HRB Statistics Series 24

Annual Report of the National Intellectual Disability Database Committee 2013

Main Findings

Caraíosa Kelly and Anne O'Donohoe

Improving people's health through research and information

HRB
Health Research Board

Claire Madden, NIDD Cover Design Winner 2013

Claire Madden is from Ballinasloe, Co. Galway where she lives with her dad Martin. For a long time, Claire has demonstrated an artistic flair and in addition to painting, enjoys batik and jewellery making. She is part of the internationally known Tonnta Street Theatre and Athlone Community Arts Group where she attends a weekly art class with teacher Sandy Hughes. In addition to her artistic talents, Claire is also a strong swimmer, enjoys music, fashion and likes going to bingo where she looks forward to meeting her friends on Sunday nights. St. Hilda's Services Athlone support Claire in achieving her personal goals and wishes in life.

HRB Statistics Series 24

Annual Report of the National Intellectual Disability Database Committee 2013

Main Findings

Caraíosa Kelly and Anne O'Donohoe

HRB
Health Research Board

About the HRB

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

Our information systems

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

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

- Activities of Irish Psychiatric Units and Hospitals (1965–2013)

- National Physical and Sensory Disability Database Committee Annual Reports (2004–2013)

- National Intellectual Disability Database Committee Annual Reports (1996–2012)

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

HRB Statistics series publications to date

Tedstone Doherty D, Walsh D, Moran R and Bannon F (2007) *High Support Community Residences Census 2006.* HRB Statistics Series 1. Dublin: Health Research Board.

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

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

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

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

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

Daly A and Walsh D (2009) *Activities of Irish Psychiatric Units and Hospitals 2008.* HRB Statistics Series 7. Dublin: Health Research Board.

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

Daly A and Walsh D (2010) *Activities of Irish Psychiatric Units and Hospitals 2009.* HRB Statistics Series 9. Dublin: Health Research Board.

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

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

Daly A and Walsh D (2011) *Irish Psychiatric Units and Hospitals Census 2010.* HRB Statistics Series 12. Dublin: Health Research Board.

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

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

Daly A and Walsh D (2011) *Activities of Irish Psychiatric Units and Hospitals 2010. Main Findings.* HRB Statistics Series 15. Dublin: Health Research Board.

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

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

Daly A and Walsh D (2012) *Activities of Irish Psychiatric Units and Hospitals 2011. Main Findings.*HRB Statistics Series 18. Dublin: Health Research Board.

Kelly F, Kelly C and O'Donohoe A (2013) *Annual Report of the National Intellectual Disability Database Committee 2012.* HRB Statistics Series 19. Dublin: Health Research Board.

Daly A and Walsh D (2013) *Activities of Irish Psychiatric Units and Hospitals 2012. Main Findings.* HRB Statistics Series 20. Dublin: Health Research Board.

Carew AM and Doyle A (2013) *Annual Report of the National Physical and Sensory Disability Database Committee 2012.* HRB Statistics Series 21. Dublin: Health Research Board.

Daly A, Walsh D and Moran R (2014) *Irish Psychiatric Units and Hospitals Census 2013.* HRB Statistics Series 22. Dublin: Health Research Board.

Carew AM and Doyle A (2014) *Annual Report of the National Physical and Sensory Disability Database Committee 2013.* HRB Statistics Series 23. Dublin: Health Research Board.

Other National Intellectual Disability Database publications

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

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

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

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

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

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

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

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

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

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

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

Contents

List of figures in Main Findings

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:

- Disability Unit, Department of Health;

- the Health Service Executive, in particular the database co-ordinators and the database administrators/managers;

- the National Federation of Voluntary Bodies providing services to people with intellectual disability;

- the parents and families of people with an intellectual disability and their representative bodies; and

- all service users throughout Ireland.

Members of the National Intellectual Disability Database Committee 2013

Ms Gráinne Duffy
Disability Unit, Department of Health

Mr Harry Harris
Disability Unit, Department of Health

Mr James Rocke
Western Care Association
Representing the National Federation of Voluntary Bodies providing services to people with intellectual disability

Ms Patricia Doherty
St Michael's House
Representing the National Federation of Voluntary Bodies providing services to people with intellectual disability

Ms Marion Meany
Health Service Executive

Ms Sarah Craig
Health Research Board

Ms Mary O'Gorman
Health Research Board

Ms Anne O'Donohoe
Health Research Board

Ms Caraíosa Kelly
Health Research Board

Chairperson's statement

It gives me great pleasure to introduce the 2013 National Intellectual Disability Main Findings Report. The report provides:

- a profile of people with intellectual disability in 2013

- details of the specialised health and personal social services provided, and

- an outline of the future need for those services

The Government has embarked on the reform of public services including a major reform of the health system. A component part of this reform is the reform of specialist health and personal social services for people with a disability. The implementation of the Value for Money (VFM) and Policy Review of Disability Services in Ireland will see a significant restructuring of the Disability Services Programme. This mirrors the message coming through from Future Health: A Strategic Framework for Reform of the Health Service 2012–2015, regarding the need to restructure service delivery, and improve organisational, financial, governance and accountability systems with the aim of providing a more effective and more accountable service. The implementation of the VFM Review will represent a seismic shift in how disability services are funded and provided and will result in shifting choice and control from professionals and administrators to the individual with a disability, and his or her family.

The VFM Review implementation plan includes the introduction of a standardised framework to commission services; individualised budgeting to bring about a closer alignment between funding and the outcomes achieved by individuals as a result of that funding; and a robust regulatory regime to ensure quality and safety.

Information will be a key resource for the reformed services. The establishment of an information structure to support the management and delivery of future disability services is one of the core strategic aims of the Implementation Framework of the VFM Review. Work has begun and will continue in the coming years to develop and implement an information structure to support the effective delivery of the services and will have regard to existing information sources and datasets such as the national databases.

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

Grainne Duffy
Chair
National Intellectual Disability Database Committee

Introduction

This report is a summary of the main findings of the sixteenth Annual Report of the National Intellectual Disability Database Committee. The report is based on validated data extracted from the National Intellectual Disability Database (NIDD) in December 2013. The 2013 dataset consists of information relating to 27,691 individuals. Of these registrations, 99.1% (27,430 records) were updated following the completion of the 2013 review of NIDD information; the remaining 261 registrations contain the last-known data in each case. Prevalence rates per thousand of population are based on up-to-date data from the 2011 Census of Population (Central Statistics Office, 2012*). Comparative data for 1996 and 2012 used in this report are from published NIDD data for these years.

In addition to this report, a complete set of tables and figures mirroring data in reports from previous years is available in user-friendly MS Excel versions on the HRB website. Summary bulletins are also available for each of the four HSE regions and 32 Local Health Offices (LHOs) at www.hrb.ie.

*Central Statistics Office (2012) Census of the population, 2011: principal demographic results. Dublin: Stationary Office.

