



HRB Statistics Series 37

Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings

Sarah Hourigan, Sarah Fanagan and Caraíosa Kelly

Research. Evidence. Action.

'Poppy Love' by Shane Molloy
NIDD Cover Design Winner 2017

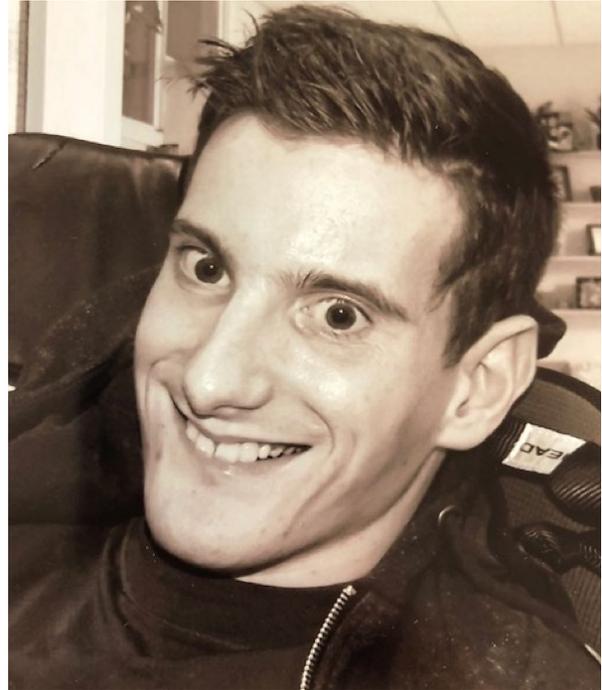
I'm Shane Molloy and I hail from lovely Headford. I live on the border of Galway and Mayo so depending on how the football is going that can decide where I say I'm from!

I live at home with my mum, Pauline, my dad, David, and my sister, Aishling. I go to Four Seasons Monday to Friday and spend some nights with my friends in Eden House. I love having the craic and everyone says that I bring the fun and laughter with me wherever I go. You see, I love to tell funny stories and the more dramatic they are the better for me! I love telling stories about places I've been, things I've done and about my family and friends.

I love listening to music and Brendan Shine is one of my all-time favourites!

I have only started doing art recently as part of my ASDAN module in Creativity. I am loving it! I am getting to explore all sorts of different objects that can make beautiful art. As I find it difficult to hold a paint brush this has opened up a whole new experience in doing art for me, like in "Poppy Love" I used a fork, a feather and a potato.

I am so excited and so proud to have won this competition. It will inspire me to go and create loads of new pieces of art and who knows what objects I'll use next!



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About the HRB

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

Our information systems

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

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

- » *Activities of Irish Psychiatric Units and Hospitals*
- » *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, sensory, neurological or speech or language disabilities.

In 2018 the NIDD and NPSDD will be merged to form the new **National Ability Supports System (NASS)**. This new system aims to reflect changes in disability services over the last number of years. All individuals who receive or require a disability-funded service due to an intellectual disability, or a persistent physical, sensory, neurological, learning, autism spectrum, and/or speech/language disability arising from disease, disorder or trauma, should be registered on NASS. The purpose of NASS is to gather information to aid the planning, development and organisation of disability services.

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- » Disability Unit, Department of Health;
- » the Health Service Executive, in particular the database coordinators and the database administrators/managers;
- » service providers;
- » 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 2017

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<p>Mr Billy McCarthy (Secretary) Disability Unit Department of Health</p>	<p>Dr Sarah Craig Health Research Board</p>
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<p>Mr Gerard Tully National Disability Unit Health Service Executive</p>	<p>Ms Anne O'Donohoe Health Research Board</p>
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⁵ Replaced Mr James Rock in November 2017

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 2017. The 2017 dataset consists of information relating to 28,388 people. Of these registrations, 88.4% (25,107 records) were updated following the 2017 annual review of NIDD information; the remaining 3,281 registrations contain the last-known data in each case.¹ Prevalence rates per thousand of population are based on data from the 2016 Census of Population.²

Comparative data referred to in this report are from previous published NIDD data for the associated years.

In addition to this report, a complete set of tables and figures, mirroring data in reports from 2016 and previous years, is available in MS Excel versions on the HRB website at www.hrb.ie.

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

2 Central Statistics Office (2017) Census 2016 Summary Results – Part 1 Dublin: Central Statistics Office.

2 Profile of the registered population

There were 28,388 people registered on the NIDD at the end of December 2017. Based on 2016 Census of Population figures, this represents a prevalence rate of 5.96 per 1,000 population. The prevalence rate for mild intellectual disability (which traditionally has been under-reported)

was 1.92 per 1,000, and the rate for moderate, severe or profound intellectual disability was 3.49 per 1,000. Figure 1 presents the number of registrations by county of residence and shows that Sligo (10.3/1,000) had the highest prevalence rate while Leitrim (4.3/1,000) had the lowest.

