Rialtas na hÉireann
Government of Ireland

# Social Impact Assessment Series:

## Specialist Disability Services for People with Intellectual Disabilities

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IGEES
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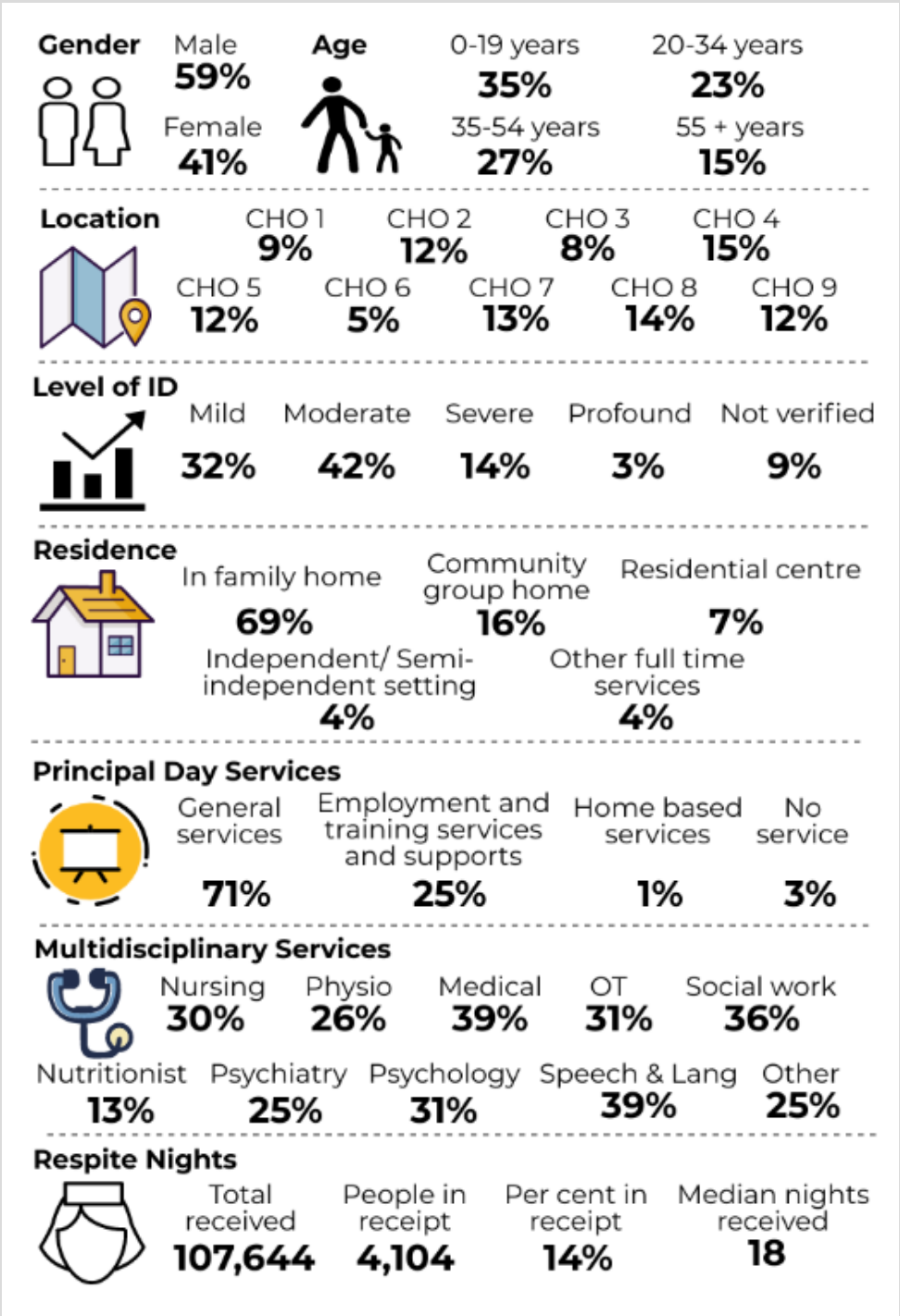
## Summary

**Overview of Disability Funding**

- 11% of gross current voted health expenditure is allocated to the disabilities service line.
- Budget allocation grew by 14% between 2010 and 2017.
- According to Census data, the rate of intellectual disability (ID) in the population has increased from 1.3% to 1.4%, from 2011 to 2016.

**Overview of people with ID registered on the National Intellectual Disability Database (NIDD) and their service use in 2017**




**Note:** Utilisation for *each* multidisciplinary service is presented and do not sum to 100%

# 1. Introduction

## 1.1 Overview

A Social Impact Assessment (SIA) is an evidence-based methodology which aims to assess the impact of a particular policy on a cohort of targeted individuals. This paper focuses on the impact of public health expenditure on specialist disability services. It undertakes a point-in-time exercise which identifies the number of individuals with intellectual disabilities (ID) receiving Health Service Executive (HSE) funded specialist disability services and the characteristics of these individuals in order to generate a profile of service users. This paper forms part of the Social Impact Assessment (SIA) series of the Irish Government Economic and Evaluation Services (IGEES) publications[1] and will represent a baseline against which future budgetary and policy changes in this area can be measured. HSE funded specialist disability services for people with intellectual disabilities was chosen for this analysis due to substantive demographic and policy change in recent years, and it is an area within overall disability services where a comprehensive dataset is available for analysis. The specific objectives of this paper are to:

- Report trends in spending on disabilities from 2010-2017;
- Present a profile of specialist disability service users based on: age, gender, level of intellectual disability, location, and principal residence;
- Provide an overview of the specialist disability services for people with intellectual disabilities and trends in service utilisation over the seven year period, 2010-2017;
- Identify further policy analysis which could be undertaken in this area, considering the findings of this paper.

In this paper ID is defined using the criteria set out in the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, (ICD-10), which is premised on intelligence quotient (IQ) and categorises degrees of ID on a scale ranging from mild to moderate, to severe to profound, based on IQ. The definition of ID provided in the ICD-10, is a "*condition of arrested or incomplete development of the mind, which is especially characterised by an impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, such as cognitive, language, motor, and social abilities*"[2]. This ICD-10 definition is used by the National Intellectual Disability Database, which is described in the next section (1.2).

[1] Irish Government Economic and Evaluation Service (IGEES). Social Impact Assessment Framework - Staff Paper 2016. Dublin: Department of Public Expenditure and Reform; 2016. Available from: https://igees.gov.ie/publications/economic-analysis/social-impact-assessment/

[2] ICD-10 Online - Classification of Diseases. Chapter V: Mental and Behavioural Disorders [Internet]. Geneva: World Health Organisation/DIMDI; 2016. Available from: https://apps.who.int/classifications/apps/icd/icd10online2004/fr-icd.htm?gf70.htm+

## 1.2 Data sources

Data for this analysis is from the National Intellectual Disability Database (NIDD), the Central Statistics Office (CSO), and the Census of the Population. CSO and Census data record overall numbers of those residing in Ireland with a disability categorised by type. The NIDD is a registry and a service planning tool which is designed to capture data on the usage of, and the need for, HSE funded specialist disability services for people with ID, nationally. It is used to inform the regional and national planning of these services by providing information on trends in demographics, current service use and future service need. Data includes:

- Personal details such as date of birth, gender, area of residence, and level of intellectual disability;
- Current service provision by type of service, agency provider, and frequency;
- Administrative details including date, the HSE area with responsibility for returning data and agency responsible for returning data; and
- Future service requirements by type of services, year when required, and frequency[3].

Data from the NIDD was extracted, by request, for the period 2010-2017 and with the support of the Health Research Board (HRB). Data on gender, level of intellectual disability, main residence, and HSE area (Community Health Organisation, CHO)[4] and type of service was extracted. The data is currently available up to 2017.

As detailed in Section 1.1, the NIDD captures level of intellectual disability on a scale ranging from mild to moderate, to severe to profound. Data on the NIDD is provided by intellectual disability service providers (HSE and non-statutory bodies), and schools. Approximately 28,000 records are created, reviewed, added to or updated on the database annually. Removal from the NIDD can also occur for several reasons, including when a person completes a particular programme, no longer requires a service, or upon the death of an individual. Furthermore, the NIDD includes children with a mild ID attending special classes in a mainstream school, specialist schools and those listed for specialist disability therapy services who do not necessarily progress to adult disability services. Therefore, when a child reaches the end of their schooling age and is no longer in receipt of or requiring specialised disability health and social services they are removed from the NIDD. A recent analysis of the NIDD by the Economic and Social Research Institute (ESRI) reported that, of those aged 17 in 2012, 69.5%

[3] This paper relates to the impact of current expenditure on specialist disability services and so the data related to future service requirements is not utilised in this SIA.

[4] See Appendix C for a map of CHO areas.

remain on the NIDD register when they are 22 in 2017, reflecting this exodus. The proportions remaining on the register are reasonably stable for those aged between 25 and 50 years old but gradually reduce thereafter[5].

Registration on the database is not mandatory for all people with ID, and because it is designed to capture data relating to *specialist* services it may not capture all individuals with ID availing of public services. For example, those with a mild ID in particular may not be fully represented as they are more likely to be using mainstream services. Furthermore, records are reviewed annually with clients to ensure information is up-to-date. However, there are no checks on whether care providers complete this form for all or just some of their clients, and while the requirement is that forms are updated annually, this may not consider those who have entered and exited such care on a number of occasions throughout the year, though this number is likely to be very low. At the time of writing, 88% of those registered had up-to-date information (registered or reviewed in 2017). Where a record was not reviewed in 2017, the most recently available data was included for reporting. However, given that most individuals with ID are in contact with services and service providers complete forms, the estimated coverage of the NIDD is 95%[6]. Finally, the NIDD does not collect information on activity level for the services provided and as such it is important to note that a registration for a service does not necessarily equate to a service need being fully met.

It is worth noting that a process commenced in 2018 to integrate the NIDD and the National Physical and Sensory Disability Database (NPSDD) into one system named the National Ability Supports System (NASS). All individuals who receive or require a HSE funded disability service will be registered on the system, this will include those with an intellectual disability, or a persistent physical, sensory, neurological, and learning, autism spectrum, and/or speech/language disability, arising from disease, disorder or trauma. Those availing of a disability funded service without a disability, for example, individuals with mental health issues using disability services will also be registered on NASS. First publications from NASS are expected in 2020.

## 1.3 Demographic Context

### *Census*

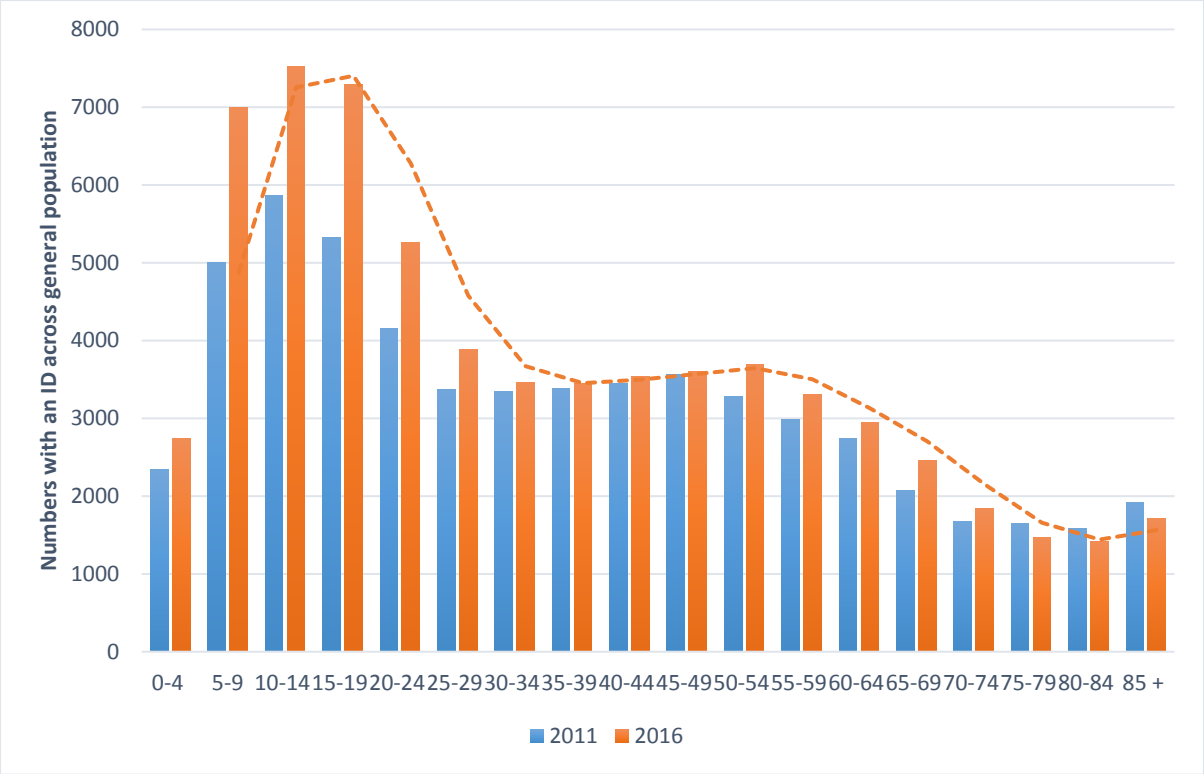
**In 2016, the Census recorded 14% of the population as having a disability and 1.4% having ID.** ID accounts for 10.4% of all disabilities recorded in the Census. Figure 1 shows that the age cohort with

[5] Baseline utilisation of specialist disability services in Ireland. Brick A., Keegan, C. & Wren, M. (2019). Available from: https://www.esri.ie/system/files/publications/WP644_1.pdf

[6] Baseline utilisation of specialist disability services in Ireland. Brick A., Keegan, C. & Wren, M. (2019). Available from: https://www.esri.ie/system/files/publications/WP644_1.pdf

the largest number of individuals with ID in 2016 was the 10-14-year age group. This was closely followed by the 15-19- and 5-9-year age groups. In other words, the largest groups with ID in the population are of school going age (5-19). This is consistent with other countries where the highest prevalence of ID is seen in child and adolescent populations[7]. Further, the lower life expectancy of those with ID relative to the general population is reflected in the lower prevalence rate as age increases.

