



Health Research Board An Bord Taighde Sláinte
Improving health through research and information



National Intellectual Disability Database Committee

Annual Report 2005

Steve Barron and Fiona Mulvany



Francis Gleeson

National Intellectual Disability Database Committee Annual Report 2005 cover design competition winner

Francis attends day services at Ormond Resources in Nenagh which is part of St. Anne's Services. He has a great interest in art and crafts and makes cards, candles and copper trees in addition to painting. Francis has also painted a special banner with his brother James celebrating the Special Olympics which was displayed over a local bank in Nenagh. Francis also works one day a week in the Whiskey Still in Dromineer, Co Tipperary. Francis plans to use his prizes to further his career in the arts area.



National Intellectual Disability Database

**Annual Report of the
National Intellectual
Disability Database Committee
2005**

Steve Barron and Fiona Mulvany

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 Intellectual Disability Services Section of the Department of Health and Children;
- the Health Service Executive areas, in particular the Regional Database Co-ordinators, the Database Administrators/Managers and the Regional Database Committees;
- the Federation of Voluntary Bodies providing Services to People with Intellectual Disability;
- the parents and families of people with intellectual disability and their representative bodies; and
- all those in intellectual disability services throughout Ireland.

Particular thanks are extended to Ms Caraíosa Kelly and Mr Gabriel Maguire, Disability Databases Division, Health Research Board, for their assistance in the preparation of this report, to the internal and external reviewers of the report, and to Ms Joan Moore, Health Research Board, for editing the text.

Published by
Health Research Board
An Bord Taighde Sláinte
73 Lower Baggot Street
Dublin 2
Ireland

t 353 1 676 1176
f 353 1 661 1856
e hrb@hrb.ie
w www.hrb.ie

ISSN 1393 9904

© Health Research Board 2005

Contents

| | |
|---|-----|
| List of Tables | 4 |
| List of Figures | 8 |
| Members of the National Intellectual Disability Database Committee 2005 | 9 |
| Chairman's Statement | 10 |
| Executive Summary | 11 |
| Chapter 1. The National Intellectual Disability Database | 15 |
| Chapter 2. Profile of the Population | 19 |
| Chapter 3. Service Provision in 2005 | 35 |
| Chapter 4. Assessment of Need 2006-2010 | 61 |
| References | 92 |
| Appendix A National Intellectual Disability Database | 93 |
| – National Planning Data Form 2005 | 94 |
| – Service categories | 98 |
| – Day service groupings | 100 |
| Appendix B Supplementary table | 101 |
| Appendix C National Intellectual Disability Database | 103 |
| – Request for Information Form | 105 |
| Appendix D Disability Databases Division Publications | 107 |

List of Tables

- 2.1 National Intellectual Disability Database, Ireland 2005.
Degree and prevalence of intellectual disability.
- 2.2 National Intellectual Disability Database, Ireland 2005.
Age, gender and degree of intellectual disability.
- 2.3 National Intellectual Disability Database, Ireland 2005.
Age and degree of intellectual disability (moderate, severe and profound): 1974, 1981, 1996, 2005.
- 2.4 National Intellectual Disability Database, Ireland 2005.
Number of people registered on each Regional Intellectual Disability Database.
- 2.5 National Intellectual Disability Database, Ireland 2005.
Number of people registered within the Regional Health Offices of the Health Service Executive.
- 2.6 National Intellectual Disability Database, Ireland 2005.
Number of people registered within the Local Health Offices of the Health Service Executive.
- 2.7 National Intellectual Disability Database, Ireland 2005.
Degree of intellectual disability by Regional Intellectual Disability Database.
- 2.8 National Intellectual Disability Database, Ireland 2005.
Degree of intellectual disability by the Regional Health Offices of the Health Service Executive.
- 2.9 National Intellectual Disability Database, Ireland 2005.
Degree of intellectual disability by the Local Health Offices of the Health Service Executive.
- 3.1 National Intellectual Disability Database, Ireland 2005.
Summary of service provision in 2005.
- 3.2 National Intellectual Disability Database, Ireland 2005.
Summary of service provision in 2005 by degree of intellectual disability and age group.
- 3.3 National Intellectual Disability Database, Ireland 2005.
Main residential circumstances.
- 3.4 National Intellectual Disability Database, Ireland 2005.
Main residential circumstances, degree of intellectual disability and age group.
- 3.5 National Intellectual Disability Database, Ireland 2005.
Residential status of people availing of day services by degree of intellectual disability and age group.

- 3.6 National Intellectual Disability Database, Ireland 2005.
Principal day service by category of persons availing of day services.
- 3.6a National Intellectual Disability Database, Ireland 2005.
Top five day activities for people with intellectual disability.
- 3.7 National Intellectual Disability Database, Ireland 2005.
Principal day service, degree of intellectual disability and age group.
- 3.8 National Intellectual Disability Database, Ireland 2005.
Overall level of residential service provision in 2005, degree of intellectual disability and age group.
- 3.9 National Intellectual Disability Database, Ireland 2005.
Overall level of day service provision in 2005, degree of intellectual disability and age group.
- 3.10 National Intellectual Disability Database, Ireland 2005.
Overall provision of multidisciplinary support services by age and access to early intervention teams.
- 3.11 National Intellectual Disability Database, Ireland 2005.
Service provision in 2005 by Regional Intellectual Disability Database.
- 3.12 National Intellectual Disability Database, Ireland 2005.
Service provision in 2005 by the Regional Health Offices of the Health Service Executive.
- 3.13 National Intellectual Disability Database, Ireland 2005.
Service provision in 2005 by the Local Health Offices of the Health Service Executive.
- 4.1 National Intellectual Disability Database, Ireland 2005.
Number of people requiring a major element of service 2006-2010.
- 4.2 National Intellectual Disability Database, Ireland 2005.
Number of people requiring residential support services 2006-2010.
- 4.3 National Intellectual Disability Database, Ireland 2005.
Number of new places required to meet need 2006-2010 by Regional Intellectual Disability Database.
- 4.4 National Intellectual Disability Database, Ireland 2005.
Number of new places required to meet need 2006-2010 by the Regional Health Offices of the Health Service Executive.
- 4.5 National Intellectual Disability Database, Ireland 2005.
Number of new places required to meet need 2006-2010 by the Local Health Offices of the Health Service Executive.

- 4.6 National Intellectual Disability Database, Ireland 2005.
Year in which service needs arise.
- 4.7 National Intellectual Disability Database, Ireland 2005.
Future full-time residential service requirements of individuals receiving no residential service in 2005.
- 4.8 National Intellectual Disability Database, Ireland 2005.
Future day service requirements of individuals receiving no day service in 2005.
- 4.9 National Intellectual Disability Database, Ireland 2005.
Future residential support service requirements of individuals receiving no residential support services in 2005.
- 4.10 National Intellectual Disability Database, Ireland 2005.
Category of service change required 2006-2010.
- 4.11 National Intellectual Disability Database, Ireland 2005.
Number of places requiring to be changed 2006-2010.
- 4.12 National Intellectual Disability Database, Ireland 2005.
Year in which service changes are required.
- 4.13 National Intellectual Disability Database, Ireland 2005.
Pattern of movement of individuals from existing residential services to future residential services 2006-2010.
- 4.14 National Intellectual Disability Database, Ireland 2005.
Pattern of movement of individuals from existing day service to future day service 2006-2010.
- 4.15 National Intellectual Disability Database, Ireland 2005.
Additional residential support services required by people availing of residential support services.
- 4.16 National Intellectual Disability Database, Ireland 2005.
Overall service requirements of people with intellectual disability resident in psychiatric hospitals.
- 4.17 National Intellectual Disability Database, Ireland 2005.
Day service requirements of people appropriately accommodated in psychiatric hospitals.
- 4.18 National Intellectual Disability Database, Ireland 2005.
Residential service requirements of people resident in psychiatric hospitals who require to be transferred to the intellectual disability sector.

- 4.19 National Intellectual Disability Database, Ireland 2005.
Day service requirements of people resident in psychiatric hospitals in 2005 who require to be transferred to the intellectual disability sector.
- 4.20 National Intellectual Disability Database, Ireland 2005
Current and future multidisciplinary support services by age and access to early intervention teams.
- 4.21 National Intellectual Disability Database, Ireland 2005.
Pattern of full-time residential service provision required 2006-2010.
- 4.22 National Intellectual Disability Database, Ireland 2005.
Pattern of day service provision required 2006-2010.
- B1. National Intellectual Disability Database, Ireland 2005.
Details of main residential circumstances, degree of intellectual disability and age group.

List of Figures

1. National Intellectual Disability Database, Ireland 2005.
Age profile of total population showing proportion at each level of intellectual disability in each age group.
2. National Intellectual Disability Database, Ireland 2005.
Prevalence of moderate, severe, and profound intellectual disability (combined) by age group: 1974, 1981, 1996, 2005.
3. National Intellectual Disability Database, Ireland 2005.
Numbers with moderate, severe, and profound intellectual disability (combined) by age group: 1974, 1981, 1996, 2005.
4. National Intellectual Disability Database, Ireland 2005.
Proportion of people with moderate, severe, and profound intellectual disability (combined) aged over 35 years: 1974, 1981, 1996, 1998-2005.
5. National Intellectual Disability Database, Ireland 2005.
Changes in overall level of residential service provision: 1996, 2000, 2005.
6. National Intellectual Disability Database, Ireland 2005.
Changes in overall level of day service provision: 1996, 2000, 2005.

Members of the National Intellectual Disability Database Committee 2005

Mr Brendan Ingoldsby (Chairman)

Services for People with Disabilities

Ms Mary O'Reilly

Services for People with Disabilities

Dr Michael Mulcahy

Intellectual Disability Services

Ms Sinéad Dooley

Intellectual Disability Services

Department of Health and Children

Hawkins House

Dublin 2

Mr James Roche

Western Care Association

Castlebar, Co Mayo

representing the Federation of Voluntary Bodies providing Services to People with Intellectual Disability

Ms Deirdre Scully

Disability Services

Health Service Executive Southern Area

Blackpool, Co Cork

representing the Health Service Executive areas

Mr Patrick McGinley

Brothers of Charity Services

Renmore, Co Galway

Ms Fiona Mulvany

Disability Databases Division

Ms Mary O'Gorman

Disability Databases Division

Mr Steve Barron

Disability Databases Division

Health Research Board

An Bord Taighde Sláinte

73 Lower Baggot Street

Dublin 2

Chairman's Statement

It gives me great pleasure to introduce the eighth Annual Report from the Intellectual Disability Database. This report provides a profile of the population with intellectual disability as it was on 31 May 2005 and details the existing level of specialised health service provision for this group. It includes an assessment of need for specialised health services for the upcoming five-year period that outlines the pattern of care required in both residential and day care services for the years 2006 to 2010 and highlights some of the issues which must be addressed in planning and delivering services.

The Intellectual Disability Database enables those involved with the planning and delivery of services to identify not only the level of need amongst those awaiting placement in services, but also the service changes required by those already in receipt of services. As noted in previous reports, this continues to be of particular importance as the population with intellectual disability is predominantly an adult one with a growing need for both residential and day services that are flexible and can change to meet long-term needs. Each Health Service Executive area receives a summary of the information for its region, including its full set of tables presented in this report. To facilitate service planning within the new health service structures, this report examines the regional distribution of service provision and service need within the Regional Health Offices and Local Health Offices of the Health Service Executive.

As in previous reports, I would like to take the opportunity to thank all those involved with the work of the database at both service provider and Health Service Executive level. I would like to emphasise the importance of timely returns to both the regional databases and the national database. It is commendable that information in respect of 2005 is being published by the Health Research Board in 2005 ensuring that service planning for 2006 will be based on the most up to date information available.

The 2005 data show that four per cent of records were not updated during the designated period for review and update of database information. Four out of five of these records show that the individuals are in receipt of services and I would urge the service providers involved to review these individuals' information as a matter of priority.

The contribution of my colleagues on the National Intellectual Disability Database Committee in steering the development of the database is much appreciated. The ongoing enhancement of the range of information available to us will continue to ensure that the resources can be targeted at the areas of most need. I would particularly like to acknowledge the contribution made by Mr Steve Barron and Ms Fiona Mulvany to the preparation of this report.

Brendan Ingoldsby
Chairman
National Intellectual Disability Database Committee

Executive Summary

DEMOGRAPHIC PROFILE

There are 24,917 people registered on the National Intellectual Disability Database (NIDD) in 2005, representing a prevalence rate of 6.36 per 1,000 population. The administrative prevalence rate for mild intellectual disability is 2.16 per 1,000 and the prevalence rate for moderate, severe, and profound intellectual disability is 3.72 per 1,000. There are more males than females at all levels of intellectual disability, with an overall ratio of 1.27 to 1. The total number with moderate, severe, and profound intellectual disability has increased by 29% 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 is the general population growth over the period. Since 1996 the increase in numbers is confined to those over 35 years of age. The proportion of people with moderate, severe, and profound intellectual disability that are aged 35 years and over has increased from 29% in 1974 to 38% in 1996, and to 47% in 2005. This reflects an increase in the lifespan of people with intellectual disability. This changing age profile observed in the data over the past three decades has major implications for service planning, including an ongoing high level of demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability, and helps to explain the ongoing demand for additional resources for this sector.

SERVICE PROVISION IN 2005

The numbers registered on the NIDD in May 2005 are as follows:

- 24,078 people with intellectual disability in receipt of services, representing 97% of the total population registered on the NIDD.
- 323 people (1% of those registered) who are without services at present and are identified as requiring appropriate services in the period 2006-2010.
- 516 people (2%) who are not availing of services and have no identified requirement for services during the planning period 2006-2010. More than one-third of this group (36%, 186 people) are in the mild or 'not verified' range of intellectual disability and their continued registration on the NIDD is being reviewed. However, the remaining two-thirds (64%, 330 people) of this group have a moderate, severe, or profound intellectual disability and the need for continued monitoring of these individuals' circumstances is highlighted.

Of the 24,078 people in receipt of services in 2005:

- 8,073 are in receipt of full-time residential services, which is 20 fewer than in 2004. This is the second consecutive year of data indicating that more people live in group homes within their communities than in residential centres.
- The number of people with intellectual disability accommodated in psychiatric hospitals has decreased by 78 since 2004, to 396.
- 23,914 people are availing of at least one day programme. Of this group, 7,938 are in full-time residential placements and 4,523 are in receipt of residential support services such as respite care.

Sixty-four per cent of all children and adults with intellectual disability (15,827 individuals) live at home with parents, siblings, relatives, or foster parents. More than one in four people with a moderate, severe, or profound intellectual disability that are aged 35 years and over are living in home settings. As the carers of adults with intellectual disability begin to age beyond their caring capacity, formal supervised living arrangements will need to be established. Because people with intellectual disability are living longer, the likelihood of their outliving their caregivers has increased substantially in recent years. These data highlight the importance of planning for such eventualities and avoiding crisis situations.

Since the first report from the NIDD in 1996, there has been significant growth in the level of provision of full-time residential services, residential support services, and day services, reflecting, in particular, the significant investment programme in the intellectual disability sector between 2000 and 2002. Key developments during the period 1996 to 2005 noted in this report include:

- A 46% growth in the number of people with intellectual disability living full-time in group homes within local communities;
- An increase in the provision of intensive residential placements designed to meet the needs of individuals with challenging behaviours, which has more than trebled from 107 places to 338 places;
- A 59% reduction in the number of people with intellectual disability accommodated in psychiatric hospitals;
- A continued expansion in the availability of residential support services, in particular planned or emergency centre-based respite services, which have grown by 360%; over 4,000 people avail of this type of residential support service allowing them to continue living with their families and in their communities;
- Increased provision in almost all areas of adult day services and in the level of support services delivered as part of a package of day services to both children and adults.

Substantial increases in service provision over the past year include:

- A large proportional increase (202%) in the number of people in open employment from 164 in 2004 to 401 in 2005. This is of particular note in relation to the use of mainstream placements for people with intellectual disability.
- An increase of 1,143 people availing of multidisciplinary support services. In 2005, there are 18,399 people availing of such services. The most common services availed of by adults are social work, psychiatry, and medical services. The most common services availed of by children are speech and language therapy, social work, and psychology.

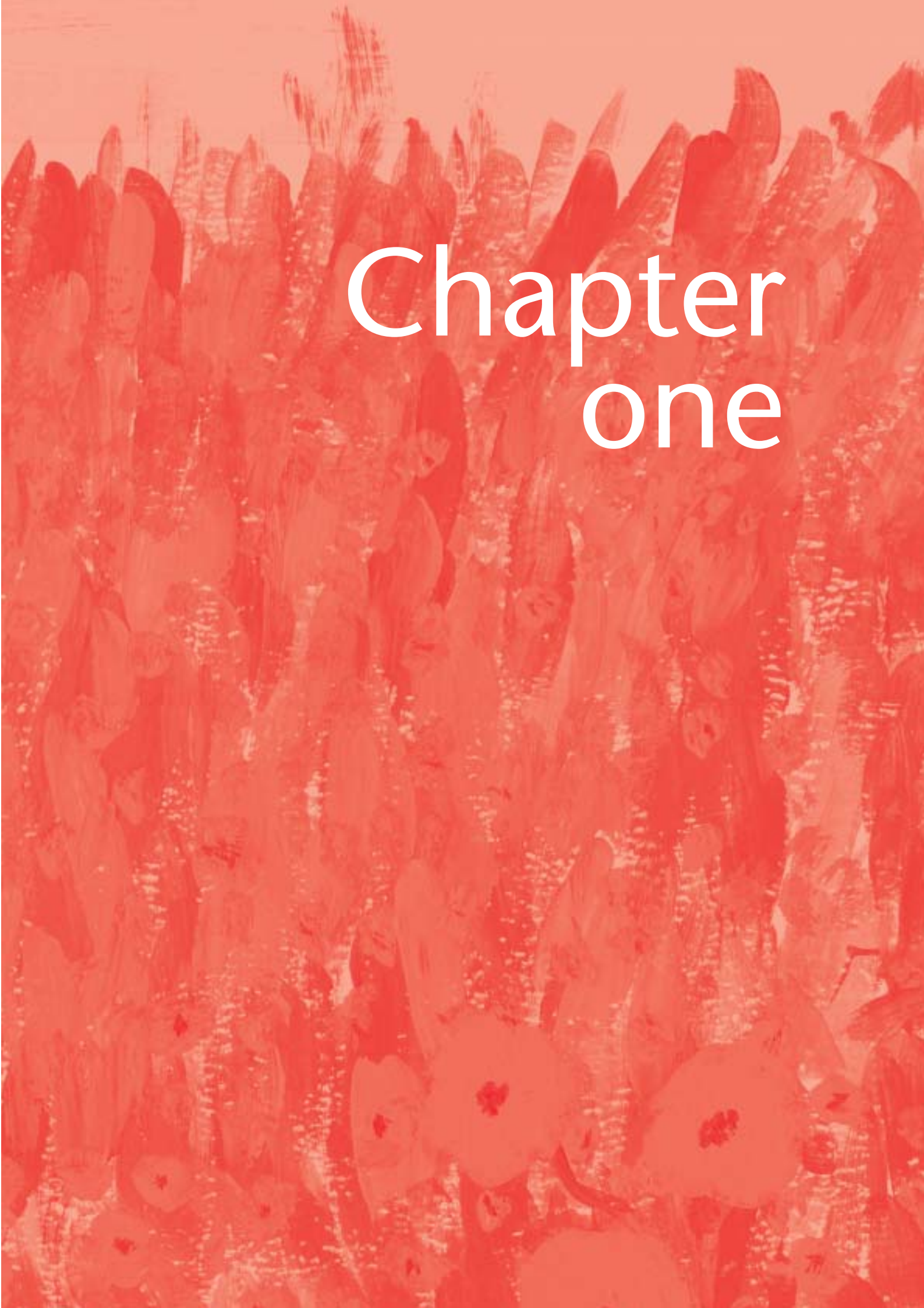
SERVICE REQUIREMENTS

In 2005 there are 2,270 people who are either without services or without a major element of service (either a full-time residential service, or a day service, or both) and require services, an increase of 60, or 3%, since 2004. To meet the needs of these individuals the following will be required during the period 2006-2010 (though most service needs arise immediately):

- 2,008 full-time residential placements, an increase of 115, or 6%, since 2004 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.
- 284 day programmes, a decrease of 63, or 18%, since 2004 and the lowest number since the database was established. This suggests that significant progress has been made in meeting the demand for day services.
- 1,840 residential support services, an increase of 77, or 4%, since 2004 and the highest number since the database was established.
- A group of 275 individuals living in psychiatric hospitals in 2005 has been identified as needing to transfer from these locations to more appropriate accommodation.

In 2005 a further 11,590 people are receiving services but require alternative, additional, or enhanced services within the next five years, an increase of 174, or 2%, since 2004. This group includes people who require an increased level of service provision, increased support within their existing services, transfers to more appropriate placements, or service changes to coincide with transition periods in their lives, for example movement from child to adult services, or from training to employment placements.

The 2005 dataset, in line with data in recent years, indicates that despite substantial levels of service provision there is significant ongoing demand for new intellectual disability services and a growing requirement to enhance existing services. This need is presenting against a background of significant investment in intellectual disability services in the period 2000-2002 and again in 2005. While the data in recent years highlight the corresponding growth in services, demographic factors and historical under-funding of intellectual disability services are contributing to long waiting lists for these services, most notably for full-time residential services. The increased birth rate in the 1960s and 1970s has resulted in a large adult population moving through the services at present, contributing to an ongoing demand for services. In addition to this, people with intellectual disability are living longer than previously, which not only contributes to the ongoing demand for services but also reduces the number of service placements freed up through death. While a further multi-annual funding package has been put in place for the period 2006-2009, this is insufficient to address all of the service demands identified in this report. In the medium term, it is expected that the increased demand for intellectual disability services will continue.



Chapter one

1. The National Intellectual Disability Database

BACKGROUND

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

The database was established on the principle that minimum information with maximum accuracy was preferred; hence, it incorporates only three basic elements of information: demographic details, current service provision, and future service requirements. The objective is to obtain this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service. Information pertaining to diagnosis is specifically excluded, as the database is not designed as a medical, epidemiological tool. The data held in any individual record represent the information available for that person at a specified point in time only. The record is updated whenever there are changes in the person's circumstances or during the annual review process in the spring of each year.

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

STRUCTURE

The relevant Programme Manager in each of the ten Health Service Executive (HSE) areas (formerly the health boards) is responsible for the administration of the database in the region. This includes the implementation and maintenance of structures for the identification of individuals and the collection, review and updating of data. In practice, this responsibility is delegated to the Regional Database Co-ordinator, whose function is to identify the persons concerned. The initial step in the generation of the national dataset is the completion of a database form for each identified individual (Appendix A). Responsibility for providing this information to the HSE areas lies primarily with the service providers, community care personnel and school principals. The designated data providers supply this information to their HSE area and a regional database is compiled. Data from the regional databases enable more sophisticated service planning at regional level and promote effective co-ordination of local services. Regional Intellectual Disability Database Committees, consisting of the Regional Database Co-ordinator, the Regional Database Administrator/Manager and representatives from the HSE area and the voluntary services, monitor the operation of the regional database in each region.

The ten regional datasets, excluding personal details such as name and address, are extracted by the Department of Health and Children and the end of the annual review and update period of NIDD information. This information forms the national dataset for that year. The Health Research Board (HRB), on behalf of the Department of Health and Children, manages the national dataset.

DATA QUALITY

The HRB oversees a system of ongoing validation which aims to identify and correct gaps and inconsistencies in the data. The database guidelines and protocols are revised and refined in response to issues highlighted by the HRB, the HSE areas and service providers. Such refinements ensure greater standardisation of data collection throughout the country. In addition, the NIDD software contains a series of technical checks which enable routine data validation to be carried out by service providers and HSE areas. There are ongoing efforts to ensure continued improvement of data quality at local, regional, and national levels.

2005 ANNUAL REPORT

This is the eighth report of the National Intellectual Disability Database Committee. The report is based on validated data received from all ten regional databases in May 2005. Adherence to scheduled export dates ensures timely reporting of data by the HRB and enables accurate comparisons between regional datasets. Regional datasets will continue to exist under the new structures of the HSE with regional information being maintained within the four new Regional Health Offices. To facilitate service planning within the new health service structures, this report examines the regional distribution of service provision and service need within the four new Regional Health Offices and the Local Health Offices (formerly Community Care Areas) of the HSE. In addition to this report, regional summary and a complete set of tables are prepared by the HRB for each Regional Intellectual Disability Database and each Regional Health Office of the HSE.

Prevalence rates per thousand population are based on up-to-date data from the Central Statistics Office, the 2002 Census of Population (Central Statistics Office, 2003).

The extent of current service provision in Ireland ensures that an almost 100% ascertainment of all persons with a moderate, severe, or profound intellectual disability is possible and expected. Inclusion of persons with a mild level of intellectual disability is sought if they are in special classes or special schools for children with intellectual disability, attending an intellectual disability service as adults, or if they are considered likely to require such a service within the next five years. Those in the average ability and borderline intellectual disability categories have been excluded from analyses because services for this group are not usually provided within intellectual disability services. In the 2005 dataset, there are 118 people recorded as being of average ability (a decrease of six since 2004) and 623 people in the borderline intellectual disability category (a decrease of two since 2004). The HSE areas are involved in an ongoing appraisal 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 2005 dataset consists of information in relation to 24,917 individuals. Ninety-one of these registrations were in the process of transferring between services when the 2005 data were extracted and their last known data are reported here. Of the 24,917 total registrations, 1,021 were not updated during the annual review period and their last known data are documented in this report.



Chapter two

2. Profile of the Population

NATIONAL LEVEL

Numbers and prevalence

In 2005 there are 24,917 people registered on the NIDD. Table 2.1 summarises the numbers and prevalence rates at each level of intellectual disability. The administrative prevalence rate for mild intellectual disability in 2005 is 2.16/1000, compared to 2.30/1000 in 2004. This figure is not a true reflection of the prevalence of mild intellectual disability as only those with mild intellectual disability accessing or requiring intellectual disability services are included in the database. The prevalence rate for moderate, severe and profound intellectual disability in 2005 is 3.72/1000, compared to 3.73/1000 in 2004.

Table 2.1. National Intellectual Disability Database, Ireland 2005.

Degree and prevalence of intellectual disability.

| | n | % | rate per 1,000 |
|-------------------|--------------|--------------|---------------------------|
| Mild | 8457 | 33.9 | 2.16 |
| Moderate | 9536 | 38.3 | 2.43 |
| Severe | 3971 | 15.9 | 1.01 |
| Profound | 1054 | 4.2 | 0.27 |
| Not verified | 1899 | 7.6 | 0.48 |
| All levels | 24917 | 100.0 | 6.36 |

Overall, the numbers registered on the NIDD have decreased by 499 people (2.0%) since 2004 (Barron and Mulvany, 2004). During the review and update period prior to the 2005 extract of data from regional datasets, 1,417 people were removed from the database and the balance is accounted for by new or reactivated registrations. The removed records consisted of 498 people who no longer required intellectual disability services (404 of whom were in the mild range of intellectual disability, eight of whom were in the moderate range, two of whom were in the severe range, and 84 of whom were recorded as level of disability 'not verified'), 271 people who had died, 22 people who were deemed more appropriately registered on the National Physical and Sensory Disability Database, 19 people who had emigrated, and 607 individuals where the reason for removal was described as 'other'. The large reduction in numbers with mild intellectual disability registered on the database is due to a national emphasis on including and retaining on the NIDD only those people with mild intellectual disability who are in receipt of, or in need of, intellectual disability services.