Figure 1. Registrations per 1,000 of the general population, by county of residence, NIDD 2017

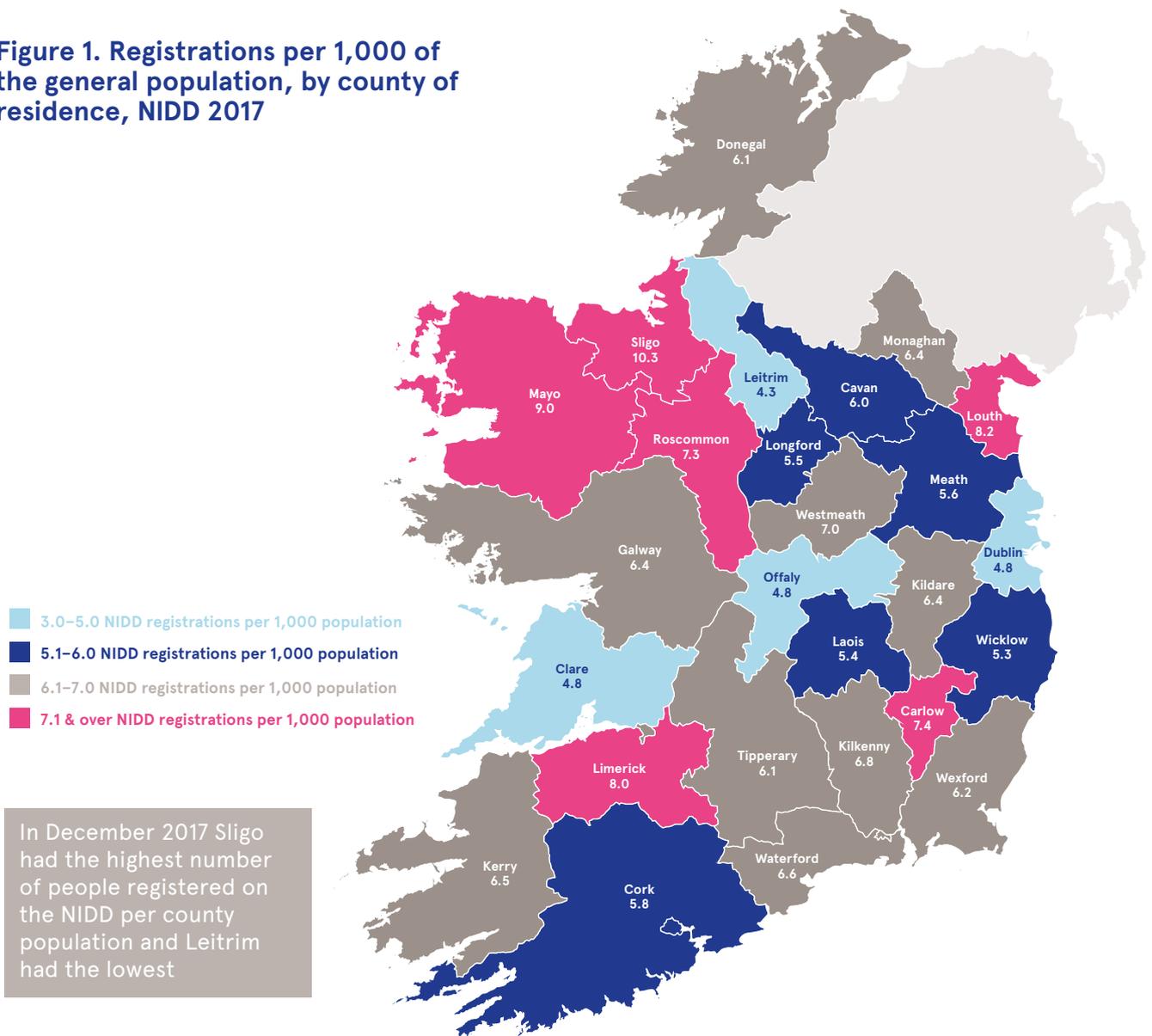
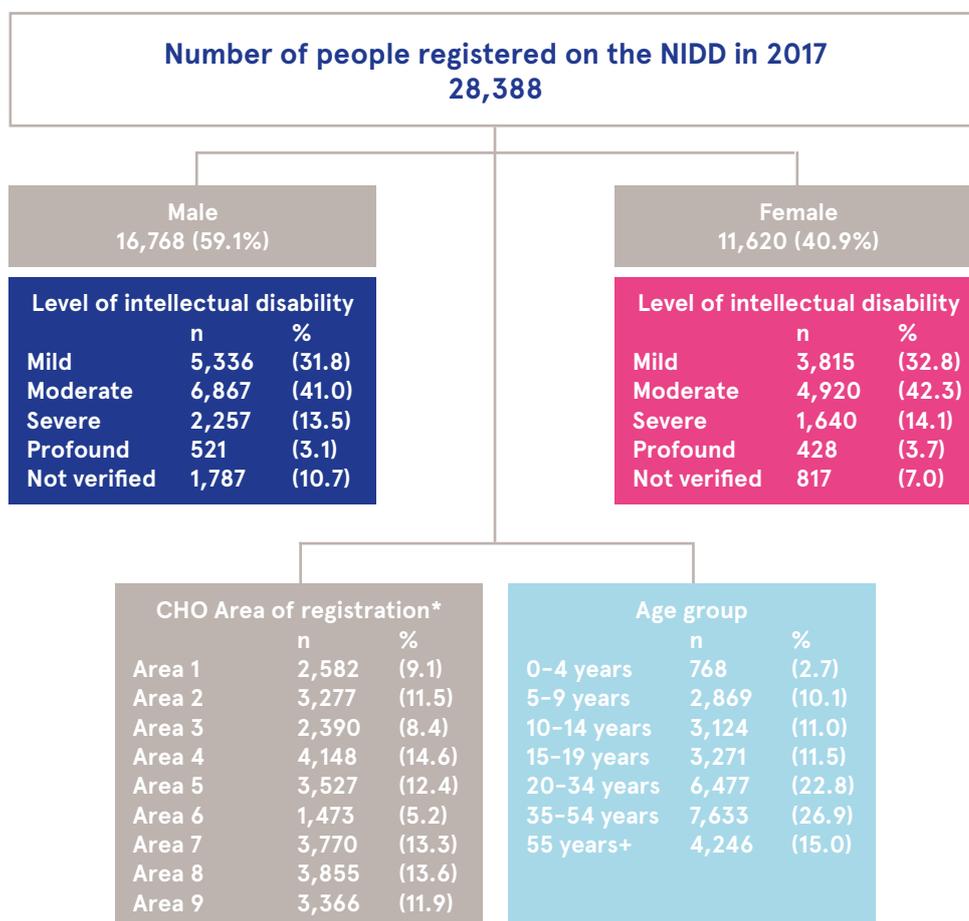