**Figure 1 Numbers with intellectual disabilities in the population, Census 2011 and 2016**




*Source: CSO Census of the Population 2011 and 2016*

**Census data shows that the prevalence of ID nationally has increased by 15% since 2011**, to 66,611 people or 1.4% of the population in 2016[8]. Increases were evident in particular among those of the school going ages of 5-19 years (40%) and in the 20-24 age group (27%). According to recent analysis from the Education sector, higher reporting of ID in these younger cohorts may in part be explained by the reduced stigma associated with mental health or intellectual difficulties, incentives to seek diagnosis for access to school supports and increased diagnoses of autism spectrum disorder[9].

[7] Prevalence of intellectual disability: A meta-analysis of population-based studies. Pallab K. Maulik, Maya N. Mascarenhas, Colin D. Mathers, Tarun Dua, Shekhar Saxena https://www.sciencedirect.com/science/article/abs/pii/S0891422210003082

[8] Census of Population 2016 – Profile 9 Health, Disability and Carers. Cork: Central Statistics Office. 2018. Available from: https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9tod/

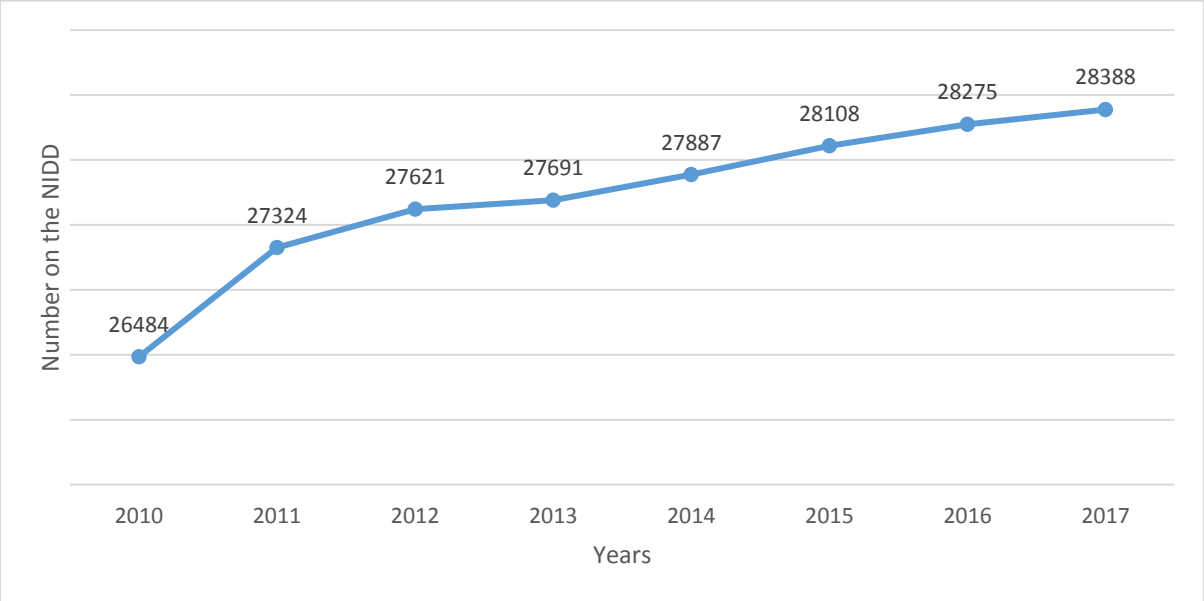
[9] Department of Education and Skills, Central Policy Unit & Irish Government Economic and Evaluation Services (IGEES). Focussed Policy Assessment on Special Needs Assistants. Dublin: Department of Education and Skills; 2016. Available from:

Increased birth rates are also another likely contributing factor as data from the Central Statistics Office (CSO) shows that birth rates rose steadily from 1994, reaching a peak in 2009 at 75,554[10].

### *NIDD*

As of December 2017, there were 28,388 people registered on the NIDD which is approximately 43% of all those recorded in Census 2016 as having ID. Based on the 2016 Census figures, this represents a prevalence rate for ID of 5.96 per 1,000 of the population. In terms of prevalence by *level* of ID, the HRB have estimated that the rate for 'mild' ID (which traditionally has been under-reported) was 1.92 per 1,000, for moderate was 2.48 per 1,000, for severe was 0.82 per 1,000 and for profound was 0.20 per 1,000[11,12]. As shown in Figure 2, **numbers registered on the NIDD have also increased in this period, rising from 26,484 in 2010 to 28,388 in 2017 (7.2%), which indicates an increase in the use of HSE-funded specialist disability services in the period under analysis.**

**Figure 2 Number of people registered on the NIDD 2010-2017**




*Source: National Intellectual Disability Database, 2010-2017*

https://www.education.ie/en/Publications/Value-For-Money-Reviews/Focused-Policy-Assessment-of-Data-on-Special-Needs-Assistants.pdf

[10] Number of Births, Death and Marriages [Internet]. Cork: Central Statistics Office (CSO). 2019: Available from: https://www.cso.ie/multiquicktables/quickTables.aspx?id=vsa02_vsa09_vsa18

[11]Health Research Board. HRB Statistics Series 37 Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings. Dublin: HRB; 2017. Available from: https://www.hrb.ie/fileadmin/2._Plugin_related_files/Publications/2018_pubs/Disability/NIDD/NIDD_Annual_Report_2017.pdf .

[12] An alternative method for estimating the prevalence of level of ID has been provided previously based on the National Disability Survey 2006, a large post-Censal sample. This survey analysed those with an intellectual disability by their level of difficulties with everyday activities, resulting in the following levels of difficulty: just a little - 17%, a moderate level – 36%, a lot of difficulty – 35% and cannot do – 13%. https://www.cso.ie/en/statistics/health/nationaldisabilitysurvey2006volume2/

# 2. Overview of Disability Services

## 2.1 Policy Context

There are several policy developments which are relevant to the period under analysis. Among them are the *Transforming Lives* programme and the introduction of the *National Standards for Residential Services for Children and Adults with Disabilities* by the Health Information and Quality Authority (HIQA) in 2013, and these policy developments provide a context in which to consider the service user profile, service utilisation, and spending data presented in this paper. The *Transforming Lives* programme to implement the recommendations of the '*Value for Money and Policy Review of the Disability Services in Ireland*'[13] has been driving the implementation of national policy to deliver a person-centred model of service provision, to ensure that people with disabilities are supported to make the type of choices about their lives which are available to everyone else in society. This includes actions pertaining to the '*Time to Move on from Congregated Settings*' Report[14], the '*New Directions - Report of the National Working Group for the review of HSE Funded Adult Day Services*'[15] and, the '*National Programme on Progressing Disability Services for Children and Young People (0 to 18 years)*'[16]. In terms of HIQA standards, mandated changes to residential services have included increasing staff-client ratios, safe-guarding measures, improvements to premises and increasing opportunities for residents to go out into the community, among other factors.

## 2.2 Disability Services

Services and supports for people with disabilities and their families cover a wide range of health and social care services such as day services, multidisciplinary support services, full-time residential care, home help, and personal assistance. The HSE funds specialist disability support services directly, as well as through voluntary organisations, for people with intellectual, physical or sensory disabilities, or autism[17]. Most of these services are delivered by voluntary organisations who provide community, residential, and rehabilitative training, and receive grant aid from the HSE under section 38 or section 39 of the Health Act.

[13] Department of Health. Value for Money and Policy Review of Disability Services in Ireland. Dublin: Department of Health; 2012. Available from: https://health.gov.ie/wp-content/uploads/2014/03/VFM_Disability_Services_Programme_2012.pdf

[14] Health Service Executive Working Group on Congregated Settings. Time to Move on from Congregated Settings – A Strategy for Community Inclusion. Health Service Executive; 2011. https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf

[15] Health Service Executive National Working Group for the Review of HSE Funded Adult Day Services. Dublin: HSE; 2009. Available from: https://www.hse.ie/eng/services/list/4/disability/newdirections/new%20directions%20report.pdf

[16] Further information available at: https://www.hse.ie/eng/services/list/4/disability/progressing-disability/

[17] Mental health disability has a separate directorate.

Residential services provided for people with ID typically take the form of community group homes and residential centres, alongside other semi-independent living arrangements. A small number of people are also in intensive placements, foster care and boarding-out arrangements, nursing homes or other care arrangements. HIQA regulates residential and group home services regardless of provider. The other types of services used by those with ID are detailed in Section 4 and Appendices A and B, and include home support/help, education-based services such as special schools, classes and resources, outreach programmes, activation centres and other day support services, employment and training services, as well as multidisciplinary services like medical services, physiotherapy, occupational therapy and psychology services. A small share of publicly-funded supports is delivered via the private sector. The profile of individuals using these private services is not captured in this paper.

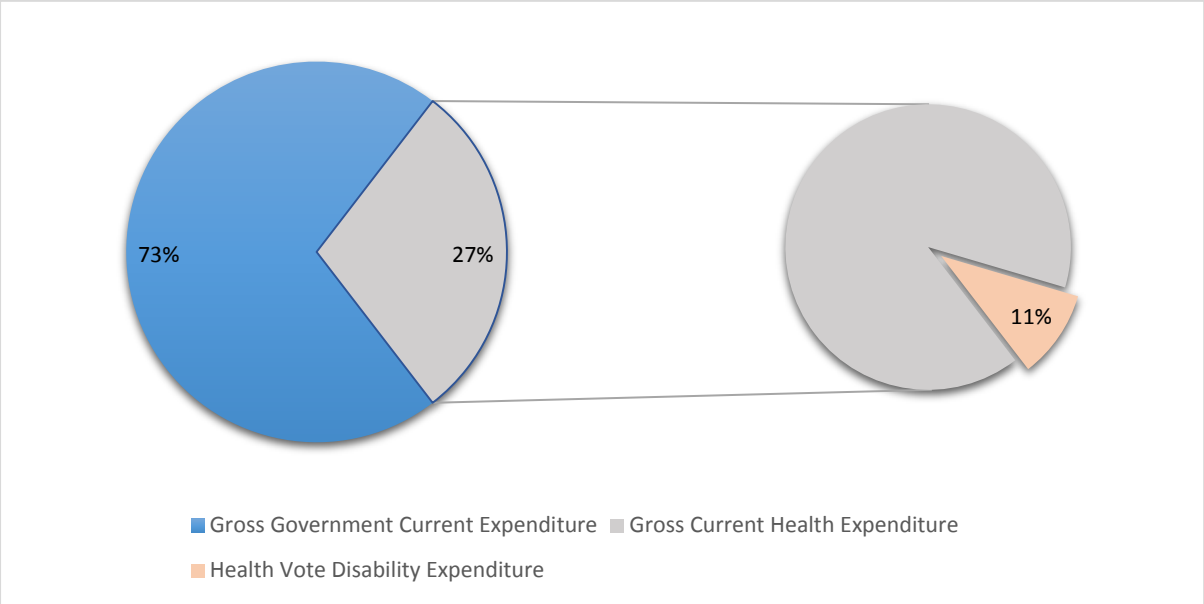
The approach to collecting data on ID and reporting activity for these services has varied over the period analysed. Up to 2012 the HSE Performance Reports included information on the number of bed nights in residential centre-based respite services, and the numbers in receipt of respite services. For 2013, the number of people with ID in funded residential care was included. Between 2010 and 2014 the Department of Health *Long Stay Activity Statistics Report* presented data on ID for people in long-stay units. However, in 2015 the data source and approach to data collection for Long Stay Activity changed, and the report now only includes information on individuals availing of the Nursing Home Support Scheme[18].

## 2.3 Health Spend on Disabilities

Health has traditionally been the second largest area of Government expenditure behind Social Protection. The voted Health allocation in 2017 reached €15.6bn[19]. Gross current Health expenditure has been on average 27% of gross Government voted current expenditure over the period under analysis (2010 to 2017). Of that, disability expenditure accounted for 11% of gross current Health expenditure and makes up 3% of total voted Government expenditure. The proportion spent on intellectual disability solely could not be fully disaggregated from the total Disability Budget at the time of writing.