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

Table 2.2. National Intellectual Disability Database, Ireland 2005.
Age, gender and degree of intellectual disability.

| Age group | Numbers | | | | | | | | | | | | | | | | | |
|--|--------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|--------------|--------------|--------------|
| | Not verified | | | Mild | | | Moderate | | | Severe | | | Profound | | | All levels | | |
| | Females | Males | Total | Females | Males | Total | Females | Males | Total | Females | Males | Total | Females | Males | Total | Females | Males | Total |
| 0-4 | 360 | 474 | 834 | 51 | 63 | 114 | 29 | 70 | 99 | 27 | 39 | 66 | 11 | 3 | 14 | 478 | 649 | 1127 |
| 5-9 | 126 | 266 | 392 | 239 | 461 | 700 | 244 | 395 | 639 | 100 | 168 | 268 | 26 | 24 | 50 | 735 | 1314 | 2049 |
| 10-14 | 29 | 53 | 82 | 444 | 734 | 1178 | 314 | 498 | 812 | 111 | 159 | 270 | 30 | 28 | 58 | 928 | 1472 | 2400 |
| 15-19 | 22 | 42 | 64 | 622 | 995 | 1617 | 375 | 556 | 931 | 110 | 179 | 289 | 24 | 36 | 60 | 1153 | 1808 | 2961 |
| 20-34 | 77 | 100 | 177 | 994 | 1255 | 2249 | 1262 | 1572 | 2834 | 436 | 658 | 1094 | 149 | 146 | 295 | 2918 | 3731 | 6649 |
| 35-54 | 102 | 101 | 203 | 932 | 1000 | 1932 | 1468 | 1562 | 3030 | 664 | 825 | 1489 | 200 | 266 | 466 | 3366 | 3754 | 7120 |
| 55 & over | 55 | 92 | 147 | 368 | 299 | 667 | 649 | 542 | 1191 | 261 | 234 | 495 | 48 | 63 | 111 | 1381 | 1230 | 2611 |
| All ages | 771 | 1128 | 1899 | 3650 | 4807 | 8457 | 4341 | 5195 | 9536 | 1709 | 2262 | 3971 | 488 | 566 | 1054 | 10959 | 13958 | 24917 |
| Prevalence rates - numbers per 1,000 of the general population for each group | | | | | | | | | | | | | | | | | | |
| 0-4 | 2.66 | 3.34 | 3.00 | 0.38 | 0.44 | 0.41 | 0.21 | 0.49 | 0.36 | 0.20 | 0.27 | 0.24 | 0.08 | 0.02 | 0.05 | 3.53 | 4.57 | 4.06 |
| 5-9 | 0.98 | 1.96 | 1.48 | 1.86 | 3.39 | 2.65 | 1.90 | 2.91 | 2.42 | 0.78 | 1.24 | 1.01 | 0.20 | 0.18 | 0.19 | 5.73 | 9.67 | 7.76 |
| 10-14 | 0.21 | 0.36 | 0.29 | 3.18 | 5.02 | 4.12 | 2.25 | 3.41 | 2.84 | 0.80 | 1.09 | 0.95 | 0.21 | 0.19 | 0.20 | 6.65 | 10.07 | 8.40 |
| 15-19 | 0.14 | 0.26 | 0.20 | 4.07 | 6.20 | 5.16 | 2.45 | 3.47 | 2.97 | 0.72 | 1.12 | 0.92 | 0.16 | 0.22 | 0.19 | 7.55 | 11.27 | 9.45 |
| 20-34 | 0.16 | 0.21 | 0.19 | 2.11 | 2.65 | 2.38 | 2.67 | 3.32 | 3.00 | 0.92 | 1.39 | 1.16 | 0.32 | 0.31 | 0.31 | 6.18 | 7.88 | 7.03 |
| 35-54 | 0.20 | 0.19 | 0.19 | 1.79 | 1.92 | 1.85 | 2.81 | 3.00 | 2.90 | 1.27 | 1.58 | 1.43 | 0.38 | 0.51 | 0.45 | 6.45 | 7.20 | 6.82 |
| 55 & over | 0.13 | 0.25 | 0.19 | 0.87 | 0.82 | 0.85 | 1.54 | 1.48 | 1.51 | 0.62 | 0.64 | 0.63 | 0.11 | 0.17 | 0.14 | 3.28 | 3.36 | 3.32 |
| All ages | 0.39 | 0.58 | 0.48 | 1.85 | 2.47 | 2.16 | 2.20 | 2.67 | 2.43 | 0.87 | 1.16 | 1.01 | 0.25 | 0.29 | 0.27 | 5.56 | 7.17 | 6.36 |

Gender differences

As Table 2.2 indicates, the number of males at all levels of intellectual disability exceeds the number of females. The number of males exceeds the number of females in all age groups except the 55 years and over age group. The overall male to female ratio is 1.27:1. This represents a prevalence rate of 7.17/1000 males and 5.56/1000 females.

Age differences

Of the persons recorded on the NIDD, 34.3% (8,537) are aged 19 years and under, 26.7% (6,649) are aged between 20 and 34 years, 28.6% (7,120) are aged between 35 and 54 years, and 10.5% (2,611) are 55 years of age and over. Figure 1 illustrates the proportion in each age group at each level of intellectual disability. The larger proportion with mild intellectual disability in the 0-19 year age group reflects the number of children in special education who receive support services from the intellectual disability sector, a proportion of whom do not transfer to the intellectual disability services after school. There is also a higher proportion in the 'not verified' category in this age group, as many young children who have an intellectual disability do not receive a definitive diagnosis of their level of intellectual disability in their earlier years.

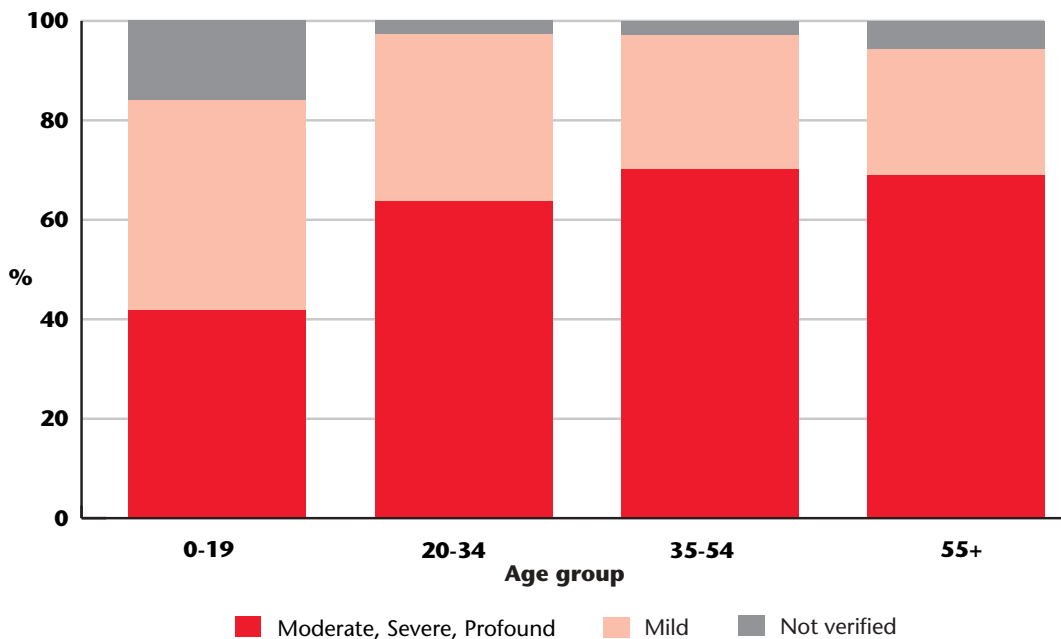


Figure 1. National Intellectual Disability Database, Ireland 2005.

Age profile of total population, showing proportion at each level of intellectual disability in each age group.

Trends over time

Recent trends

Prevalence rates for moderate, severe, and profound intellectual disability for 1996 and 2005 are compared in Table 2.3. The 1996 prevalence rates are calculated using NIDD data from 1996 and national census data from 1996. The 2005 prevalence rates are calculated using NIDD data from 2005 and national census data from 2002. Compared to the 1996 data (National Intellectual Disability Database Committee, 1997), the 2005 data in Table 2.3 demonstrate the following trends.

- A reduced prevalence rate for the 0-4 year age group. The decrease of 0.60/1000 in prevalence rate is associated with a 47.2% drop in numbers in this age group registered on the database between 1996 and 2005 and an increase in this age group in the general population between the 1996 census and the 2002 census. The prevalence rate for the 0-4 year age group, at 0.64/1000, is considerably lower than expected. Applying the prevalence rate of 3.99/1000 for the 10-14 year age group, which is the internationally accepted age range for maximum ascertainment of individuals with an intellectual disability, it is estimated that the number of children aged 0-4 years, as recorded on the database, may be underestimated by somewhere in the region of 900 cases. In compiling the database, attempts are made to discover every child with intellectual disability at the earliest possible age, but respect is also given to situations where parents are reluctant to allow information about their young child to be recorded on the database. Another potential reason for the underestimation of children in this age group is a possible move towards mainstream pre-school education. The National Intellectual Disability Database Committee requests that HSE areas prioritise the accurate recording of children in this age group so that the most comprehensive treatment and education possible can be planned.
- An overall increase in prevalence among the 5-9 year age group of 0.25/1000. This increase is observed despite a fall of 10.8% in numbers in this age group registered on the database between 1996 and 2005 and a decline in the general population in this age group during the corresponding census period.
- A slight overall increase in prevalence among the 10-14 year age group of 0.13/1000, despite a fall of 15.3% in numbers in this age group registered on the database over the nine-year period and a decline in the general population in this age group during the corresponding census period.
- An overall decrease in prevalence among the 15-19 year age group of 0.63/1000 between 1996 and 2005. A large decrease in prevalence is observed following the 1996 dataset but the rate has remained relatively stable since 1999.
- A downward trend in prevalence in the 20-34 year age group. The prevalence among 20-34 year olds has been falling consistently over the nine-year period. From 1996 to 2002 (Mulvany and Barron, 2003) this age group exhibited a higher prevalence of moderate, severe or profound intellectual disability than any other age group. The consistent decrease in prevalence over time has resulted in this group no longer exhibiting the highest prevalence of moderate, severe or profound intellectual disability in the three datasets from 2003 to 2005.
- An overall decrease in prevalence among the 35-54 year age group of 0.36/1000 since 1996, but with an upward trend apparent since 2002. This upward trend has resulted in the 35-54 year age group exhibiting the highest prevalence of moderate, severe or profound intellectual disability of any age group in the three datasets from 2003 to 2005. The significance of this upward trend is discussed later in this chapter.
- An overall increase in prevalence in the 55 and over age group. The number of people in this age group registered on the database has increased by 363 since 1996.

Table 2.3. National Intellectual Disability Database, Ireland 2005.

Age and degree of intellectual disability (moderate, severe and profound): 1974, 1981, 1996, 2005.

| Age group | Numbers | | | | | | | | | | | | | | | |
|--|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|--------------|--------------|--------------|--------------|
| | Moderate | | | Severe | | | Profound | | | All levels | | | | | | |
| | 1974 | 1981 | 1996 | 2005 | 1974 | 1981 | 1996 | 2005 | 1974 | 1981 | 1996 | 2005 | 1974 | 1981 | 1996 | 2005 |
| 0-4 | 189 | 214 | 226 | 99 | 143 | 92 | 83 | 66 | 99 | 26 | 30 | 14 | 431 | 332 | 339 | 179 |
| 5-9 | 809 | 955 | 736 | 639 | 617 | 330 | 260 | 268 | 224 | 99 | 77 | 50 | 1650 | 1384 | 1073 | 957 |
| 10-14 | 752 | 1035 | 948 | 812 | 583 | 428 | 305 | 270 | 292 | 117 | 93 | 58 | 1627 | 1580 | 1346 | 1140 |
| 15-19 | 698 | 1203 | 1072 | 931 | 445 | 508 | 378 | 289 | 241 | 154 | 132 | 60 | 1384 | 1865 | 1582 | 1280 |
| 20-34 | 1498 | 2419 | 2997 | 2834 | 1017 | 1129 | 1350 | 1094 | 441 | 340 | 460 | 295 | 2956 | 3888 | 4807 | 4223 |
| 35-54 | 1321 | 1559 | 2626 | 3030 | 626 | 612 | 1183 | 1489 | 201 | 97 | 343 | 466 | 2148 | 2268 | 4152 | 4985 |
| 55 & over | 669 | 715 | 987 | 1191 | 307 | 248 | 394 | 495 | 84 | 24 | 53 | 111 | 1060 | 987 | 1434 | 1797 |
| All ages | 5936 | 8100 | 9592 | 9536 | 3738 | 3347 | 3953 | 3971 | 1582 | 857 | 1188 | 1054 | 11256 | 12304 | 14733 | 14561 |
| Prevalence rates - numbers per 1,000 of the general population for each group | | | | | | | | | | | | | | | | |
| 0-4 | 0.60 | 0.62 | 0.83 | 0.36 | 0.45 | 0.27 | 0.30 | 0.24 | 0.31 | 0.07 | 0.11 | 0.05 | 1.36 | 0.97 | 1.24 | 0.64 |
| 5-9 | 2.55 | 2.73 | 2.31 | 2.42 | 1.95 | 0.94 | 0.82 | 1.01 | 0.71 | 0.28 | 0.24 | 0.19 | 5.20 | 3.95 | 3.37 | 3.62 |
| 10-14 | 2.52 | 3.08 | 2.72 | 2.84 | 1.95 | 1.27 | 0.88 | 0.95 | 0.98 | 0.35 | 0.27 | 0.20 | 5.45 | 4.70 | 3.86 | 3.99 |
| 15-19 | 2.61 | 3.79 | 3.20 | 2.97 | 1.66 | 1.60 | 1.13 | 0.92 | 0.90 | 0.48 | 0.39 | 0.19 | 5.17 | 5.88 | 4.72 | 4.09 |
| 20-34 | 2.78 | 3.33 | 3.93 | 3.00 | 1.88 | 1.56 | 1.77 | 1.16 | 0.82 | 0.47 | 0.60 | 0.31 | 5.48 | 5.35 | 6.31 | 4.47 |
| 35-54 | 2.13 | 2.43 | 3.25 | 2.90 | 1.01 | 0.95 | 1.46 | 1.43 | 0.32 | 0.15 | 0.42 | 0.45 | 3.46 | 3.53 | 5.14 | 4.78 |
| 55 & over | 1.08 | 1.09 | 1.45 | 1.51 | 0.50 | 0.38 | 0.58 | 0.63 | 0.14 | 0.04 | 0.08 | 0.14 | 1.71 | 1.51 | 2.11 | 2.28 |
| All ages | 1.99 | 2.35 | 2.72 | 2.43 | 1.25 | 0.97 | 1.12 | 1.01 | 0.53 | 0.25 | 0.34 | 0.27 | 3.80 | 3.60 | 4.18 | 3.72 |

Past three decades

Data from the 1974 and 1981 Censuses of Mental Handicap, carried out by the Medico-Social Research Board (Mulcahy, 1976; Mulcahy and Ennis, 1976; Mulcahy and Reynolds, 1984), enable us to monitor trends in this group over the past 31 years (Table 2.3).

The number of those more severely affected has increased by 29.4% (3,305 individuals) since 1974, which closely matches the general population increase over the 31-year period. The total number of those with a more severe disability is 14,561 in 2005, compared to 11,256 in 1974. The current prevalence rate of 3.72 per thousand is consistent with that reported in 1974 (3.80 per thousand). Of particular interest, from the point of view of service delivery is that, since 1996 this increase in numbers is confined to the two older age groups, the 35-54 year age group and the 55 years and over age group. With the exception of the 55 years and over age group in 2002, the two older age groups have shown a continued increase in numbers each year since 1996. The overall increase in numbers is influenced by a number of factors, including the general population increase in these age groups during the period, improved standards of care, and an increase in the lifespan of people with intellectual disability.

The graphical representation of the combined data for moderate, severe, and profound intellectual disability shown in Figures 2 and 3 indicates a distinct changing age profile over the 31-year period, with fewer children and young adults and more older adults availing of, or in need of, intellectual disability services. There are fewer children and young people, aged 0-19 years, with moderate, severe or profound intellectual disability now than in 1974, 1981, or 1996. This may reflect the decline in the birth rate in Ireland between 1980 and 1995, improved antenatal care, and the effectiveness of early intervention services but also raises questions regarding the under-registration of children. It is reasonable to assume that there are children with intellectual disability in mainstream education that do not have contact with specialised health services. Reluctance of parents to allow information about their children to be recorded on the database may also have an impact, particularly in the 0-4 year age group.

Cohort effect

There has been a significant increase in the number of adults currently availing of, or in need of, intellectual disability services. Closer examination suggests that the increase in the older age group almost certainly reflects a cohort effect, whereby a population bulge originating in the 1960s and lasting until the mid-1970s is moving through the services and is now translating into large numbers of adults in the older age groups. This population bulge is attributable to a high birth rate in the 1960s and 1970s and improved obstetric and paediatric care over this period. Data from the previous Censuses of Mental Handicap allow us to monitor the progress of this group through the services. In 1974, there was a high prevalence rate in the 10-14 year age group, which translated into the peak prevalence rate in 1981 in the 15-19 year age group. The peak prevalence rate in 1996 was observed in the 20-34 year age group and now, in 2005, the highest prevalence rate is seen in the 35-54 year age group. This is the third consecutive year of available data (1974, 1981, 1996, 1998 to 2005) in which the 35-54 year age group displays the highest prevalence rate and numbers of any age group with moderate, severe, and profound intellectual disability.

Figure 2. National Intellectual Disability Database, Ireland 2005.
Prevalence of moderate, severe, and profound intellectual disability (combined)
by age group: 1974, 1981, 1996, 2005.

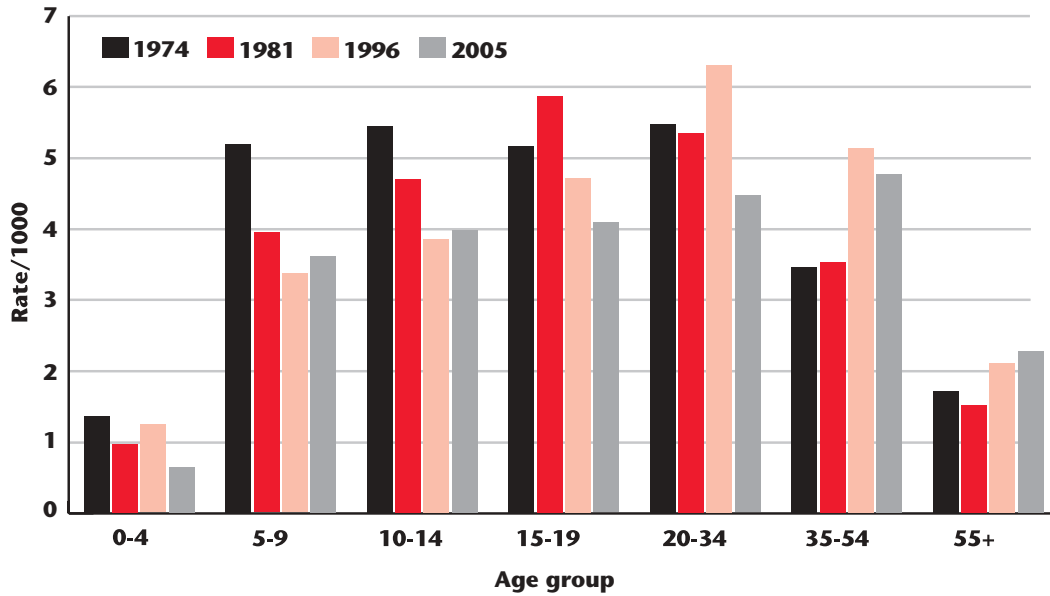
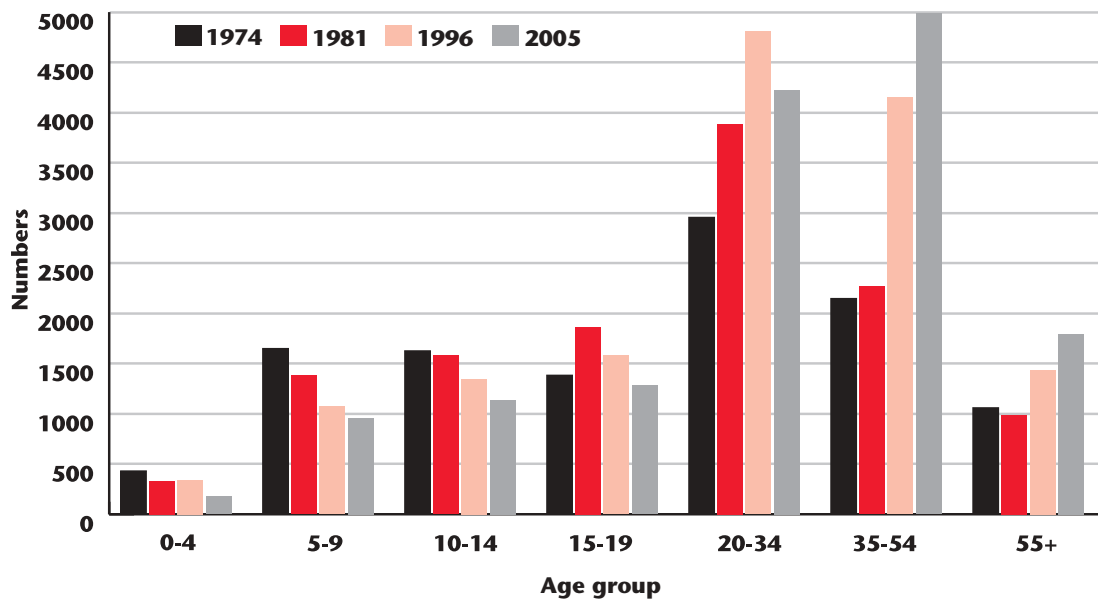


Figure 3. National Intellectual Disability Database, Ireland 2005.
Prevalence of moderate, severe, and profound intellectual disability (combined)
by age group: 1974, 1981, 1996, 2005.

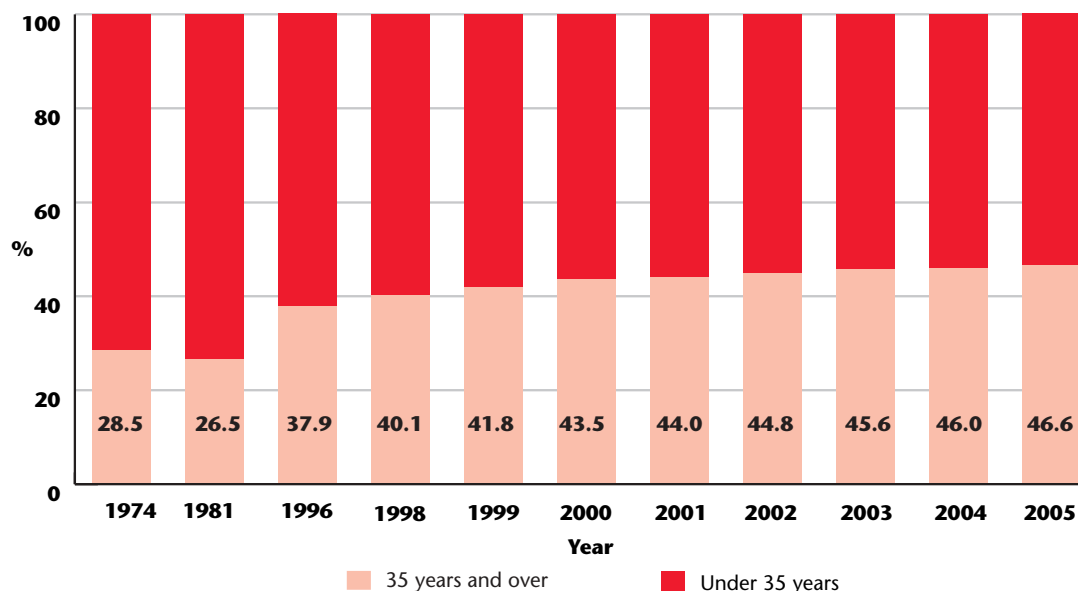


Ageing population

Figure 4 provides further evidence that the population of people with intellectual disability in Ireland is an ageing population. Increased longevity in this population is attributed in the research literature to improved health and well-being, the control of infectious diseases, the move to community living, improved nutrition, and the quality of health care services. By grouping people with a moderate, severe, or profound intellectual disability into two groups, people aged under 35 years and people aged 35 years and over, it can be seen that 28.5% of this population were aged 35 years and over in 1974, while 26.5% fell into this age category

in 1981. A steady increase in the proportion aged 35 years and over has been observed in each dataset since 1996, from 37.9% in 1996 to 46.6% in the 2005 dataset. This increase between 1996 and 2005 represents 1,196 more people with a moderate, severe, or profound intellectual disability that are aged 35 years and over.

Figure 4. National Intellectual Disability Database, Ireland 2005.
Proportion of people with moderate, severe, and profound intellectual disability (combined) aged over 35 years: 1974, 1981, 1996, 1998-2005.



Impact of observed trends

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

- As will be shown in chapter 3, residential services are primarily used by adults with a more severe intellectual disability. As the number of individuals in this group increases, increased pressure is being experienced by residential services. This is reflected in the current waiting lists for full-time residential services.
- Improved life expectancy among adults with a more severe intellectual disability places an increased demand on the health services and poses new challenges to health care professionals. Fewer places are becoming free over time, a higher degree of support within day and residential services is required, and specific support services for older people are needed.
- Chapter 3 indicates that 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 to enable this caring arrangement to continue.

Taken together, the combined effects of the baby-boom generation and increased longevity is resulting in significant demand for additional resources. This demand is now presenting, and will continue to present, major challenges to service planners and providers - this baby-boom generation, born in the 1960s and 1970s, will begin to reach age 55 in 2015, just ten years away. Failure to anticipate the associated service needs often results in crisis situations for families and for service providers. The NIDD is an invaluable resource in providing a sound evidence base for service planning and delivery. Not only does it allow us to identify specific individual service requirements arising in the next five years, but the demographic information also allows us to look further into the future and anticipate the impact of changing demographic trends.

