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Baseline utilisation of specialist disability services in Ireland

Aoife Brick*, Conor Keegan and Maev-Ann Wren

Abstract: The objective of this paper is to analyse the data on specialist disability services available in Ireland. The paper provides a baseline utilisation profile of selected services which can be used to project future service demand and expenditure. The limitations of the currently available data in providing a comprehensive picture of specialist disability services in Ireland are also outlined.

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ESRI Research Programme in Healthcare Reform

Baseline Utilisation of Specialist Disability Services in Ireland

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ABBREVIATIONS

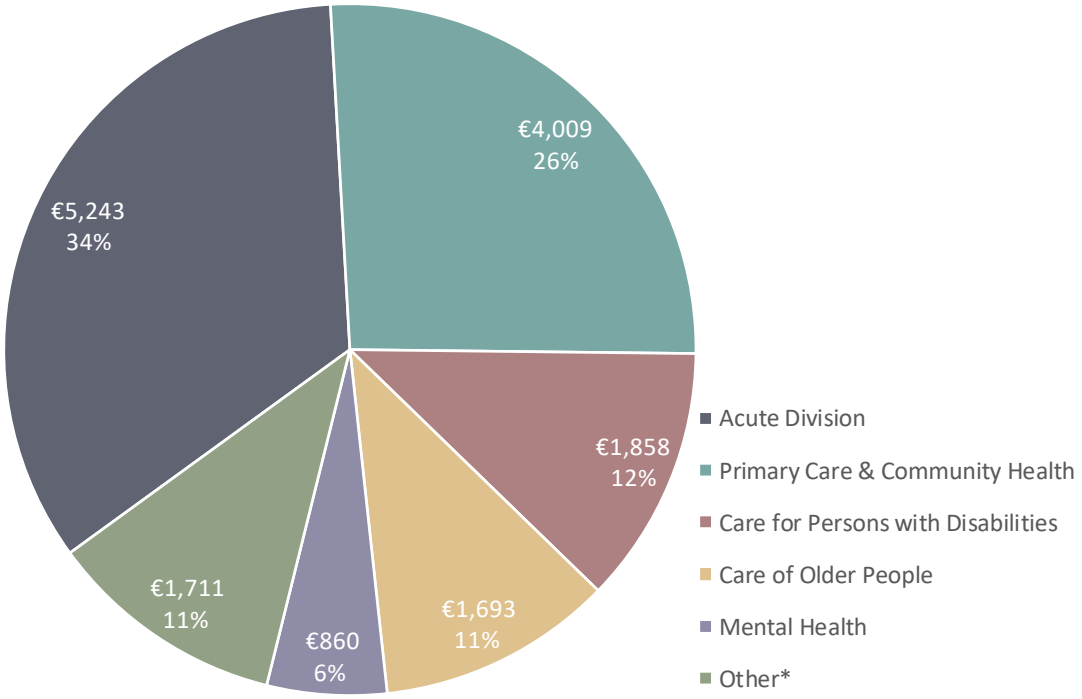
HRB	Health Research Board
HSE	Health Service Executive
ID	Intellectual Disability
NASS	National Ability Supports System
NIDD	National Intellectual Disability Database
NPSDD	National Physical and Sensory Disability Database
OGS	Occupational Guidance Service
PSD	Physical and Sensory Disability
RT	Rehabilitative Training

1 Introduction

The first report from the Hippocrates model published in 2017 provides baseline estimates and projections of public and private healthcare demand for a range of Irish health and social care services for 2015–2030. The model will be developed in stages and aims to add additional activity as data availability allows. One such area of activity that was excluded from the initial baseline analysis was disability services which accounted for 12.1 per cent of the HSE gross non-capital vote allocation or €1,858m (Figure 1) in 2017.

The focus of this paper is on services provided to those with an intellectual (ID) and/or physical and sensory disability (PSD) who require *specialist* disability services. Services provided to those with mild levels of disability which are provided through primary care or mainstream education are not included.