[18] Prior to 2015 this data was collected as part of an annual survey of long-stay units conducted by the Department of Health. This involved sending questionnaires to each unit. The survey rarely achieved more than an 80% response rate. It is no longer conducted, and data is now collected via the Nursing Homes Support Scheme together with data on capacity from the Health Information Quality Authority (HIQA).
[19] This had reached €17.1bn by 2019.

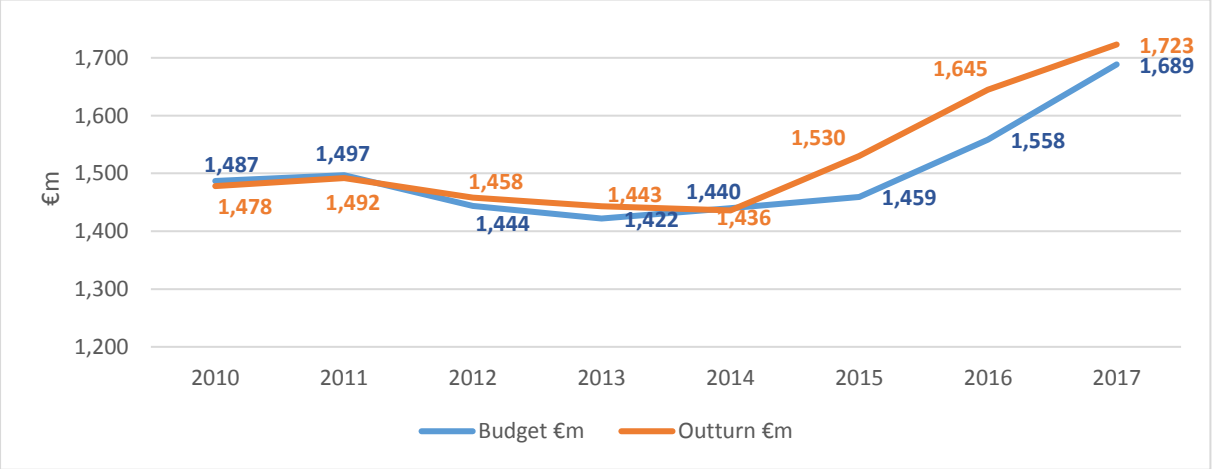
**Figure 3 Health Spend as a percentage of total Vote Spend, Disability spend as percentage of total Health Spend, 2017**




*Source: Department of Public Expenditure and Reform*

Total Health spend on disabilities increased substantially from over €1.4bn in 2010 to over €1.7bn in 2017. Figure 4 shows the annual budget provided to Health disability services and the annual spend (outturn) from 2010 to 2017. Over these 7 years, the allocation for the disabilities line in Health rose almost 14% increasing year on year since 2014. Over the same period disability spend increased at a faster rate by almost 17%, 3% more than allocation. It is important to note however, that the allocation for disability services remained below pre-recession levels until 2017. To illustrate the allocation in 2009 was close to €1.7bn, reducing to close to €1.5bn in 2010.

**Figure 4 Disabilities Budget Allocation and Spend (Outturn) 2010-2017**

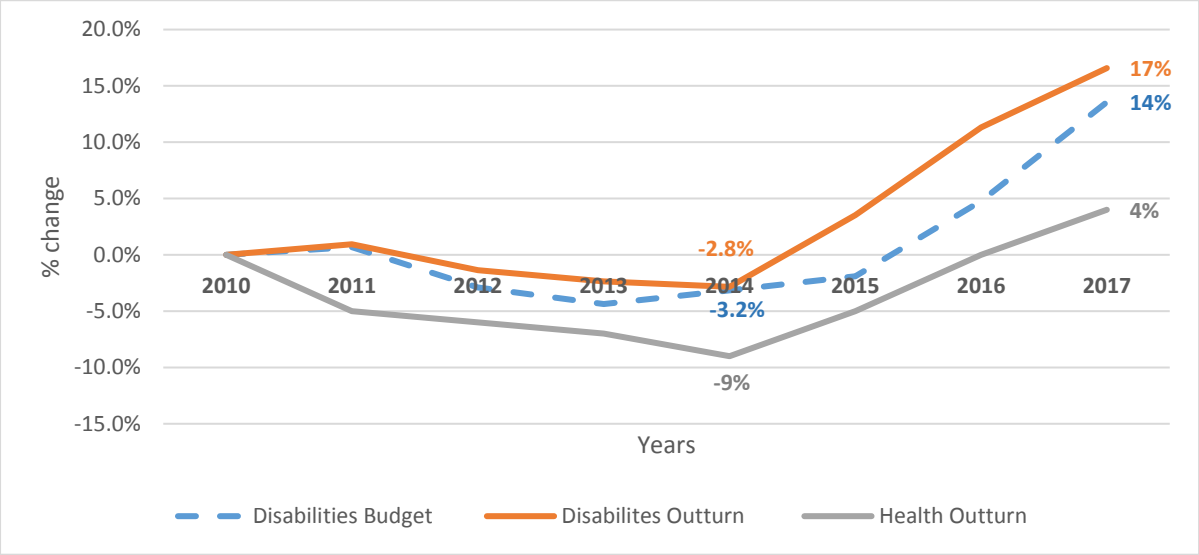



*Source: Management Data Reports, 2010-2017*

As shown in Figure 5, the trend in disabilities spend followed the overall Health spend albeit at a consistently higher rate, increasing by 20% in the same period. How much of this budget was allocated

to intellectual disability services over the period is not available as the exact spend on specialist disability services for those with ID is unknown. This level of data is not routinely included in HSE Management Data Reports as noted in Section 2.2. However, about two thirds of disability spending consists of residential services, and about 90% of those services are for people with intellectual disabilities.

**Figure 5 Health Spend, Disabilities Spend, Budget v. Outturn 2010-2017 (2010 base year)**




*Source: Management Data Reports, 2010-2017*

With the exception of 2014 where spend was marginally below budget, spend on disability services has consistently exceeded the Budget allocation since 2012. The 2017 HSE Annual Report and Financial Statement attributed the deficit in the disabilities service line in that year to the cost of providing residential supports for people with ID, including the provision of emergency placements[20]. Such emergency placements (or other *emergency* services) are at times purchased from the private system due to capacity issues. Compliance with HIQA standards was also noted as a cost pressure in the area in 2017. Since late 2013, the HSE has reported that compliance with regulation has become a significant driver of capital and revenue costs across community-based residential services such as group homes.

Section 1.3 noted that the number of people registered on the NIDD has increased by 7.2% between 2010 and 2017. It is also important to note that the general population grew by around 4%[21] between 2011 and 2016. The figures presented in this section show that from 2010-2017, current expenditure

[20] Health Service Executive. Annual Report and Financial Statements 2017. Dublin: Health Service Executive; 2017. Available from: https://www.hse.ie/eng/services/publications/corporate/hse-annual-report-and-financial-statements-2017-pdf.pdf
[21]Central Statistics Office (CSO). Population Change and Historical Perspective. Cork. CSO; 2017. Available from: https://www.cso.ie/en/media/csoie/releasespublications/documents/population/2017/Chapter_1_Population_change_and_historical_perspective.pdf

on Health increased by 4%. With population growth expected to continue, it is anticipated that expenditure on disability services will also continue to increase and competition for health care workers is likely to put pressure on pay in the sector.

Health is just one area of public expenditure allocated for disability services. €7.2 billion was invested in disability and special education supports across Social Protection, Health and Education in 2017, representing 13% of Government expenditure[22]. Special educational needs expenditure was €1.7 billion in 2017. This expenditure goes towards special education teachers, special needs assistants, school transport, assistive technology and the third level disabilities fund. €3.8 billion was allocated under Social Protection across the range of disability, illness and carers' schemes.

[22] Campbell, de Barra, Duffy, Newman, Reilly. 2017. Disability and Special Education Related Expenditure. Retrieved from:http://www.budget.gov.ie/Budgets/2018/Documents/5.Disability%20and%20Special%20Education%20Related%20Expenditure%20-%20Part%20of%20the%20Spending%20Review%202017.pdf

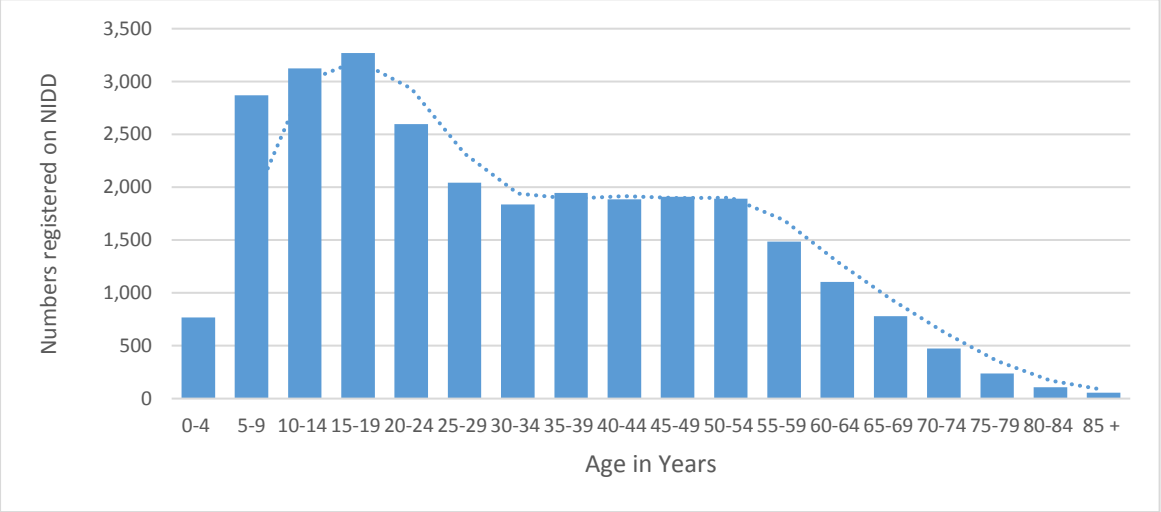
# 3. Profile of individuals with ID receiving Specialist Disability Services

This section presents the profile of individuals with ID who are registered on the NIDD on the basis that they are receiving HSE-funded specialist disability services. This profile includes information on age, gender, location and level of ID.

## 3.1 Age

**The age cohort with the greatest number registered on the NIDD in 2017 is the 15-19 group.** In line with Census data, the school going age group (5-19) broadly have the greatest numbers engaging with specialist disability services.

**Figure 6 Number of people registered on the NIDD by age group 2017**




*Source: National Intellectual Disability Database, 2017*

### *Recent Trends*

The numbers registered on the NIDD have also followed Census patterns of ID growth from 2011 to 2016: rising in the youngest and oldest age groups between 2010 and 2017. The 5-24 and the 50-74 age groups saw the highest growth in numbers on the NIDD with decreases occurring among those registered in the 0-4 and 30-49 age cohorts. The youngest cohort, those aged 0-4 years, saw the largest decrease (36%) in registrations between 2010 and 2017.

On average over the period, 86% of those registered on the NIDD are under 55 years of age; however, since 2010 there has been a 29% increase of those registered in the over 55 group in receipt of specialist disability services, compared with a 4% increase in those under 55. Nevertheless, the 55 plus age group constituted just 14% of those on the NIDD. Based on 2016 Census figures and numbers recorded on the NIDD that year, 27% of those over 55 with ID nationally engaged with specialist

disability services. The largest absolute increase since 2010 in the numbers registered on the NIDD has been seen in those aged 55-59, although all age groups over 55 have seen a steady increase. Figure 6 shows that the older the age of those over 55, the lower the numbers that are registered on the NIDD, reflecting mortality. However, the percentage rate of increase in those registered was the largest in the 70-74 and 85 years plus age groups. Over the 2010-2017 period, the number of over-70s with ID receiving specialist disability services rose by almost 50%.

General growth in the population, the ageing of caregivers and the related need for additional supports, are among the factors that may have contributed to the increase in NIDD registrations in the over 55 age group. Although the average life expectancy of the general population has increased, there has been little change in the age at death for those with ID, with their life expectancy about 19 years lower than for the general population.[23] The 2017 report from the *Intellectual Disabilities Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)* [24] focused on how the health of those with ID, over the age of 40 in Ireland is affected as they age, compared with the general population. Almost half of participants with ID over 40 rated their health as 'excellent' or 'very good'. However, the report found increased levels of chronic conditions as individuals with ID age, and significant differences in the prevalence of chronic health conditions between those with ID and the general population.

An increase in birth rates and ASD diagnoses are potential reasons for the increases in the younger group on the NIDD. The CSO records birth rates as rising steadily from 1994 to a peak of 75,554 in 2009 and declining steadily again to 62,053 in 2017. This goes a long way in explaining the increased numbers with ID between ages 5-24, and the lower rates in the youngest 0-4 age group. There appears to be a cohort of individuals with increased rates of diagnosis of ID moving through the system. Increases in diagnoses of autism spectrum disorder (ASD) may also be an important factor in the increased numbers availing of specialist disability services given that there are many people with a dual diagnosis. According to a Focused Policy Assessment (FPA) of Data on Special Needs Assistants (SNA) in 2016[25], demand for SNAs increased year on year between 2011 and 2016 and this increase

[23] See McCarron et al (2015) *Mortality Rates in the General Irish Population Compared to those with an Intellectual Disability from 2003 to 2012*. Journal of Applied Research into Intellectual Disabilities, 28(5).