REGIONAL LEVEL

Numbers on each regional database

Table 2.4 details the number of individuals included on each of the regional databases in May 2005. Each HSE area (formerly health boards) has responsibility for collecting the required information for all individuals who are in receipt of, or in need of, intellectual disability services within their area. The category 'Out of State' refers to individuals who are funded by the state but receive services outside the state. Table 2.5 details the number individuals registered within each new Regional Health Office of the HSE. Table 2.6 details the number of individuals registered within each Local Health Office (formerly Community Care Areas) of the HSE.

The numbers registered in some areas deviate from what would be expected based on the general population size of that area. The likely explanation for this is that people are registered in the area where they receive their service rather than place of birth or place of residence. Therefore, where there are a small number of service providers, the numbers registered will be small. People from these areas may travel outside their local area to access services and are then registered in that area.

Table 2.4. National Intellectual Disability Database, Ireland 2005.

Number of people registered on each Regional Intellectual Disability Database.

| | n | % |
|------------------------|--------------|--------------|
| HSE Northern Area | 3043 | 12.2 |
| HSE South-Western Area | 3251 | 13.0 |
| HSE East Coast Area | 1525 | 6.1 |
| HSE Midland Area | 1455 | 5.8 |
| HSE Mid-Western Area | 2224 | 8.9 |
| HSE North-Eastern Area | 2021 | 8.1 |
| HSE North-Western Area | 1817 | 7.3 |
| HSE South-Eastern Area | 3092 | 12.4 |
| HSE Southern Area | 3697 | 14.8 |
| HSE Western Area | 2773 | 11.1 |
| Out of State | 19 | 0.1 |
| Total | 24917 | 100.0 |

Table 2.5. National Intellectual Disability Database, Ireland 2005.

Number of people registered within the Regional Health Offices of the Health Service Executive.

| | n | % |
|---------------------|--------------|--------------|
| Dublin/Mid-Leinster | 6231 | 25.0 |
| Southern | 6789 | 27.2 |
| Western | 6814 | 27.3 |
| Dublin/North-East | 5064 | 20.3 |
| Out of State | 19 | 0.1 |
| Total | 24917 | 100.0 |

Table 2.6. National Intellectual Disability Database, Ireland 2005.

Number of people registered within the Local Health Offices of the Health Service Executive.

| | n | % |
|-----------------------------------|--------------|--------------|
| HSE Northern Area | 3043 | 12.2 |
| Northern Area 6 | 1643 | 6.6 |
| Northern Area 7 | 249 | 1.0 |
| Northern Area 8 | 1151 | 4.6 |
| HSE South-Western Area | 3251 | 13.0 |
| South-Western Area 3 | 199 | 0.8 |
| South-Western Area 4 | 840 | 3.4 |
| South-Western Area 5 | 1100 | 4.4 |
| South-Western Area 9 | 1112 | 4.5 |
| East Coast Area | 1525 | 6.1 |
| East Coast Area 1 | 636 | 2.6 |
| East Coast Area 2 | 287 | 1.2 |
| East Coast Area 10 | 602 | 2.4 |
| HSE Midland Area | 1455 | 5.8 |
| Laois-Offaly | 658 | 2.6 |
| Longford-Westmeath | 797 | 3.2 |
| HSE Mid-Western Area | 2224 | 8.9 |
| Limerick | 1014 | 4.1 |
| Tipperary NR | 700 | 2.8 |
| Clare | 510 | 2.0 |
| HSE North-Eastern Area | 2021 | 8.1 |
| Cavan-Monaghan | 583 | 2.3 |
| Louth | 930 | 3.7 |
| Meath | 508 | 2.0 |
| HSE North-Western Area | 1817 | 7.3 |
| Donegal | 925 | 3.7 |
| Sligo-Leitrim | 892 | 3.6 |
| HSE South-Eastern Area | 3092 | 12.4 |
| Carlow-Kilkenny | 908 | 3.6 |
| Tipperary SR | 605 | 2.4 |
| Waterford | 693 | 2.8 |
| Wexford | 886 | 3.6 |
| HSE Southern Area | 3697 | 14.8 |
| Cork North/South Lee ^a | 1940 | 7.8 |
| North Cork | 489 | 2.0 |
| West Cork | 394 | 1.6 |
| Kerry | 874 | 3.5 |
| HSE Western Area | 2773 | 11.1 |
| Galway | 1522 | 6.1 |
| Mayo | 906 | 3.6 |
| Roscommon | 345 | 1.4 |
| Out of State | 19 | 0.1 |
| Total | 24917 | 100.0 |

^a Cork North Lee and Cork South Lee are considered as one area for local administrative purposes within intellectual disability services.

Table 2.7 summarises the number and proportion of people at each level of intellectual disability registered in each HSE area (formerly health boards). The differences in level of intellectual disability are statistically significant between all HSE areas. The most marked discrepancies are observed between the HSE South-Western Area and the HSE East Coast Area. The HSE South-Western Area has the highest proportion of people with a moderate, severe, or profound intellectual disability (66.5%) and the lowest proportion of people with a mild

Table 2.7. National Intellectual Disability Database, Ireland 2005.

Degree of intellectual disability by the Regional Intellectual Disability Database.

| | Not verified | Mild | Moderate | Severe | Profound | All levels |
|------------------------|-------------------------|----------------------|----------------------|----------------------|---------------------|------------------------|
| | n % | n % | n % | n % | n % | n % |
| HSE Northern Area | 207 6.8 | 998 32.8 | 1213 39.9 | 546 17.9 | 79 2.6 | 3043 100.0 |
| HSE South-Western Area | 295 9.1 | 794 24.4 | 1482 45.6 | 447 13.7 | 233 7.1 | 3251 100.0 |
| HSE East Coast Area | 236 15.5 | 631 41.4 | 448 29.4 | 182 11.9 | 28 1.8 | 1525 100.0 |
| HSE Midland Area | 116 8.0 | 420 28.9 | 648 44.5 | 216 14.8 | 55 3.8 | 1455 100.0 |
| HSE Mid-Western Area | 140 6.3 | 764 34.4 | 878 39.5 | 354 15.9 | 88 4.0 | 2224 100.0 |
| HSE North-Eastern Area | 122 6.0 | 743 36.8 | 757 37.5 | 319 15.8 | 80 4.0 | 2021 100.0 |
| HSE North-Western Area | 203 11.2 | 644 35.4 | 628 34.6 | 294 16.2 | 48 2.6 | 1817 100.0 |
| HSE South-Eastern Area | 228 7.4 | 1139 36.8 | 1085 35.1 | 473 15.3 | 167 5.4 | 3092 100.0 |
| HSE Southern Area | 149 4.0 | 1287 34.8 | 1428 38.6 | 631 17.1 | 202 5.5 | 3697 100.0 |
| HSE Western Area | 203 7.3 | 1035 37.3 | 963 34.7 | 498 18.0 | 74 2.7 | 2773 100.0 |
| Out of State | 0 0.0 | 2 10.5 | 6 31.6 | 11 57.9 | 0 0.0 | 19 100.0 |
| Total | 1899 7.6 | 8457 33.9 | 9536 38.3 | 3971 15.9 | 1054 4.2 | 24917 100.0 |

intellectual disability (24.4%) of all areas. In contrast, the HSE East Coast Area has the lowest proportion of people with a moderate, severe, or profound intellectual disability (43.1%) and the highest proportion of people with a mild intellectual disability (41.4%) of all areas. This contrast is observed for the first time in 2005 as these two areas (along with the HSE Northern Area) were previously reported as one region under the HSE Eastern Region. There are a number of possible reasons for the observed contrast between the two areas. Firstly, there may be differences in classification practices between the two areas. In the HSE South-Western Area, there may be a tendency to classify people in the more severe range rather than the mild and, in the HSE East Coast Area, there may be a tendency to classify people in the mild range rather than the more severe range. Secondly, as people are registered where they receive their service, it may be possible that the HSE South-Western Area provides services focused more on the severe range and the HSE East Coast provides services focused more on the mild range. The National Intellectual Disability Database Committee intends to follow-up these discrepancies with the HSE areas involved.

Table 2.8 details the number and proportion of people at each level of intellectual disability registered in each of the new Regional Health Offices of the HSE. Table 2.9 details the number and proportion of people at each level of intellectual disability registered within each Local Health Office (formerly Community Care Areas) of the HSE.

| Table 2.8. National Intellectual Disability Database, Ireland 2005. | | | | | | |
|---|---------------------------|----------------------------|----------------------------|----------------------------|---------------------------|------------------------------|
| Degree of intellectual disability by the Regional Health Offices of the Health Service Executive | | | | | | |
| | Not verified | Mild | Moderate | Severe | Profound | All levels |
| | n | n | n | n | n | n |
| | % | % | % | % | % | % |
| Dublin/Mid-Leinster | 647 10.4 | 1845 29.6 | 2578 41.4 | 845 13.6 | 316 5.1 | 6231 100.0 |
| Southern | 377 5.6 | 2426 35.7 | 2513 37.0 | 1104 16.3 | 369 5.4 | 6789 100.0 |
| Western | 546 8.0 | 2443 35.9 | 2469 36.2 | 1146 16.8 | 210 3.1 | 6814 100.0 |
| Dublin/North-East | 329 6.5 | 1741 34.4 | 1970 38.9 | 865 17.1 | 159 3.1 | 5064 100.0 |
| Out of State | 0 0.0 | 2 10.5 | 6 31.6 | 11 57.9 | 0 0.0 | 19 100.0 |
| Total | 1899 7.6 | 8457 33.9 | 9536 38.3 | 3971 15.9 | 1054 4.2 | 24917 100.0 |

Table 2.9. National Intellectual Disability Database, Ireland 2005.

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

| | Not verified | Mild | Moderate | Severe | Profound | All levels |
|-------------------------------|-------------------------|---------------------|----------------------|---------------------|--------------------|-----------------------|
| | n % | n % | n % | n % | n % | n % |
| HSE Northern Area | 207 6.8 | 998 32.8 | 1213 39.9 | 546 17.9 | 79 2.6 | 3043 100.0 |
| Northern Area 6 | 107 6.5 | 591 36.0 | 621 37.8 | 275 16.7 | 49 3.0 | 1643 100.0 |
| Northern Area 7 | 4 1.6 | 72 28.9 | 145 58.2 | 27 10.8 | 1 0.4 | 249 100.0 |
| Northern Area 8 | 96 8.3 | 335 29.1 | 447 38.8 | 244 21.2 | 29 2.5 | 1151 100.0 |
| HSE South-Western Area | 295 9.1 | 794 24.4 | 1482 45.6 | 447 13.7 | 233 7.1 | 3251 100.0 |
| South-Western Area 3 | 3 1.5 | 43 21.6 | 141 70.9 | 12 6.0 | 0 0.0 | 199 100.0 |
| South-Western Area 4 | 83 9.9 | 171 20.4 | 407 48.5 | 144 17.1 | 35 4.2 | 840 100.0 |
| South-Western Area 5 | 83 7.5 | 312 28.4 | 407 37.0 | 135 12.3 | 163 14.8 | 1100 100.0 |
| South-Western Area 9 | 126 11.3 | 268 24.1 | 527 47.4 | 156 14.0 | 35 3.1 | 1112 100.0 |
| HSE East Coast Area | 236 15.5 | 631 41.4 | 448 29.4 | 182 11.9 | 28 1.8 | 1525 100.0 |
| East Coast Area 1 | 105 16.5 | 238 37.4 | 180 28.3 | 92 14.5 | 21 3.3 | 636 100.0 |
| East Coast Area 2 | 32 11.1 | 144 50.2 | 90 31.4 | 18 6.3 | 3 1.0 | 287 100.0 |
| East Coast Area 10 | 99 16.4 | 249 41.4 | 178 29.6 | 72 12.0 | 4 0.7 | 602 100.0 |
| HSE Midland Area | 116 8.0 | 420 28.9 | 648 44.5 | 216 14.8 | 55 3.8 | 1455 100.0 |
| Laois-Offaly | 57 8.7 | 214 32.5 | 298 45.3 | 68 10.3 | 21 3.2 | 658 100.0 |
| Longford-Westmeath | 59 7.4 | 206 25.8 | 350 43.9 | 148 18.6 | 34 4.3 | 797 100.0 |
| HSE Mid-Western Area | 140 6.3 | 764 34.4 | 878 39.5 | 354 15.9 | 88 4.0 | 2224 100.0 |
| Limerick | 62 6.1 | 417 41.1 | 336 33.1 | 157 15.5 | 42 4.1 | 1014 100.0 |
| Tipperary NR | 50 7.1 | 170 24.3 | 307 43.9 | 136 19.4 | 37 5.3 | 700 100.0 |
| Clare | 28 5.5 | 177 34.7 | 235 46.1 | 61 12.0 | 9 1.8 | 510 100.0 |
| HSE North-Eastern Area | 122 6.0 | 743 36.8 | 757 37.5 | 319 15.8 | 80 4.0 | 2021 100.0 |
| Cavan-Monaghan | 71 12.2 | 134 23.0 | 286 49.1 | 75 12.9 | 17 2.9 | 583 100.0 |

Table 2.9. continued

| | Not verified | Mild | Moderate | Severe | Profound | All levels |
|-----------------------------------|---------------------------|----------------------------|----------------------------|----------------------------|---------------------------|------------------------------|
| | n % | n % | n % | n % | n % | n % |
| Louth | 15 1.6 | 376 40.4 | 283 30.4 | 208 22.4 | 48 5.2 | 930 100.0 |
| Meath | 36 7.1 | 233 45.9 | 188 37.0 | 36 7.1 | 15 3.0 | 508 100.0 |
| HSE North-Western Area | 203 11.2 | 644 35.4 | 628 34.6 | 294 16.2 | 48 2.6 | 1817 100.0 |
| Donegal | 116 12.5 | 317 34.3 | 353 38.2 | 122 13.2 | 17 1.8 | 925 100.0 |
| Sligo-Leitrim | 87 9.8 | 327 36.7 | 275 30.8 | 172 19.3 | 31 3.5 | 892 100.0 |
| HSE South-Eastern Area | 228 7.4 | 1139 36.8 | 1085 35.1 | 473 15.3 | 167 5.4 | 3092 100.0 |
| Carlow-Kilkenny | 58 6.4 | 323 35.6 | 319 35.1 | 128 14.1 | 80 8.8 | 908 100.0 |
| Tipperary SR | 27 4.5 | 288 47.6 | 202 33.4 | 64 10.6 | 24 4.0 | 605 100.0 |
| Waterford | 13 1.9 | 239 34.5 | 266 38.4 | 139 20.1 | 36 5.2 | 693 100.0 |
| Wexford | 130 14.7 | 289 32.6 | 298 33.6 | 142 16.0 | 27 3.0 | 886 100.0 |
| HSE Southern Area | 149 4.0 | 1287 34.8 | 1428 38.6 | 631 17.1 | 202 5.5 | 3697 100.0 |
| Cork North/South Lee ^a | 44 2.3 | 677 34.9 | 704 36.3 | 373 19.2 | 142 7.3 | 1940 100.0 |
| North Cork | 20 4.1 | 127 26.0 | 240 49.1 | 82 16.8 | 20 4.1 | 489 100.0 |
| West Cork | 24 6.1 | 193 49.0 | 123 31.2 | 40 10.2 | 14 3.6 | 394 100.0 |
| Kerry | 61 7.0 | 290 33.2 | 361 41.3 | 136 15.6 | 26 3.0 | 874 100.0 |
| HSE Western Area | 203 7.3 | 1035 37.3 | 963 34.7 | 498 18.0 | 74 2.7 | 2773 100.0 |
| Galway | 54 3.5 | 565 37.1 | 531 34.9 | 322 21.2 | 50 3.3 | 1522 100.0 |
| Mayo | 121 13.4 | 331 36.5 | 302 33.3 | 135 14.9 | 17 1.9 | 906 100.0 |
| Roscommon | 28 8.1 | 139 40.3 | 130 37.7 | 41 11.9 | 7 2.0 | 345 100.0 |
| Out of State | 0 0.0 | 2 10.5 | 6 31.6 | 11 57.9 | 0 0.0 | 19 100.0 |
| Total | 1899 7.6 | 8457 33.9 | 9536 38.3 | 3971 15.9 | 1054 4.2 | 24917 100.0 |

^a Cork North Lee and Cork South Lee are considered as one area for local administrative purposes within intellectual disability services.



Chapter three

3. Service Provision in 2005

NATIONAL LEVEL

Summary of service provision

In 2005, 24,078 people with intellectual disability are receiving services, which accounts for 96.6% of the total population registered on the NIDD, compared to a service provision level of 93.8% in 2004. This represents the highest level of service provision since the formal reporting of service provision through the database was established in 1995. A further 839 (3.4%) people are identified as not being in receipt of services, of whom 323 (1.3%) have expressed a need for services in the period 2006-2010. A summary of the overall level of service provision in 2005 is provided in Table 3.1.

Table 3.1. National Intellectual Disability Database, Ireland 2005.
Summary of service provision in 2005.

| | n | % |
|--|--------------|---------------|
| Attending services on a day basis | 15976 | 64.1 |
| Receiving 5- or 7-day residential services | 7677 | 30.8 |
| Resident in a psychiatric hospital | 396 | 1.6 |
| Receiving residential support services only | 29 | 0.1 |
| Receiving no service | 323 | 1.3 |
| No identified service requirements | 516 | 2.1 |
| Total | 24917 | 100.0% |
| Note: | | |
| 4,523 day attenders and 448 full-time residents receive residential support services in addition to their principal service. | | |
| 7,938 full-time residents receive a day service in addition to their full-time residential service. | | |

Table 3.2 summarises service provision in 2005 by degree of intellectual disability and age group.

Without services

In 2005 there are 323 people (1.3%) without services and who have identified service needs in the period 2006-2010, details of which are presented in chapter 4¹. Almost two-thirds of this group are in the 'not verified' (8.7%) and mild (55.7%) categories of intellectual disability and 35.6% have a moderate, severe, or profound level of intellectual disability. The majority (90.1%) are aged 19 and over.

¹20 require a full-time residential place and a day place, 12 require a full-time residential place only, 223 require a day place only (Table 4.1), 13 require a residential support place only (Table 4.2), and 55 require multidisciplinary support services only (Table 4.20).

Table 3.2. National Intellectual Disability Database, Ireland 2005.

Summary of service provision in 2005 by degree of intellectual disability and age group.

| | Not verified | | | Mild | | | Moderate, Severe & Profound | | | All levels | | |
|---|--------------|-------------|-------------|--------------|-------------|-------------|-----------------------------|--------------|--------------|--------------|--------------|--------------|
| | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages |
| Attending services on a day basis | 1281 | 360 | 1641 | 3248 | 3625 | 6873 | 3061 | 4401 | 7462 | 7590 | 8386 | 15976 |
| Receiving 5- or 7-day residential services | 18 | 133 | 151 | 56 | 1116 | 1172 | 224 | 6130 | 6354 | 298 | 7379 | 7677 |
| Resident in a psychiatric hospital | 0 | 4 | 4 | 0 | 107 | 107 | 0 | 285 | 285 | 0 | 396 | 396 |
| Receiving residential support services only | 7 | 1 | 8 | 0 | 6 | 6 | 1 | 14 | 15 | 8 | 21 | 29 |
| Receiving no service | 9 | 19 | 28 | 17 | 163 | 180 | 6 | 109 | 115 | 32 | 291 | 323 |
| No service requirements in 2005 | 39 | 28 | 67 | 16 | 103 | 119 | 22 | 308 | 330 | 77 | 439 | 516 |
| Total | 1354 | 545 | 1899 | 3337 | 5120 | 8457 | 3314 | 11247 | 14561 | 8005 | 16912 | 24917 |

A further 516 people (2.1% of total registrations) are also without services but have no identified requirement for services within the five-year period 2006-2010. There are two likely explanations for this categorisation. Firstly, it is possible that some of this group are appropriately registered on the database but their service needs have not been adequately identified. Secondly, it is also likely that a proportion of this group, who have a mild degree of intellectual disability, are inappropriately registered on the database, as they are not seeking to avail of specialised health services. Of this group of 516 people with no identified service requirements:

- 230 (44.6%) have their circumstances formally reviewed annually and 188 (36.4%) have contingency service plans identified on the database.
- 439 (85.1%) are aged 19 years or over.
- 186 (36.0%) have a mild or 'not verified' level of intellectual disability and it is not unreasonable to assume that they genuinely do not require services at this time. The appropriateness of registering people with mild intellectual disability who have no identified need for specialised health services on the database is being monitored on an ongoing basis.
- 330 (64.0%) have a moderate, severe, or profound degree of intellectual disability. Within this group, 144 have their circumstances formally reviewed annually and 104 have contingency service plans identified on the database. While these people may not wish to avail of services at this time, it is essential that their needs are monitored on a regular basis so that changing circumstances can be identified and responded to in a timely manner. Failure to anticipate the needs of this group can result in emergency admissions to services that may not be tailored to the specific needs of the individual. The National Intellectual Disability Database Committee remains concerned about the circumstances of 22 children within this group who have a moderate, severe, or profound intellectual disability and are not availing of services and have no identified need for services in the period 2006-2010.

Availing of services

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

- Of the 15,976 individuals accessing services on a day basis in 2005, 6,873 (43.0%) have a mild level of intellectual disability and 7,590 (47.5%) are aged 18 years or under.
- There are 7,677 full-time residents in 2005, of whom 6,354 (82.8%) have a moderate, severe, or profound degree of disability, and 7,379 (96.1%) are aged 19 years or over.
- All 396 individuals with an intellectual disability residing in psychiatric hospitals are aged 19 years or over, and 285 (72.0%) have a moderate, severe, or profound degree of intellectual disability.

A further 29 individuals registered on the database in 2005 are availing of residential support services only.

Residential circumstances

Table 3.3 outlines the main residential circumstances of those registered on the NIDD in 2005. The main groupings of individuals consist of:

- 15,827 individuals (63.5%) living in a home setting with parents, relatives, or foster parents;
- 8,073 individuals (32.4%) living in full-time residential services, mainly in community group homes, residential centres, psychiatric hospitals, and intensive placements;
- 810 individuals (3.3%) living independently or semi-independently.

There are 8,073 people in receipt of full-time residential services in 2005, which is 20 fewer than in 2004. Whilst noting that there was not a significant additional investment programme in full-time residential services over the past three years, the HSE areas involved attribute this decrease to not occupying inappropriate placements that were vacated (for example, overcrowded circumstances, residential support places that were occupied on a full-time basis). HSE areas also reported that a number of vacated appropriate placements have been occupied, or are about to be occupied, since the completion of the review and update of NIDD information.

The most commonly availed of residential settings are community group homes. This is the second consecutive year of data that indicate that more full-time residents live in homes in the community (3,502) than in residential centres (3,334). The numbers of people accommodated in community group homes and in residential centres have increased and decreased respectively, on an almost continuous basis, since data collection commenced in 1996. This trend reflects a shift towards community living in the provision of residential services to people with intellectual disabilities.

In 2005, there are 451 people with intellectual disability residing full-time within mental health services either in psychiatric hospitals (396 individuals, compared with 474 individuals in 2004) or in mental health community residences (55 individuals). The 2005 dataset represents the first year of NIDD data in which mental health community residences were recorded as a residential service. Analysis of the 2004 data shows that 52 of these 55 individuals were previously recorded as full-time residents in community group homes and three were recorded as full-time residents in psychiatric hospitals.

The 2005 data indicate that 46 of the full-time residents are occupying residential support places on a full-time basis, thereby blocking these services from their intended use. There are nine individuals registered on the database who have no fixed abode. There is insufficient information on the residential circumstances of 198 people (0.8%) registered on the database, a reduction of 639 people (76.3%) since 2004. Although much progress has been made over the last year, this group needs to be further reviewed as a matter of urgency to improve the overall quality of data available from the NIDD.

Main residential circumstances: age group and degree of intellectual disability

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

Table 3.3. National Intellectual Disability Database, Ireland 2005.

Main residential circumstances.

| | n | % |
|---|--------------|--------------|
| Home setting | 15827 | 63.5 |
| At home with both parents | 10715 | 43.0 |
| At home with one parent | 3663 | 14.7 |
| At home with sibling | 858 | 3.4 |
| At home with other relative | 263 | 1.1 |
| Living with non-relative | 37 | 0.1 |
| Adoption | 24 | 0.1 |
| Foster care and boarding-out arrangements | 267 | 1.1 |
| Independent setting | 810 | 3.3 |
| Living independently | 547 | 2.2 |
| Living semi-independently | 263 | 1.1 |
| Community group homes | 3502 | 14.0 |
| 5-day community group home | 524 | 2.1 |
| 7-day (48-week) community group home | 659 | 2.6 |
| 7-day (52-week) community group home | 2319 | 9.3 |
| Residential centres | 3334 | 13.4 |
| 5-day residential centre | 111 | 0.4 |
| 7-day (48-week) residential centre | 544 | 2.2 |
| 7-day (52-week) residential centre | 2679 | 10.7 |
| Other full-time services | 1237 | 5.0 |
| Nursing home | 126 | 0.5 |
| Mental health community residence | 55 | 0.2 |
| Psychiatric hospital | 396 | 1.6 |
| Intensive placement (challenging behaviour) | 338 | 1.4 |
| Intensive placement (profound or multiple handicap) | 244 | 1.0 |
| Occupying a residential support place | 46 | 0.2 |
| Other full-time residential service | 32 | 0.1 |
| No fixed abode | 9 | 0.0 |
| Insufficient information | 198 | 0.8 |
| Total | 24917 | 100.0 |

Age differences

There are striking differences in the age profiles of individuals in the various categories of accommodation. The proportion of people living in a home setting decreases with age - 95.8% of individuals aged 0-19 years live in a home setting, declining to 68.5% of those aged between 20-34 years, 36.8% of those aged 35-54 years, and 18.0% of those aged 55 years and over.

In contrast, the proportion of people in the different age categories who are living in full-time residential services increases with age - 3.9% of all 0-19-year-olds are in receipt of full-time residential services, compared to 28.2% of 20-34-year-olds, 55.3% of 35-54-year-olds, and 73.8% of those aged 55 years and over.

The data indicate that more than one in four people with a moderate, severe, or profound intellectual disability aged 35 years and over continue to live with their families. Planning for the future care of these individuals and avoiding crisis situations when family carers can no longer provide care is of paramount importance.

Degree of intellectual disability

There are also noticeable variations between level of ability and type of residential situation. Of those people with a mild intellectual disability, 77.5% live in a home setting, compared to 52.2% of those with a moderate, severe, or profound intellectual disability. The proportion of people in full-time residential services is increased within the more severe categories of disability. Only 15.1% of people with a mild intellectual disability live in full-time residential services but this increases to 45.6% in the case of those with a moderate, severe, or profound disability.

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

- Of those in the mild range of intellectual disability who are in full-time residential services, 62.7% are in community group homes, 20.2% are in residential centres, and 17.1% are in other full-time residential services.
- Of those in full-time residential services who have a moderate, severe or profound intellectual disability, 40.1% are in community group homes, 45.1% are in residential centres and 14.8% are in other full-time residential services.

