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## **HRB Statistics Series 30**

# Annual Report of the National Intellectual Disability Database Committee 2015 Main Findings

Anne Doyle and Anne Marie Carew

**Research. Evidence. Action.**

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**'Wild Flowers' by David McKenna  
NIDD Cover Design Winner 2015**

David McKenna, originally from Drumcondra, attends Mill Lane Training Centre at Stewarts Care, Palmerstown, Dublin.

David is delighted that his artistic talent has, once again, been recognised!

His creative abilities are very impressive, from ceramic work to painting and more.

In his free time David enjoys relaxing with a pint of Guinness, playing frisbee and most importantly, dinners out with his mam.



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Anne Doyle and Anne Marie Carew

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# About the HRB

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

## Our information systems

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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*
- » *National Physical and Sensory Disability Database Committee Annual Reports*
- » *National Intellectual Disability Database Committee Annual Reports.*

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 reports 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.*

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

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*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.*

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*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.*

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*Daly A, and Craig S (2016) Activities of Irish Psychiatric Units and Hospitals 2015. Main Findings. HRB Statistics Series 29. Dublin: Health Research Board.*

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*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.*

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

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- » 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 2015

<p><b>Ms Gráinne Duffy (Chairperson)</b> Disability Unit Department of Health</p>	<p><b>Ms Mary O’Gorman</b> Health Research Board</p>
<p><b>Ms Margaret Dorney (Secretary)</b> Disability Unit Department of Health</p>	<p><b>Ms Caraíosa Kelly</b> Health Research Board</p>
<p><b>Mr Harry Harris</b> Disability Unit Department of Health</p>	<p><b>Dr Máirín Boland</b> Department of Public Health Health Service Executive</p>
<p><b>Ms Jacqueline Grogan</b> Disability Federation of Ireland</p>	<p><b>Mr Gerard Tully</b> National Disability Unit Health Service Executive</p>
<p><b>Ms Fionnuala O’Donovan</b> Chief Executive Enable Ireland</p>	<p><b>Mr Dharragh Hunt</b> National Disability Authority</p>
<p><b>Dr Sarah Craig</b> Health Research Board</p>	<p><b>Mr Declan Ryan</b> St Michael’s House <i>Representing the National Federation of Voluntary Bodies</i></p>
<p><b>Ms Anne Doyle</b> Health Research Board</p>	<p><b>Mr James Rocke</b> Western Care Association <i>Representing the National Federation of Voluntary Bodies</i></p>
<p><b>Ms Anne O’Donohoe</b> Health Research Board</p>	

# Chairperson's statement

It gives me great pleasure to introduce the 2015 Annual Report of the National Intellectual Disability Database.

The 2015 report provides:

- » a profile of people with an intellectual disability registered on the database in 2015;
- » details of the specialised health and personal social services provided; and
- » an outline of the future need for those services.

The last ten years have seen a changing mind-set around the way the State has focussed its efforts in helping to improve the lives of people with disabilities. Increasingly, our focus in providing public supports and services for people with a disability is ensuring the right to personal choice. Timely and accurate data is becoming more and more important as a tool towards our efforts to ensure that citizens with a disability can live as independently as possible, with access to appropriate social, housing and employment supports from the State.

The Programme for Partnership Government commits to establishing a taskforce this year on the implementation of personalised budgets for persons with disabilities, including actively monitoring practice, usage and trends, and especially the linkage between personalised budgets, employability and employment rates as well as community living. I am confident that the many years of hard work in establishing and maintaining this database will be of great benefit as we work towards this goal. The Department of Health will work with its many partners in the health and wider disability sector so that the choices of people with disabilities are honoured.

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.

**Gráinne Duffy**  
Chairperson  
National Intellectual Disability Database Committee

## 1

# Introduction

This report presents the main findings of the analysis of data from the National Intellectual Disability Database (NIDD). The report is based on validated data extracted from the NIDD in December 2015. The 2015 dataset consists of information relating to 28,108 individuals. Of these registrations, 90.6% (25,476 records) were updated following the 2015 annual review of NIDD information; the remaining 2,632 registrations contain the last-known data in each case<sup>1</sup>. Prevalence rates per thousand of population are based on data from the 2011 Census of Population<sup>2</sup>. Comparative data for 1996 and 2014 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 2014 and previous years, is available in user-friendly MS Excel versions on the HRB website at [www.hrb.ie](http://www.hrb.ie).

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1 The majority of the cases not reviewed were due to resource issues in two HSE areas.