[24] Growing Older with an Intellectual Disability in Ireland 2011 https://www.tcd.ie/tcaid/assets/pdf/idstildareport2011.pdf McCarron M, Haigh M, & McCallion P. Health, Wellbeing and Social Inclusion: Ageing with and Intellectual Disability in Ireland – Evidence from the First Ten Years of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing Wave 3. Dublin: Trinity College; 2017. Available from: https://www.tcd.ie/tcaid/assets/pdf/wave3report.pdf

[25]Department of Education and Skills, Central Policy Unit & Irish Government Economic and Evaluation Services (IGEES). Focussed Policy Assessment on Special Needs Assistants. Dublin: Department of Education and Skills; 2016. Available from: https://www.education.ie/en/Publications/Value-For-Money-Reviews/Focused-Policy-Assessment-of-Data-on-Special-Needs-Assistants.pdf

has been forecast to continue. One of the drivers of increased demand was attributed to an increase in the number of students with a diagnosis of autism spectrum disorder (ASD)[26], though this information is not collected on the NIDD. Numbers receiving disability services also tend to dip at the end of schooling age when those receiving school-based supports leave the system and may not progress to adult disability services, as outlined in the previous section.

## 3.2 Gender

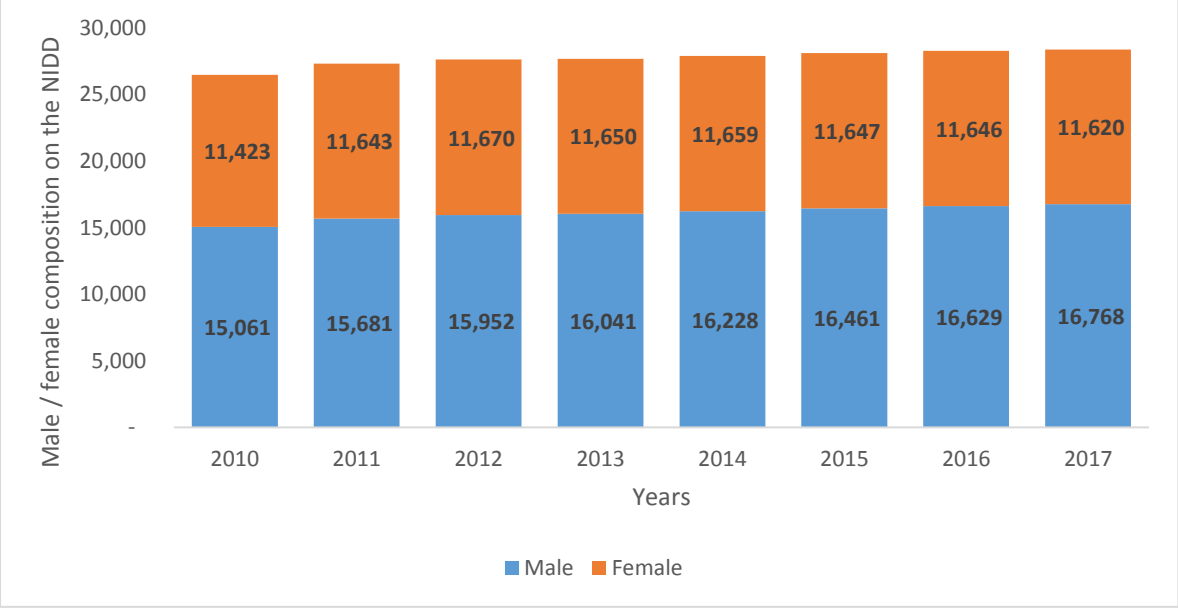
### *Census*

In terms of gender differences, rates of ID are higher among males than females. **According to Census 2016 data, the male to female ratio of persons with ID is 1.6 to 1.** The greatest gender difference is observed in the school-going age cohort of 5-19-year olds. Census data also shows that this gender difference is apparent up to the age of 74. However, from 80 years and over the average ratio of males to females for people with ID changes to 0.6 to 1. This follows the trend in the general population as females have a greater life expectancy at 65 years than their male counterparts.

### *NIDD*

**Similar to the Census, there are more males than females registered on the NIDD:** 16,768 males and 11,620 females in 2017. This represents a slightly lower ratio than the general ID population reported in the Census, at 1.4 to 1.

**Figure 7 Number of males and females registered on the NIDD, 2010-2017**




[26]The Department of Education has recently changed their model whereby professional and other medical assessment or diagnosis is no longer necessary for pupils to access educational teaching resources in schools https://www.education.ie/en/The-Education-System/Special-Education/a-new-model-for-allocating-special-education-teachers-to-mainstream-schools.pdf

*Source: National Intellectual Disability Database, 2010-2017*

### *Recent Trends*

According to Census data, **between 2011 and 2016 the number of males registered with ID increased by 19% and the number of females with ID increased by 10%.** In 2011, 59% of those with ID were male, rising to 61% in 2016. This gender difference is consistent with international trends in the prevalence of ID. To illustrate, a 2011 US study [27] found that between 1997 and 2008, boys had a higher overall prevalence of ID than girls.

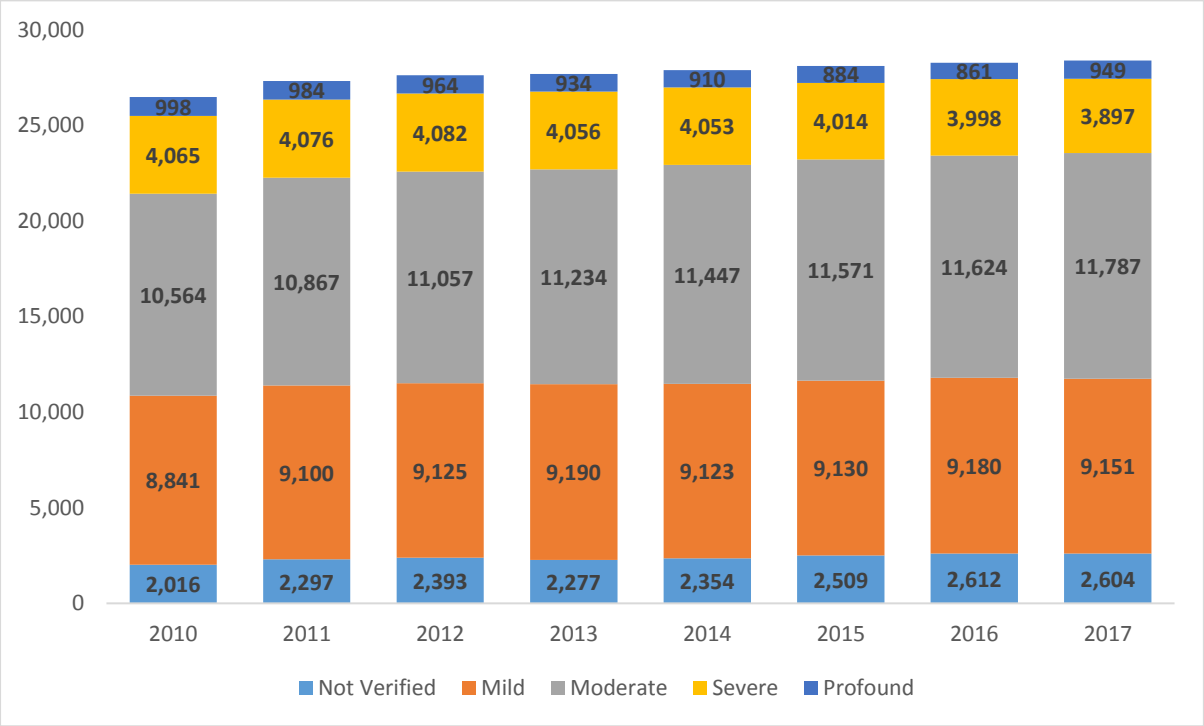
This gender difference is also apparent among those registered on the NIDD in the same period (2011-2016). In 2011 the ratio of males to females on the NIDD was 1.3 to 1. The percentage of males registered on the NIDD increased by 6% while the percentage of females registered on the NIDD increased marginally, by 0.025%.

[27] Trends in the prevalence of developmental disabilities in US children, 1997-2008. Boyle CA[1], Boulet S, Schieve LA, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, Visser S, Kogan MD. https://www.ncbi.nlm.nih.gov/pubmed/21606152

## 3.3 Level of ID

This section profiles the level of ID of those receiving specialist disability services. It also presents ID levels by gender. As of 2017 those with a moderate level of ID make up the largest group on the NIDD: 11,787 people (42%). Those with a profound ID comprise just 3% of those registered on the NIDD.

**Figure 8 Number of people registered on the NIDD by level of ID, 2010-2017**




*Source: National Intellectual Disability Database, 2010-2017*

### *Recent Trends*

**The moderate level of ID has remained the largest group in receipt of specialist disability services since 2010** when it made up 40% of all those registered and has seen the largest percentage growth of those with a verified level of ID. It has seen a 12% increase over the period since 2010. The numbers with 'severe' or 'profound' ID have both fallen over the period under analysis by 4% and 5% respectively. The largest increase (29%) has occurred in the 'not verified' category – as would be expected given these are mainly younger children. This category constitutes just 9% of those getting specialist ID services.

In terms of the gender breakdown *within* each level of ID, 58% of those registered with a 'moderate' level of ID were male in 2017. In other words, 24% of all individuals on the NIDD were males with a moderate level ID. In fact, on the NIDD there is a greater male to female ratio across every level of ID recorded.

## 3.4 Location

### *Census*

According to Census data, the Dublin region, followed by the South West region of Ireland, has the highest prevalence of ID across the country[28].

### *NIDD*

Table 1 shows the breakdown of those registered on the NIDD by Community Health Organisation (CHO) in 2017. Although this gives an indication of the geographic location of those with ID, it is important to note that some CHOs provide more services than others and some individuals on the NIDD may have moved residence to be closer to these services. **CHO Area 4 (Kerry, North Cork, North Lee, South Lee, and West Cork) has the greatest number of people registered on the NIDD since 2010,** with 4,148 people registered in 2017, representing 15% of all individuals registered on the NIDD. CHO 4 is followed by CHO 8 (Laois, Offaly, Longford, West Meath, Louth and Meath) at 14% and CHO 7 (Kildare, parts of Wicklow and parts of Dublin) at 13%. **CHO 6 (Wicklow, Dun Laoghaire, Dublin South East) has the lowest number of people in receipt of specialist disability services at 5.2%.** Allowing for the fact that Dublin is spread over three CHOs, the geographic spread of ID on the NIDD broadly reflects the spread of the population.

Table 1 also details the percentage of the total population in each CHO who are registered on the NIDD. In terms of these proportions, **CHO 2 has the biggest proportion of the area population on the NIDD (0.72%) while CHO 6 has the lowest (0.37%).** A map of the nine CHOs can be found in Appendix A.

[28]Central Statistics Office (CSO). Census of population 2016. Available from: https://statbank.cso.ie/px/pxeirestat/Statire/SelectVarVal/Define.asp?maintable=E9002&PLanguage=0

**Table 1 Number and percentage of people registered on the NIDD by Community Healthcare Organisation (CHO), 2017**

| CHO | Number registered | Percentage registered by CHO | Percentage of total CHO population on NIDD |
|---|---|---|---|
| 1: Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan | 2,582 | 9.1% | 0.66% |
| 2: Galway, Roscommon, Mayo | 3,277 | 12% | 0.72% |
| 3: Clare, Limerick, North Tipperary/East Limerick | 2,390 | 8.4% | 0.62% |
| 4: Kerry, North Cork, North Lee, South Lee, West Cork | 4,148 | 15% | 0.60% |
| 5: South Tipperary, Carlow/Kilkenny, Waterford, Wexford | 3,527 | 12% | 0.69% |
| 6: Wicklow, Dun Laoghaire, Dublin South East | 1,473 | 5.2% | 0.37% |
| 7: Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West | 3,770 | 13% | 0.54% |
| 8: Laois/Offaly, Longford/West Meath, Louth/Meath | 3,855 | 14% | 0.63% |
| 9: Dublin North, Dublin North Central, Dublin North West | 3,366 | 12% | 0.54% |
| | **28,388** | **100%** | |

*Source: National Intellectual Disability Database, 2017*

### *Recent Trends*

In terms of trends in the location of those in receipt of specialist disability services, the numbers registered have increased in all but one of the nine CHOs. Numbers registered in CHO 6 (Wicklow, Dun Laoghaire, Dublin South East) declined by 101 (-6%) in the period under analysis. CHO 4 has had the highest number registered on the NIDD since 2010; however, CHO 8 experienced the most growth in registered users, rising by 499 (+15%) since 2010.