Main Findings

There were 27,691 people registered on the National Intellectual Disability Database (NIDD) at the end of December 2013. Based on 2011 census figures, this represents a prevalence rate of 6.04 per 1,000 population. The prevalence rate for mild intellectual disability (which traditionally has been under-reported) was 2.00 per 1,000, and the rate for moderate, severe or profound intellectual disability was 3.54 per 1,000. Figure 1 presents the number of registrations by county of residence and shows that Sligo (10.6/1,000) had the highest prevalence rate while Clare (4.6/1,000) had the lowest.

In December 2013 Sligo had the highest number of people registered on the NIDD per county population and Clare had the lowest.

Donegal 6.4
Sligo 10.6
Mayo 8.1
Leitrim 4.7
Cavan 5.4
Monaghan 6.0
Louth 7.8
Roscommon 6.8
Longford 6.1
Meath 4.8
Westmeath 7.6
Galway 6.4
Dublin 4.9
Offaly 4.9
Kildare 6.9
Laois 5.7
Wicklow 5.0
Clare 4.6
Carlow 7.9
Tipperary 6.4
Kilkenny 7.4
Limerick 7.6
Wexford 6.4
Kerry 6.6
Waterford 7.0
Cork 6.0

3.0–5.0 NIDD registrations per 1,000 population
5.1–6.0 NIDD registrations per 1,000 population
6.1–7.0 NIDD registrations per 1,000 population
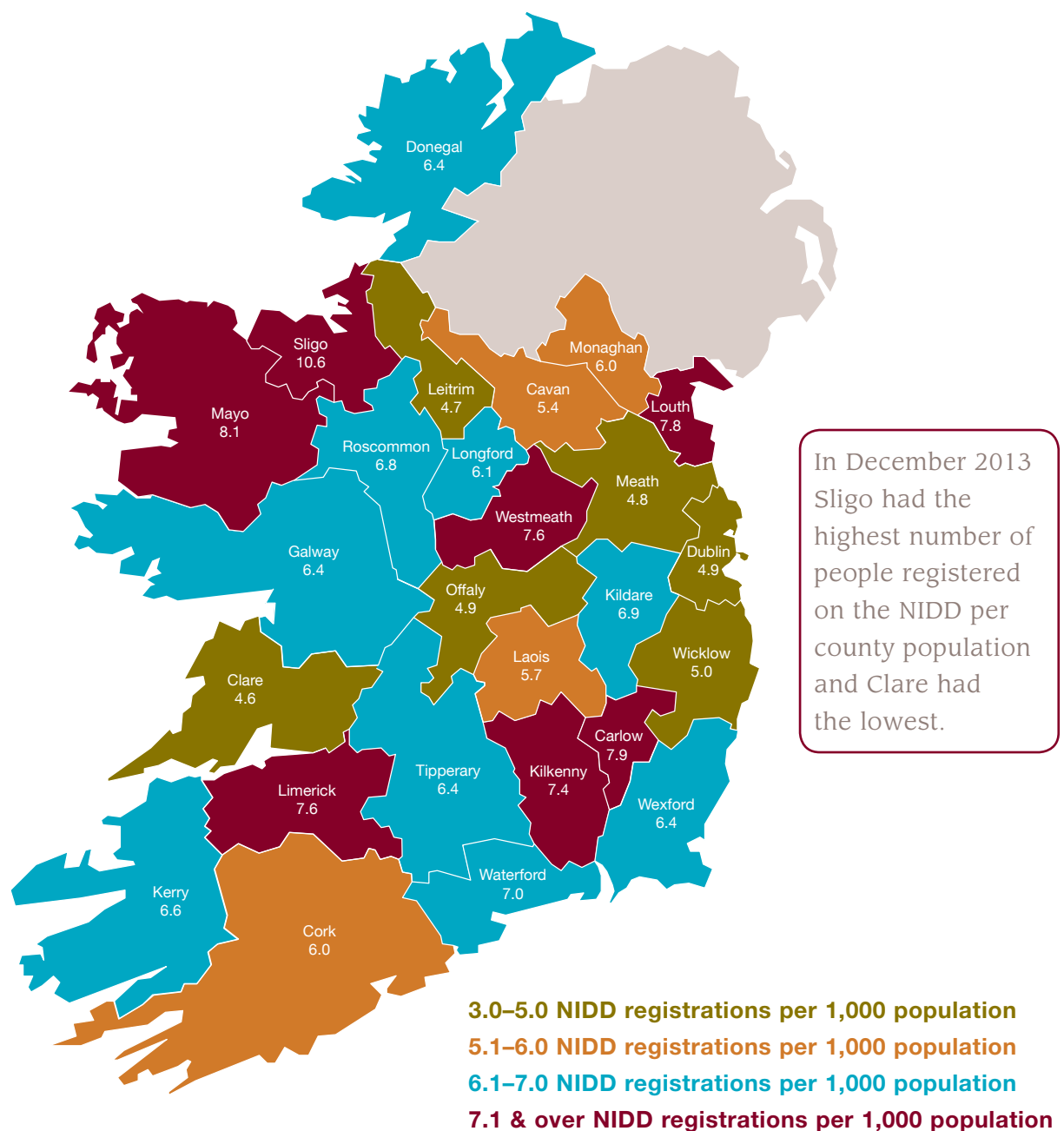7.1 & over NIDD registrations per 1,000 population

Figure 1. NIDD registrations per 1,000 of the general population, by county of residence, 2013

There were more males than females registered with an intellectual disability in all age groups except the 55-years-and-over age group, with an overall ratio of 1.38 to 1 (Figure 2).
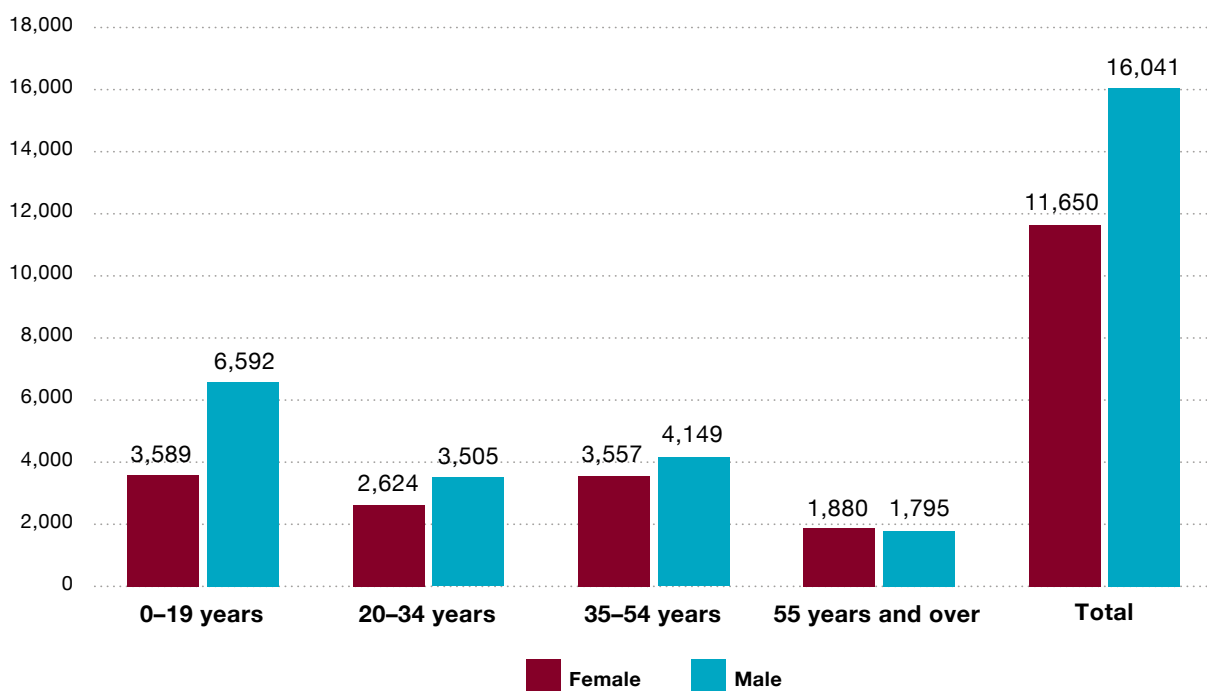