Day services

In 2005, 23,914 people, representing 96.0% of all those registered on the NIDD, are availing of day services. This represents the highest number and proportion of NIDD registrations availing of day services since the database was established.

Residential status of people availing of day services

Day services are availed of by people who live at home or in independent living settings in the community and by people who are also receiving full-time residential services. Table 3.5 summarises the level of disability and age group of people availing of day services according to their residential status.

Of the 23,914 individuals availing of day services, 33.2% (7,938) are also in full-time residential services, the majority of whom are in the moderate, severe, or profound range of intellectual disability (82.4%) and aged 19 years or over (79.6%). The remaining 66.8% (15,976) attend services on a day basis, of whom 43.0% are in the mild range of intellectual disability and 47.5% are aged 18 years or under.

Table 3.4. National Intellectual Disability Database, Ireland 2005.
Main residential circumstances, degree of intellectual disability and age group.

| | Not verified | | | | Mild | | | | Moderate, Severe & Profound | | | | All levels | | | | | | | |
|--------------------------|--------------|------------|------------|------------|-------------|-------------|-------------|-------------|-----------------------------|-------------|-------------|-------------|-------------|-------------|--------------|-------------|-------------|-------------|-------------|--------------|
| | 0-19 | 20-34 | 35-54 | 55+ | Total | 0-19 | 20-34 | 35-54 | 55+ | Total | 0-19 | 20-34 | 35-54 | 55+ | Total | 0-19 | 20-34 | 35-54 | 55+ | Total |
| Home setting | 1352 | 158 | 117 | 47 | 1674 | 3539 | 1803 | 1043 | 167 | 6552 | 3289 | 2592 | 1463 | 257 | 7601 | 8180 | 4553 | 2623 | 471 | 15827 |
| Independent setting | 0 | 7 | 35 | 22 | 64 | 2 | 144 | 349 | 105 | 600 | 0 | 20 | 87 | 39 | 146 | 2 | 171 | 471 | 166 | 810 |
| Community group home | 7 | 9 | 15 | 6 | 37 | 44 | 192 | 362 | 204 | 802 | 95 | 660 | 1459 | 449 | 2663 | 146 | 861 | 1836 | 659 | 3502 |
| Residential centre | 5 | 2 | 29 | 47 | 83 | 10 | 49 | 89 | 110 | 258 | 109 | 638 | 1480 | 766 | 2993 | 124 | 689 | 1598 | 923 | 3334 |
| Other full-time services | 8 | 1 | 4 | 22 | 35 | 6 | 47 | 86 | 80 | 219 | 51 | 279 | 410 | 243 | 983 | 65 | 327 | 500 | 345 | 1237 |
| No fixed abode | 0 | 0 | 1 | 0 | 1 | 0 | 1 | 2 | 0 | 3 | 0 | 2 | 2 | 1 | 5 | 0 | 3 | 5 | 1 | 9 |
| Insufficient information | 0 | 0 | 2 | 3 | 5 | 8 | 13 | 1 | 1 | 23 | 12 | 32 | 84 | 42 | 170 | 20 | 45 | 87 | 46 | 198 |
| Total | 1372 | 177 | 203 | 147 | 1899 | 3609 | 2249 | 1932 | 667 | 8457 | 3556 | 4223 | 4985 | 1797 | 14561 | 8537 | 6649 | 7120 | 2611 | 24917 |

Table 3.5. National Intellectual Disability Database, Ireland 2005.

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

| | Not verified | | | Mild | | | Moderate, Severe & Profound | | | All levels | | |
|---------------|--------------|-------------|-------------|--------------|-------------|-------------|-----------------------------|--------------|--------------|--------------|--------------|--------------|
| | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages |
| Residents | 17 | 133 | 150 | 55 | 1194 | 1249 | 222 | 6317 | 6539 | 294 | 7644 | 7938 |
| Day attenders | 1281 | 360 | 1641 | 3248 | 3625 | 6873 | 3061 | 4401 | 7462 | 7590 | 8386 | 15976 |
| Total | 1298 | 493 | 1791 | 3303 | 4819 | 8122 | 3283 | 10718 | 14001 | 7884 | 16030 | 23914 |

The 2005 data indicate that 135 full-time residents have no formal day programme. The day service needs of this group, where identified, are documented in chapter 4 of this report.

Details of the principal day services provided in 2005 both to residents and to those who attend services on a day basis can be seen in Table 3.6.

Similar to 2004, the top five day activities availed of by people with intellectual disability in 2005, and accounting for almost 70% of day service provision, are: activation programmes, sheltered work, special schools, rehabilitative training, and multidisciplinary support services only (Table 3.6a). People who attend services on a day basis are availing mainly of educational, training, and work programmes, reflecting both the higher level of ability and younger age profile of people in this category. Those in full-time residential services are much more likely to avail of services such as activation programmes, sheltered work, multidisciplinary support services, specific programmes for older people, and special high-support programmes.

Main day services by age group and degree of intellectual disability

Table 3.7 provides details of the principal day services availed of in 2005, categorised by age group and degree of intellectual disability.

Age differences

Of those availing of day services in 2005 (23,914 individuals), 33.0% (7,884) are aged 18 years or under, and 67.0% (16,030) are aged 19 years or over (see Table 3.7).

In 2005 there are 7,884 individuals aged 18 years and under accessing day services. The majority are in mainstream or special education services at primary and secondary level, availing of early intervention, attending both mainstream and specialised pre-school services, or are attending child education and development centres. A small number of young adults at the upper end of the age group have moved into training and employment placements. A small group of those aged 18 years or under are availing of multidisciplinary support services only, high-support or intensive services, or activation programmes.

There are 16,030 adults availing of day services in 2005. Most adults attend either activation centres (30.2%) or sheltered work centres (28.0%). The next largest groups are concentrated in the areas of rehabilitative training (8.8%), multidisciplinary support services only (8.8%),

supported employment (6.0%), programmes for the older person (3.6%), and special high-support day services (3.2%).

Table 3.6. National Intellectual Disability Database, Ireland 2005.

Principal day service by category of persons availing of day services.

| | Residents | Day attenders | Total |
|---|------------------|--------------------------|--------------|
| Home support | 6 | 233 | 239 |
| Home help | 2 | 34 | 36 |
| Early intervention team | 5 | 493 | 498 |
| Mainstream pre-school | 0 | 239 | 239 |
| Special pre-school for intellectual disability | 0 | 562 | 562 |
| Child education and development centre | 34 | 265 | 299 |
| Mainstream school | 4 | 949 | 953 |
| Resource/visiting teacher | 2 | 315 | 317 |
| Special class - primary level | 9 | 523 | 532 |
| Special class - secondary level | 7 | 208 | 215 |
| Special school | 220 | 4102 | 4322 |
| Rehabilitative training | 234 | 1237 | 1471 |
| Activation centre | 2999 | 1869 | 4868 |
| Programme for the older person | 486 | 87 | 573 |
| Special high-support day service | 407 | 132 | 539 |
| Special intensive day service | 202 | 62 | 264 |
| Sheltered work centre - includes long-term training schemes | 1966 | 2519 | 4485 |
| Sheltered employment centre | 17 | 113 | 130 |
| Multidisciplinary support services | 940 | 529 | 1469 |
| Centre-based day respite service | 8 | 17 | 25 |
| Day respite in the home | 3 | 6 | 9 |
| Other day service | 156 | 218 | 374 |
| Enclave within open employment | 5 | 18 | 23 |
| Supported employment | 143 | 814 | 957 |
| Open employment | 25 | 142 | 167 |
| Vocational training | 33 | 213 | 246 |
| Generic day services | 25 | 77 | 102 |
| Total | 7938 | 15976 | 23914 |

Table 3.6a. National Intellectual Disability Database, Ireland 2005.
Top five day activities for people with intellectual disability.

| Top five day activities All | % | Top five day activities Day attenders | % | Top five day activities Residents | % |
|---|----------|--|----------|--|----------|
| Activation centre | 20.4 | Special school | 25.7 | Activation centre | 37.8 |
| Sheltered work centre | 18.8 | Sheltered work centre | 15.8 | Sheltered work centre | 24.8 |
| Special school | 18.1 | Activation centre | 11.7 | Multidisciplinary support services only | 11.8 |
| Rehabilitative training | 6.2 | Rehabilitative training | 7.7 | Programme for older people | 6.1 |
| Multidisciplinary support services only | 6.1 | Mainstream school | 5.9 | Special high-support service | 5.1 |

Degree of intellectual disability

Of those receiving day services in 2005 (23,914 individuals), 34.0% (8,122) have a mild intellectual disability, 58.5% (14,001) have a moderate, severe, or profound intellectual disability, and 7.5% (1,791) have not yet had their degree of intellectual disability established (see Table 3.7).

The age profiles of these groups are quite different. Less than one in four (23.4%) of the population with moderate, severe, or profound intellectual disability who are availing of day services is aged 18 years or under, whereas one in two (40.7%) of the population with mild intellectual disability who are availing of day services is aged 18 years or under. The higher number of children with mild intellectual disability in receipt of services reflects the number of children in special education, a proportion of whom do not transfer to the adult intellectual disability services upon leaving school.

Of the 7,884 children availing of day services in 2005:

- 41.9% (3,303) have a mild degree of intellectual disability, most of whom avail of special education services, with smaller numbers in mainstream schools and pre-school services.
- 41.6% (3,283) have a moderate, severe, or profound intellectual disability and, while most are receiving special education services, smaller numbers are in mainstream education or pre-school services and some also avail of more intensive services such as child education and development centres.
- 16.5% (1,298) have not as yet had their degree of intellectual disability verified.

Of the 16,030 adults in receipt of day services in 2005:

- 30.1% (4,819) have a mild degree of intellectual disability, most of whom attend sheltered work centres, are in receipt of activation programmes, avail of rehabilitative training, or are in supported employment.
- 66.9% (10,718) are in the moderate, severe, or profound range and are most likely to be in receipt of activation programmes, followed by sheltered work, multidisciplinary support services only, and rehabilitative training.
- 3.1% (493) have not had their degree of intellectual disability established.

Table 3.7. National Intellectual Disability Database, Ireland 2005.

Principal day service, degree of intellectual disability and age group.

| | Not verified | | | Mild | | | Moderate, Severe & Profound | | | All levels | | |
|--|--------------|-------------|-------------|--------------|-------------|-------------|-----------------------------|--------------|--------------|--------------|--------------|--------------|
| | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages |
| Home support | 68 | 26 | 94 | 15 | 50 | 65 | 18 | 62 | 80 | 101 | 138 | 239 |
| Home help | 11 | 3 | 14 | 0 | 12 | 12 | 2 | 8 | 10 | 13 | 23 | 36 |
| Early intervention team | 395 | 0 | 395 | 47 | 0 | 47 | 56 | 0 | 56 | 498 | 0 | 498 |
| Mainstream pre-school | 162 | 0 | 162 | 51 | 0 | 51 | 26 | 0 | 26 | 239 | 0 | 239 |
| Special pre-school for intellectual disability | 257 | 0 | 257 | 100 | 0 | 100 | 205 | 0 | 205 | 562 | 0 | 562 |
| Child education and development centre | 23 | 0 | 23 | 4 | 0 | 4 | 237 | 35 | 272 | 264 | 35 | 299 |
| Mainstream school | 90 | 1 | 91 | 572 | 27 | 599 | 254 | 9 | 263 | 916 | 37 | 953 |
| Resource/visiting teacher | 77 | 0 | 77 | 172 | 9 | 181 | 57 | 2 | 59 | 306 | 11 | 317 |
| Special class - primary level | 46 | 1 | 47 | 198 | 101 | 299 | 182 | 4 | 186 | 426 | 106 | 532 |
| Special class - secondary level | 2 | 0 | 2 | 95 | 47 | 142 | 54 | 17 | 71 | 151 | 64 | 215 |
| Special school | 133 | 1 | 134 | 1950 | 117 | 2067 | 2076 | 45 | 2121 | 4159 | 163 | 4322 |
| Rehabilitative training | 1 | 42 | 43 | 34 | 597 | 631 | 19 | 778 | 797 | 54 | 1417 | 1471 |
| Activation centre | 0 | 103 | 103 | 2 | 624 | 626 | 22 | 4117 | 4139 | 24 | 4844 | 4868 |
| Programme for the older person | 0 | 15 | 15 | 0 | 77 | 77 | 0 | 481 | 481 | 0 | 573 | 573 |
| Special high-support day service | 0 | 4 | 4 | 3 | 30 | 33 | 19 | 483 | 502 | 22 | 517 | 539 |
| Special intensive day service | 1 | 2 | 3 | 5 | 16 | 21 | 6 | 234 | 240 | 12 | 252 | 264 |
| Sheltered work centre | 1 | 108 | 109 | 2 | 1716 | 1718 | 1 | 2657 | 2658 | 4 | 4481 | 4485 |
| Sheltered employment centre | 0 | 6 | 6 | 0 | 95 | 95 | 0 | 29 | 29 | 0 | 130 | 130 |
| Multidisciplinary support services | 20 | 93 | 113 | 11 | 294 | 305 | 23 | 1028 | 1051 | 54 | 1415 | 1469 |
| Centre-based day respite service | 2 | 0 | 2 | 3 | 5 | 8 | 1 | 14 | 15 | 6 | 19 | 25 |
| Day respite in the home | 2 | 1 | 3 | 0 | 1 | 1 | 1 | 4 | 5 | 3 | 6 | 9 |
| Other day service | 6 | 3 | 9 | 21 | 119 | 140 | 21 | 204 | 225 | 48 | 326 | 374 |
| Enclave within open employment | 0 | 3 | 3 | 0 | 7 | 7 | 0 | 13 | 13 | 0 | 23 | 23 |
| Supported employment | 0 | 45 | 45 | 1 | 563 | 564 | 0 | 348 | 348 | 1 | 956 | 957 |
| Open employment | 0 | 7 | 7 | 1 | 124 | 125 | 0 | 35 | 35 | 1 | 166 | 167 |
| Vocational training | 1 | 27 | 28 | 16 | 147 | 163 | 1 | 54 | 55 | 18 | 228 | 246 |
| Generic day services | 0 | 2 | 2 | 0 | 41 | 41 | 2 | 57 | 59 | 2 | 100 | 102 |
| Total | 1298 | 493 | 1791 | 3303 | 4819 | 8122 | 3283 | 10718 | 14001 | 7884 | 16030 | 23914 |

Overall level of service provision in 2005

Background

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

The 2005 dataset is the ninth in a series that commenced in 1996, and was continued in each of the seven years from 1998 to 2004. The first and fourth datasets, from 1996 (National Intellectual Disability Database Committee, 1997) and 2000 (Mulvany, 2001), have been selected for comparison with the 2005 data. The 1996 dataset is selected because it is the first in the series and the 2000 dataset is selected as a benchmark at the beginning of the significant investment programme in intellectual disability services over the period 2000-2002. The development within services over the three datasets is illustrated in Figures 5 and 6. If a particular service did not exist or was not captured by the NIDD in earlier datasets, growth rates are reported for the available years.

Overall level of residential service provision in 2005

Table 3.8 details the overall number of residential services provided to people with intellectual disability in 2005. In addition to the principal residential circumstances reported in Table 3.3, there exists a wide range of residential support services which are designed to assist people with intellectual disability to continue living with their families and in their communities. These residential supports range from holiday breaks with host families and service-based respite breaks, to the provision of regular part-time care and supported living arrangements.

Trends in residential service provision: 1996 to 2005

Figure 5 illustrates the growth in full-time residential services and residential support services during the period 1996-2005.

Key developments in the provision of full-time residential services in the period 1996-2005 include:

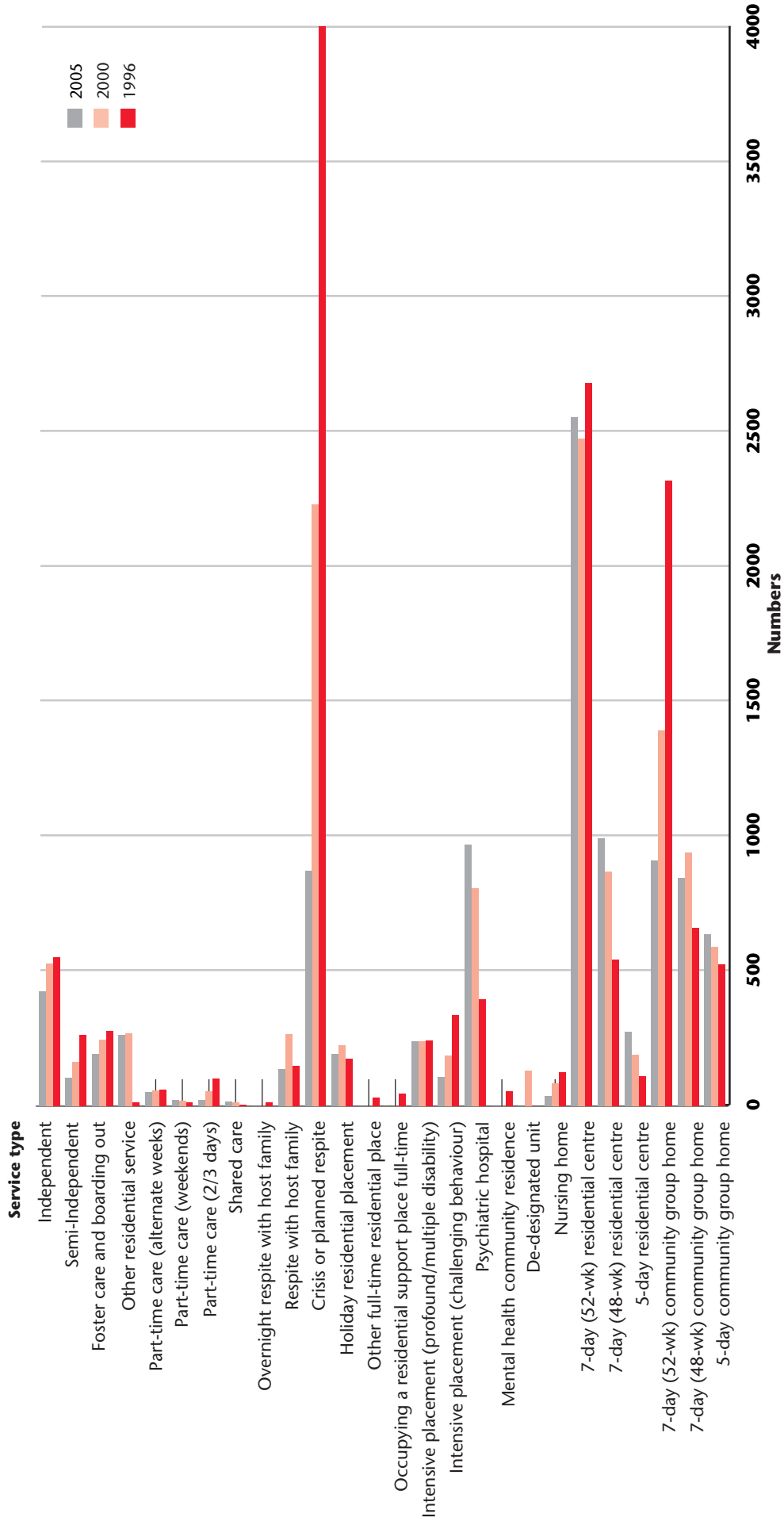
- an increase of 46.3% (1,109) in the number of people with intellectual disability living in community group homes. Community group homes are now the most commonly availed of full-time residential placements.
- an increase of 215.9% (231) in the number of intensive placements specially designed to cater for the needs of people with challenging behaviours.
- a reduction of 59.2% (574) in the number of people with intellectual disability accommodated in psychiatric hospitals during the period 1996 to 2005.

Table 3.8. National Intellectual Disability Database, Ireland 2005.

Overall level of residential service provision in 2005, degree of intellectual disability and age group.

| | Not verified | | | Mild | | | Moderate, Severe & Profound | | | All levels | | |
|---|--------------|-------------|----------|--------------|-------------|----------|-----------------------------|-------------|----------|--------------|-------------|----------|
| | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages |
| 5-day community group home | 1 | 3 | 4 | 18 | 115 | 133 | 20 | 367 | 387 | 39 | 485 | 524 |
| 7-day (48-week) community group home | 1 | 4 | 5 | 4 | 125 | 129 | 18 | 507 | 525 | 23 | 636 | 659 |
| 7-day (52-week) community group home | 4 | 24 | 28 | 21 | 519 | 540 | 46 | 1705 | 1751 | 71 | 2248 | 2319 |
| 5-day residential centre | 0 | 0 | 0 | 0 | 11 | 11 | 18 | 82 | 100 | 18 | 93 | 111 |
| 7-day (48-week) residential centre | 0 | 3 | 3 | 1 | 50 | 51 | 36 | 454 | 490 | 37 | 507 | 544 |
| 7-day (52-week) residential centre | 4 | 76 | 80 | 7 | 189 | 196 | 42 | 2361 | 2403 | 53 | 2626 | 2679 |
| Nursing home | 0 | 19 | 19 | 0 | 28 | 28 | 0 | 79 | 79 | 0 | 126 | 126 |
| Mental health community residence | 0 | 0 | 0 | 0 | 16 | 16 | 0 | 39 | 39 | 0 | 55 | 55 |
| Psychiatric hospital | 0 | 4 | 4 | 0 | 107 | 107 | 0 | 285 | 285 | 0 | 396 | 396 |
| Intensive placement | | | | | | | | | | | | |
| Intensive placement (challenging behaviour) | 2 | 0 | 2 | 2 | 40 | 42 | 12 | 282 | 294 | 16 | 322 | 338 |
| Intensive placement (profound or multiple disability) | 3 | 0 | 3 | 0 | 6 | 6 | 21 | 214 | 235 | 24 | 220 | 244 |
| Other full-time residential place | 3 | 3 | 6 | 3 | 11 | 14 | 3 | 9 | 12 | 9 | 23 | 32 |
| Occupying a residential support place | 0 | 1 | 1 | 0 | 6 | 6 | 8 | 31 | 39 | 8 | 38 | 46 |
| Holiday residential placement | 0 | 3 | 3 | 11 | 40 | 51 | 18 | 102 | 120 | 29 | 145 | 174 |
| Crisis or planned respite | 96 | 49 | 145 | 208 | 561 | 769 | 1055 | 2035 | 3090 | 1359 | 2645 | 4004 |
| Occasional respite with host family | 5 | 0 | 5 | 17 | 14 | 31 | 36 | 76 | 112 | 58 | 90 | 148 |
| Overnight respite in the home | 1 | 0 | 1 | 1 | 5 | 6 | 3 | 2 | 5 | 5 | 7 | 12 |
| Shared care or guardianship | 0 | 0 | 0 | 2 | 0 | 2 | 0 | 2 | 2 | 2 | 2 | 4 |
| Regular part-time care (2/3 days per week) | 1 | 0 | 1 | 4 | 13 | 17 | 23 | 59 | 82 | 28 | 72 | 100 |
| Regular part-time care (every weekend) | 0 | 0 | 0 | 1 | 2 | 3 | 2 | 9 | 11 | 3 | 11 | 14 |
| Regular part-time care (alternate weeks) | 0 | 0 | 0 | 2 | 4 | 6 | 7 | 48 | 55 | 9 | 52 | 61 |
| Other residential service | 1 | 0 | 1 | 1 | 7 | 8 | 2 | 3 | 5 | 4 | 10 | 14 |
| Foster care and boarding-out arrangements | 21 | 2 | 23 | 110 | 51 | 161 | 53 | 41 | 94 | 184 | 94 | 278 |
| Living semi-independently | 0 | 10 | 10 | 1 | 192 | 193 | 0 | 61 | 61 | 1 | 263 | 264 |
| Living independently | 0 | 54 | 54 | 0 | 411 | 411 | 0 | 85 | 85 | 0 | 550 | 550 |

Figure 5. National Intellectual Disability Database, Ireland 2005.
Changes in overall level of residential service provision 1996, 2000, 2005.



Between 1996 and 2005 there has been significant growth in the number of residential support places available. In particular, the data show

- an increase of 359.7% (3,133) in the number of individuals availing of centre-based respite services either as a planned or emergency intervention, bringing the total number availing of respite services in 2005 to 4,004. The vast majority of respite services are planned. The 2005 data indicate that the overall ratio of planned respite nights to crisis respite nights is more than 26:1 (i.e. there are 26 times more planned respite nights reported than crisis respite nights). Planned respite is an important service as it assists people to continue living with their families and in their communities.
- an increase of 86.2% (81) in the number of people in receipt of regular part-time care either two or three days per week, every weekend, or alternate weeks.
- an increase of 151.4% (159) in the number of people being supported to live semi-independently.

Overall level of day service provision in 2005

Table 3.9 provides details of the overall level of day service provision for people with intellectual disability. Of note in this table is the number of support services available to people with intellectual disability in addition to their principal day service reported in Table 3.6; this includes services such as home support services, early services, educational support services, centre-based and home-based day respite services, home help services, and multidisciplinary support services.

Trends in day service provision: 1996 to 2005

Figure 6 illustrates the growth in day services during the period 1996-2005.

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

- An increase of 380.2% (1,251 people) in the provision of supported employment. The 2005 data indicate that 1,580 people are in supported employment placements.
- Increases in both high-support and intensive day places. The number of high-support day places has increased by 39.0% (156 people) and the number of intensive day places has increased by 135.3% (157 people). The 2005 data indicate that 556 and 273 people attend high-support and intensive places respectively.
- An increase of 127.1% (352 people) in the number in receipt of day programmes specific to the older person. The number attending such services in 2005 is 629.
- An increase of 17.1% (741 people) in the number attending activation centres, bringing the total number to 5,067 in 2005.
- An increase of 201.5% (268 people) in the number of people in open employment. Much of this increase has occurred over the last year with the number of open employment places increasing from 164 in 2004 to 401 in 2005.

A noticeable trend during the 1996-2005 period is the increased number of people availing of mainstream services. Increases are observed in the numbers availing of mainstream pre-schools,

mainstream schools, resource teachers, and vocational training. For the second consecutive year, Table 3.6a indicates that mainstream schools are the fifth most common day activity of day attenders in 2005. Although the numbers availing of mainstream services are proportionately low, the growth is in a positive direction and should be specifically targeted by the HSE for consistent and sustained support in line with best international practice.

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

- A decrease of 15.5% (796 individuals) attending special schools. Despite this reduction, special schools are the most commonly availed of day activity for young people, with 4,340 individuals attending in 2005.
- A decrease of 18.5% (350 people) in the number attending rehabilitative training, from 1,895 in 1996 to 1,545 in 2005.
- A decrease of 56.2% (411 individuals) in the number of young people attending child education and development centres. The number attending such centres is 320 in 2005.
- A decrease of 45.7% (428 people) in the number receiving day services described as 'other'. This reduction is attributable to the expansion of the range of day services captured on the database and a national emphasis on coding services within existing service codes where possible.

The 2005 dataset also demonstrates significant growth in the provision of support services which are delivered as part of a package of day services.