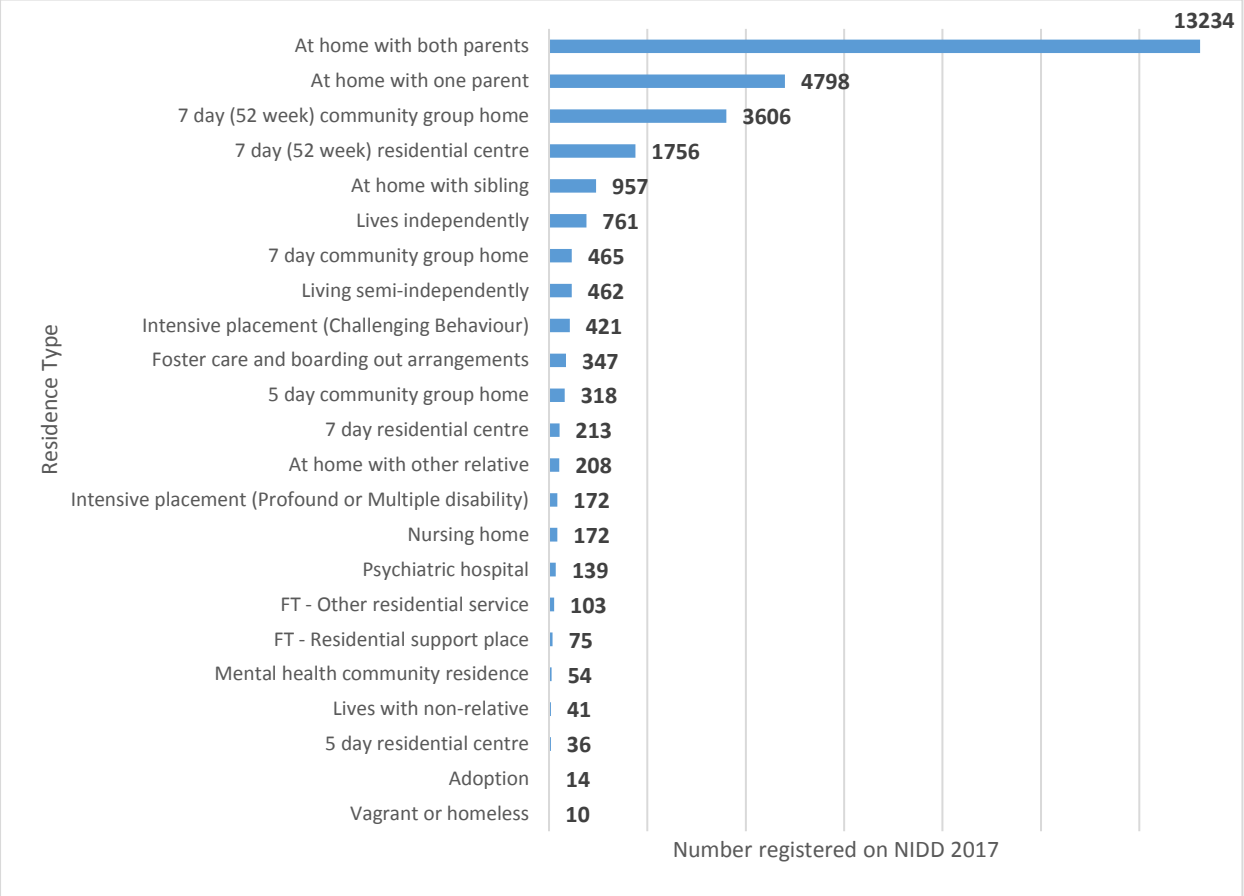
# 4. Specialist Disability Service Utilisation for people with ID

This section provides a summary of the types of specialist disability services that people with ID are receiving. Such services include a range of residential, day services, multidisciplinary support services and respite services[29].

## 4.1 Residence

A summary of the main place of residence for all people registered on the NIDD is presented in Figure 9, demonstrating the broad range of residential care services required by and used by those with ID. The figure below shows that, overall, **the majority of those registered on the NIDD report living at home with either one or both parents (64%).** Outside of the home, 7-day (52 week) community group homes are the most common type of residence (13%), followed by the 7-day (52 week) residential centre (6%).

**Figure 9 Number of people registered on the NIDD by residence type, 2017**

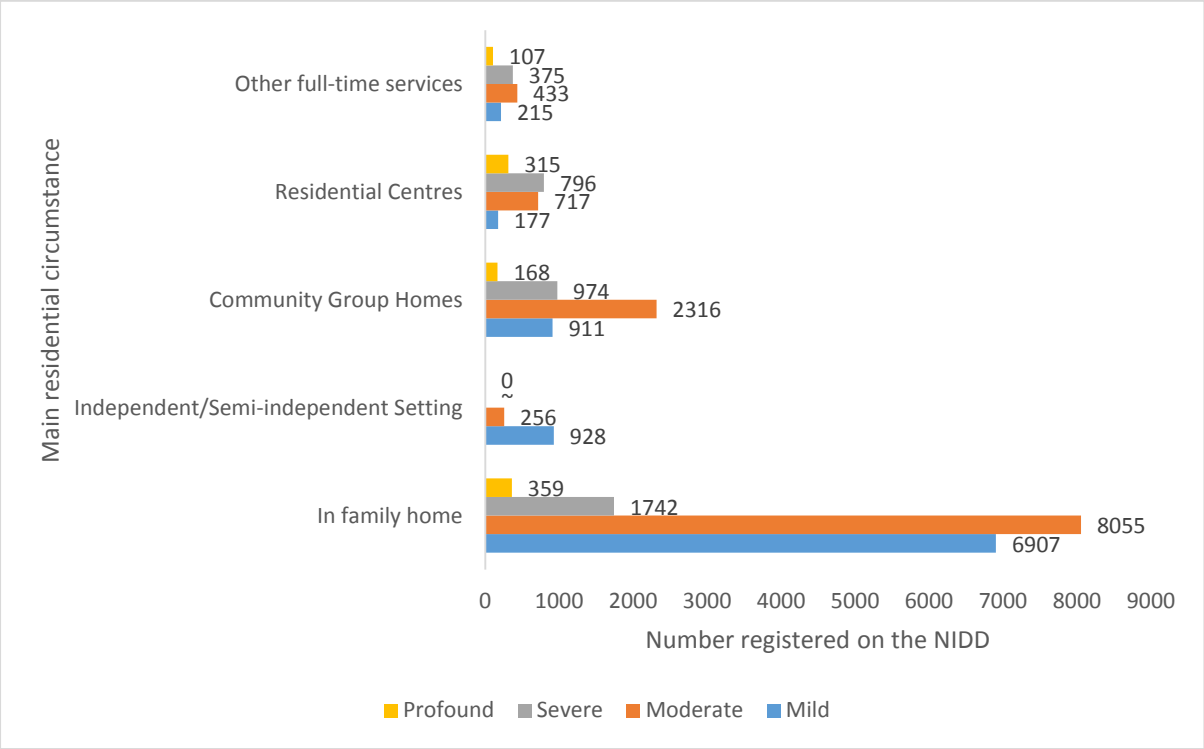



*Note: Total is 28,388. No data available for 26 people who are included in the total.*
*Source: National Intellectual Disability Database, 2010-2017*

[29] For additional data on services received by those on the NIDD see Appendices B and C.

For the purpose of further analysis, main residential circumstance is grouped into the following five categories: in family home, community group home, residential centre, independent or semi-independent setting, and other full-time services[30]. These are summarised in Figure 10 by level of ID.

**Figure 10 Number of people registered by level of ID by main residential circumstance, 2017**




*Source: National Intellectual Disability Database, 2010-2017*

Among those with a 'profound' ID, the majority are living at home (359), followed by a residential centre (315). The vast majority of those with 'mild' ID also currently live in the family home (6,907) followed by independent/semi-independent living arrangements (928) and community group homes (911).

### *Recent Trends*

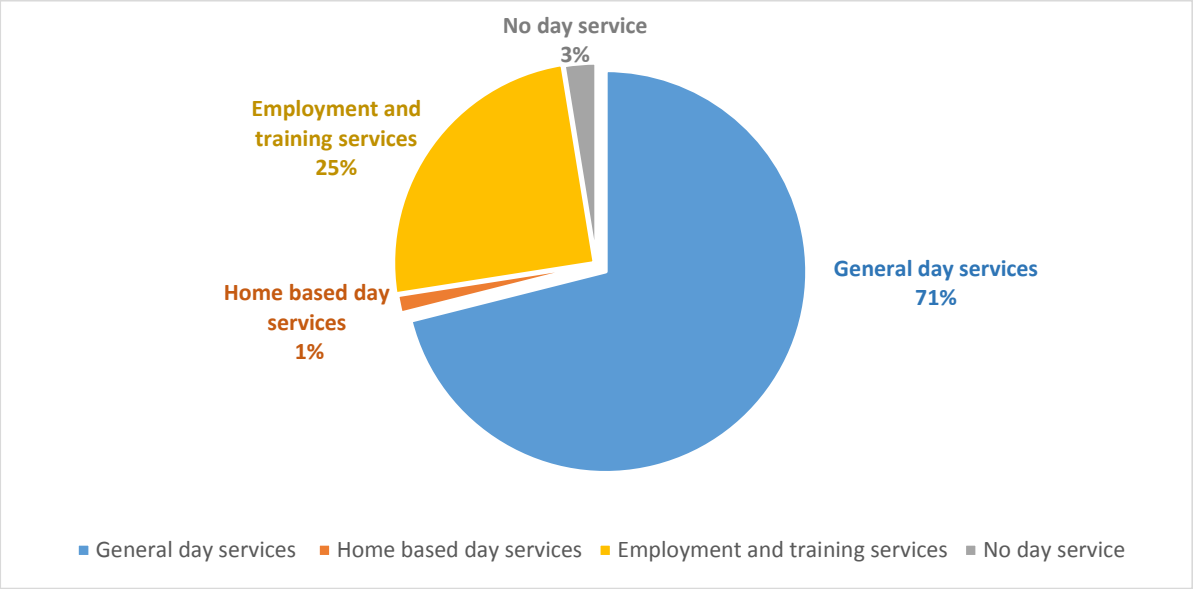
**The numbers of people who are registered on the NIDD and living at home have increased steadily since 2010 (+15%), with a decrease in the proportion living in supported residential settings.** The composition of residential care has shifted away from residential centres (-29% since 2010) towards community group homes (+7%) and in independent/semi-independent settings (+14%). Residential care in 'other full-time services' also declined (-14%).

[30] Other full-time services include nursing homes, mental health community residences, psychiatric hospitals, intensive placements (challenging behaviour), intensive placements (profound or multiple disability), Other full-time residential service and full-time residential support places.

## 4.2 Principal Day Services

Day services encompass a range of services availed of by adults and children with a disability[31]. Day services are person centred supports designed to promote individual choice and community involvement, in order to help those with ID to fulfil their potential. For ID this includes different types of the following: educational supports and services funded by the Department of Education and Skills; adult day services; employment and training programmes; and home-based support. Figure 11 details the percentage of people in receipt of HSE-funded day services in 2017 by principal service type. Educational supports and services have been separated for the purposes of analysis, as the NIDD does not offer a complete picture of these services funded by the Department of Education. Data available on the NIDD on these services is presented in Appendix B. As mentioned in section 1.2 the NIDD does not collect information on activity level for the services provided and as such it is important to note that a registration for a service does not necessarily equate to service needs being fully met.

**Figure 11 Percentage of people registered on the NIDD in receipt of a principal day service by service type 2017**




*Source: National Intellectual Disability Database, 2017*

[31] A more detailed breakdown of each service type can be found in Appendix B.

**Table 2 Number of people registered on the NIDD in receipt of a principal day service by service type and ID level 2017**

| Service Type | Not verified | Mild | Moderate | Severe | Profound | Total |
|---|---|---|---|---|---|---|
| **General day services** | 230 | 3260 | 6270 | 2860 | 780 | 13410 |
| **Employment and training services, and supports** | 40 | 2360 | 2160 | 120 | 0 | 4700 |
| **Home based day services** | 30 | 110 | 90 | 40 | 10 | 280 |
| **No day service** | 20 | 240 | 200 | 20 | ~ | 490 |

*Note: As exact figures are not available for every individual service, figures have been rounded to nearest 10.*
*Source: National Intellectual Disability Database, 2017*

**General day services make up the largest group of services used by those on the NIDD and are the most used service type for all ID levels.** Employment and training services are most utilised by those with a mild or moderate ID, as are home based services. Those with mild or moderate ID are also most likely to not use any day service.

The most frequently utilised type of adult day service are activation centres: a general day service where individuals can access a range of skills and activities such as independent living skills, personal development, education classes, social/recreational activities and health-related and therapy supports. There were 8,746 adults using this service in 2017 (44% of adults on the NIDD), for 8,242 of whom it was their principal day service. Sheltered work (2,356, 12% of adults), supported employment (1,598, 8%), and rehabilitation training (1,441, 8% of adults), were the other main forms of principal day services. Some people engaged in more than one form of day service. To illustrate: supported employment was recorded as the principal day service for 632 people but overall, around 1,600 participated in supported employment. Other forms of adult day services include special high support and intensive support day services, outreach programmes, and programmes for older persons. See Appendix A for a full breakdown of the principal day services used by those on the NIDD.

### *Recent Trends*

The NIDD classifications of day services changed in 2014, therefore for direct comparison, trends in principal day services are analysed from 2014 to 2017. While the number of people registered on the NIDD in receipt of a principal day service increased by 2% between 2014 and 2017, the numbers within individual service types changed significantly in the period. Activation centres have seen the biggest increase in registered users (+594) representing an increase of almost 8% between 2014 and 2017.