2 Central Statistics Office (2012) Census of Population, 2011: Principal demographic results. Dublin: Stationery Office.

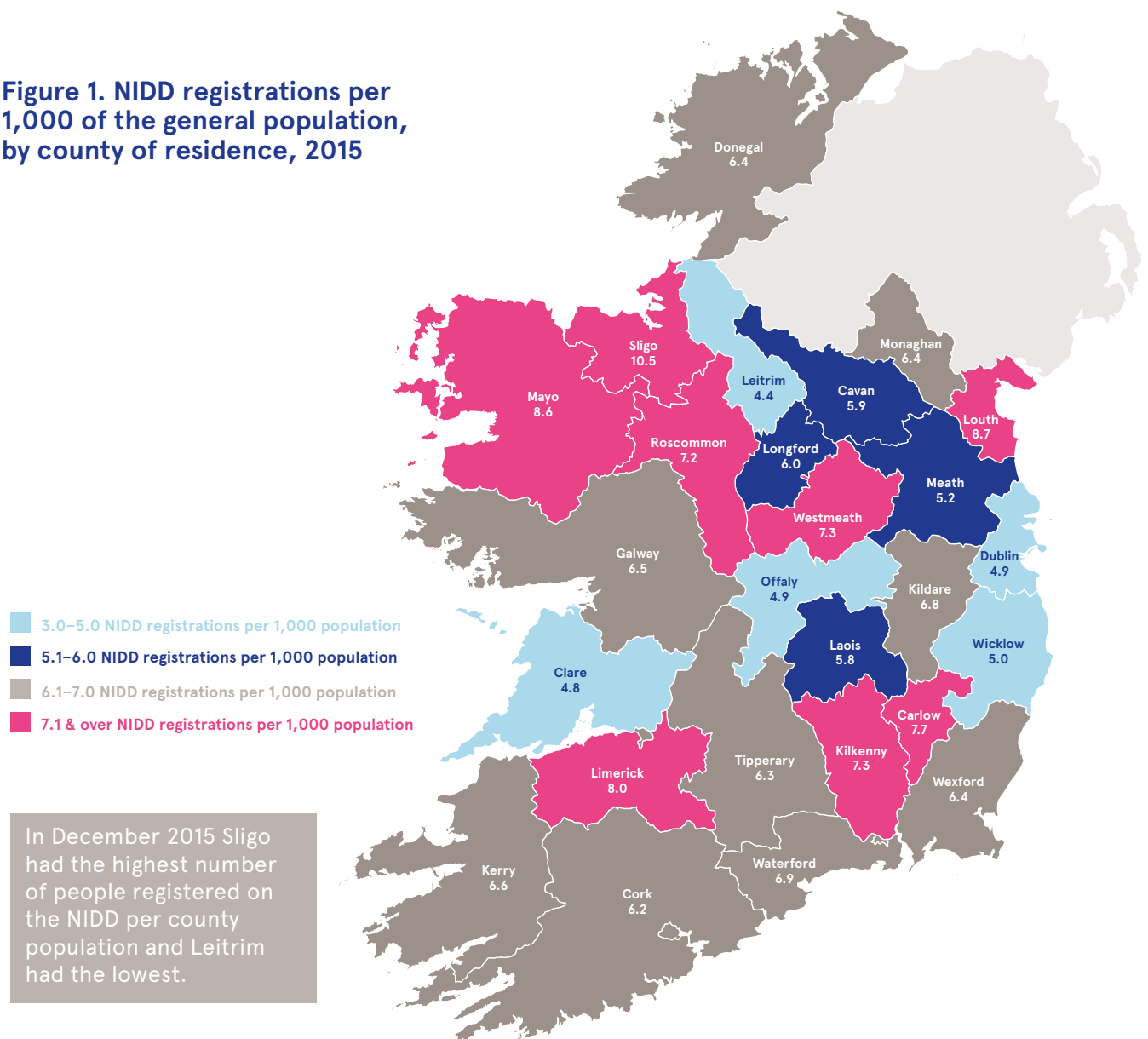
# 2

## Profile of the registered population

There were 28,108 people registered on the National Intellectual Disability Database (NIDD) at the end of December 2015. Based on 2011 Census of Population figures, this represents a prevalence rate of 6.13 per 1,000 population. The prevalence rate for mild intellectual disability (which traditionally has been under-reported) was 1.99

per 1,000, and the rate for moderate, severe or profound intellectual disability was 3.59 per 1,000. Figure 1 presents the number of registrations by county of residence and shows that Sligo (10.5/1,000) had the highest prevalence rate while Leitrim (4.4/1,000) had the lowest.

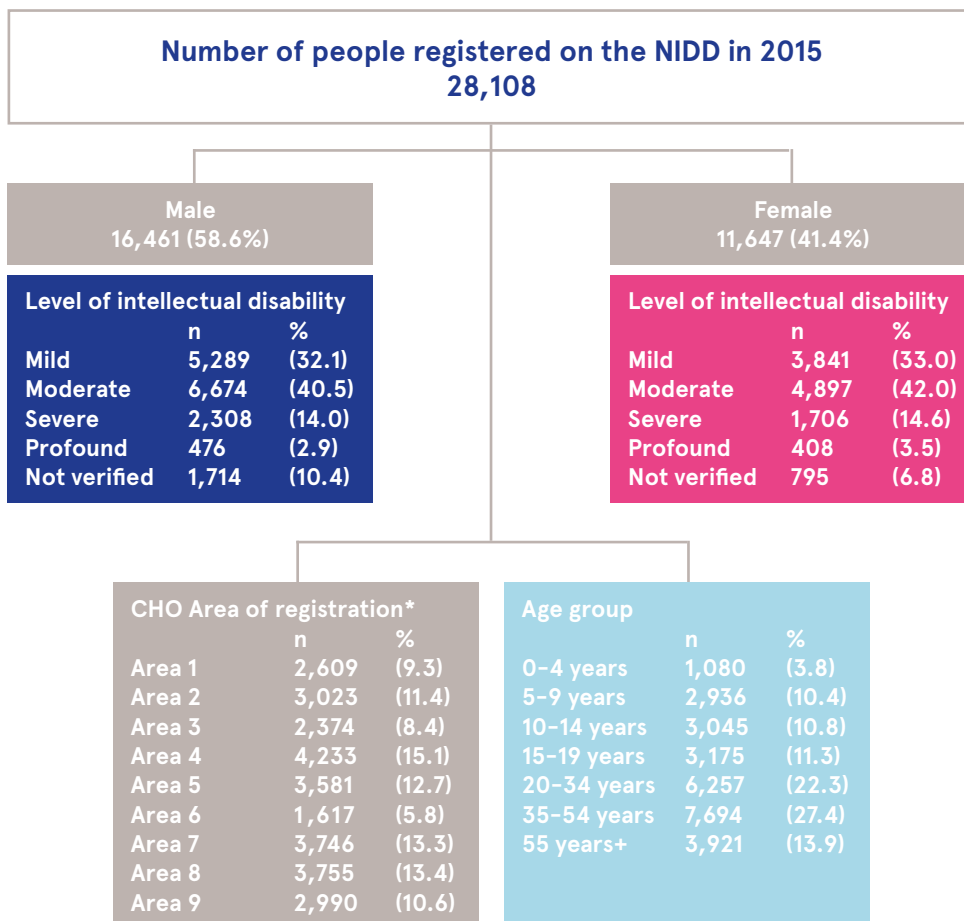
**Figure 1. NIDD registrations per 1,000 of the general population, by county of residence, 2015**



In December 2015 Sligo had the highest number of people registered on the NIDD per county population and Leitrim had the lowest.