- Increases can be seen in the numbers of individuals availing of home support, home help, resource/visiting teacher, and centre-based and home-based day respite.
- Multidisciplinary support services, including those delivered by early intervention teams, have shown very substantial increases in recent years, though this may, in part, be a function of a change in how these services are captured on the NIDD. Specific therapeutic inputs (e.g. occupational therapy, speech and language therapy; see Appendix A, National Planning Form, for full details) were recorded for the first time in 2002 and this may have prompted data collectors to record these therapeutic inputs, thereby resulting in the dramatic increase in the reporting of these services in recent years. In 2005, there are 16,781 individuals reported as receiving one or more multidisciplinary support services and 1,618 children receiving these services from an early intervention team.

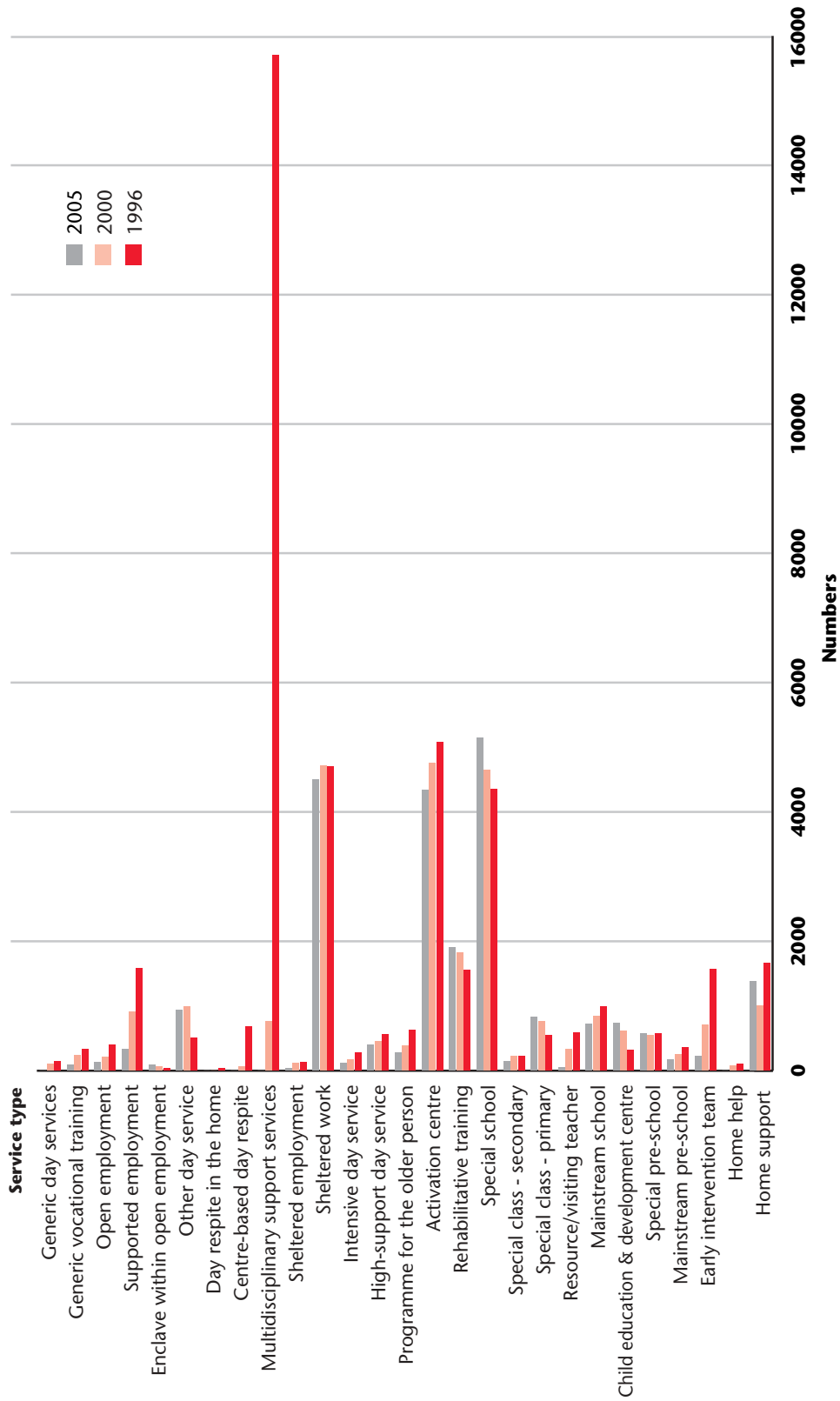
The large difference in numbers receiving multidisciplinary support services (including services delivered by early intervention teams) between Table 3.7 (principal day service provision) and Table 3.9 (overall day service provision) arises because early services and multidisciplinary support services are only recorded as a principal day service if they are the only day service that an individual receives. The majority of people who are in receipt of multidisciplinary support services or services from an early intervention team also receive another service as their principal day service. Table 3.7 reports those provided as the principal day service only, whereas Table 3.9 details the overall provision of therapeutic inputs. In addition to this, Table 3.10 details the overall provision of specific therapeutic inputs. Specific inputs are only recorded if the individual has received, or will receive, at least four inputs of that service in a twelve-month period.

Table 3.9. National Intellectual Disability Database, Ireland 2005.

Overall level of day service provision in 2005, degree of intellectual disability and age group.

| | Not verified | | | Mild | | | Moderate, Severe & Profound | | | All levels | | |
|--|--------------|-------------|----------|--------------|-------------|----------|-----------------------------|-------------|----------|--------------|-------------|----------|
| | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages | 18 and under | 19 and over | All ages |
| Home support | 199 | 50 | 249 | 244 | 156 | 400 | 579 | 428 | 1007 | 1022 | 634 | 1656 |
| Home help | 25 | 3 | 28 | 6 | 21 | 27 | 26 | 23 | 49 | 57 | 47 | 104 |
| Early intervention team | 971 | 0 | 971 | 269 | 0 | 269 | 378 | 0 | 378 | 1618 | 0 | 1618 |
| Mainstream pre-school | 222 | 0 | 222 | 81 | 0 | 81 | 59 | 0 | 59 | 362 | 0 | 362 |
| Special pre-school | 264 | 0 | 264 | 102 | 0 | 102 | 209 | 0 | 209 | 575 | 0 | 575 |
| Child education and development centre | 23 | 0 | 23 | 4 | 0 | 4 | 258 | 35 | 293 | 285 | 35 | 320 |
| Mainstream school | 91 | 1 | 92 | 586 | 29 | 615 | 271 | 10 | 281 | 948 | 40 | 988 |
| Resource/visiting teacher | 89 | 3 | 92 | 307 | 37 | 344 | 131 | 19 | 150 | 527 | 59 | 586 |
| Special class - primary | 48 | 1 | 49 | 200 | 101 | 301 | 185 | 4 | 189 | 433 | 106 | 539 |
| Special class - secondary | 2 | 0 | 2 | 95 | 47 | 142 | 54 | 18 | 72 | 151 | 65 | 216 |
| Special school | 134 | 1 | 135 | 1951 | 118 | 2069 | 2090 | 46 | 2136 | 4175 | 165 | 4340 |
| Rehabilitative training | 1 | 42 | 43 | 34 | 639 | 673 | 19 | 810 | 829 | 54 | 1491 | 1545 |
| Activation centre | 0 | 106 | 106 | 2 | 692 | 694 | 24 | 4243 | 4267 | 26 | 5041 | 5067 |
| Programme for the older person | 0 | 15 | 15 | 0 | 90 | 90 | 0 | 524 | 524 | 0 | 629 | 629 |
| High-support day service | 0 | 4 | 4 | 3 | 32 | 35 | 24 | 493 | 517 | 27 | 529 | 556 |
| Intensive day service | 1 | 2 | 3 | 5 | 17 | 22 | 6 | 242 | 248 | 12 | 261 | 273 |
| Sheltered work | 1 | 113 | 114 | 3 | 1820 | 1823 | 3 | 2759 | 2762 | 7 | 4692 | 4699 |
| Sheltered employment | 0 | 6 | 6 | 0 | 97 | 97 | 0 | 31 | 31 | 0 | 134 | 134 |
| Multidisciplinary support services | 222 | 283 | 505 | 1914 | 2877 | 4791 | 2558 | 8927 | 11485 | 4694 | 12087 | 16781 |
| Centre-based day respite programme | 31 | 1 | 32 | 92 | 62 | 154 | 275 | 219 | 494 | 398 | 282 | 680 |
| Day respite in the home | 6 | 2 | 8 | 3 | 5 | 8 | 8 | 10 | 18 | 17 | 17 | 34 |
| Other day service | 23 | 5 | 28 | 41 | 137 | 178 | 61 | 242 | 303 | 125 | 384 | 509 |
| Enclave within open employment | 0 | 3 | 3 | 0 | 15 | 15 | 0 | 18 | 18 | 0 | 36 | 36 |
| Supported employment | 0 | 49 | 49 | 1 | 854 | 855 | 0 | 676 | 676 | 1 | 1579 | 1580 |
| Open employment | 0 | 7 | 7 | 1 | 227 | 228 | 0 | 166 | 166 | 1 | 400 | 401 |
| Vocational training | 1 | 29 | 30 | 45 | 181 | 226 | 3 | 72 | 75 | 49 | 282 | 331 |
| Generic day services | 0 | 2 | 2 | 6 | 54 | 60 | 6 | 68 | 74 | 12 | 124 | 136 |

Figure 6. National Intellectual Disability Database, Ireland 2005.
Changes in overall level of day service provision 1996, 2000, 2005.



- Overall, 18,399 individuals receive one or more multidisciplinary support services (including those provided by early intervention teams). This represents an increase of 1,143 people since 2004. As was the case in 2004, the most commonly availed of multidisciplinary support services are social work (9,155 individuals), medical services (7,109 individuals), psychology (7,043 individuals), and psychiatry (5,888 individuals).
- The most common services availed of by adults are social work (5,715 adults), psychiatry (5,379 adults), and medical services (5,264 adults).
- The most common services availed of by children are speech and language therapy (1,397 children aged six years and under and 2,731 children aged seven to eighteen years), social work (1,128 children aged six years and under and 2,312 children aged seven to eighteen years), and psychology (1,072 children aged six years and under and 2,065 children aged seven to eighteen years).
- Early intervention teams usually provide services to children aged six years and under and 86.1% (1,569 children) of this age group receiving multidisciplinary support services have access to an early intervention team. There are also 49 children aged seven years and over who receive services from an early intervention team.

Table 3.10. National Intellectual Disability Database, Ireland 2005.

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

| | Aged 6 and under | | | Aged 7-18 | | | Aged 19 and over | Total |
|---------------------------|--------------------|------------------------|-------------|--------------------|------------------------|-------------|------------------|--------------|
| | Provided by an EIT | Not provided by an EIT | Total | Provided by an EIT | Not provided by an EIT | Total | | |
| Medical services | 789 | 94 | 883 | 22 | 940 | 962 | 5264 | 7109 |
| Nursing | 717 | 67 | 784 | 19 | 814 | 833 | 3083 | 4700 |
| Nutrition | 211 | 39 | 250 | 6 | 389 | 395 | 1806 | 2451 |
| Occupational therapy | 801 | 101 | 902 | 15 | 1238 | 1253 | 1482 | 3637 |
| Physiotherapy | 1064 | 119 | 1183 | 20 | 1202 | 1222 | 2116 | 4521 |
| Psychiatry | 79 | 13 | 92 | 7 | 410 | 417 | 5379 | 5888 |
| Psychology | 911 | 161 | 1072 | 27 | 2038 | 2065 | 3906 | 7043 |
| Social work | 1015 | 113 | 1128 | 22 | 2290 | 2312 | 5715 | 9155 |
| Speech & language therapy | 1199 | 198 | 1397 | 35 | 2696 | 2731 | 805 | 4933 |
| Other | 522 | 92 | 614 | 13 | 995 | 1008 | 3017 | 4639 |
| Number of people | 1569 | 253 | 1822 | 49 | 4441 | 4490 | 12087 | 18399 |

Note

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

REGIONAL LEVEL

Table 3.11 provides summary details of the level of service provision in 2005 recorded on each Regional Intellectual Disability Database of the HSE areas (formerly health boards). The ensuing discussion of regional service provision relates to these ten areas. Tables 3.12 and 3.13 provide details of the level of service provision in 2005 within each Regional Health Office and within each Local Health Office (formerly Community Care Areas) of the Health Service Executive.

Nationally, 96.6% of people (24,078) with an intellectual disability registered on the NIDD are in receipt of services in 2005. Regionally, the highest level of service provision is in the HSE Midland Area where 99.2% of the population registered on the database are receiving services. The lowest level of service provision is in the HSE East Coast Area where 93.8% of the registered population with intellectual disability are in receipt of services.

Nationally, 32.4% (8,073) of those registered on the NIDD in 2005 are in receipt of a full-time residential service. Regionally, this proportion varies from 25.5% in the HSE North-Eastern Area to 38.6% in the HSE South-Western Area.

At national level, 64.1% (15,976) of the database population are attending services on a day basis and this proportion ranges from 57.8% in the HSE South-Western Area to 72.7% in the HSE North-Eastern Area.

Nationally, 1.3% (323) of registrations are without services but are identified as requiring services in the five-year period 2006–2010. The HSE North-Western Area has the highest proportion of people without any service and awaiting services within the next five years (5.3%) and there are two other HSE Areas above the national average (the HSE Mid-Western Area at 2.2% and the HSE Western Area at 1.6%). The HSE South-Western Area has the lowest proportion in this group with no service and awaiting services (0.3%).

Although significantly reduced over recent datasets, there remains a considerable number of people registered on the database in 2005 (516, or 2.1%) who are not availing of services and have no identified need for service within the five-year period 2006–2010. As mentioned earlier in this chapter, there are two likely explanations for this categorisation. Firstly, it is possible that some of this group are appropriately registered on the database but their service needs have not been adequately identified. Secondly, it is also likely that a proportion of this group, who have a mild degree of intellectual disability, are inappropriately registered on the database, as they are not seeking to avail of specialised health services. The number of people identified in this category varies widely between HSE Areas. The HSE Midland Area has the lowest recorded proportion of registrations with no service requirements, at 0.2%. The HSE East Coast Area has the highest proportion of individuals in this category, at 5.4% of the region's registered population. Given that the HSE East Coast Area also exhibits the lowest level of service provision, it is likely that a proportion of this group are appropriately registered but their service needs have not been adequately identified.

The data show that, while considerable efforts are being made to review and refine the database, the National Intellectual Disability Database Committee feels that the proportion of people with intellectual disability reported as being in receipt of services (96.6%) is still being kept artificially low because of the number of people described as having no identified service requirements in 2005 (516 individuals, or 2.1% of total registrations). Although the number in

this category has fallen from 1,216 over the past year, a critical appraisal of the remaining individuals is required to establish both their possible need for services and the appropriateness of their registration on the NIDD. The National Intellectual Disability Database Committee urges the HSE areas involved to prioritise this work and so improve the overall quality of information held on the NIDD.

Table 3.11. National Intellectual Disability Database, Ireland 2005.

Service provision in 2005 by Regional Intellectual Disability Database.

| | 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 2005 | Total |
|------------------------|--|---|---|--|-----------------------------|--|------------------------|
| | n % | n % | n % | n % | n % | n % | n % |
| HSE Northern Area | 1789 58.8 | 945 31.1 | 199 6.5 | 0 0.0 | 19 0.6 | 91 3.0 | 3043 100.0 |
| HSE South-Western Area | 1875 57.7 | 1255 38.6 | 2 0.1 | 3 0.1 | 11 0.3 | 105 3.2 | 3251 100.0 |
| HSE East Coast Area | 1023 67.1 | 397 26.0 | 2 0.1 | 9 0.6 | 12 0.8 | 82 5.4 | 1525 100.0 |
| HSE Midland Area | 992 68.2 | 433 29.8 | 14 1.0 | 4 0.3 | 9 0.6 | 3 0.2 | 1455 100.0 |
| HSE Mid-Western Area | 1360 61.2 | 749 33.7 | 24 1.1 | 3 0.1 | 48 2.2 | 40 1.8 | 2224 100.0 |
| HSE North-Eastern Area | 1470 72.7 | 516 25.5 | 2 0.1 | 2 0.1 | 14 0.7 | 17 0.8 | 2021 100.0 |
| HSE North-Western Area | 1110 61.1 | 594 32.7 | 1 0.1 | 3 0.2 | 96 5.3 | 13 0.7 | 1817 100.0 |
| HSE South-Eastern Area | 2114 68.4 | 820 26.5 | 100 3.2 | 1 0.0 | 35 1.1 | 22 0.7 | 3092 100.0 |
| HSE Southern Area | 2395 64.8 | 1134 30.7 | 24 0.6 | 3 0.1 | 35 0.9 | 106 2.9 | 3697 100.0 |
| HSE Western Area | 1846 66.6 | 817 29.5 | 28 1.0 | 1 0.0 | 44 1.6 | 37 1.3 | 2773 100.0 |
| Out of State | 2 10.5 | 17 89.5 | 0 0.0 | 0 0.0 | 0 0.0 | 0 0.0 | 19 100.0 |
| All regions | 15976 64.1 | 7677 30.8 | 396 1.6 | 29 0.1 | 323 1.3 | 516 2.1 | 24917 100.0 |

Table 3.12. National Intellectual Disability Database, Ireland 2005.

Service provision in 2005 by Regional Health Offices of the Health Service Executive.

| | Attending services on a day basis | Receiving 5- or 7-day residential services | Resident in a psychiatric hospital | Receiving residential support services only | Receiving no service | No service requirements in 2005 | Total |
|-------------------------|--|---|---|--|-----------------------------|--|------------------------------|
| | n % | n % | n % | n % | n % | n % | n % |
| Dublin/ Mid-Leinster | 3890 62.4 | 2085 33.5 | 18 0.3 | 16 0.3 | 32 0.5 | 190 3.0 | 6231 100.0 |
| Southern | 4509 66.4 | 1954 28.8 | 124 1.8 | 4 0.1 | 70 1.0 | 128 1.9 | 6789 100.0 |
| Western | 4316 63.3 | 2160 31.7 | 53 0.8 | 7 0.1 | 188 2.8 | 90 1.3 | 6814 100.0 |
| Dublin/ North-East | 3259 64.4 | 1461 28.9 | 201 4.0 | 2 0.0 | 33 0.7 | 108 2.1 | 5064 100.0 |
| Out of State | 2 10.5 | 17 89.5 | 0 0.0 | 0 0.0 | 0 0.0 | 0 0.0 | 19 100.0 |
| All areas | 15976 64.1 | 7677 30.8 | 396 1.6 | 29 0.1 | 323 1.3 | 516 2.1 | 24917 100.0 |

Table 3.13. National Intellectual Disability Database, Ireland 2005.

Service provision in 2005 by Local Health Offices of the Health Service Executive.

| | Attending services on a day basis | Receiving 5- or 7-day residential services | Resident in a psychiatric hospital | Receiving residential support services only | Receiving no service | No service requirements in 2005 | Total |
|-------------------------------|--|---|---|--|-----------------------------|--|-----------------------------|
| | n % | n % | n % | n % | n % | n % | n % |
| HSE Northern Area | 1789 58.8 | 945 31.1 | 199 6.5 | 0 0.0 | 19 0.6 | 91 3.0 | 3043 100.0 |
| Northern Area 6 | 992 60.4 | 601 36.6 | 0 0.0 | 0 0.0 | 10 0.6 | 40 2.4 | 1643 100.0 |
| Northern Area 7 | 179 71.9 | 58 23.3 | 0 0.0 | 0 0.0 | 0 0.0 | 12 4.8 | 249 100.0 |
| Northern Area 8 | 618 53.7 | 286 24.8 | 199 17.3 | 0 0.0 | 9 0.8 | 39 3.4 | 1151 100.0 |
| HSE South-Western Area | 1875 57.7 | 1255 38.6 | 2 0.1 | 3 0.1 | 11 0.3 | 105 3.2 | 3251 100.0 |
| South-Western Area 3 | 95 47.7 | 89 44.7 | 0 0.0 | 0 0.0 | 0 0.0 | 15 7.5 | 199 100.0 |
| South-Western Area 4 | 604 71.9 | 226 26.9 | 0 0.0 | 1 0.1 | 1 0.1 | 8 1.0 | 840 100.0 |
| South-Western Area 5 | 588 53.5 | 456 41.5 | 2 0.2 | 0 0.0 | 3 0.3 | 51 4.6 | 1100 100.0 |
| South-Western Area 9 | 588 52.9 | 484 43.5 | 0 0.0 | 2 0.2 | 7 0.6 | 31 2.8 | 1112 100.0 |
| HSE East Coast Area | 1023 67.1 | 397 26.0 | 2 0.1 | 9 0.6 | 12 0.8 | 82 5.4 | 1525 100.0 |
| East Coast Area 1 | 408 64.2 | 183 28.8 | 2 0.3 | 3 0.5 | 6 0.9 | 34 5.3 | 636 100.0 |
| East Coast Area 2 | 191 66.6 | 82 28.6 | 0 0.0 | 0 0.0 | 4 1.4 | 10 3.5 | 287 100.0 |
| East Coast Area 10 | 424 70.4 | 132 21.9 | 0 0.0 | 6 1.0 | 2 0.3 | 38 6.3 | 602 100.0 |
| HSE Midland Area | 992 68.2 | 433 29.8 | 14 1.0 | 4 0.3 | 9 0.6 | 3 0.2 | 1455 100.0 |
| Laois-Offaly | 513 78.0 | 127 19.3 | 7 1.1 | 2 0.3 | 6 0.9 | 3 0.5 | 658 100.0 |
| Longford-Westmeath | 479 60.1 | 306 38.4 | 7 0.9 | 2 0.3 | 3 0.4 | 0 0.0 | 797 100.0 |
| HSE Mid-Western Area | 1360 61.2 | 749 33.7 | 24 1.1 | 3 0.1 | 48 2.2 | 40 1.8 | 2224 100.0 |
| Limerick | 633 62.4 | 303 29.9 | 20 2.0 | 2 0.2 | 31 3.1 | 25 2.5 | 1014 100.0 |
| Tipperary NR | 373 53.3 | 299 42.7 | 0 0.0 | 1 0.1 | 13 1.9 | 14 2.0 | 700 100.0 |
| Clare | 354 69.4 | 147 28.8 | 4 0.8 | 0 0.0 | 4 0.8 | 1 0.2 | 510 100.0 |
| HSE North-Eastern Area | 1470 72.7 | 516 25.5 | 2 0.1 | 2 0.1 | 14 0.7 | 17 0.8 | 2021 100.0 |
| Cavan-Monaghan | 451 77.4 | 114 19.6 | 0 0.0 | 1 0.2 | 8 1.4 | 9 1.5 | 583 100.0 |
| Louth | 596 64.1 | 333 35.8 | 1 0.1 | 0 0.0 | 0 0.0 | 0 0.0 | 930 100.0 |
| Meath | 423 83.3 | 69 13.6 | 1 0.2 | 1 0.2 | 6 1.2 | 8 1.6 | 508 100.0 |

Table 3.13. (continued)

| | 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 2005 | Total |
|-----------------------------------|--|---|---|--|-----------------------------|--|----------------------|
| | n % | n % | n % | n % | n % | n % | n % |
| HSE North-Western Area | 1110 | 594 | 1 | 3 | 96 | 13 | 1817 |
| Donegal | 61.1 | 32.7 | 0.1 | 0.2 | 5.3 | 0.7 | 100.0 |
| | 666 | 189 | 1 | 1 | 58 | 10 | 925 |
| | 72.0 | 20.4 | 0.1 | 0.1 | 6.3 | 1.1 | 100.0 |
| Sligo-Leitrim | 444 | 405 | 0 | 2 | 38 | 3 | 892 |
| | 49.8 | 45.4 | 0.0 | 0.2 | 4.3 | 0.3 | 100.0 |
| HSE South-Eastern Area | 2114 | 820 | 100 | 1 | 35 | 22 | 3092 |
| Carlow-Kilkenny | 68.4 | 26.5 | 3.2 | 0.0 | 1.1 | 0.7 | 100.0 |
| | 558 | 287 | 25 | 1 | 21 | 16 | 908 |
| | 61.5 | 31.6 | 2.8 | 0.1 | 2.3 | 1.8 | 100.0 |
| Tipperary SR | 448 | 111 | 36 | 0 | 8 | 2 | 605 |
| | 74.0 | 18.3 | 6.0 | 0.0 | 1.3 | 0.3 | 100.0 |
| Waterford | 444 | 240 | 1 | 0 | 5 | 3 | 693 |
| | 64.1 | 34.6 | 0.1 | 0.0 | 0.7 | 0.4 | 100.0 |
| Wexford | 664 | 182 | 38 | 0 | 1 | 1 | 886 |
| | 74.9 | 20.5 | 4.3 | 0.0 | 0.1 | 0.1 | 100.0 |
| HSE Southern Area | 2395 | 1134 | 24 | 3 | 35 | 106 | 3697 |
| Cork North/South Lee ^a | 64.8 | 30.7 | 0.6 | 0.1 | 0.9 | 2.9 | 100.0 |
| | 1146 | 752 | 1 | 1 | 14 | 26 | 1940 |
| | 59.1 | 38.8 | 0.1 | 0.1 | 0.7 | 1.3 | 100.0 |
| North Cork | 344 | 81 | 14 | 0 | 12 | 38 | 489 |
| | 70.3 | 16.6 | 2.9 | 0.0 | 2.5 | 7.8 | 100.0 |
| West Cork | 275 | 93 | 2 | 1 | 6 | 17 | 394 |
| | 69.8 | 23.6 | 0.5 | 0.3 | 1.5 | 4.3 | 100.0 |
| Kerry | 630 | 208 | 7 | 1 | 3 | 25 | 874 |
| | 72.1 | 23.8 | 0.8 | 0.1 | 0.3 | 2.9 | 100.0 |
| HSE Western Area | 1846 | 817 | 28 | 1 | 44 | 37 | 2773 |
| Galway | 66.6 | 29.5 | 1.0 | 0.0 | 1.6 | 1.3 | 100.0 |
| | 1013 | 464 | 23 | 1 | 18 | 3 | 1522 |
| | 66.6 | 30.5 | 1.5 | 0.1 | 1.2 | 0.2 | 100.0 |
| Mayo | 570 | 276 | 5 | 0 | 25 | 30 | 906 |
| | 62.9 | 30.5 | 0.6 | 0.0 | 2.8 | 3.3 | 100.0 |
| Roscommon | 263 | 77 | 0 | 0 | 1 | 4 | 345 |
| | 76.2 | 22.3 | 0.0 | 0.0 | 0.3 | 1.2 | 100.0 |
| Out of State | 2 | 17 | 0 | 0 | 0 | 0 | 19 |
| | 10.5 | 89.5 | 0.0 | 0.0 | 0.0 | 0.0 | 100.0 |
| All areas | 15976 | 7677 | 396 | 29 | 323 | 516 | 24917 |
| | 64.1 | 30.8 | 1.6 | 0.1 | 1.3 | 2.1 | 100.0 |

^a Cork North Lee and Cork South Lee are considered as one area for local administrative purposes within intellectual disability services.