FIGURE 1 HSE Gross Non-Capital Vote Allocation, 2017 (€m)



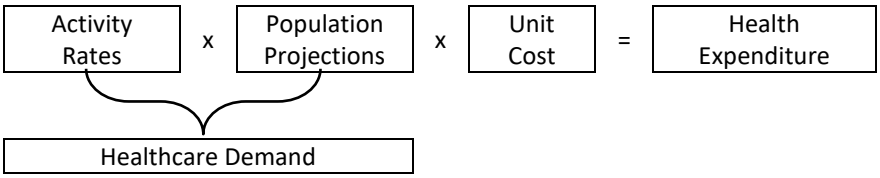
Note: * Other includes statutory pensions, health and wellbeing, long term charges repayment scheme, and other
Source: Department of Health (2019)

The objective of the following paper is to analyse the types of specialist disability services data available and how these might be incorporated into the Hippocrates model.[1] The Hippocrates model employs a macro-simulation approach to project demand for and expenditure on health and social care services. The model disaggregates demand and expenditure estimates for each healthcare service by age and sex (2) and aims to include both public and private activity and cost wherever possible. The first step in the modelling is to estimate utilisation and

1 Services provided in the primary care setting are not included in this analysis.

demand in the base year. In the next step, healthcare demand is projected based on projected population growth and ageing, with sensitivity analyses exploring alternative assumptions about population growth, unmet need and demand, and healthy ageing. Projections of expenditure (Figure 2) will be developed by applying cost data to projected demand.

FIGURE 2 Hippocrates Model



We are cognisant of the substantial work done in this area by Working Group 1 (WG1) (Strategic Planning) of the Transforming Lives Programme. This programme was established to implement the recommendations from the Value for Money and Policy Review of Disability Services in Ireland (3). The first report from WG1 published in 2018, examined the future needs for disability services in Ireland to 2026 and in doing so grappled with the very challenging data environment in this area to establish a baseline from which to estimate future demand (4). The Hippocrates model work programme will draw upon the above work to inform future work packages on unmet need for disability services and for establishing scenarios for projecting demand.

The specific objective with this paper is to provide baseline utilisation data for specialist disability services which can be included in the Hippocrates model. The limitations of the currently available data in providing a comprehensive picture of specialist disability services in Ireland are also outlined.

Section 2 outlines the data available on specialist disability services in Ireland while section 3 details the methods used to generate service utilisation profiles for these services. Sections 4 and 5 present detailed findings on service utilisation and utilisation rates for the ID and PSD populations by age and sex. Section 6 presents utilisation data and utilisation rates for rehabilitation training services while section 7 concludes.

2 Data Sources

There are several data sources on which this paper draws to establish baseline service utilisation for specialist disability services.

- Two databases are available from the Health Research Board (HRB); the first and more comprehensive is the National Intellectual Disability Database (NIDD), the second is the National Physical and Sensory Disability Database

(NPSDD). The NIDD and NPSDD are discussed in detail in the following sections. It must be noted that 2017 is the last year in which the NIDD and NPSDD are available. The two datasets have since been merged into the National Ability Supports System (NASS). This dataset collects all the data previously collected as well as additional information including the frequency of use of services. The data are as yet unavailable.

- The HSE Disability Services Key Performance Indicators (KPIs) provide utilisation information on selected specialist services provided by HSE Disability Services. Of particular relevance here are data on the numbers of people in receipt of residential services, day services, respite services, home help, and personal assistance (5). There is no age or sex disaggregation available for KPIs but they can be disaggregated by ID and PSD. The data are submitted by HSE local disability managers and collated centrally.[2] They are used nationally for service planning, target setting, and tracking progress. It should be noted that the KPIs report on HSE funded services only. Also, for this work the 2017 KPI definitions are used.
- The HSE Occupational Guidance Service (OGS) database contains detailed data, disaggregated by age and sex, of people with a rehabilitative training place.

There are benefits and issues with each data source, so to create as accurate a baseline for projection as possible a combination of sources will be required. The following sections will discuss each of the sources in detail and outline how it is proposed to include these data in the Hippocrates model for each of the main service categories.

2.1 National Intellectual Disability Database

The NIDD is a national service-planning database established in 1995 and administered by the HRB on behalf of the Department of Health. The database captures data on the usage and need for specialist disability services among people with ID. Information is collected on residential (including respite), day, and multidisciplinary support service usage and future service need. The data are gathered through a three-step process. Firstly, service providers collect information on the clients for whom they are responsible.[3] Secondly the data are returned by service providers (statutory and non-statutory) to the database managers in each HSE area who check the integrity of the returns. Finally, each year an extract of data records are taken from the database by the HRB, validated, analysed and published in the NIDD annual reports (6). Returns are made on a voluntary basis and those in receipt of services or their next of kin must give their

2 All local area disability managers were contacted to gauge if any more detailed data on the age and sex of individual service users are collected at local level but no further data were available.