Figure 2 below displays a summary profile of the number of people registered on the NIDD in 2017 by gender, age group and CHO area of registration.

Figure 2. Profile of the population registered, NIDD 2017



*** The 9 Community Health 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

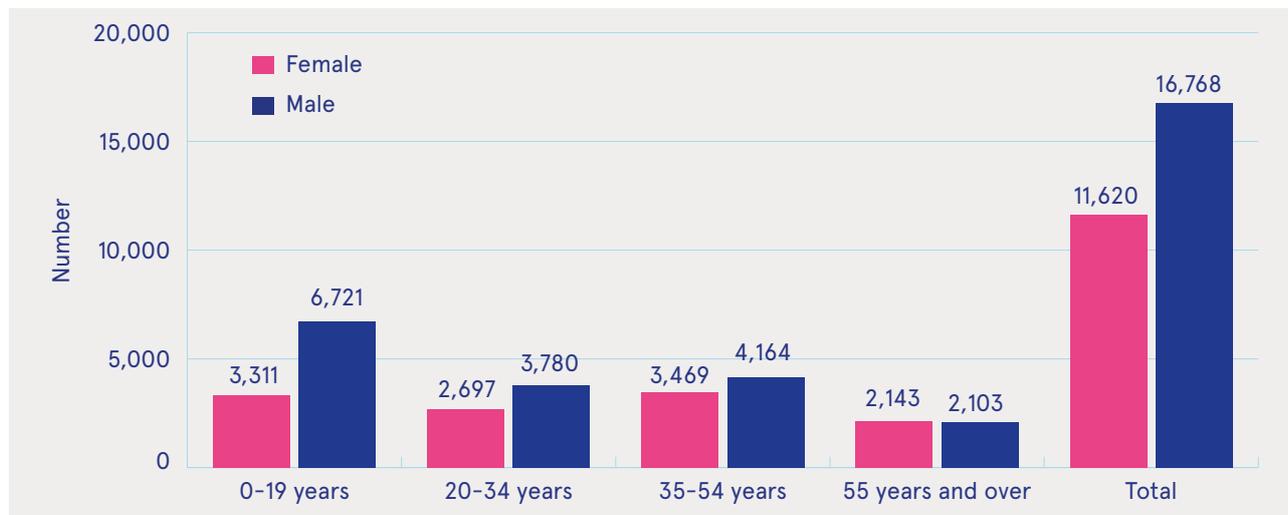
Area 7 - Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West

Area 8 - Laois/Offaly, Longford/West Meath, 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 1.44 to 1 (Figure 3).

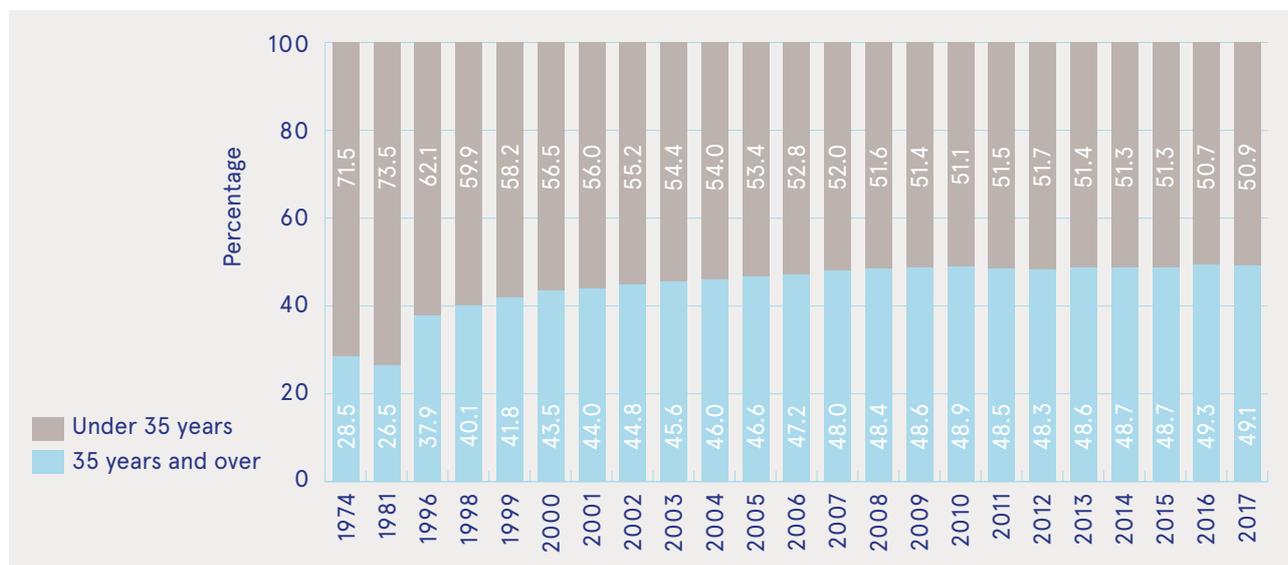
Figure 3. Number of people registered by age group and gender, NIDD 2017