Chapter four

4. Assessment of Need 2006–2010

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

A - Unmet need: describes people who are without any service whatsoever, who are without a major element of service such as day or residential, or who are without residential support services, and require these services in the period 2006–2010. It excludes those whose *only* requirement is for multidisciplinary support services (including those to be delivered by an early intervention team) as these are dealt with in category D below.

B - Service change: describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2006–2010, and includes children who will require access to health-funded services in the period. It excludes those whose *only* service change requirement is for multidisciplinary support services (including those to be delivered by an early intervention team) as these are dealt with in category D below.

C - Persons with intellectual disability who are accommodated in psychiatric hospitals: includes people who need to transfer out of psychiatric hospitals in the period 2006–2010 and people who are resident in the psychiatric services but require an appropriate day service within the same time period. For completeness, multidisciplinary support services requirements, where applicable, are noted in the tables.

D - Multidisciplinary support services: documents the multidisciplinary support services (including those to be delivered by early intervention teams) that are required in the period 2006–2010 by all individuals registered on the NIDD. This section includes the multidisciplinary support service requirements of the unmet need and service change groups as well as those of people with intellectual disability within the psychiatric services.

In 2005 the NIDD facilitated 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 for the unmet need, service change, and people with intellectual disability within the psychiatric services groups but the level of additional need of these individuals is noted in the relevant sections of the text as well as in the multidisciplinary support services section.

A - UNMET NEED

Full-time residential and day services

The data returned in 2005 indicate that 2,270 people will require major elements of service, either a full-time residential service or a day service, or both, in the five-year period 2006–2010 (Table 4.1), a increase of 60 since 2004. Of this group of 2,270 people:

- 255 (11.2%) have no service and require full-time residential and/or day services,
- 1,973 (86.9%) receive a day service but require a residential service,
- 28 (1.2%) receive a residential service but also require a day service,
- 14 (0.6%) receive residential support services only, and require full-time residential and/or day services.

Table 4.1 provides a breakdown of this group by level of intellectual disability. Of the 255 people who are without services in 2005, 96 (37.6 %) have a moderate, severe, or profound level of intellectual disability and 143 (56.1%) have a mild level of intellectual disability. The group which receives one major element of service, day or residential, but which needs the other element (2,001 individuals), consists mainly (73.1%) of people in the moderate, severe, or profound ranges of intellectual disability.

Four hundred and seventy-seven of the individuals who have an unmet need for a full-time residential service also require an additional future residential service, of whom 94.5% require a residential support service, in the period 2006–2010. Twelve of the individuals who have an unmet need for a day service also require one additional future day service in the period 2006–2010.

Table 4.1. National Intellectual Disability Database, Ireland 2005.

Number of people requiring a major element of service 2006-2010.

| | No service | Receives minimal residential support only | Receives day only - requires residential | Receives residential only - requires day | Total |
|-----------------------------|------------------------|---|--|--|-------------|
| Not verified | 16 | 1 | 48 | 1 | 66 |
| Mild | 143 | 5 | 480 | 10 | 638 |
| Moderate, severe & profound | 96 | 8 | 1445 | 17 | 1566 |
| All levels | 255^a | 14^b | 1973 | 28 | 2270 |

^a Of the 255, 20 require residential and day, 12 require residential only, and 223 require day only.

^b Of the 14, 2 require residential and day, 1 requires residential only, and 11 require day only.

Residential support services

The 2005 data indicate that 1,803 people are without residential support services and will require these services in the period 2006–2010, an increase of 81 (4.7%) since 2004 (Table 4.2). In excess of 99% of this group are already in receipt of a major element of service. Thirteen individuals who require residential support services are without services in 2005, of whom three

have a moderate level of intellectual disability, six have a mild intellectual disability, and the remaining four individuals' level of intellectual disability has not yet been verified.

One hundred and seventy-three individuals who have an unmet need for a residential support service also require a second future residential service. Almost 80% of these secondary future residential service requirements are also residential support services.

Table 4.2. National Intellectual Disability Database, Ireland 2005.

Number of people requiring residential support services 2006-2010.

| | No service | Receives day only - requires residential support | Receives residential & day - requires residential support | Total |
|-----------------------------|-------------------|---|--|--------------|
| Not verified | 4 | 124 | 5 | 133 |
| Mild | 6 | 679 | 75 | 760 |
| Moderate, severe & profound | 3 | 781 | 126 | 910 |
| All levels | 13 | 1584 | 206 | 1803 |

Number of places required to meet need

The number of additional residential, day, and residential support places required over the period 2006–2010 to provide these people with services is identified in Table 4.3 by each Regional Intellectual Disability Database (formerly health boards). The key figures in this table are summarised below.

- Following a slight downward trend during the years 2000 to 2002, the number of new residential places required has increased sharply (by 23.0% or 375 places) over the past three years. The current figure of 2,008 is the highest since the database was established. Almost one in four of this group (73.3%, 1,471 individuals) have a moderate, severe, or profound intellectual disability. Chapter 2 noted 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. This information would suggest that the number of new full-time residential places required is likely to increase over the coming years as those with a more severe disability advance in age.
- The number of new day places required has been falling steadily since 1996. The current figure of 284 is 72.6% less than that in 1996 and is the lowest since the database was established, suggesting that significant progress has been made in meeting the demand for day services.
- The demand for residential supports has increased steadily since 1998. The current figure of 1,840 represents an increase of 77 (4.4%) since 2004 and is the highest since national data collection began.

Table 4.3 also displays each Regional Intellectual Disability Database's proportion of total NIDD registrations to allow more meaningful comparisons to be drawn between areas. The number of new residential and residential support places required in each area is broadly in line with what would be expected considering the relative proportions registered in each area but the number of new day places required is not, as summarised below.

- The HSE North-Western Area returns 7.3% of total NIDD registrations but requires 33.8% of the new day places required.
- The HSE Mid-Western Area returns 8.9% of total NIDD registrations but requires 17.6% of the new day places required.
- HSE Northern Area returns 12.2% of total NIDD registrations but requires only 2.5% of the new day places required.

**Table 4.3. National Intellectual Disability Database, Ireland 2005.
Number of new places required to meet need 2006-2010 by Regional Intellectual Disability Database.**

| | Residential | Day | Residential support | % of total NIDD registrations |
|------------------------|--------------------|------------|----------------------------|--------------------------------------|
| HSE Northern Area | 302 | 7 | 92 | 12.2 |
| HSE South-Western Area | 257 | 12 | 180 | 13.0 |
| HSE East Coast Area | 135 | 9 | 94 | 6.1 |
| HSE Midland Area | 169 | 8 | 122 | 5.8 |
| HSE Mid-Western Area | 105 | 50 | 184 | 8.9 |
| HSE North-Eastern Area | 154 | 10 | 157 | 8.1 |
| HSE North-Western Area | 124 | 96 | 180 | 7.3 |
| HSE South-Eastern Area | 260 | 33 | 192 | 12.4 |
| HSE Southern Area | 289 | 31 | 370 | 14.8 |
| HSE Western Area | 213 | 28 | 268 | 11.1 |
| Out of State | 0 | 0 | 1 | 0.1 |
| Total | 2008 | 284 | 1840^a | 100.0 |

^a The total number of residential support places required is different to the figure in Table 4.2 (n=1,803) as 35 of the group who have no existing service and require a day service will also need a residential support service and 2 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 1,840.

Tables 4.4 and 4.5 show the number of new places required to meet need over the next five years within each Regional Health Office and within each Local Health Office (formerly Community Care Areas) of the Health Service Executive. Each area's proportion of total NIDD registrations is included to allow meaningful comparisons to be drawn between areas.

Table 4.4. National Intellectual Disability Database, Ireland 2005.
Number of new places required to meet need 2006-2010 by the Regional Health Offices of the Health Service Executive.

| | Residential | Day | Residential support | % of total NIDD registrations |
|---------------------|-------------|------------|-------------------------|-------------------------------|
| Dublin/Mid-Leinster | 561 | 29 | 396 | 25.0 |
| Southern | 549 | 64 | 562 | 27.2 |
| Western | 442 | 174 | 632 | 27.3 |
| Dublin/North-East | 456 | 17 | 249 | 20.3 |
| Out of State | 0 | 0 | 1 | 0.1 |
| Total | 2008 | 284 | 1840^a | 100.0 |

^a The total number of residential support places required is different to the figure in Table 4.2 (n=1,803) as 35 of the group who have no existing service and require a day service will also need a residential support service and 2 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 1,840.

Year in which services are required

Table 4.6 identifies the year in which the service needs arise. Most of the service needs are immediate, reflecting the backlog of people awaiting services over the past number of years.

SUMMARY OF UNMET SERVICE REQUIREMENTS

Details of the types of services required by people who are without a major element of service or without residential support services in 2005 are set out in Tables 4.7 to 4.9.

Full-time residential services

Of the group that requires full-time residential services (2,008 individuals, see Table 4.7):

- 73.3% (1,471) consists of people in the moderate, severe, and profound ranges of intellectual disability. Of these 1,471 individuals, 1,159 require residential placements in community group homes, 181 require residential accommodation in a campus setting, and 122 require specialised intensive placements because of their increased dependency.
- 24.3% (487) consists of people with mild intellectual disability. Of these 487 individuals, 426 require residential placements in community group homes, 34 require residential accommodation in a campus setting, and 24 require specialised intensive placements due to their increased dependency.
- 2.5% (50) have not yet had their level of intellectual disability verified.

Of those requiring full-time residential services, only 1.7% (34 individuals) are without a current day service.

Table 4.5. National Intellectual Disability Database, Ireland 2005.

Number of new places required to meet need 2006-2010 by the Local Health Offices of the Health Service Executive.

| | Residential | Day | Residential support | % of total NIDD registrations |
|-----------------------------------|--------------------|------------|----------------------------|--------------------------------------|
| HSE Northern Area | 302 | 7 | 92 | 12.2 |
| Northern Area 6 | 110 | 7 | 36 | 6.6 |
| Northern Area 7 | 50 | 0 | 10 | 1.0 |
| Northern Area 8 | 142 | 0 | 46 | 4.6 |
| HSE South-Western Area | 257 | 12 | 180 | 13.0 |
| South-Western Area 3 | 13 | 0 | 3 | 0.8 |
| South-Western Area 4 | 170 | 0 | 36 | 3.4 |
| South-Western Area 5 | 38 | 1 | 71 | 4.4 |
| South-Western Area 9 | 36 | 11 | 70 | 4.5 |
| HSE East Coast Area | 135 | 9 | 94 | 6.1 |
| East Coast Area 1 | 62 | 4 | 38 | 2.6 |
| East Coast Area 2 | 40 | 2 | 23 | 1.2 |
| East Coast Area 10 | 33 | 3 | 33 | 2.4 |
| HSE Midland Area | 169 | 8 | 122 | 5.8 |
| Laois-Offaly | 70 | 7 | 54 | 2.6 |
| Longford-Westmeath | 99 | 1 | 68 | 3.2 |
| HSE Mid-Western Area | 105 | 50 | 184 | 8.9 |
| Limerick | 40 | 33 | 53 | 4.1 |
| Tipperary NR | 34 | 14 | 52 | 2.8 |
| Clare | 31 | 3 | 79 | 2.0 |
| HSE North-Eastern Area | 154 | 10 | 157 | 8.1 |
| Cavan-Monaghan | 47 | 5 | 24 | 2.3 |
| Louth | 56 | 0 | 49 | 3.7 |
| Meath | 51 | 5 | 84 | 2.0 |
| HSE North-Western Area | 124 | 96 | 180 | 7.3 |
| Donegal | 35 | 59 | 80 | 3.7 |
| Sligo-Leitrim | 89 | 37 | 100 | 3.6 |
| HSE South-Eastern Area | 260 | 33 | 192 | 12.4 |
| Carlow-Kilkenny | 79 | 16 | 102 | 3.6 |
| Tipperary SR | 59 | 11 | 20 | 2.4 |
| Waterford | 51 | 5 | 42 | 2.8 |
| Wexford | 71 | 1 | 28 | 3.6 |
| HSE Southern Area | 289 | 31 | 370 | 14.8 |
| Cork North/South Lee ^b | 157 | 12 | 184 | 7.8 |
| North Cork | 59 | 9 | 33 | 2.0 |
| West Cork | 36 | 7 | 50 | 1.6 |
| Kerry | 37 | 3 | 103 | 3.5 |
| HSE Western Area | 213 | 28 | 268 | 11.1 |
| Galway | 113 | 11 | 120 | 6.1 |
| Mayo | 81 | 15 | 118 | 3.6 |
| Roscommon | 19 | 2 | 30 | 1.4 |
| Out of State | 0 | 0 | 1 | 0.1 |
| Total | 2008 | 284 | 1840^a | 100.0 |

^a The total number of residential support places required is different to the figure in Table 4.2 (n=1,803) as 35 of the group who have no existing service and require a day service will also need a residential support service and 2 of the group with an existing residential service and requiring a day service will also need a residential support service, giving a total of 1,840.

^b Cork North Lee and Cork South Lee are considered as one area for local administrative purposes within intellectual disability services.

Table 4.6. National Intellectual Disability Database, Ireland 2005.

Year in which service needs arise.

| | 2006 | 2007 | 2008 | 2009 | 2010 | All years |
|---------------------|-------------|-------------|-------------|-------------|-------------|------------------|
| Residential | 1763 | 97 | 65 | 48 | 35 | 2008 |
| Day | 284 | 0 | 0 | 0 | 0 | 284 |
| Residential support | 1759 | 30 | 20 | 27 | 4 | 1840 |

Day services

As in previous years, demand for day services among those reported as not being in receipt of such services in 2005 is confined almost exclusively to adult services (Table 4.8). Of the 284 individuals who require day services, the largest demand comes from 243 people who have no service whatsoever at the moment. Of the 243 people with no service:

- The majority (57.6%, 140 individuals) have a mild intellectual disability and their principal service requirements are in the training and employment fields.
- 36.6% (89 individuals) have a moderate, severe, or profound range of intellectual disability and the principal service requirements are for activation programmes, sheltered work, and rehabilitative training (Table 4.8).

A second group with day service needs consists of 28 people who are in full-time residential services but do not have access to formal day programmes. This figure has fallen from 196 in 2003, suggesting that significant progress has been made over the last two years in the provision of day services to full-time residents who had no formal day programme. The remaining need in 2005 among this group consists mainly of activation programmes.

A third group with day service needs consists of 13 people who are accessing residential support services only and require a variety of day services.

Residential support services

Residential support services, such as respite and regular part-time care, are required by 1,840 people (Table 4.9), most of whom live at home and are either in receipt of a day service (86.1%, 1,584 individuals) or have no day service (2.6%, 48 individuals). An additional 11.2% (206 individuals) are full-time residents and need a residential support service either to enhance, or as an alternative to, their existing services.

- People with moderate, severe, or profound intellectual disability account for half (50.1%, 921 individuals) of the demand for residential support services, while people with mild intellectual disability account for 42.4% (781 individuals). The remaining 7.5% (138 individuals) have not yet had their degree of intellectual disability verified.
- Most of the demand is for centre-based respite services (56.5%, 1,039 individuals), semi-independent and independent living arrangements (20.8%, 383 individuals), holiday residential placements (8.9%, 164 individuals), and occasional respite care with a host family (5.4%, 100 individuals).

Table 4.7. National Intellectual Disability Database, Ireland 2005.

Future full-time residential service requirements of individuals receiving no residential service in 2005.

| | No service - requires residential service | | | Receives residential support only - requires residential service | | | Receives day service - requires residential service | | | Overall need | | |
|---|---|----------|-----------|--|----------|----------|---|----------|-----------|--------------|-------------|-------------|
| | NV | Mild | All | NV | Mild | All | NV | Mild | All | NV | Mild | All |
| 5-day community group home | 0 | 1 | 4 | 5 | 0 | 0 | 2 | 2 | 6 | 110 | 213 | 329 |
| 7-day (48-week) community group home | 0 | 0 | 4 | 4 | 0 | 0 | 0 | 0 | 8 | 67 | 240 | 315 |
| 7-day (52-week) community group home | 1 | 3 | 7 | 11 | 0 | 0 | 1 | 1 | 19 | 245 | 688 | 952 |
| 5-day residential centre | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 3 | 5 | 17 | 25 |
| 7-day (48-week) residential centre | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 3 | 52 | 55 |
| 7-day (52-week) residential centre | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 5 | 25 | 112 | 142 |
| Nursing home | 0 | 1 | 1 | 2 | 0 | 0 | 0 | 0 | 3 | 2 | 8 | 13 |
| Mental health community residence | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Psychiatric hospital | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Intensive placement (challenging behaviour) | 0 | 0 | 5 | 5 | 0 | 0 | 0 | 0 | 4 | 16 | 54 | 74 |
| Intensive placement (profound or multiple disability) | 0 | 1 | 2 | 3 | 0 | 0 | 0 | 0 | 0 | 7 | 61 | 68 |
| All services | 2 | 7 | 23 | 32 | 0 | 0 | 3 | 3 | 48 | 480 | 1445 | 1973 |
| | | | | | | | | | | 50 | 487 | 1471 |
| | | | | | | | | | | | 8 | 63 |
| | | | | | | | | | | | | 71 |

Table 4.8. National Intellectual Disability Database, Ireland 2005.
Future day service requirements of individuals receiving no day service in 2005.

| | No service - requires day service | | | Receives residential support only - requires day service | | | Receives residential service only - requires day service | | | Overall need | | | | | | |
|--|-----------------------------------|------------|-----------|--|----------|----------|--|-----------|----------|--------------|-----------|-----------|-----------|------------|------------|------------|
| | NV | Mild | MSP AII | NV | Mild | MSP AII | NV | Mild | MSP AII | NV | Mild | MSP AII | | | | |
| Home support | 1 | 5 | 10 | 16 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 2 | 5 | 10 | 17 |
| Home help | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Mainstream pre-school | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Special pre-school | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 |
| Child education and development centre | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Mainstream school | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 |
| Resource/visiting teacher | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Special class – primary | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Special class – secondary | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 |
| Special school | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 0 | 1 | 0 | 1 |
| Rehabilitative training | 3 | 44 | 10 | 57 | 0 | 1 | 0 | 1 | 0 | 1 | 0 | 1 | 3 | 46 | 10 | 59 |
| Activation centre | 1 | 9 | 31 | 41 | 0 | 0 | 3 | 3 | 1 | 2 | 12 | 15 | 2 | 11 | 46 | 59 |
| Programme for the older person | 1 | 4 | 6 | 11 | 0 | 0 | 0 | 0 | 0 | 1 | 3 | 4 | 1 | 5 | 9 | 15 |
| Special high-support day service | 0 | 1 | 4 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 1 | 5 | 6 |
| Special intensive day service | 0 | 0 | 3 | 3 | 0 | 0 | 1 | 1 | 0 | 1 | 0 | 1 | 0 | 1 | 4 | 5 |
| Sheltered work centre | 1 | 22 | 15 | 38 | 0 | 2 | 1 | 3 | 0 | 0 | 1 | 1 | 1 | 24 | 17 | 42 |
| Sheltered employment centre | 0 | 5 | 0 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 5 | 0 | 5 |
| Centre-based day respite service | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Day respite in the home | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Other day service | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Enclave within open employment | 0 | 2 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 2 |
| Supported employment | 3 | 24 | 4 | 31 | 0 | 1 | 0 | 1 | 0 | 3 | 0 | 3 | 3 | 28 | 4 | 35 |
| Open employment | 2 | 5 | 3 | 10 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 2 | 6 | 3 | 11 |
| Vocational training | 1 | 17 | 3 | 21 | 0 | 1 | 1 | 2 | 0 | 0 | 0 | 0 | 1 | 18 | 4 | 23 |
| Generic day services | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 |
| All services | 14 | 140 | 89 | 243 | 1 | 5 | 7 | 13 | 1 | 10 | 17 | 28 | 16 | 155 | 113 | 284 |

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 4.9. National Intellectual Disability Database, Ireland 2005.

Future residential support service requirements of individuals receiving no residential support services in 2005.

| | No service - requires residential support | | | Receives day service - requires residential support | | | Receives residential service - requires residential support | | | Receives residential and day services - requires residential support | | | Overall need | | |
|--|---|-----------|-----------|---|------------|-------------|---|----------|----------|--|-----------|------------|--------------|------------|-------------|
| | NV | Mild | All | NV | Mild | All | NV | Mild | All | NV | Mild | All | NV | Mild | All |
| Foster care and boarding-out | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 2 |
| Living independently | 1 | 2 | 3 | 5 | 49 | 59 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 9 | 73 |
| Living semi-independently | 2 | 8 | 14 | 16 | 178 | 234 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 45 | 310 |
| Holiday residential placement | 0 | 1 | 2 | 4 | 40 | 94 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 4 | 164 |
| Crisis or planned respite | 4 | 12 | 22 | 75 | 341 | 986 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 7 | 1039 |
| Occasional respite care with host family | 2 | 1 | 3 | 13 | 35 | 95 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 100 |
| Overnight respite in the home | 0 | 0 | 0 | 4 | 2 | 10 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 10 |
| Shared care or guardianship | 0 | 1 | 1 | 1 | 1 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 7 |
| Regular part-time care (2/3 days per week) | 0 | 0 | 0 | 2 | 11 | 29 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 29 |
| Regular part-time care (every weekend) | 0 | 0 | 0 | 2 | 4 | 11 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 12 |
| Regular part-time care (alternate weeks) | 0 | 0 | 0 | 1 | 5 | 10 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 11 |
| Other residential service | 0 | 1 | 3 | 1 | 13 | 50 | 0 | 0 | 0 | 0 | 0 | 0 | 3 | 7 | 83 |
| All services | 9 | 26 | 48 | 124 | 679 | 1584 | 0 | 1 | 2 | 5 | 75 | 206 | 138 | 781 | 1840 |

B - SERVICE CHANGE

The term 'service change' describes those who already have an intellectual disability service but will require that service to be changed or upgraded during the period 2006–2010, and includes children availing of educational services in 2005 who will require access to health-funded services in the period. Changes in service provision relate to:

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

Changes in service provision exclude people whose only service change requirement is for multidisciplinary support services (including those to be delivered by an early intervention team). Multidisciplinary support services requirements are detailed in the multidisciplinary support services section later in the chapter.

There are 2,194 people included in the data presented in the section on unmet need above (Tables 4.1 and 4.2) who are missing one element of service and require their existing element of service to be changed in some way.

- 1,086 people with an unmet need for a full-time residential place require a change in their day service.
- 8 people with an unmet need for a day service require a change in their full-time residential placement. One person with an unmet need for a day service requires a change in their residential support service.
- 1,099 people with an unmet need for a residential support service require a change in their day service.

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

Categories of service change requirements

Table 4.10 indicates that 11,590 people who are receiving services in 2005 will require a change to their existing service provision in the period 2006–2010, an increase of 174 (1.5%) since 2004. Of the 11,590 requiring a service change:

- 7,994 (69.0%) are day attenders (of whom 750 also avail of residential support services).
- 3,095 (26.7%) are full-time residents (of whom 2,317 also avail of day services).
- 501 (4.3%) receive residential support services only.

A breakdown of the category of service change required by level of intellectual disability is provided in Table 4.10.

- People in the moderate, severe and profound ranges of intellectual disability account for 7,271 (62.7%) of the service changes.
- People in the mild range require 3,375 (29.1%) of the service changes.
- 944 (8.1%) of the service changes are required by people whose level of intellectual disability has not been verified.

Table 4.10. National Intellectual Disability Database, Ireland 2005.
Category of service change required 2006-2010.

| | Residential and day | Residential only | Day only | Day and residential support | Residential support only | Total requiring service changes |
|-----------------------------|----------------------------|-------------------------|-----------------|------------------------------------|---------------------------------|--|
| Not verified | 23 | 24 | 841 | 32 | 24 | 944 |
| Mild | 228 | 101 | 2770 | 170 | 106 | 3375 |
| Moderate, severe & profound | 2066 | 653 | 3633 | 548 | 371 | 7271 |
| All levels | 2317 | 778 | 7244 | 750 | 501 | 11590 |

Number of places required to address service changes

The numbers of places involved in addressing the required service changes are summarised in Table 4.11. Day services are described under four headings: health, education, employment, and generic, and the programmes included under each heading are outlined in Appendix A.

Table 4.11. National Intellectual Disability Database, Ireland 2005.
Number of places requiring to be changed 2006-2010.

| | |
|----------------------------|--------------|
| Residential | 3095 |
| Day | 10311 |
| Of which: | |
| Health services | 7217 |
| Education services | 1103 |
| Employment services | 1494 |
| Generic services | 497 |
| Residential support | 1251 |

The number of places required exceeds the number of people requiring service changes because some people require changes in both their residential and day services. In addition, it is important to note that, although 11,590 people require service changes, this demand does not translate into 11,590 new places. In many instances, these individuals will be vacating their existing placement when they receive their change of service. This will free up places for other people requiring a service change and those with unmet needs. For example, when young adults move into sheltered work from training, their training place is freed up for the young adults leaving school. It is also important to note that this entire group gets some level of service at present so a certain level of funding is already committed to these individuals.

Year in which service changes are required

Table 4.12 identifies the years in which the service changes are required. Again, as with the unmet need data, most of the service changes are required immediately.

| Table 4.12. National Intellectual Disability Database, Ireland 2005. | | | | | | |
|--|-------------|-------------|-------------|-------------|-------------|------------------|
| Year in which service changes are required | | | | | | |
| | 2006 | 2007 | 2008 | 2009 | 2010 | All years |
| Residential | 3005 | 69 | 13 | 4 | 4 | 3095 |
| Day | 8986 | 690 | 354 | 200 | 81 | 10311 |
| Of which: | | | | | | |
| Health services | 6379 | 414 | 224 | 137 | 63 | 7217 |
| Employment services | 1390 | 80 | 19 | 3 | 2 | 1494 |
| Educational services | 953 | 93 | 33 | 19 | 5 | 1103 |
| Generic services | 264 | 103 | 78 | 41 | 11 | 497 |
| Residential support | 1232 | 3 | 9 | 6 | 1 | 1251 |

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 4.13 to 4.15.

Residential service change

Table 4.13 indicates that 3,095 individuals in full-time residential services in 2005 will require an upgrading or change of accommodation within the next five years. For most of this group (62.6%, 1,939 individuals) a change of service type is required.

- Residential placements in the community are required by 1,096 individuals (35.4%).
- Intensive services for either challenging behaviour or profound or multiple disability are required by 661 individuals (21.4%).
- Centre-based placements are required by 136 individuals (4.3%).

- Nursing home placements are required by 44 individuals (1.4%).
- Two individuals have been identified as requiring admission to a psychiatric hospital.

The remaining 1,156 individuals (37.4%) require an enhancement in their existing service type.