Figure 2 below displays a summary profile of the number of people registered on the NIDD in 2015 by gender, age group and CHO area of registration.

**Figure 2. Profile of the population registered on the NIDD, 2015**

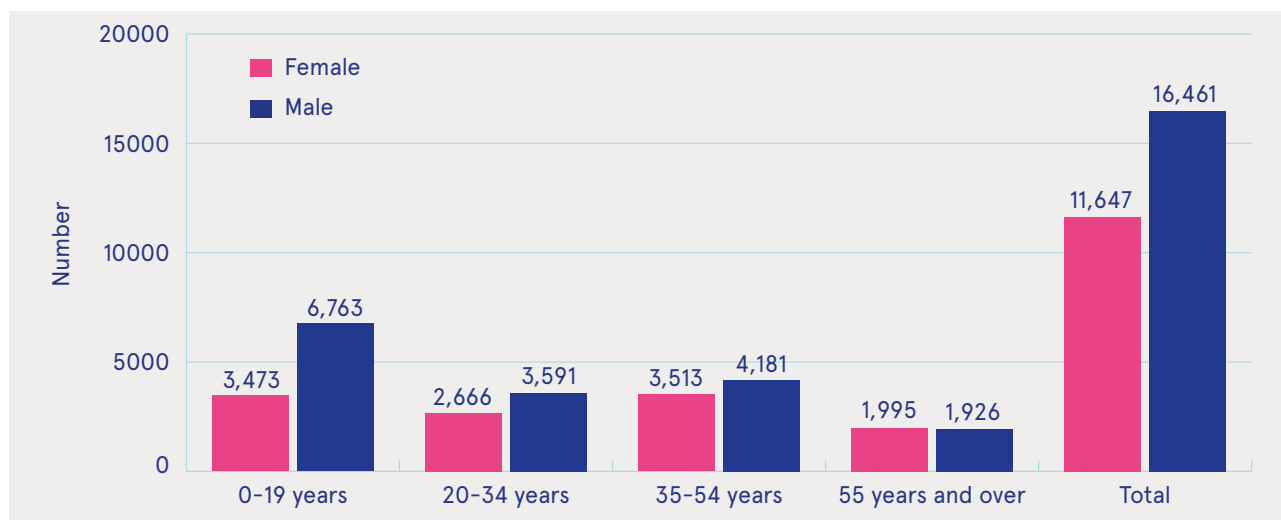


**\*The 9 Community Healthcare Organisations (CHOs) are:**  
**Area 1** - Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan  
**Area 2** - Galway, Roscommon, Mayo  
**Area 3** - Clare, Limerick, North Tipperary/East Limerick  
**Area 4** - Kerry, North Cork, North Lee, South Lee, West Cork  
**Area 5** - South Tipperary, Carlow/Kilkenny, Waterford, Wexford  
**Area 6** - Wicklow, Dun Laoghaire, Dublin South East  
**Area 7** - Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West  
**Area 8** - Laois/Offaly, Longford/Westmeath, Louth/Meath  
**Area 9** - Dublin North, Dublin North Central, Dublin North West

There were more males than females registered with an intellectual disability in all age groups except those aged 55 years and over, with an overall ratio of 1.41 to 1 (Figure 3).



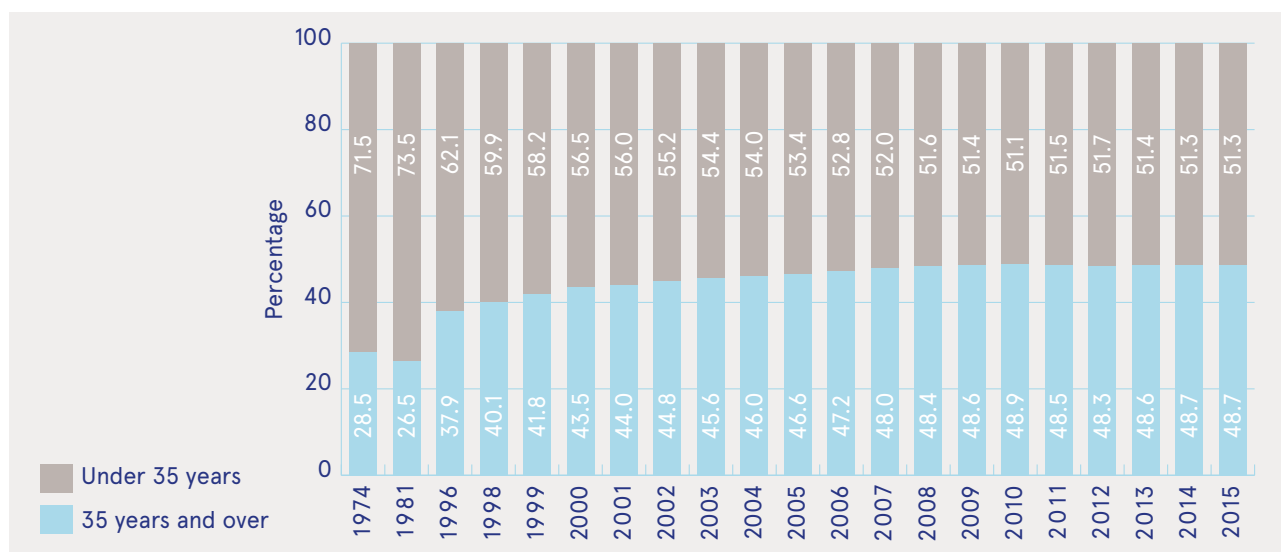
**Figure 3. Number of people registered on the NIDD, by age group and gender, 2015**



The total number of individuals recorded as having moderate, severe or profound intellectual disability has increased by 46.3% since the first Irish Census of Mental Handicap<sup>3,4</sup> – as it was referred to then – was carried out more than forty years ago 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 percentage aged 35 years and over increased

from 28.5% in 1974 to 37.9% in 1996 when NIDD data were first reported, and to 48.7% in 2015 (Figure 4). These figures reflect a steady increase in the lifespan of people with intellectual disability although this has levelled off in the last two years. 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.