The total number of people recorded as having moderate, severe or profound intellectual disability has increased by 47.8% since the first Irish Census of Mental Handicap^{3,4} – as it was referred to then – was carried out more than forty years ago in 1974. Some of the factors contributing to this increase in numbers are 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 49.1% in 2017 (Figure 4). These figures reflect an increase in the lifespan of people with intellectual disability which 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 1974–2017, NIDD 2017



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 2017

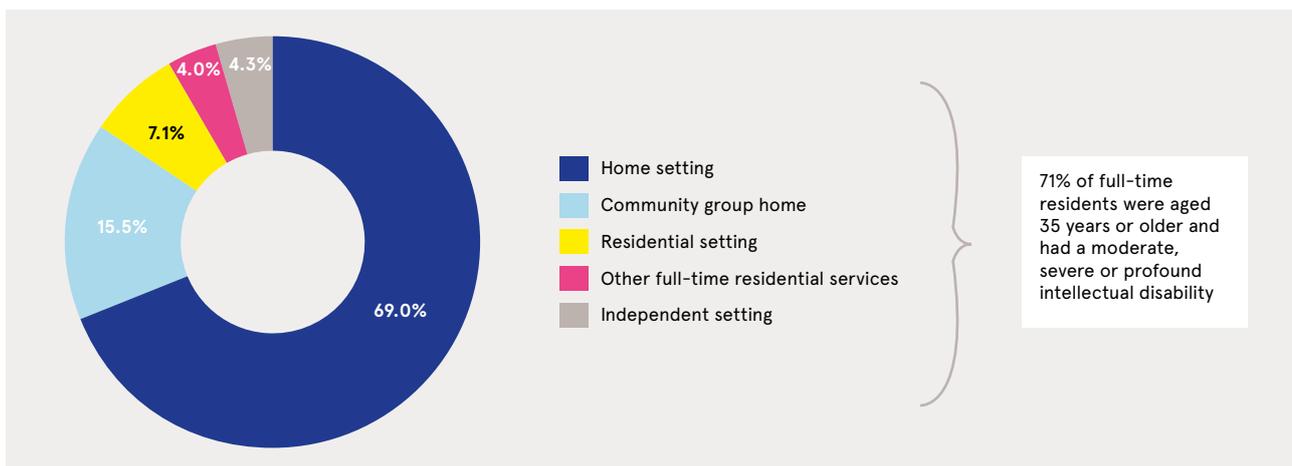
The numbers registered on the NIDD in December 2017 were as follows:

- » 27,985 people with intellectual disability were in receipt of services, representing 98.5% of the total population registered on the NIDD.
- » 259 people (0.9% of those registered) were not availing of services in 2017 and were identified as requiring services in the period 2018–2022.
- » 171 people (0.6%) were not availing of services and had no identified requirement for services during the planning period 2018–2022.
- » 19,599 individuals (69.0%) lived at home with parents, siblings, relatives or foster parents in 2017. Almost one third (2,579, 31.6%) of people aged 35 years or over with moderate, severe or profound intellectual disability lived at home in 2017. As people with intellectual disability live longer, their service use and need and that of their carers changes, which has implications for service-planning.

Of the 27,985 people who were in receipt of services in 2017:

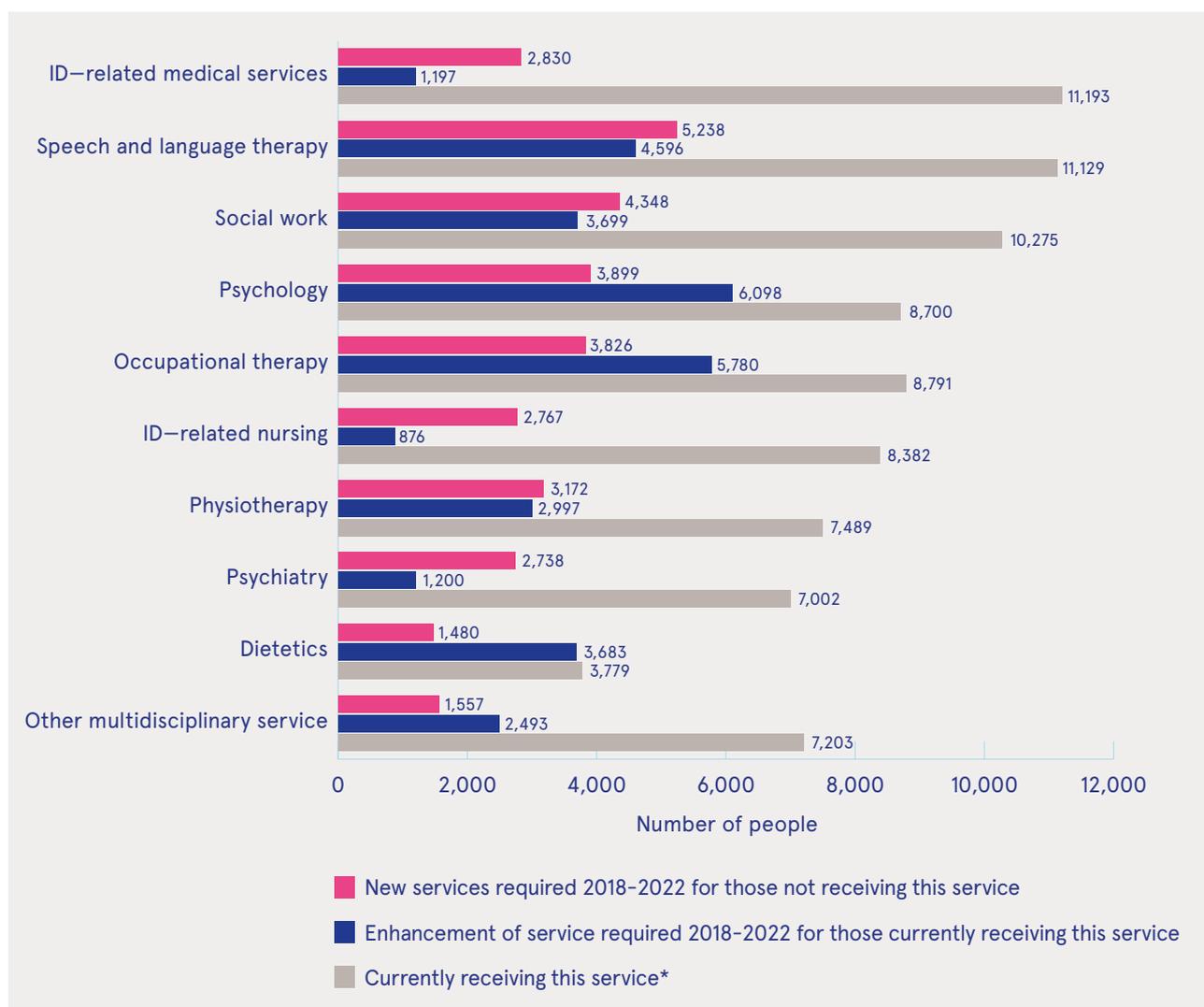
- » 7,530 (26.9%) were in receipt of full-time residential services, a decrease of 1.1% from the 2016 figure. The data indicate that more people live in community group homes than in residential centres (Figure 5).
- » Of the 7,530 full-time residents, 6,201 (82.4%) had a moderate, severe or profound level of intellectual disability, 6,530 (86.7%) were aged 35 years or over, 4,389 (58.3%) were living in community group homes and 2,005 (26.6%) were living in residential centres.
- » 27,902 (99.7%) people availed of at least one day programme in 2017. This figure has increased significantly since NIDD data were first reported in 1996. Not all of these services are HSE funded. Of this group, 7,498 (26.9%) were in full-time residential care.

Figure 5. Main residential circumstance, NIDD 2017



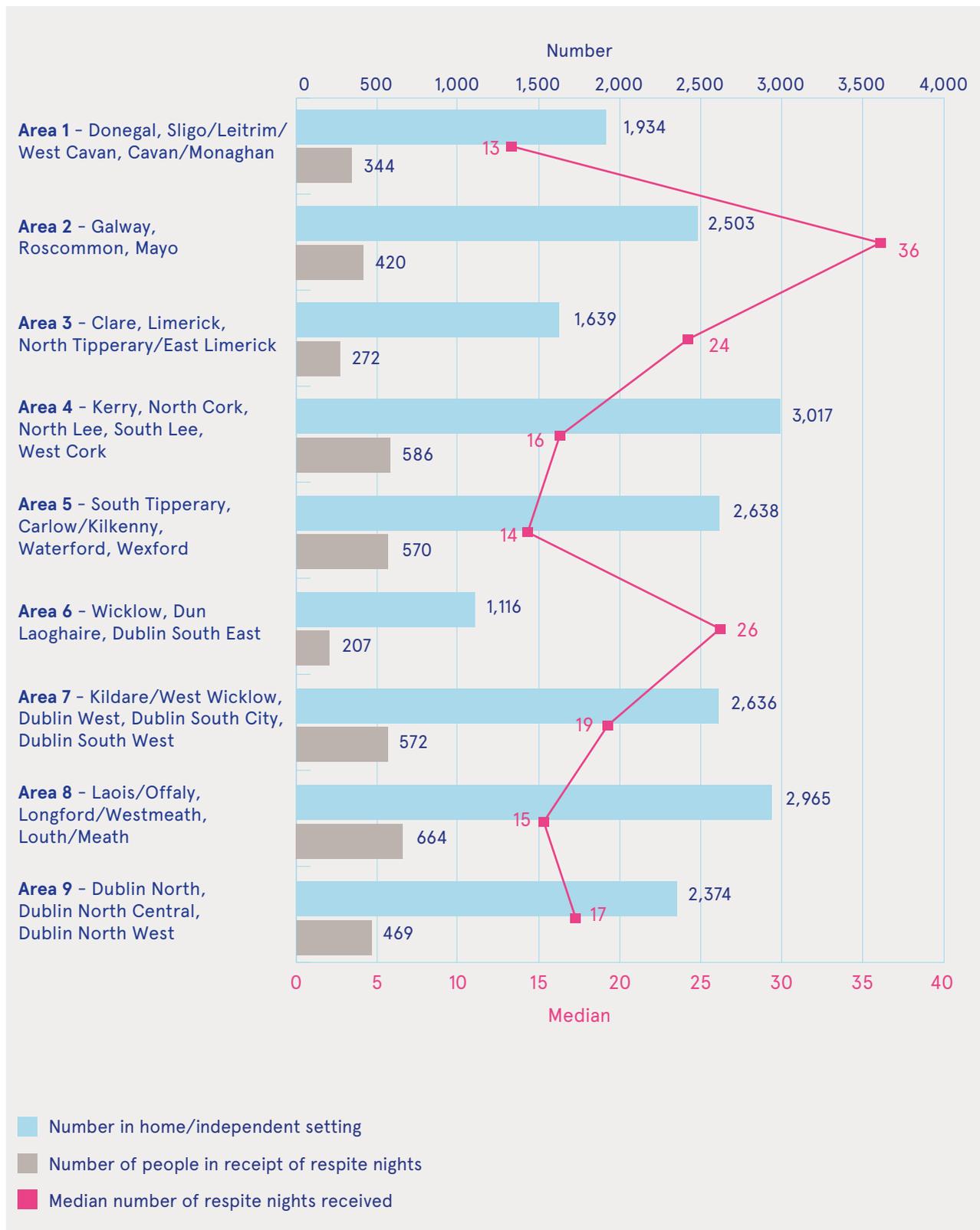
- » 23,583 (84.3%) people availed of one or more multidisciplinary support services (Figure 6) – this varies by CHO area. The services most commonly availed of by adults were medical services, social work and psychiatry. The services most commonly availed of by children were speech and language therapy, occupational therapy and physiotherapy.
- » The number of people with intellectual disability accommodated in psychiatric hospitals decreased by 9 (6.1%), from 148 in 2016 to 139 in 2017. Almost three quarters (101, 72.7%) were residing in CHO area 9; and over one third (52, 37.4%) require a transfer to an alternative residential facility in the period 2018–2022.
- » In 2017, a total of 4,104 people received respite services (representing a 6.4% decrease on those accessing this service in 2016), with a median of 18 nights received nationally. The data showed marked differences between CHO areas in respite service provision (Figure 7).