3 If a client receives services from more than one provider the main provider is responsible for collating all data.

written consent. In 2017, 88.4 per cent of registrations in the NIDD were reviewed (7).[4]

The NIDD is thought to be highly representative of the population with an ID in Ireland. The HRB estimate coverage at 95%[5] on the basis that most individuals with an ID are in contact with services and it is service providers who provide the returns to the HRB. The HRB acknowledge that there is possible under-representation of individuals in the mild ID category as they do not tend to engage with specialist disability services. It is also thought that individuals with autism are underrepresented in the database. In addition, if a person acquires a disability after the age of 65 they would likely be cared for through Older Persons Services rather than Specialist Disability Services.

As the NIDD is highly representative of the overall ID population if expenditure data obtained as part of a future work package is at a more disaggregated level than the utilisation data presented here it would be possible to further disaggregate the NIDD by service type. For example, rather than looking only at 'day services' it would be possible to look at 'activation centres', 'open employment' etc. The analysis presented in section 4 is based on validated NIDD data extracts from December 2012, 2015, 2016, and 2017 and published annual reports.

2.2 National Physical and Sensory Disability Database

The NPSDD is a national service-planning database established in 2002 and administered by the HRB on behalf of the Department of Health. The database captures data on the usage and need for specialist disability services among people with PSD. Unlike the NIDD, individuals included in the NPSDD are 65 years or younger. Information is collected on day, residential, and multidisciplinary support service usage and future service need. The data are collected by the HSE and returned to the HRB on an annual basis. Returns are made on a voluntary basis and those in receipt of services or their next of kin must give their consent.

Coverage of the NPSDD is problematic. For many years the target population for the database was estimated as 10.53 per 1,000 of the population aged 65 years or younger. This target population figure comes from a study carried out as part of the development of the NPSDD in 2001 and is based on information from one area in the country (South Tipperary) (8). This figure was used to extrapolate the estimated national target population for a period of time, however, it has since ceased to be used due to temporal changes in demographic profile and service

4 Most of the cases not reviewed in 2017 were in two HSE areas. The proportion of cases reviewed each year has varied from 99.4 per cent in 2012 to 84.8 per cent in 2016.

5 Personal Communication with HRB 25 July 2018.

utilisation. In the absence of an alternative this figure is used to estimate a target population of 44,126[6] for 2017 which is an increase of 6.5 per cent on 2007 (41,442). In 2017, the number of people actually registered was 20,676 (9) implying coverage of 47.1 per cent. This is a significant decrease on the coverage of 67.9 per cent achieved in 2007 which according to the HRB is due in large part, to a lack of resources to carry out new registrations and undertake reviews of existing registrations.

In addition to an estimated coverage level of 47.1 per cent of individuals with PSD in the NPSDD there are several additional issues with the NPSDD highlighted by the HRB. While it is recommended that registrations are reviewed in full each year this has not being achieved. In 2017, it was reported that just 9,956 (48.2 per cent) of the current registrations had been reviewed in the previous five years and of these current service use and future service requirements data are only available for 5,654 (27.3 per cent) records registered or reviewed in 2017 (9). It is not possible to say how representative those registered are of the overall population with PSD and therefore to know how valid the data collected on those registered and reviewed are of service utilisation for the overall population.

The analysis presented in section 6 is based on a validated data extract from December 2017. Unlike the NIDD analysis no comparisons across years are made using the NPSDD data due to the issues with coverage.

2.3 HSE Key Performance Indicators

A range of services are provided by specialist disability service providers throughout the country. Through its KPIs the HSE collects information on residential services, day services, respite services, home support, and personal assistant hours. Data on these services are also collected by the NIDD and NSPDD.

2.4 National Occupational Guidance System

Rehabilitative training (RT) places are provided to individuals for a period of between one and four years. The quality of the data in the area of RT is significantly better than that for other areas as a case management system, the 'National Occupational Guidance System', exists. This system provides comprehensive data on RT service use, measured in terms of the number of services users and the of whole-time equivalents by age and sex. For this reason, we will use it rather than NIDD/NPSDD to include RT in the projection model. The analysis presented in section 6 is based on a validated data extract from December 2017.

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6 Using CSO Census of Population 2016 aged 65 years or less of 4,168,454 the target would be slightly less at 43,894.

3 Methods

The methods used to establish the baseline data for disability services in the following sections vary by service due to the data availability and quality issues outlined in section 2. Utilisation profiles by age and sex for disability services are calculated separately for the ID and PSD populations as per the availability of the data. Table 1 outlines the services for which baseline utilisation has been established and the data used to do so. It also outlines which services will be initially excluded from the Hippocrates Model to project demand for specialist disability services in the future, until the data environment improves.