Figure 2. Number of people registered on the NIDD, by age group and gender, 2013

The total number of individuals recorded as having a moderate, severe or profound intellectual disability has increased by 44% since the first Census of Mental Handicap* in the Republic of Ireland was carried out in 1974. One of the factors contributing to this increase in numbers is the growth in the general population over the period, resulting from increased births, a reduction in the number of deaths and an increase in net migration. Of the people with moderate, severe or profound intellectual disability, the proportion aged 35 years or over increased from 29% in 1974 to 38% in 1996 when NIDD data were first reported, and to 49% in 2013 (Figure 3). These figures reflect a steady increase in the lifespan of people with intellectual disability. This changing age profile, observed in the data over the past four decades, has implications for service planning; as there is a continuing high level of demand for services designed to meet the needs of older people with intellectual disability, in addition to support services for ageing care givers.

*Mulcahy M (1976) Census of the mentally handicapped in the Republic of Ireland 1974: non-residential. Dublin: Medico-Social Research Board.
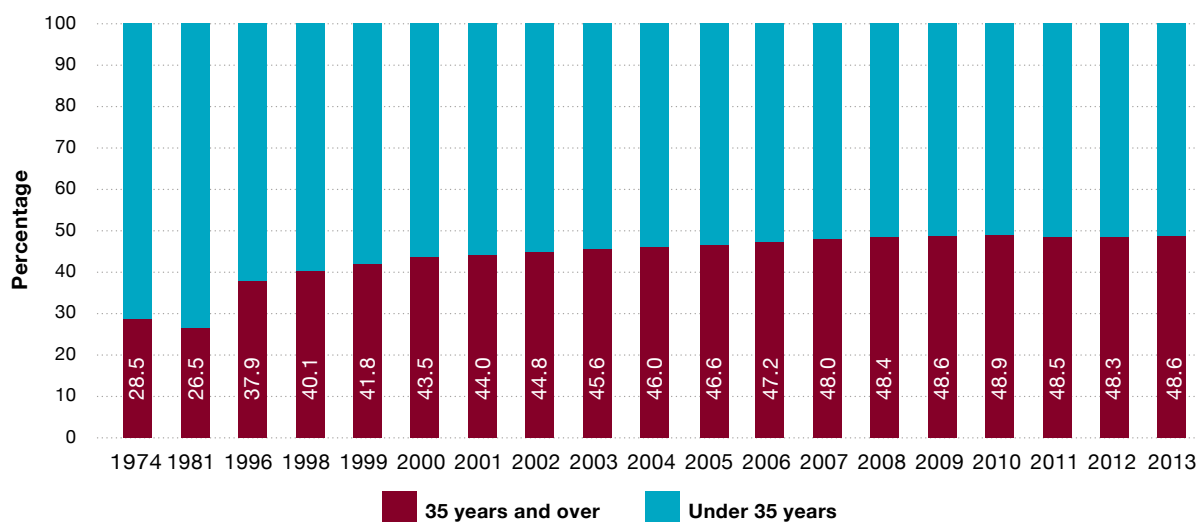
Figure 3. Proportion of people with moderate, severe, or profound intellectual disability (combined), by age group, 1974–2013

Service provision in 2013

The numbers registered on the NIDD in December 2013 were as follows:

- 27,318 people with intellectual disability who were in receipt of services, representing 98.7% of the total population registered on the NIDD. This was the highest number of people in receipt of services since the database was established in 1995.

- 234 people (0.8% of those registered) who were without services in 2013 and who were identified as requiring appropriate services in the period 2014–2018.

- 139 people (0.5%) who were not availing of services and had no identified requirement for services during the planning period 2014–2018.

Of the 27,318 people who were in receipt of services in 2013:

- 7,972 (29.2%) were in receipt of full-time residential services, a decrease of 1.6% on the 2012 figure. This is the tenth consecutive year in which the data indicate that more people live in community group homes than in residential centres (Figure 4). The majority (82%) of full-time residents had a moderate, severe or profound level of intellectual disability, were aged 35 years or over (83%), and lived in a community group home (54%) or residential centre (31%). It is recognised that this group may require greater residential supports and have increased medical needs as they age.

- 27,272 (99.8%) people availed of at least one day programme in 2013. This is the highest number registered as receiving such services since NIDD data were first reported in 1996. Of this group, 7,943 were in full-time residential care.

- 23,431 (84.6%) people availed of one or more multidisciplinary support service. The services most commonly availed of by adults were social work, medical services and psychiatry. The services most commonly availed of by children were speech and language therapy, occupational therapy and psychology (Figure 10).

- Sixty-seven per cent of those registered on the NIDD (18,498 individuals) lived at home with parents, siblings, relatives or foster parents in 2013. Almost a quarter of over-35s who had a moderate, severe or profound intellectual disability lived at home in 2013. Because people with intellectual disability are living longer, the likelihood of them outliving their caregivers has increased substantially in recent years, which has implications for planning of support services.

Over 80% of full-time residents were aged 35 years or older & had a moderate, severe or profound intellectual disability.
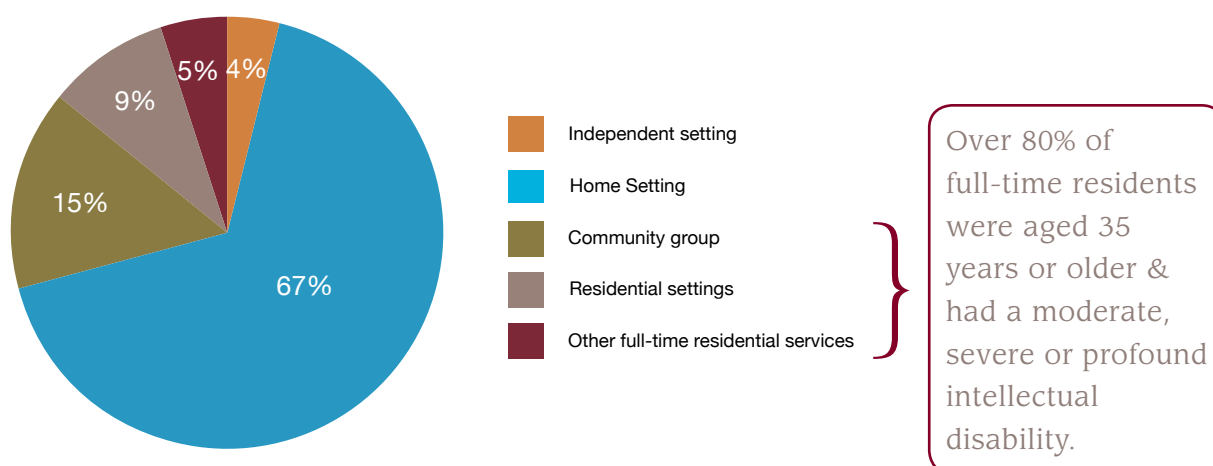
Figure 4. Main residential circumstance, NIDD 2013

- The number of people with intellectual disability accommodated in psychiatric hospitals decreased by 17 (8.9%), from 192 in 2012 to 175 in 2013 (Figure 6).