Increases also occurred for those attending mainstream schooling and autism units, with the growth in the younger population with ID and increases in autism diagnoses likely contributing factors.

The numbers in receipt of outreach programmes and generic day services also increased over the period. While there were substantial declines in numbers engaging with sheltered work centres (419), representing a 31% decrease, there were also declines in supported employment, and rehabilitative training over the period. The decline in numbers in these services, and sheltered work specifically, reflected the policy for day services set out in *New Directions*, with the emphasis on supporting people to engage in mainstream community activities.

## 4.3 Multidisciplinary Services

Multidisciplinary services cover a range of additional services utilised by those on the NIDD such as medical, mental health and dietician services, as well as speech and language therapy, social work, physiotherapy and occupational therapy. It is important to note that individuals with intellectual disabilities and their families require a range of supports and services as they age, particularly where physical and mental health needs overlap, where medical needs are complex, and where service users present with challenging behaviour. The range of multidisciplinary service that people registered on the NIDD are accessing are summarised in Table 3.

**Table 3 Multidisciplinary services 2017 by level of ID**

| | Not verified | Mild | Moderate | Severe | Profound | Total |
|---|---|---|---|---|---|---|
| **Community nursing** | 693 | 1,688 | 3,376 | 2,104 | 521 | **8,382** |
| **Dietician** | 250 | 561 | 1,369 | 1,175 | 424 | **3,779** |
| **Medical services** | 1,033 | 2,630 | 4,619 | 2,314 | 597 | **11,193** |
| **Occupational therapy** | 1,465 | 1,789 | 2,938 | 1,994 | 605 | **8,791** |
| **Physiotherapy** | 1,222 | 1,266 | 2,588 | 1,828 | 585 | **7,489** |
| **Psychiatry** | 134 | 1,693 | 3,099 | 1,666 | 410 | **7,002** |
| **Psychology** | 949 | 2,139 | 3,694 | 1,561 | 357 | **8,700** |
| **Social work** | 892 | 2,714 | 4,466 | 1,798 | 405 | **10,275** |
| **Speech and language therapy** | 1,719 | 2,395 | 4,142 | 2,245 | 628 | **11,129** |
| **Other multidisciplinary service** | 788 | 1,748 | 2,925 | 1,374 | 368 | **7,203** |
| **Total** | **9,145** | **18,623** | **33,216** | **18,059** | **4,900** | **83,943** |

*Source: National Intellectual Disability Database, 2017*

Medical services are the largest area of service utilisation, with 11,193 of those on the NIDD in receipt of these services in 2017. This is closely followed by speech and language therapy with 11,129 recipients in 2017.

**Table 4 Percentage of individuals of each ID level engaging in multidisciplinary services 2017**

| | Not verified | Mild | Moderate | Severe | Profound |
|---|---|---|---|---|---|
| **Community nursing** | 27% | 18% | 29% | 54% | 55% |
| **Nutritionist** | 10% | 6% | 12% | 30% | 45% |
| **Medical services** | 40% | 29% | 39% | 59% | 63% |
| **Occupational therapy** | 56% | 20% | 25% | 51% | 64% |
| **Physiotherapy** | 47% | 14% | 22% | 47% | 62% |
| **Psychiatry** | 5% | 19% | 26% | 43% | 43% |
| **Psychology** | 36% | 23% | 31% | 40% | 38% |
| **Social work** | 34% | 30% | 38% | 46% | 43% |
| **Speech and language therapy** | 66% | 26% | 35% | 58% | 66% |
| **Other multidisciplinary service** | 30% | 19% | 25% | 9% | 39% |

*Source: National Intellectual Disability Database, 2017*

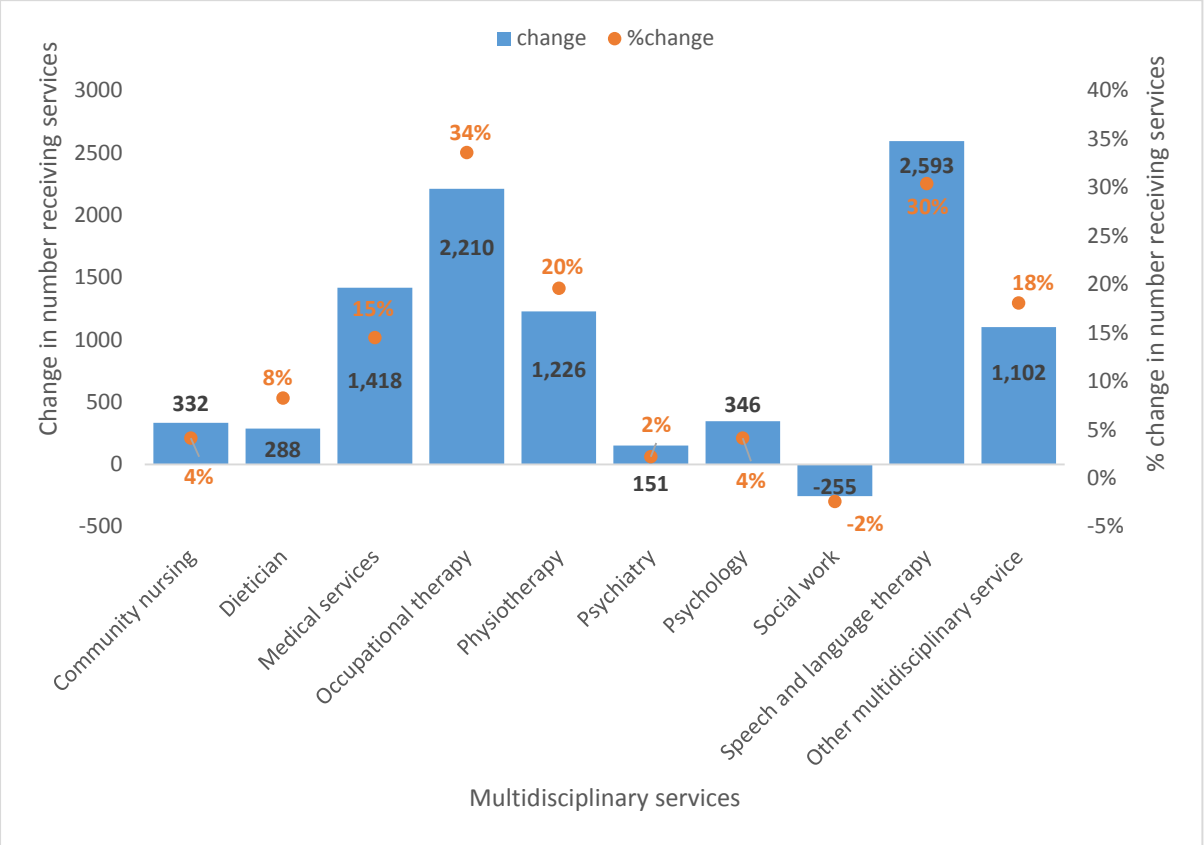
In terms of ID level, utilisation of services tends to increase with ID level severity. Greater proportions of those with a severe or profound ID use nearly all multidisciplinary services when compared with those with a mild or moderate level of ID. This gives an indication of the complexity of needs of these individuals. The 'not verified' category (mostly young children) have high usage rates of speech and language therapy and occupational therapy.

### *Recent Trends*

The number of people registered on the NIDD receiving medical services, speech and language therapy, occupational therapy and physiotherapy, among others have increased in the period between 2010 and 2017, which may indicate the changing patterns of service use needed by a growing older adult population with ID and a large cohort of school age children with ID. Occupational therapy saw a 34% increase in registered users on the NIDD from 2010 to 2017 with speech and language therapy seeing a 30% increase[32].

[32] See Appendix B for more detail on changes in numbers utilizing multidisciplinary services between 2010 to 2017.

**Figure 12 Change in the number of people registered on the NIDD in receipt of multidisciplinary support services, and percentage change, by service type, 2010-2017**




*Note: Therapeutic inputs are only recorded if the person has received, or will receive, at least four inputs of that service in a 12-month period. The number of therapeutic inputs received exceeds the number of people as many people receive more than one input/service.*
*Source: National Intellectual Disability Database, 2010-2017*

## 4.4 Respite Services

The main form of respite service delivered is overnight care away from home, with a limited amount of domiciliary respite and day respite services. In this section, the total number of people and proportion of people on the NIDD in receipt of respite nights, as well as the median number of respite nights received are profiled by CHO area.

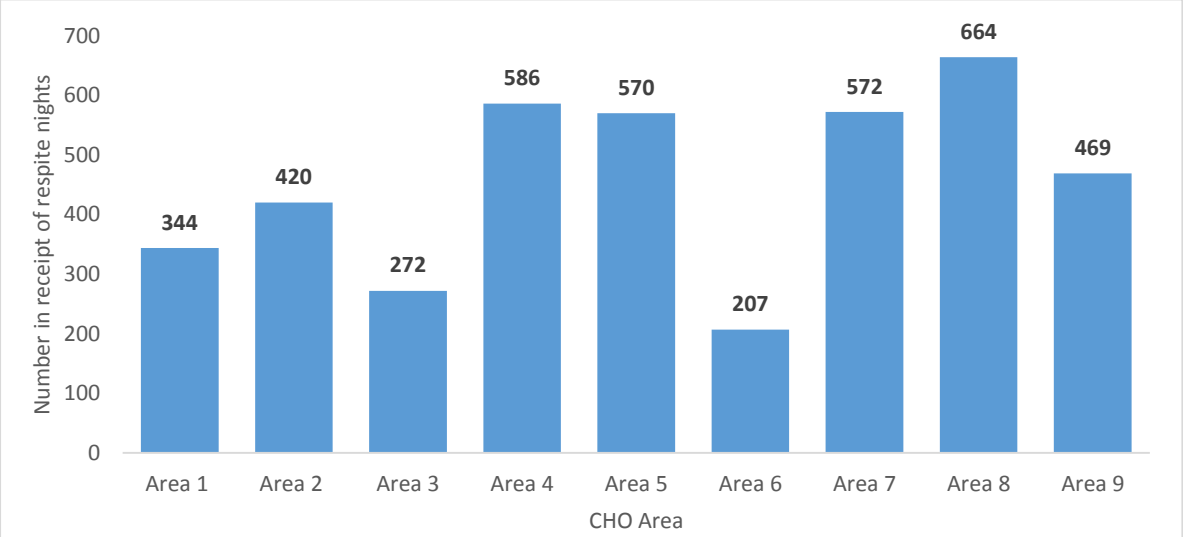
**Overall, 14% of those registered on the NIDD in 2017 were in receipt of respite night services.** The proportion of people registered on the NIDD who received overnight respite in each CHO area is shown in the table below. The highest *proportion* of those receiving respite nights was in CHO 8 (17%), which also had the highest *number* of people registered on the NIDD in receipt of respite nights (664). The lowest share who received respite was in CHO 3 (11%), which had one of the higher median number of respite nights. CHO 1 had the lowest median number of respite nights, but also a below-average proportion of people receiving respite.

**Table 5 Percentage of individuals on the NIDD in receipt of respite nights, median and total number of respite nights received by CHO area.**

| CHO | % of those registered on NIDD receiving respite nights | Median no of respite nights | Total no of respite nights |
|---|---|---|---|
| **CHO1** Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan | 13% | 13 | 5,554 |
| **CHO2** Galway, Roscommon, Mayo | 13% | 36 | 20,278 |
| **CHO3** Clare, Limerick, North Tipperary/East Limerick | 11% | 24 | 8,299 |
| **CHO4** Kerry, North Cork, North Lee, South Lee, West Cork | 14% | 16 | 16,579 |
| **CHO5** South Tipperary, Carlow/Kilkenny, Waterford, Wexford | 16% | 14 | 10,120 |
| **CHO6** Wicklow, Dun Laoghaire, Dublin South East | 14% | 26 | 6,652 |
| **CHO7** Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West | 15% | 19 | 15,220 |
| **CHO8** Laois/Offaly, Longford/West Meath, Louth/Meath | 17% | 15 | 14,393 |
| **CHO9** Dublin North, Dublin North Central, Dublin North West | 14% | 17 | 10,549 |
| **All CHOs** | **14%** | **18** | **107,644** |

*Source: National Intellectual Disability Database, 2017*

**Figure 13 Number of people registered on the NIDD in receipt of respite nights, 2017**




*Source: National Intellectual Disability Database, 2017*

### *Recent Trends*

**Between 2014 and 2017[33], the total number of respite nights received by those registered on the NIDD declined by 13%,** from 124,302 in 2014 to 107,644 in 2017. **The total number of people registered on the NIDD in receipt of respite nights also declined** by 307 (-7%) since 2014.

Seven out of the nine CHO regions saw numbers of people on the NIDD receiving respite nights decline over the period with the exception of CHOs 4 and 8. The numbers receiving respite in CHO 8 (Laois/Offaly, Longford/West Meath, Louth/Meath) increased by 4% over the period, while CHO 4 grew by a substantial 44% since 2014 to be the area with the second highest number of individuals in receipt of respite nights in 2017. This is the largest percentage increase of any of the CHOs over the period. The decline in the percentage of people in receipt of respite nights in CHO 6 between 2014 and 2017 is notably larger than the average decline: -37% compared with -7% overall.