- 413 individuals need their existing service upgraded to include care at weekends and holiday times.
- 26 individuals require less care and could return to their families at weekends and holiday times.
- 717 individuals who need an enhancement of their existing service provision (shaded area of Table 4.13). Over two-thirds of this group need increased support in their existing placement.

Two hundred and thirty-two of the 3,095 individuals who require an upgrading or change of accommodation also require an additional future residential service, over two-thirds of which are residential support services.

Day service change

Within the next five years, 10,311 individuals will require a change, enhancement, or upgrading of their day service (Table 4.14).

- Health-funded services are required in 70.0% (7,217 individuals) of the changes or enhancements.
- Employment services are required in 14.5% (1,494 individuals) of the changes or enhancements.
- Educational services are required in 10.7% (1,103 individuals) of the changes or enhancements.
- Generic services are required in 4.8% (497 individuals) of the changes or enhancements.

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

Health services

Of the 7,217 service changes required within health-funded services, 5,319 (73.7%) are requirements for an alternative or additional service and 1,898 (26.3%) are requirements for an enhancement of the person's existing service (Table 4.14). The majority of the demand for alternative or additional health-funded services occurs within the more care-focused services.

- 1,022 individuals require high-support or intensive placements, the majority of whom currently attend activation programmes (422 individuals), or receive multidisciplinary support services as their only day service (262 individuals).

Table 4.13. National Intellectual Disability Database, Ireland 2005.

Pattern of movement of individuals from existing residential service to future residential service 2006-2010.

| Full-time residential service in 2005 | Full-time residential service required in the period 2006-2010 | | | | | | | | | | | Total services 2005 |
|--|--|-------------------|-------------------|----------|------------------|------------------|--------------|----------------------|--------------------------|-----------------------------|-------------|---------------------|
| | 5-day CGH | 7-day (48-wk) CGH | 7-day (52-wk) CGH | 5-day RC | 7-day (48-wk) RC | 7-day (52-wk) RC | Nursing Home | Psychiatric Hospital | Intensive placement (CB) | Intensive placement (P/M D) | | |
| 5-day community group home (CGH) | 25 | 87 | 135 | 0 | 2 | 6 | 0 | 0 | 7 | 4 | 266 | |
| 7-day (48-week) community group home | 0 | 63 | 118 | 1 | 8 | 9 | 0 | 0 | 17 | 9 | 225 | |
| 7-day (52-week) community group home | 3 | 17 | 412 | 0 | 2 | 25 | 23 | 0 | 62 | 38 | 582 | |
| 5-day residential centre (RC) | 7 | 13 | 38 | 2 | 5 | 14 | 0 | 0 | 8 | 0 | 87 | |
| 7-day (48-week) residential centre | 2 | 76 | 90 | 0 | 37 | 54 | 3 | 0 | 34 | 10 | 306 | |
| 7-day (52-week) residential centre | 2 | 15 | 741 | 0 | 6 | 92 | 16 | 0 | 254 | 195 | 1321 | |
| Nursing home | 0 | 1 | 31 | 0 | 0 | 2 | 1 | 0 | 4 | 6 | 45 | |
| Intensive placement (challenging behaviour) (CB) | 0 | 4 | 32 | 3 | 5 | 48 | 1 | 2 | 42 | 5 | 142 | |
| Intensive placement (profound/multiple disability) (P/M D) | 0 | 1 | 6 | 0 | 0 | 19 | 0 | 0 | 4 | 43 | 73 | |
| Occupying a residential support place | 2 | 2 | 25 | 0 | 0 | 4 | 0 | 0 | 1 | 1 | 35 | |
| Other full-time residential place | 0 | 1 | 7 | 0 | 0 | 2 | 1 | 0 | 1 | 1 | 13 | |
| Total services required | 41 | 280 | 1635 | 6 | 65 | 275 | 45 | 2 | 434 | 312 | 3095 | |

The abbreviations in the third row of the table headings refer to the placement descriptions outlined in column one.

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

- 896 individuals require activation programmes, the majority of whom currently receive multidisciplinary support services as their only day service (312 individuals), attend special schools (201 individuals), or attend sheltered work (177 individuals).
- 754 individuals require services specific to older people, the majority of whom currently attend activation programmes (326 individuals) or sheltered work (252 individuals).

A large part of the demand for alternative or additional health-funded services also comes from

- 921 individuals who require rehabilitative training, the majority of whom currently attend special schools (685 individuals), and
- 711 individuals who require a sheltered work centre, the majority of whom currently attend rehabilitative training (283 individuals), attend special schools (181 individuals), or attend activation programmes (118 individuals).

The above data on current services and demand for future services highlight the progression of individuals through the services from special schools to rehabilitative training and on to sheltered work.

Demand for alternative or additional health-funded services specifically for children (pre-school services, child education and development centres, and centre-based day respite services) account for only 565 of the 5,317 (10.6%) alternative or additional health-funded services required. The main demand is for mainstream and specialised pre-school services.

There are also 1,898 individuals who need to have their existing health-funded service enhanced (shaded area of Table 4.14). Most of these people are attending activation (807 individuals, 42.5%) or attending sheltered work (565 individuals, 29.8%). The main enhancements required are an increased level of support (73.2%) and an increased level of service provision from part-time to full-time (16.9%).

Employment services

Of the 1,494 service changes required within employment services, 1,429 (95.6%) are requirements for an alternative placement and 65 (4.4%) are requirements for an enhancement of the person's existing placement (Table 4.14).

Most of the demand for alternative employment opportunities comes from 1,250 individuals who require supported employment, the majority of whom currently attend sheltered work (554 individuals) or rehabilitative training (305 individuals).

There are 65 individuals who require their existing employment placement to be enhanced (shaded area of Table 4.14). Sixty-two of these avail of supported employment and over half need their placement to be increased from part-time to full-time.

Educational services

Of the 1,103 service changes required within educational services, 938 (85.0%) are requirements for an alternative service and 165 (15.0%) are requirements for an enhancement of the child's existing service (Table 4.14).

Table 4.14. National Intellectual Disability Database, Ireland 2005.

Pattern of movement of individuals from existing day service to future day service 2006-2010.

| Day service in 2005 | Day service required in the period 2006-2010 | | | | | | | | | | | | | | | | | | | All | | | | | | | | |
|---|--|-----------|------------|------------|-----------|------------|------------|-----------|------------|------------|------------|-------------|------------|------------|------------|-------------|-----------|------------|----------|-----------|-----------|-------------|------------|------------|-----------|--------------|-----|-----|
| | HS | HH | MPS | SPS | CEDC | MS | RT | SCP | SCS | SS | RHT | AC | POP | SHS | SI | SWC | SEC | CDR | DRH | | OTH | E | SE | OE | VT | GD | | |
| Home support (HS) | 16 | 0 | 29 | 33 | 4 | 3 | 2 | 2 | 0 | 1 | 3 | 6 | 3 | 0 | 0 | 6 | 0 | 0 | 1 | 2 | 0 | 4 | 0 | 0 | 3 | 0 | 118 | |
| Home help (HH) | 2 | 0 | 7 | 4 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 2 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 21 | |
| Early intervention team ^a | 18 | 2 | 127 | 106 | 0 | 32 | 9 | 1 | 0 | 11 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 308 | |
| Mainstream pre-school (MPS) | 3 | 0 | 19 | 12 | 2 | 116 | 3 | 12 | 0 | 4 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 174 | |
| Special pre-school (SPS) | 12 | 1 | 57 | 52 | 16 | 69 | 8 | 33 | 0 | 159 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 4 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 412 | |
| Child education & development centre (CEDC) | 12 | 0 | 2 | 0 | 16 | 1 | 2 | 0 | 0 | 9 | 2 | 64 | 0 | 6 | 6 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 122 | |
| Mainstream school (MS) | 43 | 1 | 2 | 1 | 0 | 46 | 24 | 36 | 28 | 17 | 1 | 1 | 0 | 1 | 0 | 1 | 1 | 40 | 0 | 1 | 0 | 9 | 2 | 24 | 0 | 320 | | |
| Resource/visiting teacher (RT) | 7 | 0 | 11 | 3 | 0 | 31 | 16 | 2 | 9 | 20 | 11 | 0 | 0 | 0 | 0 | 1 | 0 | 2 | 0 | 0 | 1 | 0 | 1 | 0 | 20 | 134 | | |
| Special class – primary (SCP) | 16 | 0 | 0 | 0 | 1 | 13 | 11 | 5 | 182 | 17 | 8 | 4 | 0 | 0 | 1 | 3 | 0 | 3 | 0 | 1 | 0 | 1 | 0 | 1 | 0 | 1 | 267 | |
| Special class – secondary (SCS) | 0 | 1 | 0 | 0 | 0 | 2 | 1 | 0 | 3 | 1 | 26 | 13 | 0 | 1 | 0 | 7 | 1 | 7 | 0 | 0 | 0 | 4 | 0 | 24 | 0 | 91 | | |
| Special school (SS) | 123 | 2 | 1 | 0 | 10 | 7 | 4 | 4 | 2 | 95 | 685 | 201 | 0 | 44 | 20 | 181 | 29 | 52 | 0 | 4 | 4 | 44 | 23 | 310 | 0 | 1845 | | |
| Rehabilitative training (RHT) | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 45 | 59 | 8 | 10 | 4 | 283 | 6 | 0 | 0 | 6 | 1 | 305 | 13 | 42 | 6 | 788 | | |
| Activation centre (AC) | 34 | 6 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 47 | 807 | 326 | 183 | 239 | 118 | 6 | 7 | 0 | 2 | 3 | 157 | 5 | 7 | 0 | 1947 | | |
| Programme for the older person (POP) | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 10 | 206 | 5 | 61 | 7 | 0 | 0 | 0 | 1 | 0 | 2 | 0 | 0 | 0 | 3 | 296 | |
| Special high-support service (SHS) | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 1 | 16 | 15 | 12 | 114 | 99 | 11 | 0 | 0 | 0 | 1 | 0 | 4 | 0 | 1 | 0 | 1 | 0 | 276 |
| Special intensive service (SI) | 2 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 3 | 5 | 1 | 8 | 52 | 0 | 0 | 1 | 0 | 0 | 2 | 0 | 2 | 0 | 0 | 0 | 76 | |
| Sheltered work centre (SWC) | 11 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 56 | 177 | 252 | 29 | 23 | 565 | 24 | 0 | 0 | 22 | 13 | 554 | 34 | 10 | 4 | 1777 | | |
| Sheltered employment centre (SEC) | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 1 | 15 | 0 | 1 | 0 | 23 | | |
| Multidisciplinary support services ^a | 12 | 0 | 6 | 3 | 1 | 3 | 0 | 1 | 1 | 9 | 22 | 312 | 115 | 103 | 159 | 23 | 3 | 1 | 0 | 5 | 1 | 36 | 17 | 8 | 1 | 842 | | |
| Centre-based day respite service (CDR) | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 1 | 0 | 2 | 4 | 1 | 1 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 13 | |
| Day respite in the home (DRH) | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 3 | |
| Other day service (OTH) | 1 | 1 | 0 | 1 | 1 | 1 | 0 | 0 | 0 | 3 | 6 | 15 | 14 | 8 | 3 | 32 | 0 | 0 | 0 | 4 | 0 | 14 | 0 | 2 | 0 | 106 | | |
| Enclave with open employment (E) | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | |
| Supported employment (SE) | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 4 | 3 | 14 | 2 | 1 | 7 | 6 | 1 | 0 | 2 | 1 | 62 | 17 | 3 | 16 | 144 | | |
| Open employment (OE) | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 3 | 1 | 1 | 0 | 0 | 0 | 9 | 3 | 3 | 0 | 23 | | |
| Vocational training (VT) | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 10 | 2 | 1 | 0 | 0 | 0 | 25 | 2 | 0 | 0 | 0 | 0 | 60 | 42 | 3 | 0 | 145 | | |
| Generic day service (GD) | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 3 | 0 | 0 | 3 | 0 | 1 | 0 | 0 | 0 | 28 | 0 | 0 | 0 | 2 | 39 | | |
| All services | 319 | 19 | 262 | 216 | 51 | 324 | 102 | 84 | 233 | 360 | 966 | 1703 | 960 | 515 | 673 | 1276 | 82 | 123 | 1 | 51 | 25 | 1312 | 157 | 462 | 35 | 10311 | | |

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

The abbreviations in the third row of the table headings refer to the programme descriptions outlined in column one. The shaded areas of the table represent existing services that require alteration or enhancement.

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

- 309 children who require special classes, particularly at secondary level. The majority of those requiring special classes at secondary level (230 children) currently attend special classes at primary level (182 children).
- 278 children who require a mainstream school placement, the majority of whom currently attend a mainstream (116 children) or specialised (69 children) pre-school.
- 265 children who require a special school placement, the majority of whom currently attend special pre-schools (159 children).

There are 165 children who require their existing educational placement to be enhanced (shaded area of Table 4.14), the majority of whom currently attend special schools (95 children). Over half the enhancements identified require the child's existing service at primary level to be carried through to secondary level. There is also a significant demand for increased support within existing educational placements.

Generic services

Of the 497 service changes required within generic services, 492 (99.0%) are requirements for an alternative service and 5 (1.0%) are requirements for an enhancement of the person's existing service (Table 4.14).

Most of the demand for alternative generic services comes from 459 individuals who require vocational training, the majority of whom currently attend special schools (310 individuals).

Three individuals attending vocational training and two individuals availing of generic day services require their existing generic service to be enhanced (shaded area of Table 4.14).

Pattern of movement within day services

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

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

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

²The services involved include home support services, early intervention team, resource/visiting teacher, home help, multidisciplinary support services, centre-based day respite service, and day respite in the home.

Table 4.14 maps the pattern of movement of individuals from their existing day service to their future day service. The main day service and the first future day service recorded on the NIDD are used to indicate the existing and future day services.

Residential support service change

The database indicates that 1,251 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 2006–2010 (Table 4.15). Additional or alternative support services are required by 394 individuals (31.5%), and 857 individuals (68.5%) require their existing service to be upgraded (shaded area of Table 4.15).

The principal residential support service changes or enhancements include:

- more frequent centre-based crisis or planned respite breaks for people already availing of this service. Of these 829 individuals, 753 currently receive planned respite and require an enhanced service, 11 receive crisis respite and require their support to be planned, and 69 are in receipt of both planned and crisis respite and require increased planned respite.
- more regular part-time care arrangements for people already accessing crisis or planned respite services (102 people).
- occasional holiday residential placements and occasional respite care with a host family for people currently availing of crisis or planned respite (77 people).
- opportunities to experience semi-independent living arrangements for people receiving centre-based respite breaks (65 people).

One hundred and ninety-five individuals of the 1,251 who are receiving residential support services and require that service to be changed also require an additional future residential service. More than three-quarters of these additional future residential services are residential support services.

As with certain types of day service, it is important to note that existing residential support services may be retained by the individual when 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.

C - PERSONS WITH INTELLECTUAL DISABILITY WHO ARE ACCOMMODATED IN PSYCHIATRIC HOSPITALS

The data from the NIDD for 2005 identify 396 individuals with intellectual disability, all aged 20 years or over, accommodated in psychiatric hospitals. Table 4.16 details the overall service requirement status of people resident in psychiatric hospitals by level of intellectual disability.

Table 4.15. National Intellectual Disability Database, Ireland 2005.

Additional residential support services required by people availing of residential support services.

| | Residential support service required 2006-2010 | | | | | | | | | | | Total | |
|--|---|----------------------|---------------------------|-------------------------------|---------------------------|---------------------------------------|---------------------------|--|--|--|-------------------------------|----------|---------------------------|
| | Foster care and boarding-out | Living independently | Living semi-independently | Holiday residential placement | Crisis or planned respite | Occasional respite care (host family) | Shared care /guardianship | Regular part-time care (2/3 days per week) | Regular part-time care (every weekend) | Regular part-time care (alternate weeks) | Overnight respite in the home | | Other residential service |
| Foster care and boarding-out | 0 | 1 | 7 | 3 | 9 | 1 | 0 | 2 | 1 | 0 | 0 | 0 | 24 |
| Living semi-independently | 0 | 10 | 15 | 7 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 34 |
| Holiday residential placement | 0 | 0 | 2 | 1 | 10 | 2 | 0 | 1 | 0 | 5 | 0 | 1 | 22 |
| Crisis or planned respite | 2 | 9 | 65 | 46 | 829 | 31 | 12 | 57 | 13 | 32 | 1 | 4 | 1101 |
| Occasional respite care (host family) | 0 | 1 | 1 | 0 | 23 | 5 | 1 | 1 | 0 | 1 | 0 | 0 | 33 |
| 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 | 1 | 0 | 0 | 8 | 0 | 0 | 1 | 2 | 3 | 0 | 0 | 15 |
| Regular part-time care (every weekend) | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 3 |
| Regular part-time care (alternate weeks) | 0 | 0 | 1 | 1 | 2 | 2 | 0 | 0 | 1 | 1 | 0 | 0 | 8 |
| Overnight respite in the home | 0 | 0 | 0 | 0 | 2 | 1 | 0 | 0 | 0 | 0 | 3 | 0 | 6 |
| Other residential service | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 4 |
| All services | 2 | 23 | 92 | 58 | 888 | 42 | 13 | 62 | 18 | 43 | 4 | 6 | 1251 |

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

Table 4.16. National Intellectual Disability Database, Ireland 2005.

Overall service requirements of people with intellectual disability resident in psychiatric hospitals in 2005.

| | No service requirements | | | | Has service requirements | | | | Total |
|---|-------------------------|-----------|-----------------------------|------------|--------------------------|-----------|-----------------------------|------------|------------|
| | Not verified | Mild | Moderate, Severe & Profound | All levels | Not verified | Mild | Moderate, Severe & Profound | All levels | |
| Resident in a psychiatric hospital - no day programme | 0 | 2 | 13 | 15 | 1 | 6 | 47 | 54 | 69 |
| Resident in a psychiatric hospital - with day programme | 1 | 27 | 55 | 83 | 2 | 71 | 169 | 242 | 325 |
| Resident in a psychiatric hospital - with residential support service | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 1 |
| Resident in a psychiatric hospital - with residential support service and day programme | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 1 |
| All residents | 1 | 29 | 69 | 99 | 3 | 78 | 216 | 297 | 396 |

Of this group, 297 (75.0%) individuals have service requirements in the period 2006–2010, of whom:

- 275 have an appropriate alternative residential facility identified for them (124 of whom will also require a day service). The residential service requirements of this group are shown in Table 4.18 and their day service requirements are shown in Table 4.19.
- 17 are recorded as appropriately placed within the psychiatric hospital but have identified day service requirements (one of whom also requires a residential support service and one of whom also requires increased support within a psychiatric hospital). The day service requirements of these 17 people are shown in Table 4.17.
- two are recorded as appropriately placed within the psychiatric hospital but require residential support services.
- three are recorded as appropriately placed within the psychiatric hospital but require increased support within a psychiatric hospital.

Of the 275 people who need to transfer from psychiatric to intellectual disability services for provision of their residential services, 36.0% (99 individuals) will require places in residential centres, 32.0% (88 individuals) will require intensive placements, and 28.4% (78 individuals) will require community group home places. Ten individuals need to move to nursing homes. Almost all of the need arises immediately (Table 4.18).

Table 4.17. National Intellectual Disability Database, Ireland 2005.

Day service requirements of people appropriately accommodated in psychiatric hospitals.

| Services required 2006-2010 | | | | | | | | |
|---|---------------------|-------------------|--------------------------------|----------------------------------|-----------------------|----------------------|--------------------|--------------|
| Day service in 2005 | Vocational training | Activation centre | Programme for the older person | Special high support day service | Sheltered work centre | Supported employment | Other day services | All services |
| No day programme | 0 | 2 | 1 | 0 | 0 | 0 | 0 | 3 |
| Home help | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 |
| Activation centre | 1 | 3 | 0 | 0 | 0 | 0 | 0 | 4 |
| Sheltered work centre | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 |
| Multidisciplinary support services only | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 2 |
| Other day programme | 0 | 3 | 2 | 0 | 1 | 0 | 0 | 6 |
| All services | 1 | 8 | 3 | 2 | 1 | 1 | 1 | 17 |

Note

5 of the 17 also have multidisciplinary support services requirements. These are documented in the multidisciplinary support services section later in this chapter.

Table 4.18. National Intellectual Disability Database, Ireland 2005.

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

| | Year in which residential service is required | | |
|--|--|----------|------------|
| | 2006 | 2008 | 2006-2010 |
| 7-day (48-week) community group home | 2 | 0 | 2 |
| 7-day (52-week) community group home | 75 | 1 | 76 |
| 7-day (48-week) residential centre | 2 | 0 | 2 |
| 7-day (52-week) residential centre | 97 | 0 | 97 |
| Nursing home | 10 | 0 | 10 |
| Intensive placement (challenging behaviour) | 65 | 0 | 65 |
| Intensive placement (profound/multiple disability) | 23 | 0 | 23 |
| All residential services | 274 | 1 | 275 |

Of this same group of 275 people, 124 will also require an appropriate day service. The greatest demand is for high-support or intensive day programmes (53.2%, 66 people), activation programmes (21.8%, 27 people), and programmes for older people (14.5%, 18 people). All day services are required immediately (Table 4.19).

Table 4.19. National Intellectual Disability Database, Ireland 2005.

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

| | Year in which day service is required |
|--|---------------------------------------|
| | 2006 |
| Rehabilitative training | 2 |
| Activation centre | 27 |
| Programme for the older person | 18 |
| Special high-support day service | 50 |
| Special intensive day service | 16 |
| Sheltered work centre | 5 |
| Sheltered employment centre | 2 |
| Supported employment | 1 |
| Generic day services | 1 |
| Other day service | 2 |
| All day services | 124 |
| Note: | |
| 53 of the 124 also have multidisciplinary support services requirements. These are documented in the multidisciplinary support services section later in this chapter. | |

The 2005 data suggest that the current day and residential programmes for 99 people with intellectual disability resident in psychiatric hospitals are appropriate and these people have no identified service needs in the period 2006–2010 (Table 4.16). More than two-thirds (69 people) of this group have a moderate, severe, or profound intellectual disability, more than a quarter (29 people) have a mild disability and one individual’s level of disability is not yet verified. Within this group are 16 people who have no formal day programme. The day service needs of this group need to be reviewed.

D - MULTIDISCIPLINARY SUPPORT SERVICES

Although the NIDD facilitates the recording of two future day services, earlier sections of this chapter detail the first future day service only so that individuals are not double-counted. Future multidisciplinary support services, including those to be delivered by early intervention teams, are only recorded as a first future day service if these support services are the only future day service required. In reality these services are required in addition to a more substantial day service component. To avoid under-reporting the demand for these services, they are excluded from the unmet need, service change, and psychiatric hospitals sections above and they are reported separately below in Table 4.20. A ‘requirement’ refers to a new type of therapeutic input that the individual does not currently receive and an ‘enhancement’ refers to a change in the delivery of a therapeutic input that the individual currently receives (e.g. an increase in the provision of the specific service or a change in service provider). Data from Table 3.11 are reproduced in Table 4.20 to compare current service provision with the demand for future services.

Multidisciplinary support services are currently availed of by 18,399 people, 14,701 of whom have further requirements for such services. A further 2,145 individuals who do not currently access such services require them. Therefore, there are 16,846 (14,701 plus 2,145) individuals with a need for multidisciplinary support services whose needs involve either an enhancement of a type of service currently received (3,017 individuals), a requirement for a new type of service (5,079 individuals), or both (8,750 individuals). Of this 16,846 people with future multidisciplinary support service needs, 117³ receive no service whatsoever at present. Ninety-nine per cent of the demand is immediate.

Despite high levels of current provision, there is substantial demand for new services and enhanced services of all the therapeutic inputs, in particular, psychology, social work, and speech and language therapy. For example, 7,043 individuals currently receive a psychology service, 3,820 of whom need an enhancement of their service, and a further 6,209 individuals who do not receive a psychology service require one.

The data suggest that there is a significant shortfall of occupational therapy and nutrition services as these are the only therapeutic inputs where the demand for new services exceeds current service provision. For example, 3,637 individuals are currently in receipt of occupational therapy, 2,306 of whom need an enhancement of their service, and a further 5,514 individuals who are not in receipt of occupational therapy require it.

OVERALL SERVICE PROVISION TO PEOPLE WITH INTELLECTUAL DISABILITY AND THE PATTERN OF CARE REQUIRED IN THE PERIOD 2006–2010

The data presented in this chapter in relation to unmet need for services and demand for service changes need to be considered together to enable the future pattern of care to be forecast. The database indicates that there are large numbers of people who require residential services for the first time and also that there are significant numbers who require changes to, or enhancements of, their existing residential or day placements (or both). Not all service changes will require the individual to move to a new placement as many require enhancements such as increased support which can be made available in their existing placement. Where the enhancement involves a move to a new placement, the freed-up place may become available to others who have an identified need for such a placement. The existing placements occupied by these individuals are secure until their new places become available. Such movement is part of the ongoing development of services and is tangible evidence of the ability of the database to match needs with service provision.

Pattern of care required in full-time residential services

As is indicated in Table 4.21, demand for full-time residential services in the period 2006–2010 will come from three distinct groups already identified in this chapter:

- 2,008 individuals living at home who require full-time residential services for the first time,
- 275 individuals resident in psychiatric hospitals who require to transfer to the intellectual disability services, and

³62 of the 117 also have other future service requirements that are included in the 'unmet need' section at the beginning of this chapter.

Table 4.20. National Intellectual Disability Database, Ireland 2005.

