</b>	<b>56</b>	<b>279</b>	<b>476</b>	<b>276</b>	<b>1087</b>	<b>74</b>	<b>333</b>	<b>566</b>	<b>383</b>	<b>1356</b>
<b>Other full-time services</b>	0	0	4	12	16	0	0	6	29	35	0	2	36	67	105	0	2	46	108	156
Nursing home																				
Mental health community residence	0	0	0	0	0	0	0	6	14	20	0	0	7	26	33	0	0	13	40	53
Psychiatric hospital	0	0	0	1	1	0	8	41	38	87	0	12	78	99	189	0	20	119	138	277
Intensive placement (Challenging Behaviour)	0	0	1	0	1	2	28	25	5	60	21	156	195	42	414	23	184	221	47	475
Intensive placement (Profound or Multiple handicap)	3	0	0	0	3	1	2	4	1	8	20	84	128	26	258	24	86	132	27	269
Full time 'other' residential service	5	0	1	0	6	5	9	1	4	19	7	8	17	13	45	17	17	19	17	70
Full time resident in residential support place	1	1	0	0	2	1	6	1	3	11	8	17	15	3	43	10	24	16	6	56
<b>No fixed abode</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>5</b>	<b>3</b>	<b>3</b>	<b>12</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>2</b>	<b>5</b>	<b>1</b>	<b>6</b>	<b>5</b>	<b>5</b>	<b>17</b>
<b>Insufficient Information</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>3</b>	<b>0</b>	<b>0</b>	<b>4</b>	<b>2</b>	<b>14</b>	<b>28</b>	<b>16</b>	<b>60</b>	<b>3</b>	<b>17</b>	<b>28</b>	<b>16</b>	<b>64</b>
	<b>1706</b>	<b>73</b>	<b>105</b>	<b>70</b>	<b>1954</b>	<b>3494</b>	<b>2133</b>	<b>2174</b>	<b>861</b>	<b>8662</b>	<b>3884</b>	<b>4051</b>	<b>5292</b>	<b>2223</b>	<b>15450</b>	<b>9084</b>	<b>6257</b>	<b>7571</b>	<b>3154</b>	<b>26066</b>

# Appendix D

## National Intellectual Disability Database publications

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

Mulvany F (2000) *Annual report of the National Intellectual Disability Database Committee 1998/1999*. Dublin: Health Research Board.

Mulvany F (2001) *Annual report of the National Intellectual Disability Database Committee 2000*. Dublin: Health Research Board.

Mulvany F (2003) *Annual report of the National Intellectual Disability Database Committee 2001*. Dublin: Health Research Board.

Mulvany F and Barron S (2003) *Annual report of the National Intellectual Disability Database Committee 2002*. Dublin: Health Research Board.

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

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

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

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

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

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

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

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