[33] While the data for respite services details the number of *people in receipt of respite nights* between 2010 and 2017, the *total number of respite nights received* is only available for 2014 to 2017, and therefore this 3-year period is analysed in this section.

# 5. Discussion

The aim of this paper was to provide a profile of service users from a broad area of public expenditure (disability) that has seen considerable demographic and policy change over the last decade. Data from the NIDD, a database of service users with intellectual disabilities who are in receipt of HSE funded specialist disability services, was analysed for this purpose, as this national registry is well-positioned to capture trends in service provision, and trends in service user profiles over time. While the NIDD is a rich dataset to base this analysis on there are some data limitations which have been outlined in Section 1.2. To illustrate, registration on the NIDD is not mandatory for all people with ID, and the database is intended to capture utilisation of *specialist* disability services. Therefore, there are individuals with mild ID who may be receiving mainstream services and supports who are not recorded on the database[34]. To this extent, the NIDD does not present a complete picture of the extent to which people with intellectual disabilities have access to services, which limits the extent to which spending to support individuals with ID can be fully estimated and analysed. Nevertheless, the NIDD is the most appropriate dataset for the purpose of this profile and analysis. In the remainder of this section, key findings of this paper are discussed in terms of the changing demographic and policy landscape, and spending. Directions for further analysis are also outlined.

### *People with Intellectual Disabilities*

The Census data analysed has shown that between 2011 and 2016 the percentage of people in the population with intellectual disability increased from 1.3% to 1.4% (66,611 people). From 2010-2017 the numbers of people registered on the NIDD also increased by 7%, from 26,484 to 28,288.

**In terms of level of ID, the number of people with 'moderate' and 'mild' ID registered on the NIDD has increased, whereas the number of those with 'severe' or 'profound' ID has reduced.** Those classified as having a 'moderate' ID have consistently been the largest level of ID over the period. In terms of gender, in line with the ratio of males to females with ID in the population, **there is a higher ratio of males to females registered on the NIDD**, and the growth in numbers registered on the NIDD over the period was also disproportionally males. Although Census data records a 10% increase in the number of women with ID in the years 2011 to 2016, females registered on the NIDD grew by just 0.025%.

[34] Under s 26 of the Disability Act 2005, public bodies are legally obliged to include people with disabilities in mainstream services alongside other service users, where this is practicable and appropriate. So, for example people with a mild ID may avail of physiotherapy services they need via primary care.

**The level of ID recorded as 'not verified' has risen considerably by 29%.** 'Not verified' is a clinical term which means that the level of ID is not yet verified for the person, rather than a gap in data administration. This occurs most commonly in very young children. The rates of 'not verified' are higher for those aged 18 or younger: 27% compared with 1.2% for those aged over 18. This is partially attributable to clinical aspects surrounding diagnosis, delays in assessment, and inability to diagnose due to very young age. To illustrate, the number of individuals registered on the NIDD with a 'not verified' level of ID for 0-6 years is 1,152 compared with 994 aged 7-12 years, and 228 aged 13-17 years. The potential increase in the number of people with autism spectrum disorder (ASD) entering the NIDD, for whom level of ID may not be relevant, may also be contributing to the increase in the 'not verified' category. It is important to note that disability services are based on assessment of need, not level of ID. More complete data to come on stream from the new National Ability Supports System database will provide a fuller picture across physical, sensory, and intellectual disabilities, and autism, including where people have more than one diagnosis, and will provide a better guide as to the factors driving the level and variety of supports needed compared with what current ID level, an IQ-based measure, can show.

There is a growing number of older adults with ID as evidenced by the growth in those aged 55 and older registered on the NIDD. Changes to the age profile of people with ID in receipt of specialist disability services will have an impact on the types of services and supports required by recipients. In particular, an older population of persons with disability will lead to increased requirements for full-time residential care at a stage when parents are no longer able to provide this care at home or may have passed away.

Further to this, the increased number of young people with ID in the population and registered on the NIDD is likely reflective of increased birth rates and increases in ASD diagnoses. A certain proportion of those who are attending school will no longer access specialist disability services when they leave, while others will transition to community-based services. Calculation of the percentage of school leavers and forecasting the range of services they may need will be important in planning for this area of public expenditure.

### *Service Utilisation*

**The majority of people with ID receiving specialist disability services live at home with one or both parents (69%)** and a comparatively small number of people live at home with another relative or independently (4.3%). There has been a reduction in the number of residents in large residential centres and increases in community-based living under 'Time to move on from Congregated Settings'.

Between 2012 and 2017, 661 people transitioned from congregated settings, and 165 transitioned in 2018. In 2017, 7,530 (27%) of people on the NIDD were in receipt of full-time residential services. Of those in receipt of full-time residential services, the majority live in community group homes (58%) compared with residential centres (27%). In 2017, of the 7,530 full-time residents, 6,201 (82%) had a moderate, severe or profound level of intellectual disability, 6,530 (87%) were aged 35 years or over.

The overall proportion of people with intellectual disabilities living at home has risen over this period. This has been the outcome of a fall in the number of residential places available over the period, alongside a growing number of adults with intellectual disability due to population change. The introduction of regulation and standards for residential services has been a factor leading to a decline in the overall number of residential places available. The numbers registered on the NIDD who live in residential centres have seen a steady decline since 2010 (-29%), with engagement with other full-time services also declining (-14%). The reduction in numbers of people with ID living in residential centres between 2010 and 2017 and the increase in numbers living in community group homes reflects policy changes. The *'Time to move on from Congregated Settings'* strategy for social inclusion, developed between 2008 and 2011, prioritises the movement of people with disabilities from large congregated institutions of ten or more people to a new model of support in the community. These developments, along with the introduction of regulation by HIQA in 2013 and associated costs in terms of staffing, as well as improvements to premises and practices, are important to consider in the context of disability expenditure.

There is evidence of increased utilisation of multidisciplinary services such as speech and language therapy, occupational therapy, medical services and physiotherapy. This is broadly reflective of changing patterns of service use by a growing older population with ID and a recent growth in those of school-going age registered for specialist disability services.

There was considerable change in the utilisation of adult day services for people with ID between 2014 and 2017. The NIDD data showed that utilisation of activation centres increased by almost 8% in this 3-year period. The numbers of people with ID utilising outreach programmes and generic day services also increased over the period and there was a decline in the number attending sheltered work centres, supported employment, and rehabilitative training over the period. These changes in day services are reflective of policy moves towards more mainstream, community-based, person centred supports. Broadly, the HSE *Transforming Lives Programme* sets out an approach to day services that aims to ensure that all disability supports are available in the community so that people with disabilities have the widest choice and options with regards to how to live their life and how to spend

their time. More specifically, the *New Directions* approach to adult day services emphasises person centred support that is tailored to individual need and that is flexible and responsive. And more recently the *New Directions Review of HSE Day Services and Implementation Plan 2012-2016*[35] highlighted the need to reconfigure the role of the HSE in relation to training and employment. Focusing on the HSE's remit for the provision of health and personal social services, the report suggests the need for the transfer of responsibility for employment programmes and supports to the Department of Jobs, Enterprise and Innovation and FÁS (now SOLAS). On this basis, the Department of Health and HSE have been working in collaboration with the Department of Employment and Social Protection and the Department of Education and Skills (DES) as part of the Comprehensive Employment Strategy 2015-2024 and coordinated by the Department of Justice and Equality (which has a coordinating role for disability matters). With the assistance of the National Disability Authority (NDA), a pilot project to test the policy approach for a comprehensive supported employment programme has been developed which will provide learning for any future scaling of such an approach for people with intellectual disabilities[36].

Turning to respite services, **in 2017 14% of those registered on the NIDD were in receipt of respite night services, a 13% increase since 2014.** Regional variation in terms of the total number of respite nights received, the number of people receiving respite nights and the median number of respite nights received per person was observed in this analysis. CHO 2 (Galway, Roscommon, Mayo) has the highest median number of respite nights received at 36, followed by CHO 6 (Wicklow, Dun Laoghaire, Dublin South East) with a median of 26 nights per person. However, the number in receipt of respite nights in CHO6 in 2017 had fallen by 37% compared with smaller decreases in other areas. In some cases, respite beds are being occupied on a long-term basis by individuals for whom no residential place has been available, thus reducing availability of respite where this occurs.

Furthermore, **the overall number of people on the NIDD in receipt of, and the total number of respite nights received, have reduced between 2011 and 2017** and the commencement of HIQA regulation in 2013 has impacted on personal space requirements and reduced capacity in places. Further, the HSE have reported the impact of two trends on the availability of respite beds: an increase in the demand for their use by older adults requiring long-term residential placements, and instances whereby beds that are vacated by residents, who return home at weekends or for holidays, can no

[35] Health Service Executive Personal Support Services for Adults with Disabilities. New Directions Review of HSE Day Services and Implementation Plan 2012 – 2016. Dublin: HSE; 2012. Available from: http://www.inclusionireland.ie/sites/default/files/documents/Reports/new_directions.pdf

[36] https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_employment_affairs_and_social_protection/reports/2018/2018-07-27_report-on-supports-available-to-people-with-disabilities-transitioning-from-education-or-training-into-employment_en.pdf

longer be used for respite. Further analysis could focus on the degree to which need for respite services has changed, in particular in areas which have shown a large decrease in utilisation.

### *Health Spend*

While recognising the 7% growth in the numbers of people registered on the NIDD since 2010, the allocation for the disabilities service line rose by almost 14% during the same period, while spend has risen by 17%; broadly returning to pre-austerity levels. However, this is a period where the incidence and prevalence of ID and other disabilities has increased, where demands for services have increased, and where several policies relevant to this sector have been implemented. **While the overall proportion of the disability budget allocation which is spent on ID is unknown, residential services account for 63% of disability line expenditure and around 90% of those who receive a residential service are people with ID.** Overall unit cost of providing residential services has increased, reflecting a combination of increased staffing requirements for fire safety and other reasons identified during regulatory inspections, pay increases, and an increasing proportion of people with intensive support needs. Although relatively few, these individuals can have a very high impact in cost terms. Further analysis of the unit costs of residential service provision would be of benefit given the level of expenditure for these types of services.

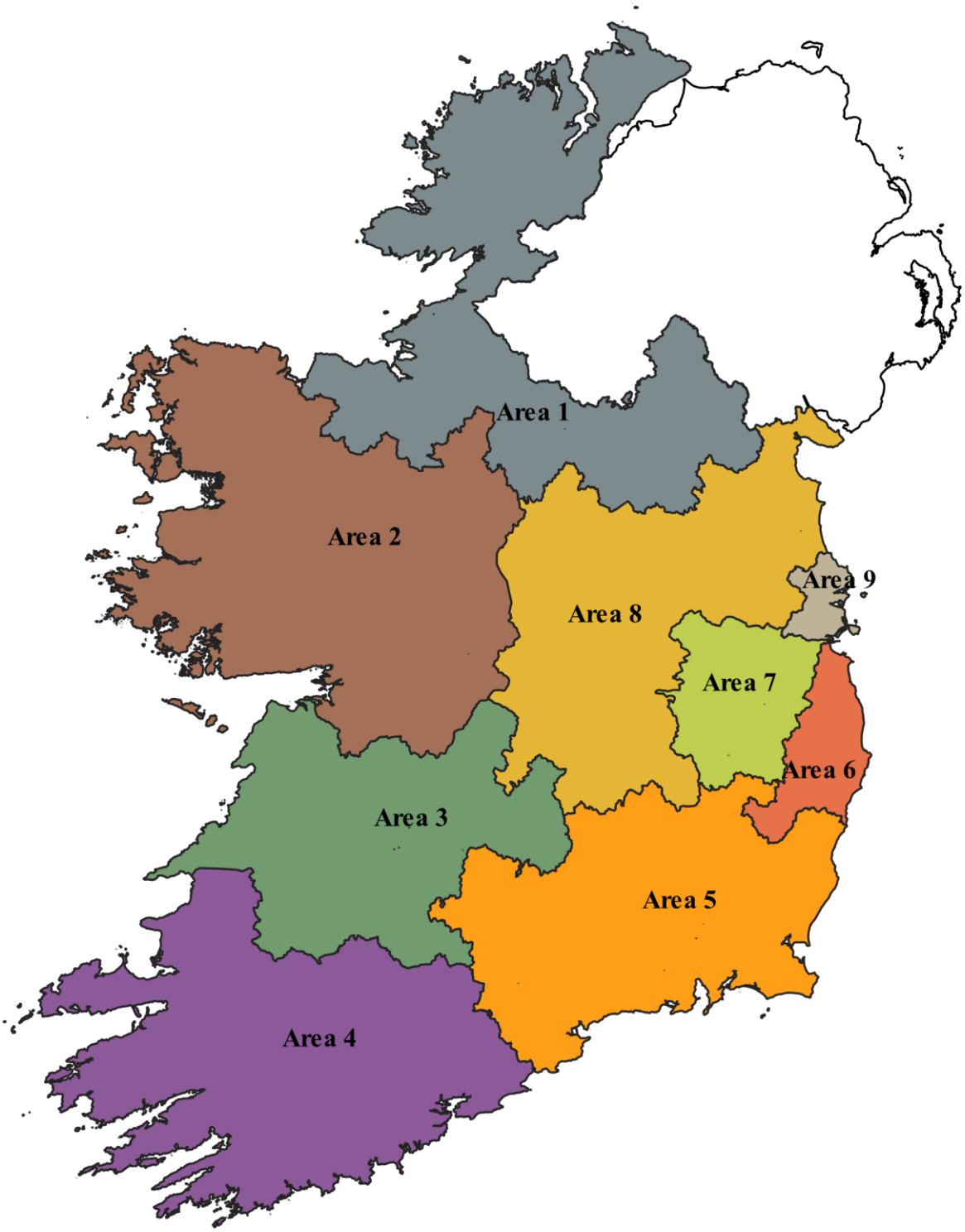
A further 22% of the annual disability budget in 2017 was spent on day services. However, there have also been considerable policy developments in this area. In line with the *Transforming Lives* and *New Directions* policy approaches, there has been notable increases in community-based services like activation centres, outreach programmes and other day services over the period, that support people with ID to live a full life.