Future service requirements 2014–2018

Unmet Need

The 2013 data indicate that 4,488 new residential, day and residential support places will be needed to meet the service requirements of those who do not currently avail of these services. The following services will be needed in the period 2014–2018 (most service needs were recorded as being immediate):

- 2,215 new full-time residential placements (Figure 5), a decrease of 56, or 2.5%, on the projected number required in 2012. Almost three quarters (71%) of this group had a moderate, severe or profound level of intellectual disability and 54% were aged 35 years and over. The majority (85%) required placements in community group homes.

- 2,043 residential support services, a decrease of 11 on the projected number required in 2012. The majority of this group (90%) lived at home or independently in the community. A high level of need for these services still exists, even though there were almost 5,400 people availing of residential support services in 2013 (Figure 5).
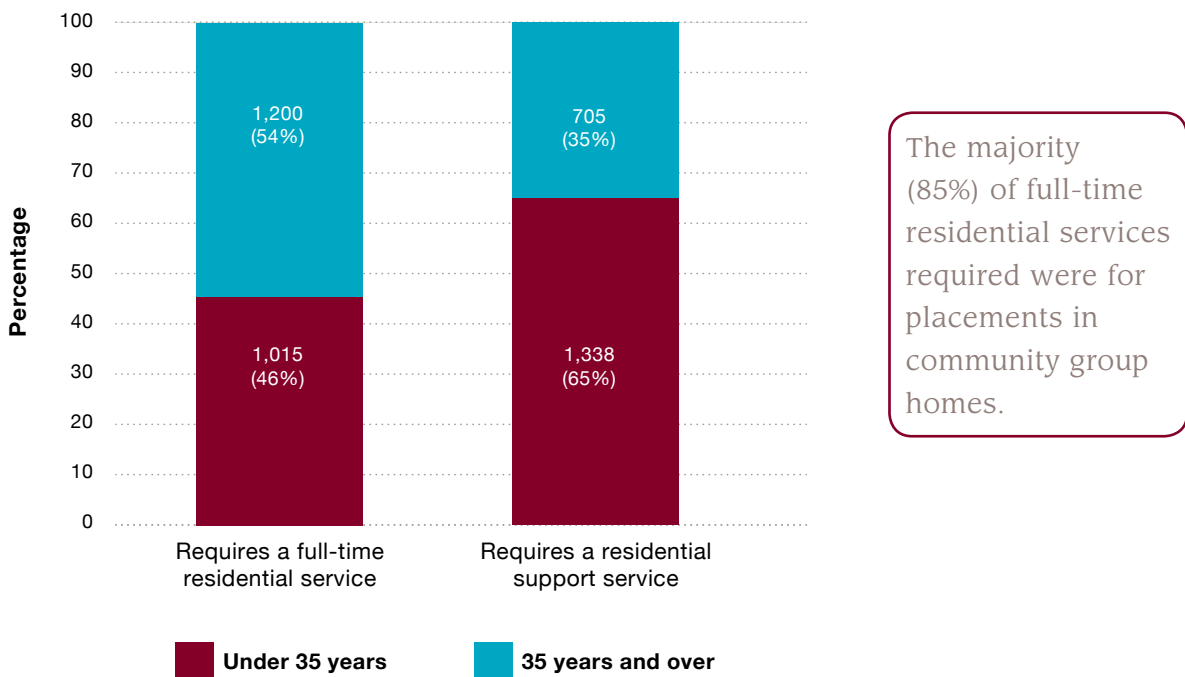

The majority (85%) of full-time residential services required were for placements in community group homes.

Figure 5. Unmet need – number of people requiring residential service or residential support service by age group, NIDD 2014–2018

- 190 day programmes (this figure excludes multidisciplinary support services (Figure 10) and services provided by early intervention teams). This number is in addition to the services required by 850 young adults who, as they approach the age of 18, are preparing to leave the education system to take up a range of training and supported/sheltered employment opportunities, which traditionally have been funded by the health sector.

- 66 individuals who were living in psychiatric hospitals in 2013 have been identified as needing to transfer from these locations to more appropriate accommodation (Figure 6).
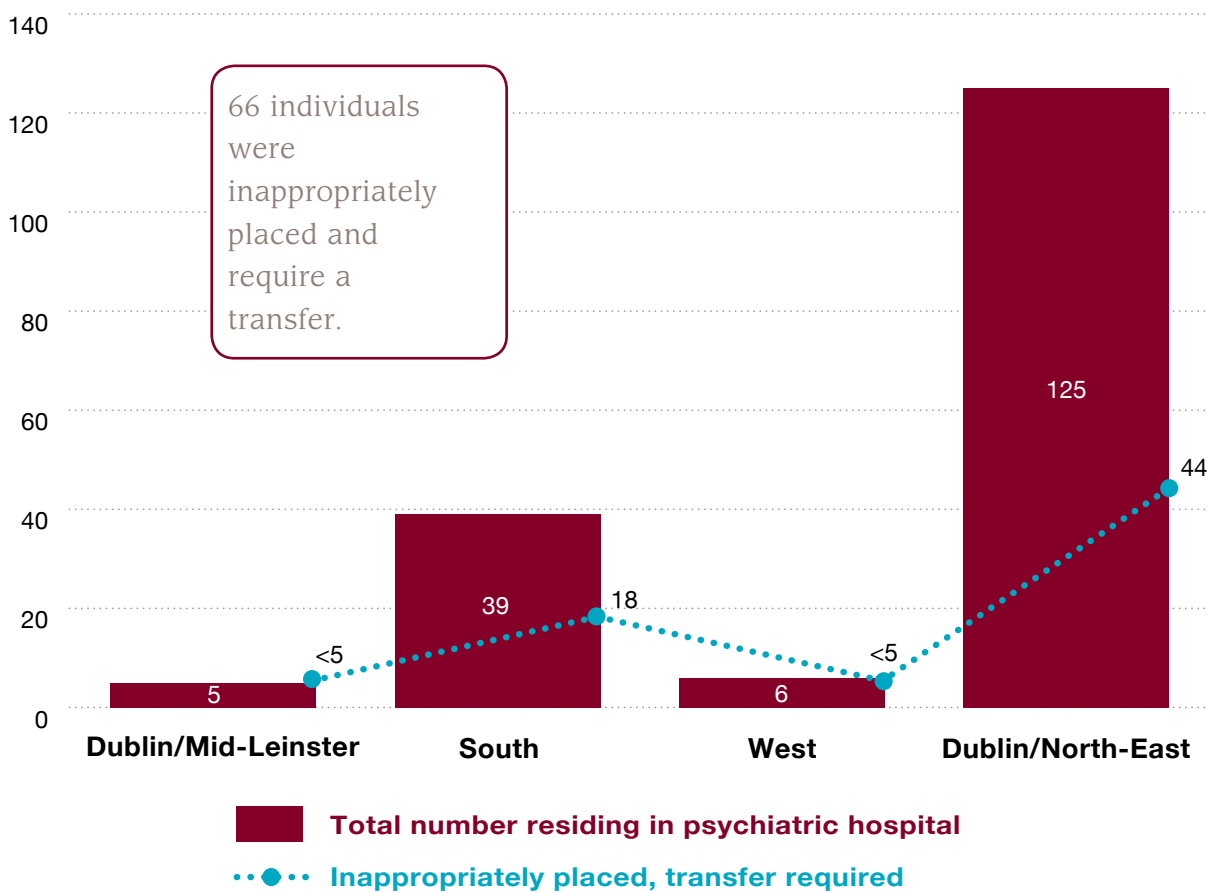