Figure 6. Multidisciplinary support services received in 2017 and required in the period 2018–2022, NIDD 2017



*Further analysis on current services is available by CHO area in the full set of NIDD tables and figures 2017 on the HRB website.

Figure 7. Use of respite nights, by CHO area of residence, NIDD 2017



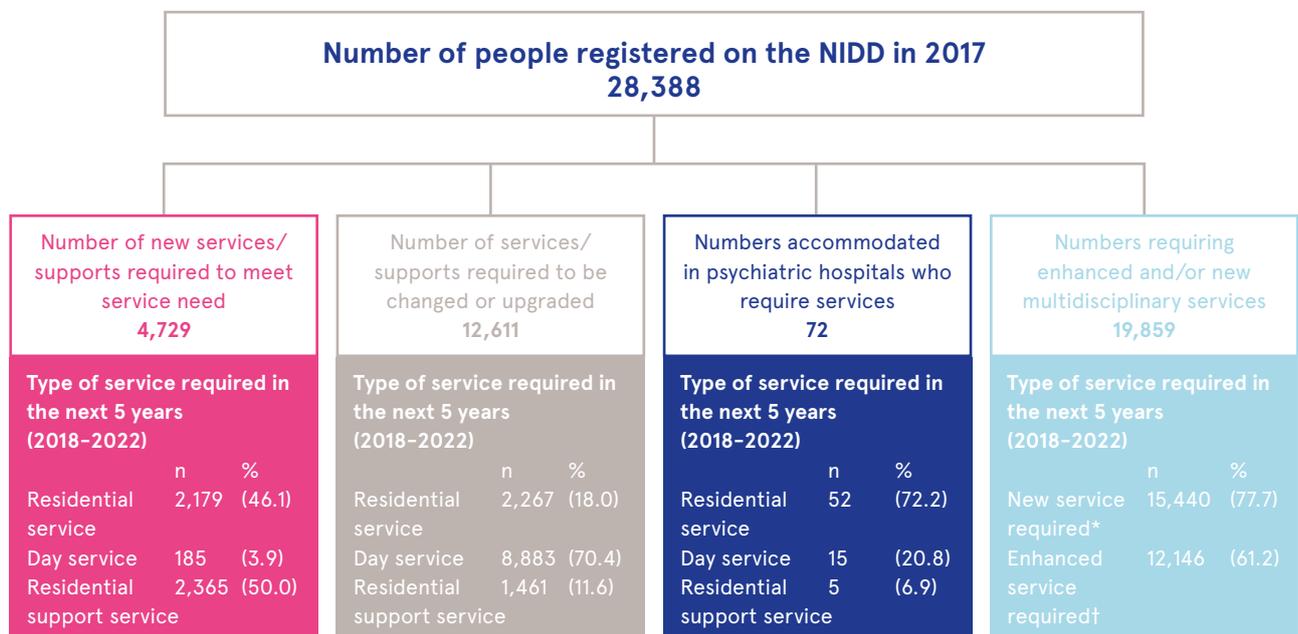
4

Future service requirements 2018–2022

The NIDD collects information on the service requirements that people with intellectual disability, their families and key workers identify as a required need for the next five years. Figure 8 provides summary data on the four distinct categories of requirements for the five-year period, 2018–2022:

- » 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, NIDD 2017



* 'New service required' refers to a new type of therapeutic service that the individual does not currently receive.