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

| | Currently receiving service | | | | | Enhancement of service required 2006-2010 by people currently receiving this input | | | | | New service required 2006-2010 by people not currently receiving this input | | | | |
|---------------------------|-----------------------------|------------|-------------|------------------|--------------|--|------------|-------------|------------------|--------------------------|---|------------|-------------|------------------|--------------------------|
| | Aged 6 and under | | Aged 7-18 | Aged 19 and over | Total | Aged 6 and under | | Aged 7-18 | Aged 19 and over | Total | Aged 6 and under | | Aged 7-18 | Aged 19 and over | Total |
| | EIT | Not EIT | | | | EIT | Not EIT | | | | EIT | Not EIT | | | |
| Medical services | 789 | 94 | 962 | 5264 | 7109 | 311 | 68 | 345 | 2268 | 2992 | 127 | 44 | 353 | 825 | 1349 |
| Nursing | 717 | 67 | 833 | 3083 | 4700 | 339 | 53 | 341 | 1155 | 1888 | 48 | 16 | 250 | 1001 | 1314 |
| Nutrition | 211 | 39 | 395 | 1806 | 2451 | 80 | 35 | 182 | 766 | 1063 | 167 | 48 | 540 | 2877 | 3632 |
| Occupational therapy | 801 | 101 | 1253 | 1482 | 3637 | 416 | 115 | 752 | 1203 | 2306 | 360 | 101 | 1223 | 3830 | 5514 |
| Physiotherapy | 1064 | 119 | 1222 | 2116 | 4521 | 499 | 118 | 650 | 1297 | 2564 | 100 | 35 | 494 | 1871 | 2500 |
| Psychiatry | 79 | 13 | 417 | 5379 | 5888 | 43 | 12 | 197 | 3051 | 3303 | 39 | 15 | 391 | 828 | 1273 |
| Psychology | 911 | 161 | 2065 | 3906 | 7043 | 438 | 140 | 1141 | 2101 | 3820 | 287 | 66 | 1409 | 4447 | 6209 |
| Social work | 1015 | 113 | 2312 | 5715 | 9155 | 492 | 128 | 1312 | 3341 | 5273 | 81 | 40 | 667 | 2651 | 3439 |
| Speech & language therapy | 1199 | 198 | 2731 | 805 | 4933 | 674 | 186 | 1518 | 479 | 2857 | 257 | 70 | 1047 | 3215 | 4589 |
| Other | 522 | 92 | 1008 | 3017 | 4639 | 75 | 17 | 203 | 970 | 1265 | 158 | 62 | 479 | 1786 | 2485 |
| Number of people | 1569 | 253 | 4490 | 12087 | 18399 | 943 | 260 | 2772 | 7792 | 11767^a | 814 | 212 | 2979 | 9824 | 13829^a |

^a 'Enhancement of service required' refers to a change in the delivery of a therapeutic input that the individual currently receives. 'New service required' refers to a new type of therapeutic input that the individual does not currently receive. There are 8,750 individuals whose multidisciplinary support service change involves both a requirement and an enhancement. Therefore, the actual number of people represented in this table as requiring enhanced and/or additional services is 11,767 + 13,829 – 8,750 = 16,846.

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

- 3,095 individuals in full-time residential services within the intellectual disability sector who require changes to their existing placement. Of this group, 1,939 require alternative services and 1,156 require their existing service to be enhanced. Not all of the group who require service enhancements will move to new placements. For example, 498 out of the 1,156 individuals (43.1%) require increased support in their existing 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 4.21 outlines the pattern of full-time residential service provision that will be required in the period 2006–2010 to meet this demand. A total of 2,318 residential places will be required – an increase of 120 since 2004.

- 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, 2,580 community-based placements will be required during the period, a substantial increase of 192 since 2004.
- There will also be a shortfall of 769 intensive residential placements, an increase of 11 since 2004. It should be noted that there are significantly higher costs associated with the provision of these intensive placements.

Pattern of care required in day services

As can be seen from Table 4.22, demand for day services over the next five years comes from four distinct groups:

- 284 individuals who are without day services,
- 124 individuals resident in psychiatric hospitals who will require an appropriate day service when they transfer to intellectual disability services,
- 17 individuals appropriately placed in psychiatric hospitals but requiring a day programme within that setting, and
- 10,301 individuals in existing day services within the intellectual disability sector who require changes to, or enhancements of, their existing placement. Of this group 8,178 require alternative or additional services and 2,133 require their existing service to be enhanced. The majority (7,217) of these service changes are within the health sector. Many of the changes are required to address transitional needs such as moving from child to adult services or moving from training into employment. Not all of the group who require service enhancements will move to new placements. Again, as is seen with the requirement for enhancement of residential placements, 1,476 out of the 2,133 identified individuals (69.2%) require increased support in their existing placements. However, the entire group has been factored into the overall calculation of placement requirements, as some costs will be incurred in upgrading 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. However, unlike the situation with full-time residential services, not

Table 4.21. National Intellectual Disability Database, Ireland 2005.
Pattern of full-time residential service provision required 2006-2010.

| | New services required by people living at home | New services required by people transferring from psychiatric hospitals | Service changes required by people in existing full-time residential places | Places vacated by people in full-time residential places | Shortfall (-)/ Excess of places arising from demand |
|---|--|---|---|--|--|
| 5-day community group home | 336 | 0 | 41 | 266 | -111 |
| 7-day (48-week) community group home | 319 | 2 | 280 | 225 | -376 |
| 7-day (52-week) community group home | 964 | 76 | 1635 | 582 | -2093 |
| 5-day residential centre | 25 | 0 | 6 | 87 | 56 |
| 7-day (48-week) residential centre | 55 | 2 | 65 | 306 | 184 |
| 7-day (52-week) residential centre | 143 | 97 | 275 | 1321 | 806 |
| Nursing home | 15 | 10 | 45 | 45 | -25 |
| Mental health community residence | 1 | 0 | 0 | 0 | -1 |
| Psychiatric hospital | 0 | 0 | 2 | 0 | -2 |
| Intensive placement (challenging behaviour) | 79 | 65 | 434 | 142 | -436 |
| Intensive placement (profound or multiple disability) | 71 | 23 | 312 | 73 | -333 |
| Other/unspecified intellectual disability service | 0 | 0 | 0 | 13 | 13 |
| Designated residential support placement | 0 | 0 | 0 | [35 ^a] | 0 |
| Total | 2008 | 275 | 3095 | 3060 | -2318 |

^a 35 designated residential support places being blocked by full-time residents will be freed up but they have not been deducted from the total number of full-time residential places required as they should not be made available for full-time use.

all existing places will become available. As previously explained in this chapter, people who are accessing, or who require, home support, early services, resource/visiting teachers, multidisciplinary supports, centre- and home-based day respite or home help services will not be freeing up existing services when their future needs are met.

Table 4.22 outlines the pattern of day service provision that will be required in the period 2006–2010 to meet demand. The data in the table have been adjusted to reflect the fact that not all existing services will be freed up.

A total of 1,864 day places will be required – a decrease of 49 places on the corresponding 2004 figure. The table shows two distinct trends consistent with previous years – a decrease in the numbers of young children requiring certain services and a considerable demand for the full spectrum of adult services. The data indicate that over the next five years there will be:

- Small reductions nationally in the number of children requiring special pre-school services, special classes at primary level, and placements in child education and development centres. There will be a significant reduction in the number of children requiring special schools (1,484 children). However, there is a small demand within this group for mainstream pre-school services, special classes at secondary level, and resource/visiting teachers. This demand may be greater than the data indicate due to the possible under-estimation of young children on the database mentioned in chapter 2.
- A shortfall of training and employment opportunities. In the period 2006–2010, 341 vocational training placements and 239 rehabilitative training placements need to be developed to meet the demand that exists for those services. There will be a shortfall of 1,204 supported employment opportunities and 145 placements in open employment during this time.
- The ageing population with intellectual disability discussed in chapter 2 is resulting in increased demand for specific programmes for the older person and there will be a shortfall of 700 such places over the next five years.
- As with residential services, there is significant demand for high-support and intensive day placements. Over the next five years, 297 high-support day placements and 618 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.
- The data indicate that demands for activation programmes and sheltered work placements are likely to be met as other identified service needs are met and existing services are consequently freed up.

Table 4.22. National Intellectual Disability Database, Ireland 2005.
Pattern of day service provision required 2006-2010.

| | New services required by people without day services | New services required by people transferring from psychiatric hospitals | Service changes required by people within psychiatric hospitals | Service changes required by people receiving day services | Places vacated by people receiving day services | Shortfall (-)/ Excess of places arising from demand |
|--|--|---|---|---|---|---|
| Home support | 17 | 0 | 0 | 319 | 0 | -336 |
| Home help | 0 | 0 | 0 | 19 | 0 | -19 |
| Mainstream pre-school | 0 | 0 | 0 | 262 | 174 | -88 |
| Special pre-school | 1 | 0 | 0 | 216 | 412 | 195 |
| Child education and development centre | 0 | 0 | 0 | 51 | 122 | 71 |
| Mainstream school | 1 | 0 | 0 | 324 | 320 | -5 |
| Resource/visiting teacher | 0 | 0 | 0 | 102 | 0 | -102 |
| Special class - primary | 0 | 0 | 0 | 84 | 267 | 183 |
| Special class - secondary | 1 | 0 | 0 | 233 | 91 | -143 |
| Special school | 1 | 0 | 0 | 360 | 1845 | 1484 |
| Rehabilitative training | 59 | 2 | 0 | 966 | 788 | -239 |
| Activation centre | 59 | 27 | 8 | 1703 | 1947 | 150 |
| Programme for the older person | 15 | 18 | 3 | 960 | 296 | -700 |
| Special high-support day service | 6 | 50 | 2 | 515 | 276 | -297 |
| Special intensive day service | 5 | 16 | 0 | 673 | 76 | -618 |
| Sheltered work centre | 42 | 5 | 1 | 1276 | 1777 | 453 |
| Sheltered employment centre | 5 | 2 | 0 | 82 | 23 | -66 |
| Centre-based day respite service | 0 | 1 | 0 | 123 | 0 | -124 |
| Day respite in the home | 0 | 0 | 0 | 1 | 0 | -1 |
| Other day service | 0 | 2 | 1 | 51 | 106 | 52 |
| Enclave within open employment | 2 | 0 | 0 | 25 | 1 | -26 |
| Supported employment | 35 | 0 | 1 | 1312 | 144 | -1204 |
| Open employment | 11 | 0 | 0 | 157 | 23 | -145 |
| Vocational training | 23 | 0 | 1 | 462 | 145 | -341 |
| Generic day services | 1 | 1 | 0 | 35 | 39 | 2 |
| All services | 284 | 124 | 17 | 10311 | 8872 | -1864 |

CONCLUSION

Continued demand for services

The 2005 dataset, in line with data in recent years, indicates that despite substantial levels of service provision there is significant ongoing demand for new intellectual disability services and a growing requirement to enhance existing services. This need is presenting against a background of significant investment in intellectual disability services in the period 2000–2002 and again in 2005. While the data in recent years highlight the corresponding growth in services, demographic factors discussed in chapter 2, and historical under-funding of intellectual disability services are contributing to long waiting lists for these services, most notably for full-time residential services. The increased birth rate in the 1960s and 1970s has resulted in a large adult population moving through the services at present, contributing to an ongoing demand for services. In addition to this, people with intellectual disability are living longer than previously, which not only contributes to the ongoing demand for services, but also reduces the number of service placements freed up through death. While a further multi-annual funding package has been put in place for the period 2006–2009, this is insufficient to address all of the service demands identified in this report. In the medium term, it is expected that the increased demand for intellectual disability services will continue.

References

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

Central Statistics Office (2003) *Census 2002. Principal Demographic Results*. Dublin: Stationery Office.

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 (2001) *Annual Report of the National Intellectual Disability Database Committee 2000*. Dublin: Health 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.



Appendix A

CURRENT SERVICE PROVISION

DAY SERVICES

40. Agency providing main day service (Appendix A)
41. Type of main day service (Appendix B)
42. Current level of main day service support 0. 1. 2. 3. 4. 5.
43. Main day service: number of days received each week [0.0-7.0]
44. Agency providing second day service (Appendix A)
45. Type of second day service (Appendix B)
46. Current level of second day service support 0. 1. 2. 3. 4. 5.
47. Second day service: number of days received each week [0.0-7.0]
48. Agency providing third day service (Appendix A)
49. Type of third day service (Appendix B)
50. Current level of third day service support 0. 1. 2. 3. 4. 5.
51. Third day service: number of days received each week [0.0-7.0]

RESIDENTIAL SERVICES

54. Agency providing main residential service (Appendix A)
55. Type of main residential circumstance (Appendix B)
56. Current level of main residential service support A. B. C. D. Z.
57. Agency providing secondary residential service (Appendix A)
58. Type of secondary residential circumstance (Appendix B)
59. Current level of secondary residential service support A. B. C. D. Z.
60. If Planned Respite or Crisis Respite is the secondary residential service, indicate number of nights
availed of in the past 12 months: Total Planned Crisis
61. Health Board responsible for funding current services

MULTIDISCIPLINARY SUPPORT SERVICES

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

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

66. Are current services provided by an early intervention team? 1=yes 2=no 3=n/a
67. Year in which future services are required
68. Will future services be provided by an early intervention team? 1=yes 2=no 3=n/a

FUTURE SERVICE REQUIREMENTS

REQUIRED DAY SERVICES

70. Type of day service (1) required (Appendix B) |__|__|
71. Level of support required in day service (1) 0. 1. 2. 3. 4. 5.
72. Year in which day service (1) is required |__|__|__|__|
73. Primary reason for duplication on current and future day service (1) |__|__|
74. Type of day service (2) required (Appendix B) |__|__|
75. Level of support required in day service (2) 0. 1. 2. 3. 4. 5.
76. Year in which day service (2) is required |__|__|__|__|
77. Primary reason for duplication on current and future day service (2) |__|__|

CONTINGENCY DAY SERVICES

81. Type of day service required - contingency plan |__|__|
82. Level of (contingency plan) day support required 0. 1. 2. 3. 4. 5.
83. Primary reason for duplication on current and contingency day service |__|__|
84. Primary reason for duplication on future and contingency day service |__|__|

RESIDENTIAL SERVICES

85. Type of residential service (1) required (Appendix B) |__|__|__|
86. Level of support required in residential service (1) A. B. C. D. Z.
87. Year in which residential service (1) is required |__|__|__|__|
88. Primary reason for duplication on current and future residential service (1) |__|__|
89. Type of residential service (2) required (Appendix B) |__|__|__|
90. Level of support required in residential service (2) A. B. C. D. Z.
91. Year in which residential service (2) is required |__|__|__|__|
92. Primary reason for duplication on current and future residential service (2) |__|__|

CONTINGENCY RESIDENTIAL SERVICES

93. Type of residential service required - contingency plan |__|__|__|
94. Level of (contingency plan) residential support required A. B. C. D. Z.
95. Primary reason for duplication on current and contingency residential service |__|__|
96. Primary reason for duplication on future and contingency residential service |__|__|

97. Health Board responsible for funding future services |__|__|

DAY SUPPORT LEVEL CODES

Coding for variables 42, 46, 50, 71, 75 & 82

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

RESIDENTIAL SUPPORT LEVEL CODES

Coding for variables 56, 59, 86, 90 & 94

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

ADDITIONAL INFORMATION

100. Date of completion/review |_|_|-|_|_|-|_|_|_|_|
 101. Person responsible for update of form _____ |_|_|_|
 102. Unit/Centre of person responsible _____ |_|_|_|
 103. Agency returning record |_|_|_|_|_|_|_|
 104. Health Board returning record |_|_|
 105. CCA returning record |_|_|
 106. Date consent received |_|_|-|_|_|-|_|_|_|_|

107. Reason for removal |_|

If transferred (1) please indicate: to HB |_|_| to CCA |_|_| to Agency |_|_|_|_|_|_|_|
 to National Physical & Sensory Disability Database |_|

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"/> Other reason | <input type="radio"/> Duplication between health boards |
| | <input type="radio"/> Duplication within health board |

108. Date of removal |_|_|-|_|_|-|_|_|_|_|

NATIONAL PERFORMANCE INDICATOR (NPI)

To be completed for all people in full-time residential services (codes 115 to 172)

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

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

SERVICE CATEGORIES

Day programmes

Home support
Mainstream pre-school
Special pre-school for intellectual disability
Mainstream school
Special class - primary level
Special class - secondary level
Special school
Child education and development centre (Programme for children with severe or profound intellectual disability)
Vocational training (e.g. FÁS, VEC, CERT, NTDI)
Rehabilitative training
Activation centre/adult day centre
Programme for the older person
Special high-support day service (e.g. relating to challenging behaviour) less than 1:1 staff ratio
Special intensive day service (e.g. relating to challenging behaviour) 1:1 staff ratio contact or greater
Sheltered work centre - may include long-term training schemes
Sheltered employment centre (receives pay and pays PRSI)
Enclave within open employment
Supported employment
Open employment
Other day programme
Resource teacher/visiting teacher
Early services
Generic day services
Home help
Annual review
Multidisciplinary support services for school age children or adults
Full-time resident with no formal day programme
Centre-based day respite service
Day respite in the home

Residential circumstances

At home, with both parents
At home, with one parent
At home with sibling
At home with relative
Lives with non-relative (e.g. neighbour or family friend)
Adoption
Foster care (includes 'boarding-out' arrangements)
Living independently
Living semi-independently - maximum 2 hours supervision daily
Vagrant or homeless

5-day community group home - goes home for weekends/holidays
7-day x 48-week community group home - goes home for holidays
7-day x 52-week community group home
5-day village-type/residential centre - goes home for weekends/holidays
7-day x 48-week village-type/residential centre - goes home for holidays
7-day x 52-week village-type/residential centre
Nursing home
Mental health community residence
Psychiatric hospital
Other intensive placement with special requirements due to challenging behaviour
Other intensive placement with special requirements due to profound or multiple handicap

Holiday residential placement
Crisis or planned respite
Occasional respite care with a host family in a scheme such as Home Sharing or Share-a-Break
Shared care or guardianship (usually 5 or 7 days per week)
Regular part-time care - 2-3 days per week
Regular part-time care - every weekend
Regular part-time care - alternate weeks
Other residential service
Overnight respite in the home

DAY SERVICE GROUPINGS

Health

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

Education

- Mainstream school
- Resource/visiting teacher
- Special class - primary
- Special class - secondary
- Special school

Employment

- Enclave within open employment
- Supported employment
- Open employment

Generic

- Vocational training
- Generic day services



Appendix B

Table B.1. National Intellectual Disability Database, Ireland 2005.

Details of main residential circumstances, degree of intellectual disability and age group.

| Residential circumstances | Not verified | | | | | Mild | | | | | Moderate-Severe-Profound | | | | | All levels | | | | |
|---|--------------|------------|------------|--------------|--------------|-------------|-------------|-------------|--------------|--------------|--------------------------|-------------|-------------|--------------|--------------|-------------|-------------|-------------|--------------|--------------|
| | 0-19 | 20-34 | 35-54 | 55+ All ages | 55+ All ages | 0-19 | 20-34 | 35-54 | 55+ All ages | 55+ All ages | 0-19 | 20-34 | 35-54 | 55+ All ages | 55+ All ages | 0-19 | 20-34 | 35-54 | 55+ All ages | |
| Home setting | 1352 | 158 | 117 | 47 | 1674 | 3539 | 1803 | 1043 | 167 | 6552 | 3289 | 2592 | 1463 | 257 | 7601 | 8180 | 4553 | 2623 | 471 | 15827 |
| At home with both parents | 1118 | 120 | 36 | 2 | 1276 | 2628 | 1303 | 396 | 12 | 4339 | 2627 | 1944 | 514 | 15 | 5100 | 6373 | 3367 | 946 | 29 | 10715 |
| At home with one parent | 208 | 34 | 46 | 6 | 294 | 727 | 413 | 420 | 31 | 1591 | 582 | 565 | 599 | 32 | 1778 | 1517 | 1012 | 1065 | 69 | 3663 |
| At home with sibling | 1 | 2 | 30 | 29 | 62 | 10 | 22 | 159 | 84 | 275 | 3 | 37 | 310 | 171 | 521 | 14 | 61 | 499 | 284 | 858 |
| At home with other relative | 4 | 2 | 4 | 8 | 18 | 51 | 22 | 50 | 34 | 157 | 14 | 16 | 25 | 33 | 88 | 69 | 40 | 79 | 75 | 263 |
| Living with non-relative | 0 | 0 | 0 | 1 | 1 | 1 | 8 | 9 | 3 | 21 | 3 | 2 | 9 | 1 | 15 | 4 | 10 | 18 | 5 | 37 |
| Adoption | 1 | 0 | 0 | 0 | 1 | 8 | 7 | 0 | 0 | 15 | 5 | 2 | 1 | 0 | 8 | 14 | 9 | 1 | 0 | 24 |
| Foster care and boarding-out arrangements | 20 | 0 | 1 | 1 | 22 | 114 | 28 | 9 | 3 | 154 | 55 | 26 | 5 | 5 | 91 | 189 | 54 | 15 | 9 | 267 |
| Independent/Semi-independent setting | 0 | 7 | 35 | 22 | 64 | 2 | 144 | 349 | 105 | 600 | 0 | 20 | 87 | 39 | 146 | 2 | 171 | 471 | 166 | 810 |
| Living independently | 0 | 5 | 29 | 20 | 54 | 1 | 96 | 238 | 73 | 408 | 0 | 11 | 45 | 29 | 85 | 1 | 112 | 312 | 122 | 547 |
| Living semi-independently | 0 | 2 | 6 | 2 | 10 | 1 | 48 | 111 | 32 | 192 | 0 | 9 | 42 | 10 | 61 | 1 | 59 | 159 | 44 | 263 |
| Community group home | 7 | 9 | 15 | 6 | 37 | 44 | 192 | 362 | 204 | 802 | 95 | 660 | 1459 | 449 | 2663 | 146 | 861 | 1836 | 659 | 3502 |
| 5-day community group home | 1 | 2 | 1 | 0 | 4 | 18 | 53 | 53 | 9 | 133 | 21 | 156 | 204 | 6 | 387 | 40 | 211 | 258 | 15 | 524 |
| 7-day (48-week) community group home | 1 | 2 | 1 | 1 | 5 | 4 | 28 | 74 | 23 | 129 | 23 | 134 | 335 | 33 | 525 | 28 | 164 | 410 | 57 | 659 |
| 7-day (52-week) community group home | 5 | 5 | 13 | 5 | 28 | 22 | 111 | 235 | 172 | 540 | 51 | 370 | 920 | 410 | 1751 | 78 | 486 | 1168 | 587 | 2319 |
| Residential centres | 5 | 2 | 29 | 47 | 83 | 10 | 49 | 89 | 110 | 258 | 109 | 638 | 1480 | 766 | 2993 | 124 | 689 | 1598 | 923 | 3334 |
| 5-day residential centre | 0 | 0 | 0 | 0 | 0 | 1 | 7 | 2 | 1 | 11 | 19 | 41 | 39 | 1 | 100 | 20 | 48 | 41 | 2 | 111 |
| 7-day (48-week) residential centre | 1 | 0 | 2 | 0 | 3 | 2 | 16 | 23 | 10 | 51 | 39 | 164 | 226 | 61 | 490 | 42 | 180 | 251 | 71 | 544 |
| 7-day (52-week) residential centre | 4 | 2 | 27 | 47 | 80 | 7 | 26 | 64 | 99 | 196 | 51 | 433 | 1215 | 704 | 2403 | 62 | 461 | 1306 | 850 | 2679 |
| Other full-time services | 8 | 1 | 4 | 22 | 35 | 6 | 47 | 86 | 80 | 219 | 51 | 279 | 410 | 243 | 983 | 65 | 327 | 500 | 345 | 1237 |
| Nursing home | 0 | 0 | 2 | 17 | 19 | 0 | 1 | 10 | 17 | 28 | 0 | 1 | 40 | 38 | 79 | 0 | 2 | 52 | 72 | 126 |
| Mental health community residence | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 4 | 12 | 16 | 0 | 0 | 17 | 22 | 39 | 0 | 0 | 21 | 34 | 55 |
| Psychiatric hospital | 0 | 1 | 2 | 1 | 4 | 1 | 19 | 41 | 46 | 107 | 2 | 18 | 125 | 140 | 285 | 3 | 38 | 168 | 187 | 396 |
| Intensive placement (Challenging behaviour) | 2 | 0 | 0 | 0 | 2 | 2 | 19 | 20 | 1 | 42 | 13 | 141 | 118 | 22 | 294 | 17 | 160 | 138 | 23 | 338 |
| Intensive placement (profound or multiple handicap) | 3 | 0 | 0 | 0 | 3 | 0 | 3 | 2 | 1 | 6 | 24 | 97 | 98 | 16 | 235 | 27 | 100 | 100 | 17 | 244 |
| Full-time resident in 'other' residential service | 3 | 0 | 0 | 3 | 6 | 3 | 4 | 4 | 3 | 14 | 3 | 3 | 4 | 2 | 12 | 9 | 7 | 8 | 8 | 32 |
| Full-time resident in residential support place | 0 | 0 | 0 | 1 | 1 | 0 | 1 | 5 | 0 | 6 | 9 | 19 | 8 | 3 | 39 | 9 | 20 | 13 | 4 | 46 |
| No fixed abode | 0 | 0 | 1 | 0 | 1 | 0 | 1 | 2 | 0 | 3 | 0 | 2 | 2 | 1 | 5 | 0 | 3 | 5 | 1 | 9 |
| Insufficient information | 0 | 0 | 2 | 3 | 5 | 8 | 13 | 1 | 1 | 23 | 12 | 32 | 84 | 42 | 170 | 20 | 45 | 87 | 46 | 198 |
| Total | 1372 | 177 | 203 | 147 | 1899 | 3609 | 2249 | 1932 | 667 | 8457 | 3556 | 4223 | 4985 | 1797 | 14561 | 8537 | 6649 | 7120 | 2611 | 24917 |



Appendix C

Requesting information from the National Intellectual Disability Database

1. Requests for information from the national dataset should be made to the National Intellectual Disability Database Committee using the official Request Form.
2. Any individual requiring information from the National Intellectual Disability Database is required to make a written submission to this Committee outlining the information required, the reason the information is required and the manner in which the information will be used, subject to the following provision:
 - a. A student of a professional discipline, seeking information from the National Intellectual Disability Database will be requested to ask their professional supervisor to make the application on their behalf.
3. On receiving a request for information, the chairperson of the National Intellectual Disability Database Committee will discuss the request with the other members of the committee at the earliest possible opportunity. The committee will satisfy itself:
 - a. that the use of the National Intellectual Disability Database is a valid one in view of the proposed use or research project; and
 - b. that there is no doubt concerning violation of client confidentiality.

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

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

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

Requesting information from Regional Intellectual Disability Databases

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

National Intellectual Disability Database Request for Information Form

| | |
|---|--|
| Name of Applicant | |
| Address | |
| Telephone Number | |
| Email address | |
| Name of agency/academic institution (where applicable) | |
| Date requested | |
| Details of the type of analysis required | |
| Reason for request - please be as specific as possible in describing why the information is required and how the data will be used - general explanations such as, 'research purposes' should not be used (Continue on separate page if necessary) | |
| <p>Declaration of confidentiality: <i>If I am given access to this data, I undertake to ensure the security of all information supplied to me. I undertake to maintain the confidentiality of all information in relation to clients. I will not make any such information available, in any form, to any unauthorised person or in any form that could lead to identification of any person or persons. I have read these guidelines and understand the conditions that are specified.</i></p> | |
| <p>Signature of applicant: _____ Date: _____</p> | |

Office Use Only:

| | |
|---|--|
| Date request received | |
| Received by | HRB <input type="checkbox"/> DoHC <input type="checkbox"/> |
| Date considered by NIDDC | |
| Decision of NIDDC | |
| Any conditions which are to be applied to the request | |
| <p>Signed (on behalf of NIDDC): _____ Date: _____</p> | |



Appendix D

DISABILITY DATABASES DIVISION 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.

Galligan K and Mulvany F (2004) *National Physical and Sensory Disability Database; A Preliminary Analysis – June 2004*. Dublin: Health Research Board.

Requests for additional statistical information

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

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

All queries about accessing data from the National Intellectual Disability Database should be addressed to the Disability Databases Division, Health Research Board, 73 Lower Baggot St, Dublin 2.