**Figure 4. Percentage of people with moderate, severe or profound intellectual disability (combined), by age group, 1974–2015**



3 Mulcahy M (1976) Census of the mentally handicapped in the Republic of Ireland 1974: non-residential. Dublin: Medico-Social Research Board.

4 Mulcahy M and Ennis B (1976) Census of the mentally handicapped in the Republic of Ireland 1974: residential. Dublin: Medico-Social Research Board.

## 3

# Service provision in 2015

The numbers registered on the NIDD in December 2015 were as follows:

- » 27,733 people with intellectual disability were in receipt of services, representing 98.7% of the total population registered on the NIDD.
- » 223 people (0.8% of those registered) were without services in 2015 and were identified as requiring appropriate services in the period 2016–2020.
- » 152 people (0.5%) were not availing of services and had no identified requirement for services during the planning period 2016–2020.

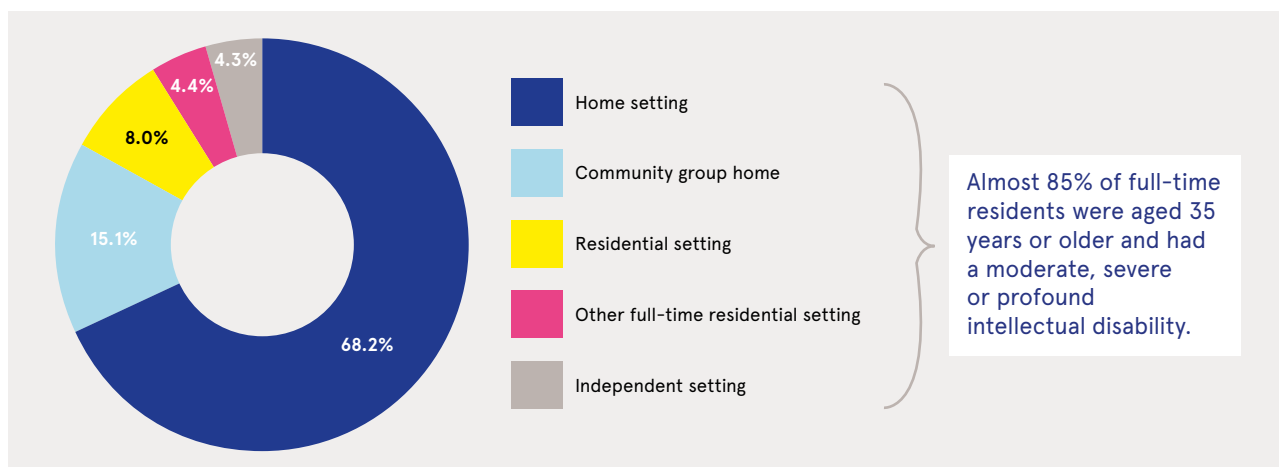
Of the 27,733 people who were in receipt of services in 2015:

- » Sixty nine per cent (19,157 individuals) lived at home with parents, siblings, relatives or foster parents in 2015. Almost one third (30.2%) of people aged 35 years or over with moderate, severe or profound intellectual disability lived

at home in 2015. As people with intellectual disability live longer, their service use and need and that of their carers changes which has implications for service-planning.