Figure 6. Number of individuals registered on the NIDD who were resident in psychiatric hospitals and require a residential transfer in 2013, by HSE region

Service Change

Of those in receipt of services in 2013, 11,519 people required alternative, additional, or enhanced services in the period 2014–2018, a decrease of 365, or 3.2%, since 2012. This group included people who required an increased level of service provision, additional support within their existing services, transfer to more appropriate placements, or a service change to coincide with a transition period in their lives, such as a move from child to adult services, or from education to training and/or employment placements. To address the required service changes over the next five years:

• 9,968 day places will require changes or enhancements (Figure 7). The majority are for health-funded services which are required by 6,653 individuals (66.7%). Education services are required by 1,367 individuals (13.7%), employment services are required by 1,313 individuals (13.2%), and generic services are required by 635 individuals (6.4%).
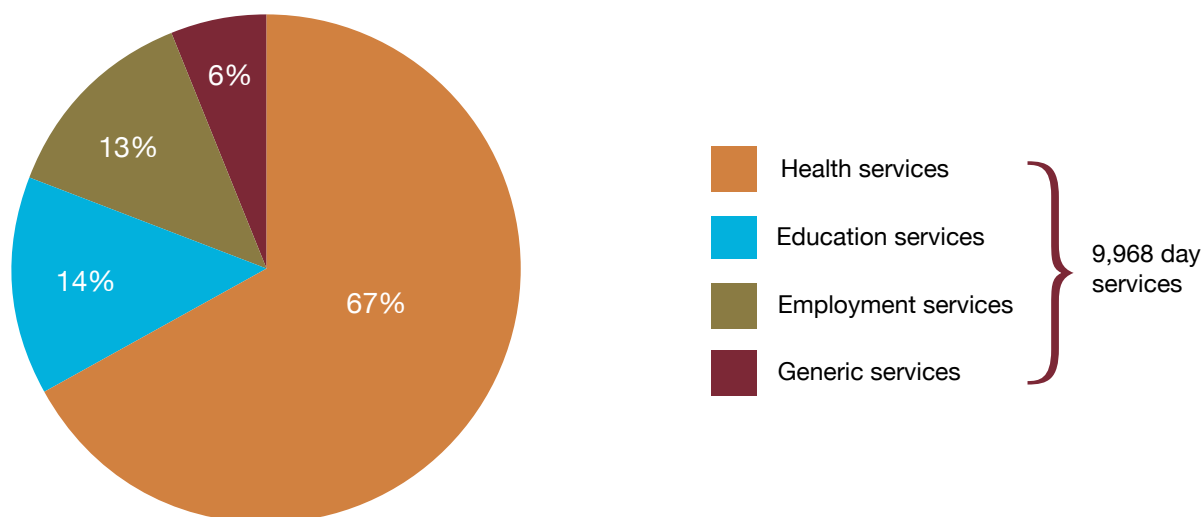

Figure 7. Number and type of day services requiring change or enhancement, NIDD 2014–2018

• Of the 850 children (aged 16–19 years) who were in an education setting in 2013, one third (280 individuals) require rehabilitative training, 247 (29.1%) require vocational training and 134 (15.8%) require activation programmes in the next 5 years 2014–2018 (Figure 8).
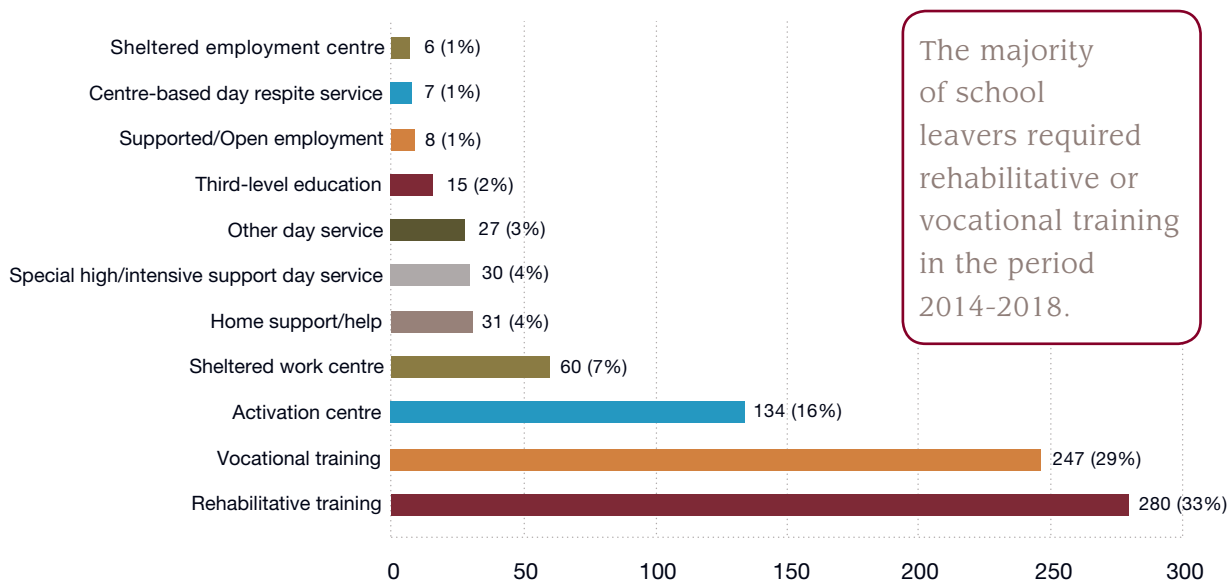
Figure 8. Future day service requirements of individuals aged 16–19 years and in an education setting, NIDD 2014–2018

The majority of school leavers required rehabilitative or vocational training in the period 2014-2018.