### *Conclusion and Further Analysis*

To conclude, this paper has provided a baseline against which future policy and/or budget changes can be considered, in terms of the profile of those on the NIDD and their service utilisation. However, there are some data limitations and areas requiring further analysis. Based on the two data sources used in the paper: the NIDD and CSO data, it was not possible to analyse ID by socioeconomic status or by the deprivation index. This type of information is not collected on the NIDD, while CSO indicators of socio-economic position are based on occupation, which is not appropriate for the ID population given that many are classified as being out of the labour market. Looking ahead, further analysis of the unit cost of disability services for which provision has increased, as well as outcomes for service users, is likely to provide insight that is relevant to this increased spend and a consideration of impact. Further analysis could also focus on the data available on the NIDD in terms of future service requirements, particularly for those who will transition from school to adult disability services, which

will support future planning and budget allocation. The data on unmet need could also be analysed to provide insight on the level of activity received by those who are registered for particular services. The integration of the NIDD database and NPSDD data into one system, the National Ability Supports System (NASS) is an important development to enable such future research.

## Appendix A – CHO areas




*Source: Department of Health*

## Appendix B – Day Services

**Number of people registered on the NIDD in receipt of a principal day service by service type and level of ID 2017**

| Service Type | Service | Not verified | Mild | Moderate | Severe | Profound | Total |
|---|---|---|---|---|---|---|---|
| | No day service | 24 | 240 | 198 | 20 | ~ | 486 |
| **Home based day services** | Home support | 28 | 99 | 75 | 35 | 11 | 248 |
| | Home help | 0 | 11 | 13 | ~ | 0 | 27 |
| | Day respite in the home | ~ | ~ | 0 | 0 | ~ | ~ |
| **Educational services and supports** | Early services | 425 | 60 | 13 | 5 | ~ | 505 |
| | Child education and development centre | 12 | 0 | 8 | 94 | 15 | 129 |
| | Mainstream pre-school | 198 | 25 | 12 | ~ | 0 | 237 |
| | Special pre-school | 222 | 26 | 53 | 18 | ~ | 322 |
| | Mainstream school | 741 | 913 | 757 | 41 | 0 | 2452 |
| | Special class - primary | 105 | 126 | 129 | 35 | 10 | 405 |
| | Special class - secondary | 22 | 120 | 131 | 12 | ~ | 288 |
| | Special school | 398 | 1696 | 1787 | 638 | 107 | 4626 |
| | Resource teacher | 53 | ~ | 6 | ~ | ~ | 63 |
| | Autism unit | 81 | 153 | 152 | 17 | 0 | 403 |
| | Home tutor | 5 | ~ | 5 | ~ | ~ | 14 |
| | Special Needs Assistant | ~ | ~ | 0 | 0 | 0 | ~ |
| | Third level education | ~ | 47 | 15 | 0 | 0 | 66 |
| **Employment and training services and supports** | Sheltered work centre | 6 | 931 | 1215 | 94 | ~ | 2250 |
| | Sheltered employment centre | ~ | 24 | 9 | 0 | 0 | 35 |
| | Enclave within open employment | ~ | ~ | ~ | 0 | 0 | 5 |
| | Supported employment | 7 | 377 | 248 | 0 | 0 | 632 |
| | Open employment | ~ | 109 | 33 | ~ | 0 | 144 |
| | Vocational training | ~ | 169 | 55 | ~ | 0 | 226 |
| | Rehabilitative training | 31 | 753 | 600 | 22 | ~ | 1407 |
| **General day services** | Activation centre | 33 | 1955 | 4104 | 1664 | 486 | 8242 |
| | Programme for the older person | ~ | 97 | 355 | 101 | 11 | 566 |
| | Special high support day service | ~ | 44 | 265 | 319 | 117 | 747 |
| | Special intensive day service | ~ | 51 | 198 | 195 | 39 | 485 |
| | Multidisciplinary support services | 65 | 541 | 598 | 414 | 92 | 1710 |
| | Centre-based day respite service | 0 | ~ | 5 | ~ | ~ | 11 |
| | Outreach programme | 30 | 189 | 161 | 35 | ~ | 419 |
| | Other day service | 47 | 205 | 281 | 104 | 34 | 671 |
| | Generic day services | 52 | 179 | 303 | 24 | ~ | 559 |
| **All services** | **Total** | **2,604** | **9,151** | **11,787** | **3,897** | **949** | **28,388** |

*Note: ~ indicates there are less than 5 people in the cell. ID level is not verified for some on the NIDD.*
*Source: National Intellectual Disability Database, 2017*

**Number of people registered on the NIDD in receipt of a principal day service by service type and year, and change 2014-2017**

| Service Type | Service | 2014 | 2015 | 2016 | 2017 | Change 2014-2017 |
|---|---|---|---|---|---|---|
| | No day service | 420 | 426 | 462 | 486 | 66 |
| **Home based services** | Home support | 209 | 212 | 210 | 248 | 39 |
| | Home help | 28 | 31 | 28 | 27 | -1 |
| | Day respite in the home | ~ | ~ | ~ | ~ | ~ |
| **Educational services and supports** | Early services | 553 | 704 | 647 | 505 | -48 |
| | Child education and development centre | 152 | 137 | 122 | 129 | -23 |
| | Mainstream pre-school | 283 | 237 | 282 | 237 | -46 |
| | Special pre-school | 459 | 328 | 338 | 322 | -137 |
| | Mainstream school | 2169 | 2296 | 2327 | 2452 | 283 |
| | Special class - primary | 395 | 401 | 441 | 405 | 10 |
| | Special class - secondary | 228 | 252 | 235 | 288 | 60 |
| | Special school | 4751 | 4769 | 4670 | 4626 | -125 |
| | Resource teacher | 62 | 39 | 32 | 63 | 1 |
| | Autism unit | 259 | 326 | 368 | 403 | 144 |
| | Home tutor | 15 | 21 | 22 | 14 | -1 |
| | Special Needs Assistant | ~ | ~ | ~ | ~ | ~ |
| | Third level education | 56 | 70 | 72 | 66 | 10 |
| **Employment and training services and supports** | Sheltered work centre | 2669 | 2564 | 2487 | 2250 | -419 |
| | Sheltered employment centre | 51 | 52 | 38 | 35 | -16 |
| | Enclave within open employment | 9 | 14 | 11 | 5 | -4 |
| | Supported employment | 758 | 765 | 662 | 632 | -126 |
| | Open employment | 157 | 152 | 158 | 144 | -13 |
| | Vocational training | 277 | 276 | 280 | 226 | -51 |
| | Rehabilitative training | 1585 | 1477 | 1468 | 1407 | -178 |
| **General day services** | Activation centre | 7648 | 7769 | 7946 | 8242 | 594 |
| | Programme for the older person | 625 | 592 | 577 | 566 | -59 |
| | Special high support day service | 762 | 772 | 781 | 747 | -15 |
| | Special intensive day service | 428 | 468 | 479 | 485 | 57 |
| | Multidisciplinary support services | 1605 | 1582 | 1622 | 1710 | 105 |
| | Centre-based day respite service | 20 | 20 | 18 | 11 | -9 |
| | Outreach programme | 237 | 305 | 360 | 419 | 182 |
| | Other day service | 573 | 588 | 617 | 671 | 98 |
| | Generic day services | 437 | 456 | 505 | 559 | 122 |
| **All services** | **Total** | **27,887** | **28,108** | **28,271** | **28,388** | **501** |

*Note: ~ indicates there are less than 5 people in the cell.*
*Source: National Intellectual Disability Database, 2014-2017*

**Change in the number of people registered on the NIDD in receipt of a principal day service, by service type and level of ID (2014-2017)**

| Service Type | Service | Not verified | Mild | Moderate | Severe | Profound | Total |
|---|---|---|---|---|---|---|---|
| | No day service | 5 | 25 | 35 | 1 | ~ | 66 |
| **Home based services** | Home support | -13 | 26 | 15 | 12 | -1 | 39 |
| | Home help | ~ | 0 | 1 | ~ | 0 | -1 |
| | Day respite in the home | ~ | ~ | 0 | 0 | ~ | ~ |
| **Educational services and supports** | Early services | -47 | 20 | -12 | -8 | ~ | -48 |
| | Child education and development centre | -4 | ~ | 1 | -15 | -4 | -23 |
| | Mainstream pre-school | -28 | 0 | -13 | ~ | 0 | -46 |
| | Special pre-school | -104 | -24 | 7 | -14 | ~ | -137 |
| | Mainstream school | 227 | 7 | 42 | 7 | 0 | 283 |
| | Special class - primary | 17 | -19 | 7 | 2 | 3 | 10 |
| | Special class - secondary | 13 | 26 | 18 | 2 | ~ | 60 |
| | Special school | 115 | -169 | -44 | -21 | -6 | -125 |
| | Resource teacher | 14 | ~ | -1 | ~ | ~ | 1 |
| | Autism unit | 9 | 59 | 68 | 8 | 0 | 144 |
| | Home tutor | -3 | ~ | ~ | ~ | ~ | -1 |
| | Special Needs Assistant | ~ | ~ | 0 | 0 | 0 | ~ |
| | Third level education | ~ | -1 | 9 | 0 | 0 | 10 |
| **Employment and training services and supports** | Sheltered work centre | -3 | -189 | -209 | -17 | ~ | -419 |
| | Sheltered employment centre | ~ | -12 | -3 | 0 | 0 | -16 |
| | Enclave within open employment | ~ | ~ | ~ | 0 | 0 | -4 |
| | Supported employment | -21 | -74 | -30 | ~ | 0 | -126 |
| | Open employment | ~ | -12 | -2 | ~ | 0 | -13 |
| | Vocational training | ~ | -21 | -27 | ~ | 0 | -51 |
| | Rehabilitative training | 10 | -22 | -145 | -21 | ~ | -178 |
| **General day services** | Activation centre | 5 | 308 | 353 | -127 | 55 | 594 |
| | Programme for the older person | ~ | -14 | -20 | -21 | 1 | -59 |
| | Special high support day service | ~ | -6 | 17 | -17 | -10 | -15 |
| | Special intensive day service | ~ | 5 | 38 | 14 | -1 | 57 |
| | Multidisciplinary support services | 16 | 18 | 51 | 27 | -7 | 105 |
| | Centre-based day respite service | 0 | ~ | 0 | ~ | ~ | -9 |
| | Outreach programme | 22 | 70 | 70 | 19 | ~ | 182 |
| | Other day service | 23 | 28 | 15 | 22 | 10 | 98 |
| | Generic day services | 1 | 21 | 99 | 1 | ~ | 122 |
| **All services** | **Total** | **250** | **28** | **340** | **-156** | **39** | **501** |

*Note: ~ indicates there are less than 5 people in the cell. ID level is not verified for some on the NIDD.*
*Source: National Intellectual Disability Database, 2014-2017*

## Appendix C – Multidisciplinary Services

**Change in the number of people registered on the NIDD in receipt of multidisciplinary support services, by service type and level of ID (2010-2017)**

| Service | Not verified | Mild | Moderate | Severe | Profound | Total |
|---|---|---|---|---|---|---|
| **Community nursing** | -144 | 74 | 371 | 83 | -52 | 332 |
| **Nutritionist** | -63 | 43 | 227 | 60 | 21 | 288 |
| **Medical services** | 44 | 514 | 846 | -12 | 26 | 1,418 |
| **Occupational therapy** | 311 | 411 | 1,005 | 419 | 64 | 2,210 |
| **Physiotherapy** | 87 | 240 | 647 | 238 | 14 | 1,226 |
| **Psychiatry** | 8 | 120 | 322 | -243 | -56 | 151 |
| **Psychology** | 150 | -126 | 253 | 4 | 65 | 346 |
| **Social work** | -32 | -360 | 139 | -31 | 29 | -255 |
| **Speech and language therapy** | 305 | 219 | 1,199 | 687 | 183 | 2,593 |
| **Other multidisciplinary service** | 305 | 177 | 475 | 99 | 46 | 1,102 |

*Note: ID level is not verified for some on the NIDD.*
*Source: National Intellectual Disability Database, 2010-2017*

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