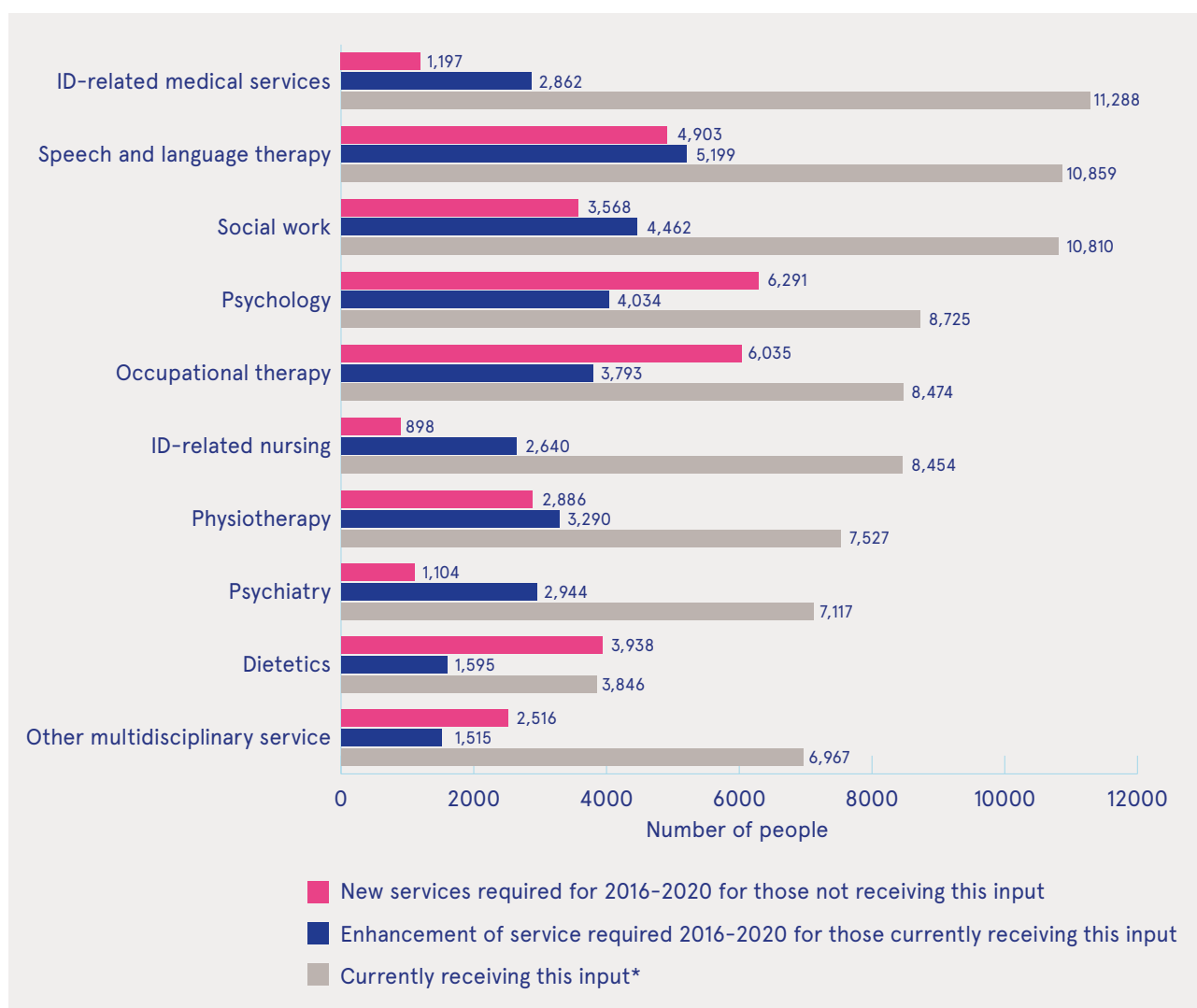
- » 7,724 (27.9%) were in receipt of full-time residential services, a decrease of 2.1% from the 2014 figure. The data indicate that more people live in community group homes than in residential centres (Figure 5). The majority (82.6%) of full-time residents had a moderate, severe or profound level of intellectual disability, were aged 35 years or over (84.8%), and lived in a community group home (55.1%) or residential centre (29.0%).

**Figure 5. Main residential circumstance, NIDD 2015**



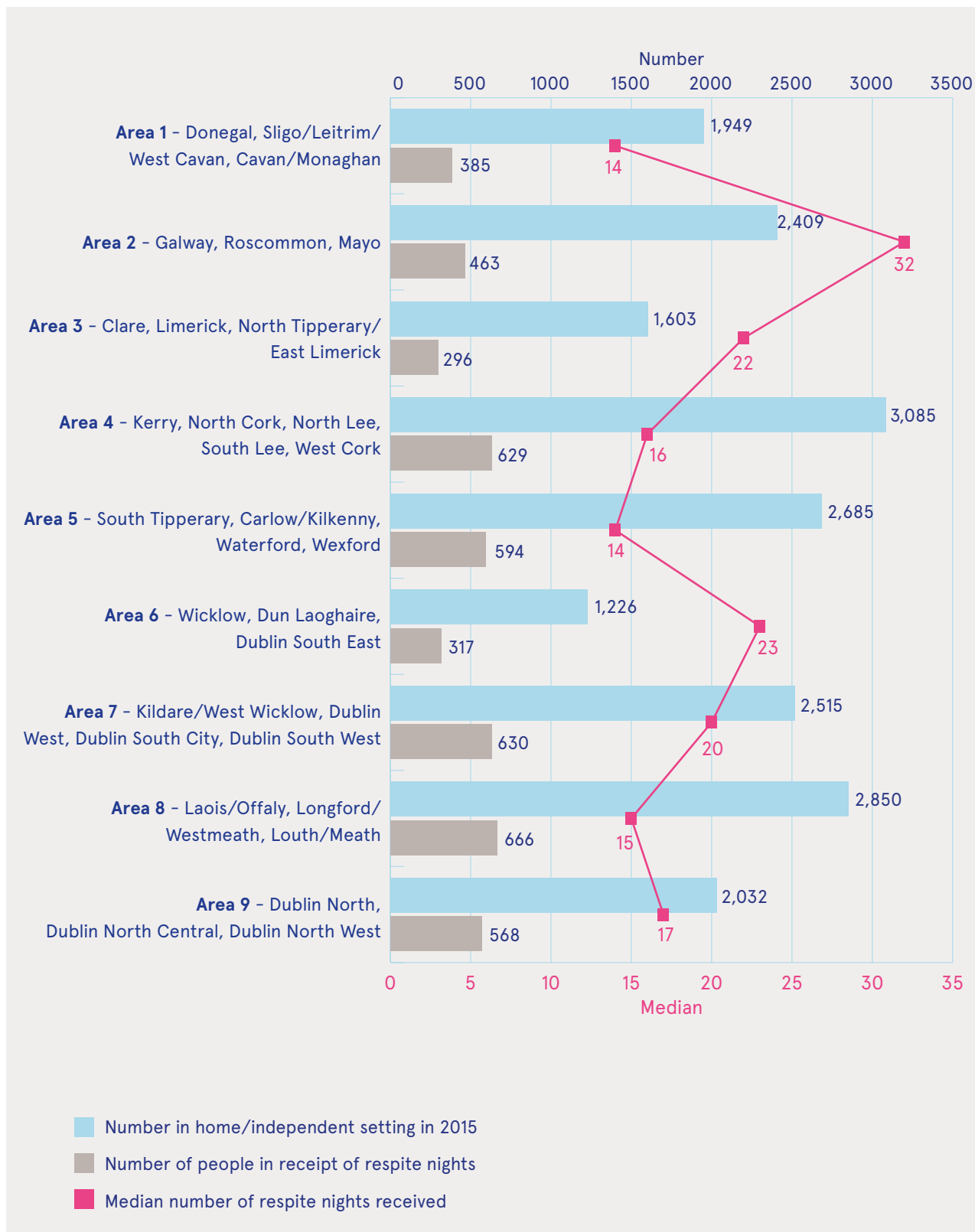
- » 27,682 (99.8%) people availed of at least one day programme in 2015. This is the highest number registered as receiving such services since NIDD data were first reported in 1996. Of this group, 7,700 were in full-time residential care.
- » 23,828 (85.9%) people availed of one or more multidisciplinary support services (Figure 6) – this varies by CHO area. 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 medical services.
- » The number of people with intellectual disability accommodated in psychiatric hospitals decreased by 11 (6.6%), from 165 in 2014 to 154 in 2015. More than two thirds (69.5%) were residing in CHO area 9; and over one third (37.6%) require a transfer to an alternative residential facility in the period 2016–2020.
- » In 2015, the data showed marked differences between CHO areas in the total number of people receiving respite and in the median number of nights received. For example, fewer people received a greater number of nights in the Galway, Mayo, Roscommon CHO area while more people received substantially less nights in the Kerry, North Cork, North Lee, South Lee and West Cork area (Figure 7).