- 2,548 individuals in residential places require changes or enhancements to their service: The majority (89%) of this group had a moderate, severe or profound intellectual disability and were aged 35 years or older (83%) (Figure 9). Almost two thirds (60%) require a move to an alternative residential service, of which (62%) require a move to a community group home and 31% to an intensive placement, for either challenging behaviour or multiple disabilities.

- 1,674 residential support places will require changes or enhancements (Figure 9). Most of this need is for more frequent centre-based crisis or planned respite breaks for people already availing of this service (1,191 Individuals).
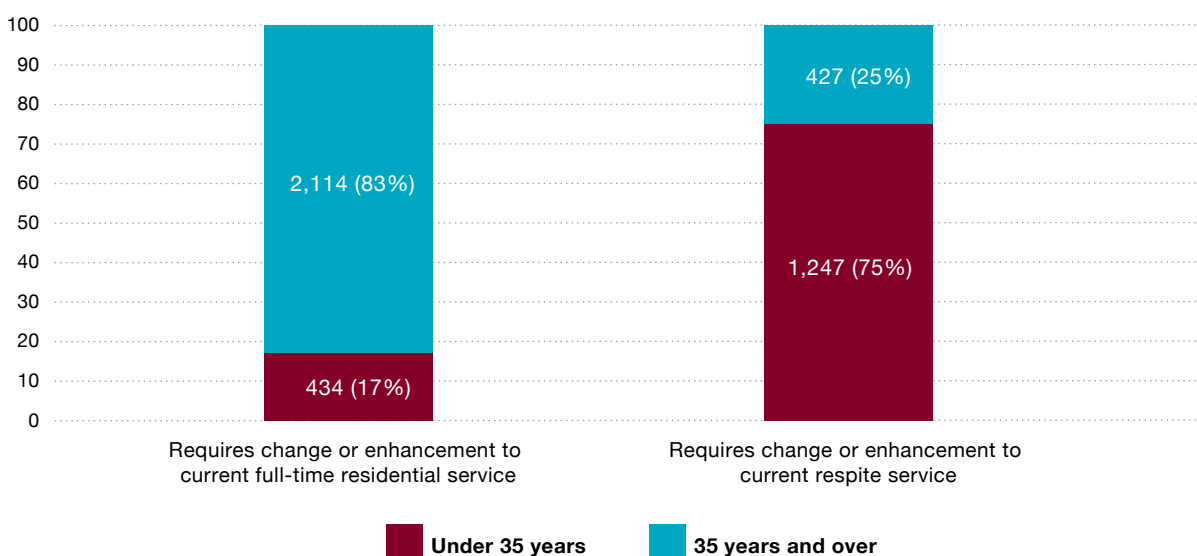
Figure 9. Service change – number of people requiring a change to, or enhancement of, their current service by age group, NIDD 2014–2018

Despite high levels of service provision in 2013, there remained a significant demand for new and enhanced multidisciplinary support services. Seventy percent (19,383 individuals) of the population registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2014–2018. There was substantial demand for all the therapeutic inputs, in particular, psychology, occupational and speech and language therapies (Figure 10).

Psychology services, speech and language and occupational therapies remain in high demand.
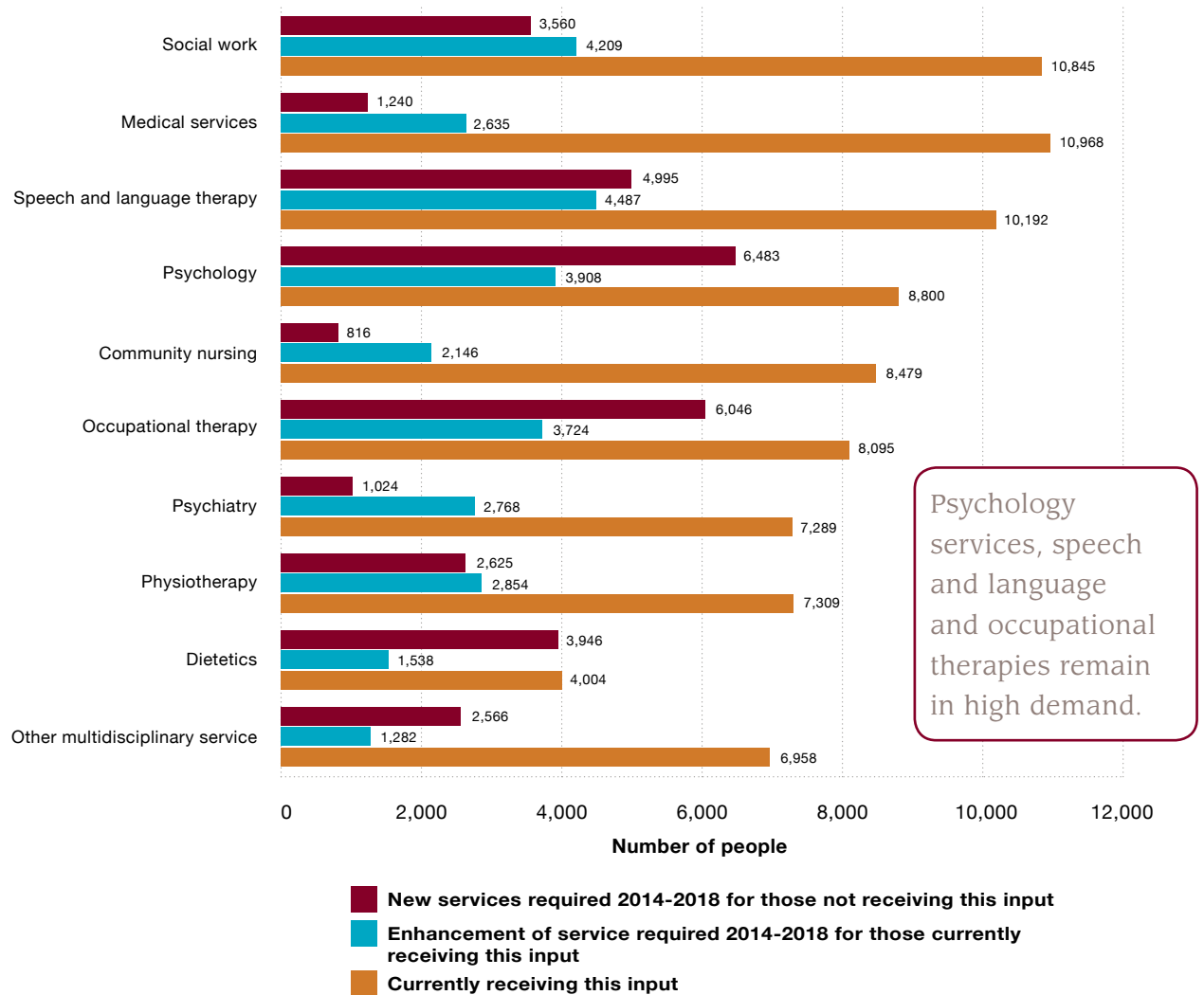
Figure 10. Multidisciplinary support services recieved in 2013, and required in the period 2014–2018, NIDD 2013

Key trends 1996–2013

Since the establishment of the database in 1996, there here has been significant growth in the level of provision of full-time residential services, residential support services, and day services. Key developments during the 17–year period 1996 to 2013 (Figure 11) include:

- An increase of 78% (from 2,393 in 1996 to 4,270 in 2013) in the number of people with intellectual disability living full-time in community group homes, whilst the numbers accommodated in residential centres decreased by 36% in the same period.