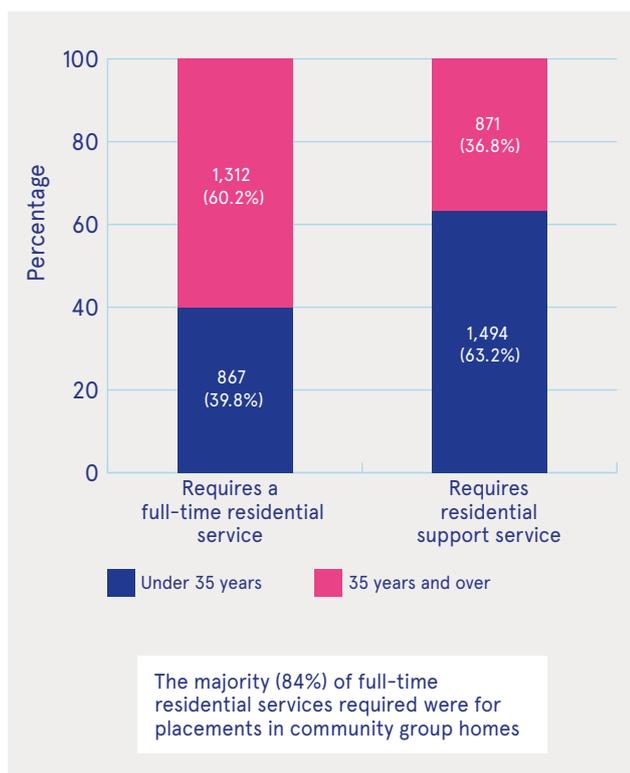
† 'Enhanced service required' refers to a change in the delivery of a therapeutic service that the individual currently receives. There are 7,727 people whose multidisciplinary support service change involves both a new service and an enhanced service, therefore the actual number of people requiring a new and/or enhanced service is (15,440 + 12,146) - 7,727 = 19,975

Unmet need

The 2017 data indicate that 4,729 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 2018–2022 (most service needs were recorded as being immediate):

- » 2,179 new full-time residential placements (Figure 9), an increase of 15 places, or 0.7%, on the projected number required in 2016. Almost three quarters (1,575, 72.3%) of this group had a moderate, severe or profound level of intellectual disability and 1,312 people (60.2%) were aged 35 years and over. The majority (1,839, 84.4%) require placements in community group homes.
- » 2,365 new residential support services, an increase of 121 on the projected number required in 2016. The majority of this group (2,150, 90.9%) 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 2018–2022, NIDD 2017



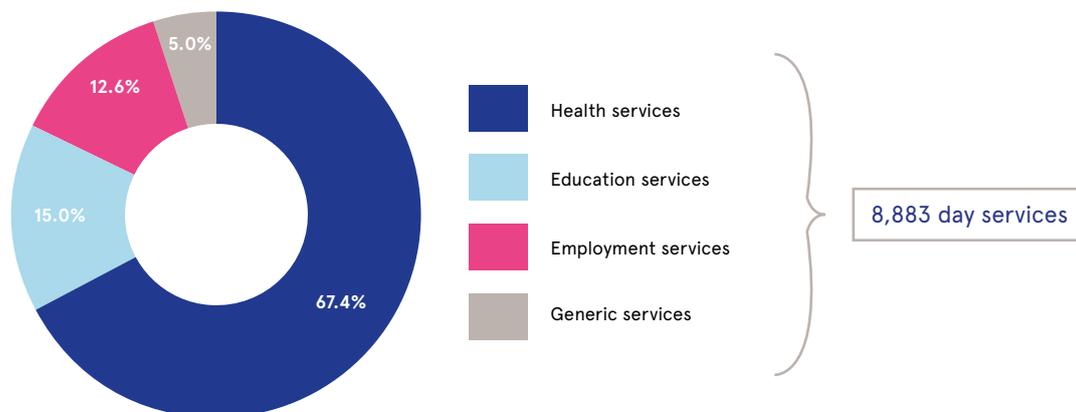
- » 185 day programmes (this figure excludes multidisciplinary support services (Figure 6) and services provided by early intervention teams). This number is in addition to the services required by 689 young adults who are preparing to leave the education system to take up a range of training and supported employment opportunities.
- » Fifty-two people who were living in psychiatric hospitals in 2017 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 2017, 10,418 (37.2%) people require alternative, additional, or enhanced services in the period 2018–2022 (resulting in a total number of 12,611 required place changes), a decrease of 261 or 2.4%, since 2016. 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:

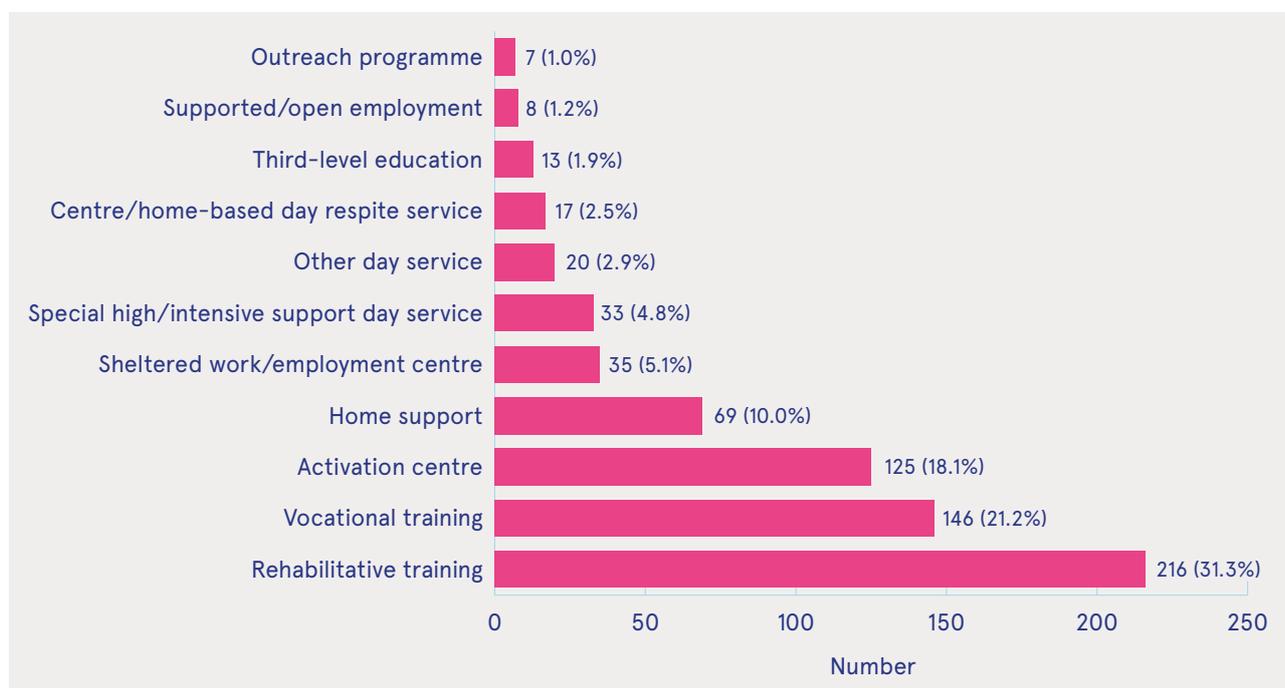
- » 8,883 day places will require changes or enhancements (Figure 10). The majority are for health-funded services which are required by 5,989 (67.4%) people. Education services are required by 1,333 (15.0%) people, employment services are required by 1,121 (12.6%) people, and services such as training in domestic tasks or work skills are required by 440 (5.0%) people.

Figure 10. Number and type of day services requiring change or enhancement 2018–2022, NIDD 2017



» Of the 689 young people (aged 16–19 years) who were in an education setting in 2017, 216 (31.3%) require rehabilitative training, 146 (21.2%) require vocational training and 125 (18.1%) require activation programmes in the next 5 years 2018–2022 (Figure 11).

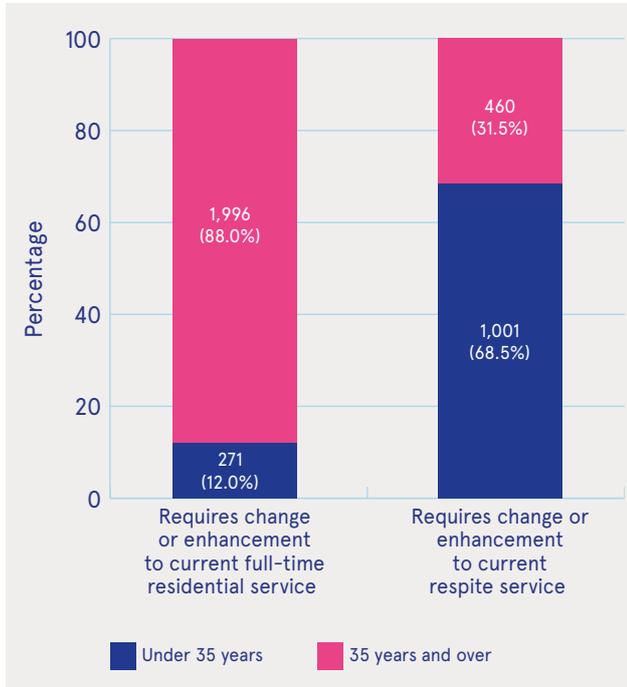
Figure 11. Future day service requirements of people aged 16–19 years in an education setting 2018–2022, NIDD 2017



» 2,267 people in full-time residential places require a change or upgrading of their current service in the next five years 2018–2022. Of this group, 1,318 (58.1%) require a move to an alternative residential service including 806 (35.6%) who require a move to a community group home and 413 (18.2%) to an intensive placement, for either challenging behaviour or multiple disabilities. A further 949 (41.9%) people require an upgrade of their existing residential service type. The majority of this group (2,040, 90%) had moderate, severe or profound intellectual disability, and 1,996 (88%) were aged 35 years or older (Figure 12).

» 1,461 people require changes or enhancements to their residential support places. Most of this need was for more frequent centre-based crisis or planned respite breaks for people already availing of this service (982, 67.2%).

Figure 12. Service change – number of people requiring a change to, or enhancement of, their current service by age group 2018–2022, NIDD 2017



Despite high levels of service provision in 2017, there remains a significant demand for new and enhanced multidisciplinary support services.

Sixty-nine percent of those registered on the NIDD (19,589 people) require a new and/or enhanced multidisciplinary support service in the period 2018–2022. The main therapeutic services required are psychology, occupational and speech and language therapies (Figure 6).

5

Summary

This report and associated tables are based on information collected from 28,388 individuals registered on the database at the end of December 2017. 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 such as respite are required for people who wish to continue to live as independently as possible. Between 2016 and 2017 there was a decrease in respite provision.
- » The improved life expectancy among adults with severe intellectual disability 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.
- » 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 2017 was high and future demand for these services continues for the five-year period 2018–2022.
- » 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.

A full set of tables and figures based on 2017 NIDD data are available on the HRB website www.hrb.ie.