**Figure 6. Multidisciplinary support services received in 2015, and required in the period 2016–2020, NIDD 2015**



\*Further analysis on current services is available by CHO area in the full set of NIDD tables and figures 2015.

Figure 7. Use of respite nights, by CHO area of residence, NIDD 2015



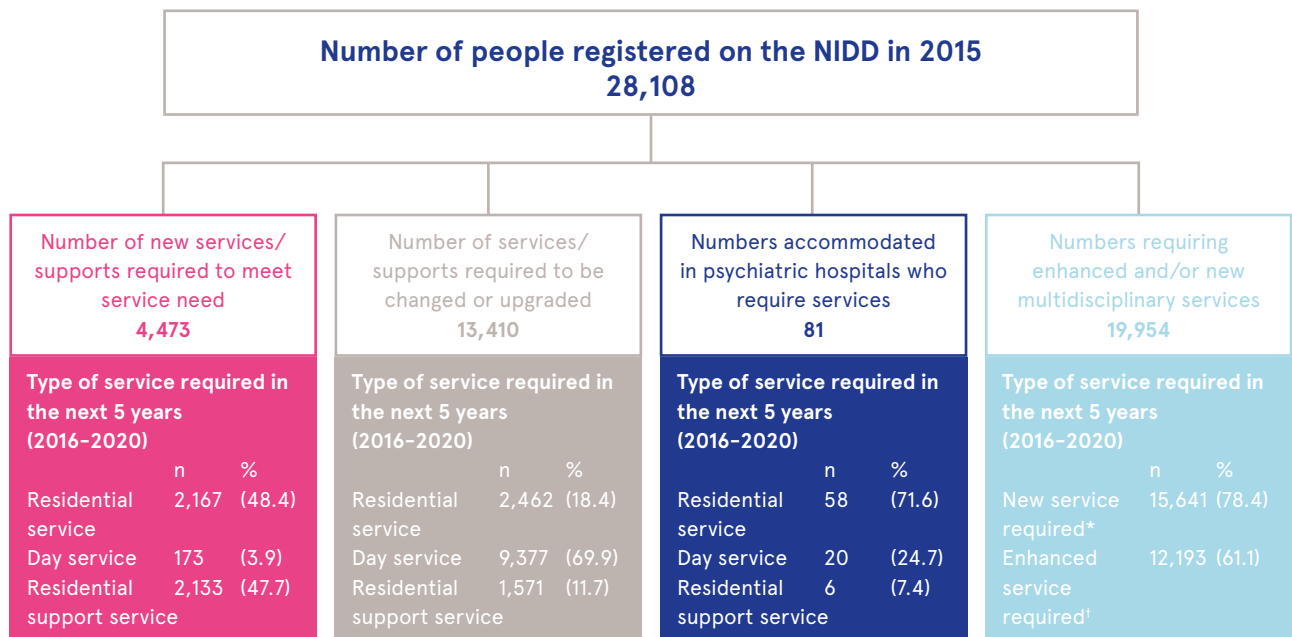
# 4

## Future service requirements 2016–2020

The NIDD collects information on the service requirements of people with intellectual disability for the next five years. Figure 8 provides summary data on the four distinct categories of requirements for the five-year period, 2016–2020:

- » New services required
- » Required changes to existing services
- » Services required by those accommodated in psychiatric hospitals
- » New or enhanced multidisciplinary services.