- An 82% reduction (from 970 in 1996 to 175 in 2013) in the number of people with intellectual disability accommodated in psychiatric hospitals.

There is a continuing shift away from the more traditional institutional models of care towards community living.
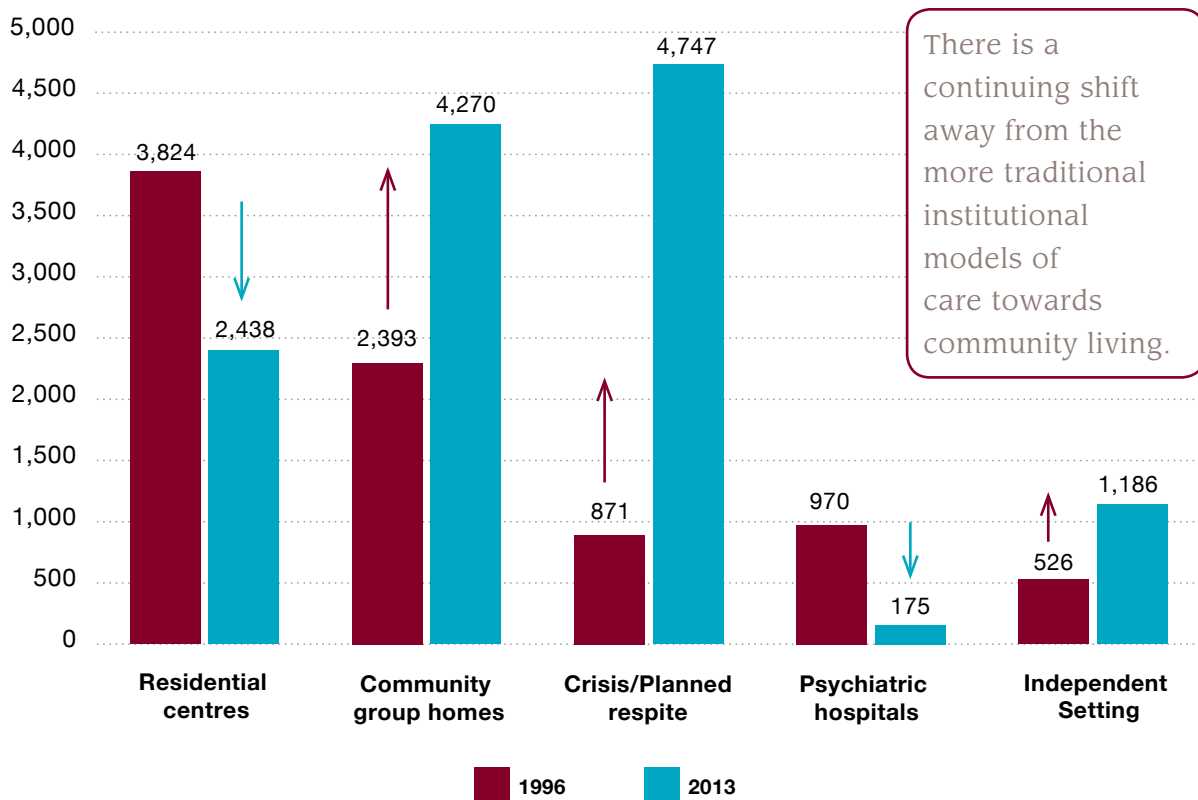
Figure 11. Key trends in residential circumstance, NIDD 1996–2013

- In the period 1996–2013, a substantial expansion in the availability of residential support services, which allow people to continue to live at home with their families in their local communities. In 2013, the data showed marked differences between HSE regions in the total number of people receiving respite and in the median number of nights received. For example, less people received more nights in the HSE West region while more people received substantially less nights in the HSE South region (Figure 12).

Level of respite support provided can vary depending on where you live.

Legend:
- Number living in a home setting
- Median number of respite nights recieved
- Number of people in receipt of respite nights

Figure 12. Regional variation in use of respite nights, by HSE region of residence, NIDD 2013

• Increased provision in almost all types 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 (Figures 13 & 14). Marked increases were observed in the number of supported employment, rehabilitative training and special high support day placements provided to adults with an intellectual disability over the 17-year period (Figure 13).

Greater numbers of employment and training placements are now provided to adults with an intellectual disability.

Service	1996	2013
Generic/other day services	754	1,311
Vocational training	1,906	354
Outreach programme*		321
Day respite services *		457
Activation centre	4,227	7,657
Rehabilitative training*		1,614
Third level education*		52
Programme for the older person	277	716
Home support/help	560	1,053
Open employment	130	308
Supported employment	328	1,654
Enclave within open employment	86	10
Sheltered work/employment centre	4,493	3,022
Special high/intensive support placements	429	1,166