**Figure 8. Summary of service requirements of those registered on the NIDD, 2015**



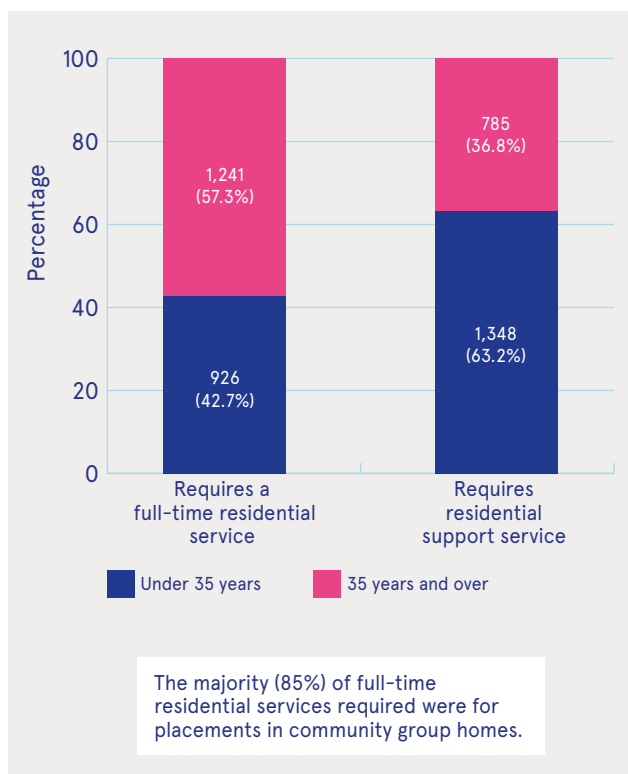
\* 'New service required' refers to a new type of therapeutic input that the individual does not currently receive.  
 † 'Enhanced service required' refers to a change in the delivery of a therapeutic input that the individual currently receives. There are 7,880 individuals whose multidisciplinary support service change involves both a new service and an enhanced service, therefore the actual number of people requiring a new and/or enhanced service is (15,641 + 12,193) - 7,880 = 19,954.

## Unmet need

The 2015 data indicate that 4,473 new residential, day and residential support services will be needed to meet the requirements of those who do not currently avail of these services. The following services will be needed in the period 2016–2020 (most service needs were recorded as being immediate):

- » 2,167 new full-time residential placements (Figure 9), a decrease of one place, or 0.04%, on the projected number required in 2014. Almost three quarters (72.4%) of this group had a moderate, severe or profound level of intellectual disability and 57.3% were aged 35 years and over. The majority (85.4%) require placements in community group homes.
- » 2,133 new residential support services, an increase of 100 on the projected number required in 2014. The majority of this group (89.9%) live at home or independently in the community. A high level of need for these services still exists (Figure 9).

**Figure 9. Unmet need – number of people requiring residential service or residential support service by age group, NIDD 2016–2020**



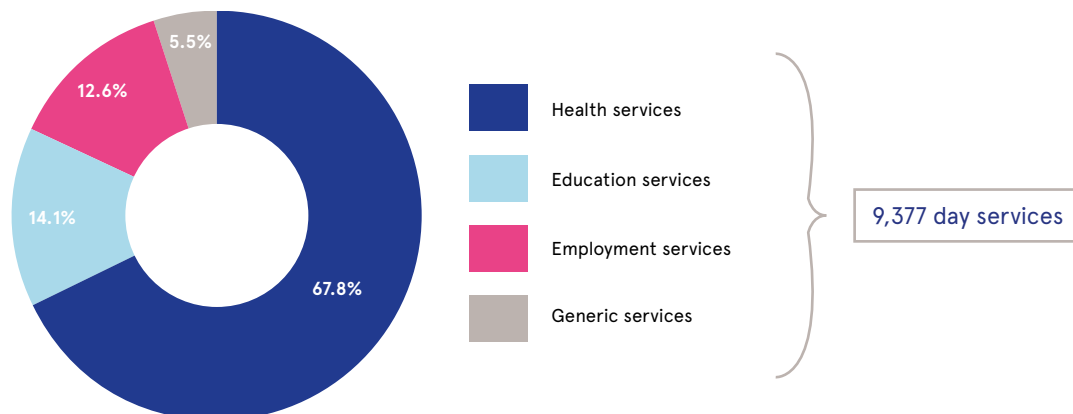
- » 173 day programmes (this figure excludes multidisciplinary support services (Figure 6) and services provided by early intervention teams). This number is in addition to the services required by 784 young adults who, as they approach the age of 18, are preparing to leave the education system to take up a range of training and supported employment opportunities. 58 individuals who were living in psychiatric hospitals in 2015 have been identified as needing to transfer from these locations to more appropriate accommodation such as community group homes or intensive placements for profound/multiple disabilities and/or challenging behaviour. The majority of those requiring a transfer were registered in the CHO area 9.

## Service change

Of those in receipt of services in 2015, 10,943 people require alternative, additional, or enhanced services in the period 2016–2020 (resulting in a total number of 13,410 required place changes), a decrease of 292, or 2.6%, since 2014. This group includes 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:

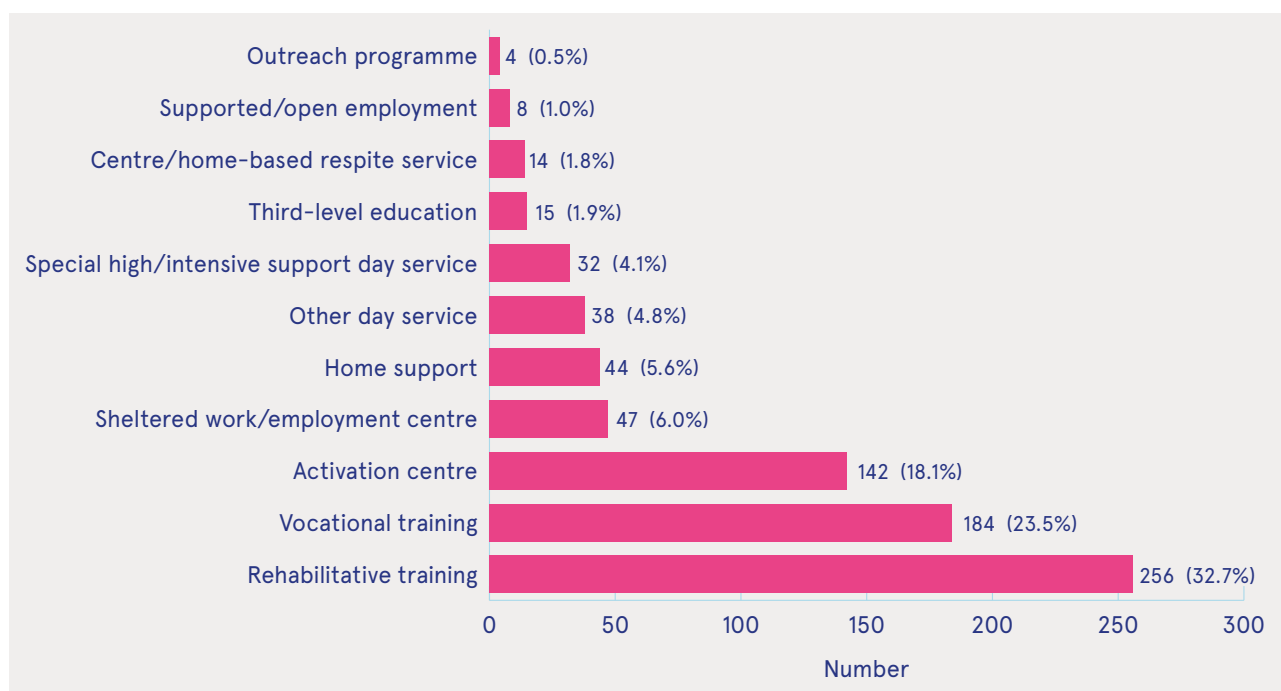
- » 9,377 day places will require changes or enhancements (Figure 10). The majority are for health-funded services which are required by 6,357 individuals (67.8%). Education services are required by 1,320 individuals (14.1%), employment services are required by 1,185 individuals (12.6%), and generic services such as training in domestic tasks or work skills required by 515 individuals (5.5%).

**Figure 10. Number and type of day services requiring change or enhancement, NIDD 2016–2020**



» Of the 784 young people (aged 16–19 years) who were in an education setting in 2015, one third (256 individuals) require rehabilitative training, 184 (23.5%) require vocational training and 142 (18.1%) require activation programmes in the next 5 years 2016–2020 (Figure 11).

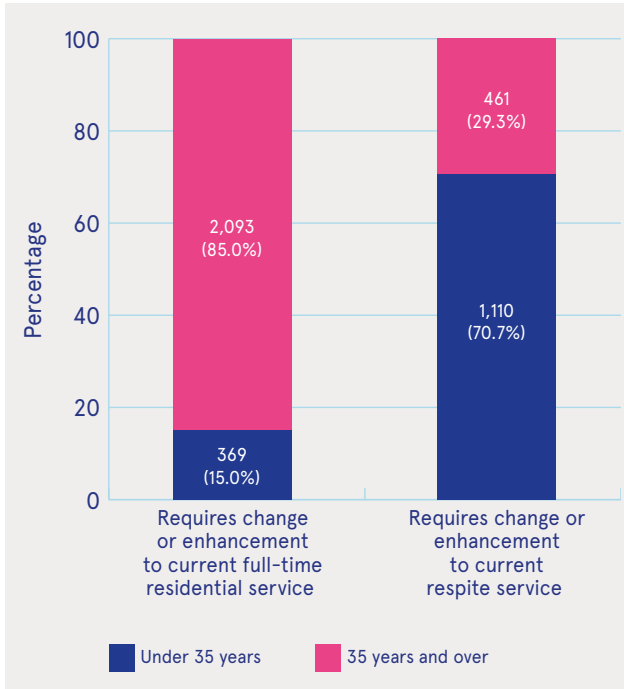
**Figure 11. Future day service requirements of individuals aged 16–19 years in an education setting, NIDD 2016–2020**



» 2,462 individuals in residential places require changes or enhancements to their service. The majority (90.2%) of this group had moderate, severe or profound intellectual disability, and were aged 35 years or older (85.0%) (Figure 12). Almost two thirds (58.7%) require a move to an alternative residential service, of which 61.3% require a move to a community group home and 31.3% to an intensive placement, for either challenging behaviour or multiple disabilities.

» 1,571 individuals require changes or enhancements to their residential support places (Figure 12). Most of this need was for more frequent centre-based crisis or planned respite breaks for individuals already availing of this service (1,061 individuals).

**Figure 12. Service change – number of people requiring a change to, or enhancement of, their current service by age group, NIDD 2016–2020**



Despite high levels of service provision in 2015, there remains a significant demand for new and enhanced multidisciplinary support services. Seventy percent (19,954 individuals) of those registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2016–2020. There are 7,880 individuals whose multidisciplinary support service change involves both a new service and an enhanced service, therefore the actual number of people requiring a new and/or enhanced service is 19,954 (15,641 + 12,193 - 7,880). The main therapeutic inputs required are psychology, occupational and speech and language therapies (Figure 6).



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## Summary

This report and associated tables are based on information collected from over 28,100 individuals registered on the database at the end of December 2015, and it represents the recorded service use and needs of this group of people. Notable points from this report include:

- » The majority of adults with intellectual disability continue to live with their families with the aid of additional support services. As their caregivers age, a wide range of additional services are required for people who wish to continue to live as independently as possible.
- » The improved life expectancy among adults with severe intellectual disability, while welcome, has placed an ever-increasing demand on 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 additional medical services to cater for their specific needs.
- » There is a continuing shift away from the more traditional institutional models of care towards community-based living arrangements for those requiring residential services. This is set to continue as funding is made available for decongregation.
- » The proportion of those registered who are in receipt of day services continues to rise. Many of those in receipt of day services are also benefiting from additional supports, such as home support, home help and respite services.
- » The demand for services for school leavers remains high, particularly in the areas of training and employment.
- » The level of provision of multidisciplinary support services in 2015 was high and future demand for these services continues for the five-year period 2016–2020. There was an increase in residential support provision between 2014 and 2015.
- » High levels of unmet need continue to exist among a significant number of individuals who are registered on the NIDD, particularly those who are aged 35 years and over and require a full time residential place in the next 5 years.