■ 1996   ■ 2013

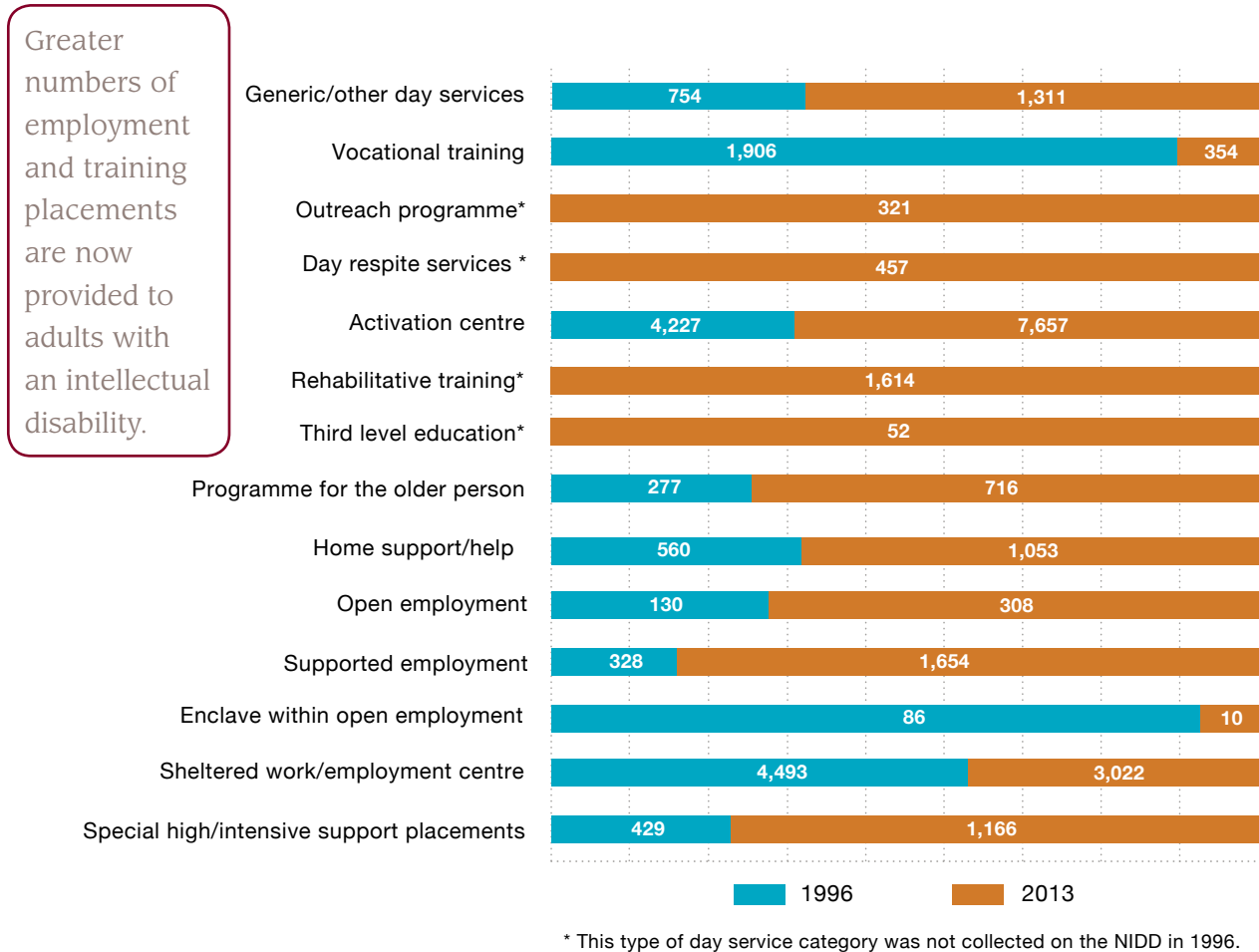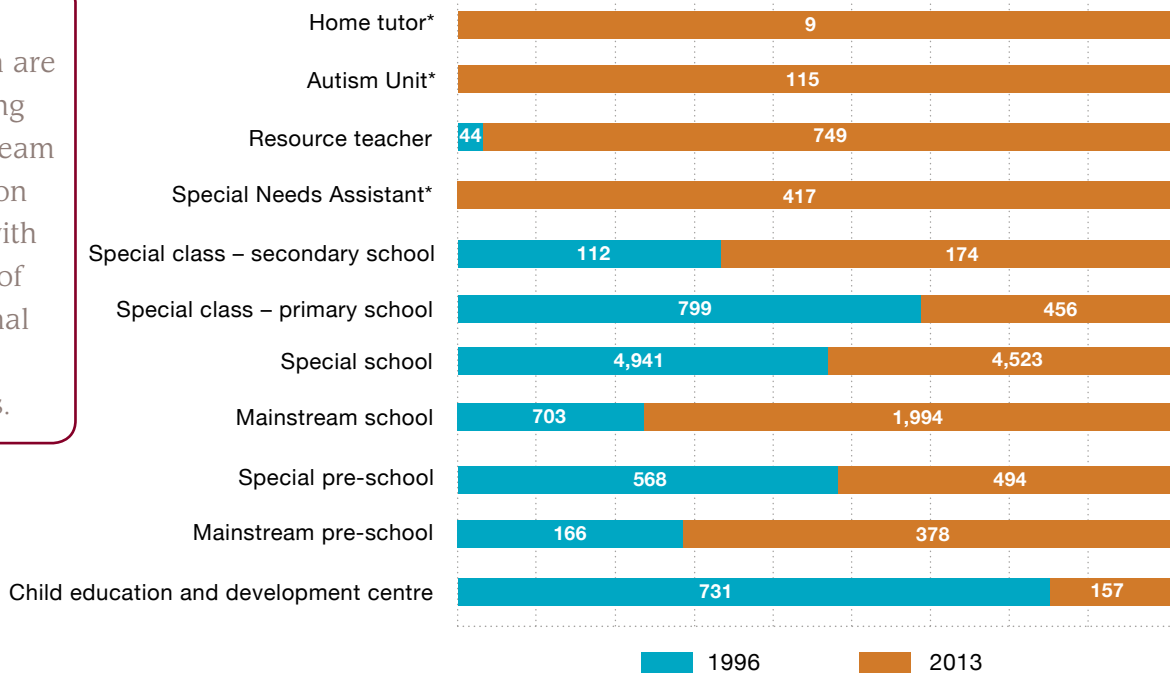* This type of day service category was not collected on the NIDD in 1996.

Figure 13. Trends in day services for adults with intellectual disability, NIDD 1996–2013

* This type of day service category was not collected on the NIDD in 1996.

- Notable trends observed in children's day services from 1996 to 2013 were the increasing number of individuals who availed of mainstream schooling, resource teachers and special needs assistant (Figure 14).

> More children are accessing mainstream education today with the aid of additional support services.

Category	1996	2013
Home tutor*		9
Autism Unit*		115
Resource teacher	44	749
Special Needs Assistant*		417
Special class – secondary school	112	174
Special class – primary school	799	456
Special school	4,941	4,523
Mainstream school	703	1,994
Special pre-school	568	494
Mainstream pre-school	166	378
Child education and development centre	731	157

* This type of day service category was not collected on the NIDD in 1996.

Figure 14. Trends in education services for children with intellectual disability, NIDD 1996–2013

* This type of day service category was not collected on the NIDD in 1996.

Summary

As a national health information system collecting data about service provision and requirements in the intellectual disability area, the NIDD continues to assist health service managers and policy makers in planning these services. This main findings report, based on information collected from over 27,500 individuals registered on the database at the end of December 2013, represents the cumulative service use and needs of this group of people. Notable points from this report include:

- A continuing shift away from the more traditional institutional models of care towards community-based living arrangements for those requiring residential services.

- The proportion of those registered who are in receipt of day services continues to increase every year. Many of those in receipt of day services are also benefiting from additional supports, such as home support, home help and respite services.

- For young people in transition from the education system to HSE-funded day services, the demand for services, particularly in the areas of training and employment, remains high.

- Despite the high level of multidisciplinary support services provided in 2013, there remains a substantial demand in the five-year period 2014–2018 for new services and enhanced services relating to all the therapeutic inputs, especially psychology, speech and language therapy and occupational therapy.

- The data on respite services show high levels of provision in 2013, albeit with varying degrees of provision across the country.

- The majority of adults with intellectual disability continue to live with their families with the aid of additional support services. As their caregivers age beyond their care-giving capacity, a wide range of additional services are required for people who wish to continue to live at home as independently as possible.

- The improvement in life expectancy among adults with a more severe intellectual disability has placed an increased demand on the full-time residential services as fewer places are becoming free over time. Older service users availing of day and residential services also require a higher degree of support within these services, including increased medical services to cater for their specific needs.

- Even with increasing levels of service provision there remain high levels of unmet need among a critical number of individuals who are registered on the NIDD. Although the data in recent years highlight a growth in the provision of many services, demographic factors are contributing to an increasing need for services.

- Finally, the report demonstrates the value of the NIDD as a resource which enables the identification of key areas of priority. It also facilitates the examination of trends over time, showing changes in the demographics of those registered, their requirements, and the types of service provided.

Improving people's health through research and information

HRB

Health Research Board