TABLE 1 Baseline Utilisation: Service Data Sources

Service	Data Source		Hippocrates Inclusion
	Estimated Age/ Sex Profile	Utilisation	
Residential Services	NIDD, NPSDD	KPI	Yes – ID Only
Respite Services	NIDD, NPSDD	KPI	No
Home Support	NIDD, NPSDD	KPI	No
Personal Assistance	NIDD, NPSDD	KPI	No
Day Services	NIDD, NPSDD	KPI	Yes – ID Only
Multidisciplinary Services	NIDD	NIDD	No
Rehabilitative Training	OGS	OGS	Yes

With the exception of RT and multidisciplinary services, utilisation data, total number of users and total number of hours used, are sourced from the 2017 KPIs provided by the National Business Information Unit at the HSE. To generate an age and sex profile for these services which can be applied to the KPIs the NIDD and NPSDD service data are aggregated according to the KPI definitions as published in the HSE Disability Services Key Performance Indicator Metadata 2018 (5). Final service user age and sex profiles for each service are achieved by applying the age and sex distributions from the NIDD/NPSDD to the total number of users/hours reported in the KPIs.[7] Rates per 1,000 population are then calculated using Census of Population figures and ESRI population estimates for intercensal years.

In the case of multidisciplinary services where KPI data are not available, the NIDD is used to estimate the number of users for the ID population but no estimates were possible for the PSD population due to poor coverage.

In addition to the baseline utilisation profile by age and sex additional analyses of the NIDD are undertaken in section 4, examining patterns of registrations and changes in service utilisation over time. Given the coverage issues with the NPSDD these comparative analyses were not undertaken for that dataset.

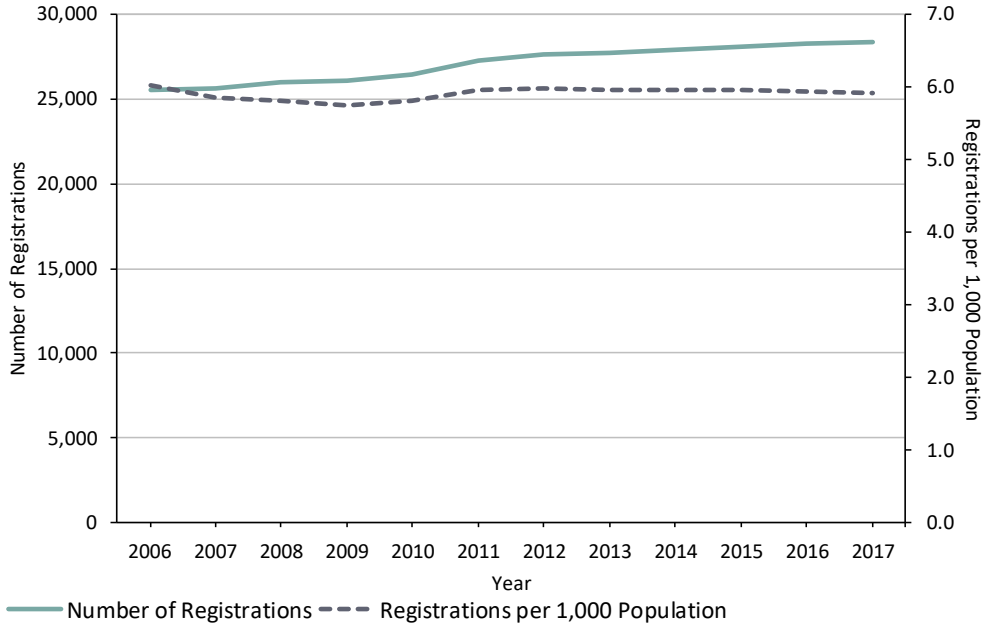
7 While privately funded service utilisation is not included in KPIs, as discussed in later sections, for the majority of disability services private provision does not appear to be a big component of total service provision.

4 NIDD – Findings

4.1 Registrations Over Time 2006–2017

The number of NIDD registrations have increased year on year between 2006 and 2017, with an average annual increase of 1 per cent. However, when examined on a population basis there was an average annual decrease of 0.2 per cent in the number of registrations per 1,000 population. The numbers of registrations were at their lowest in 2006 (25,518) and peaked in 2017 (28,388), while registrations per 1,000 population were at their lowest in 2009 (5.75) and peaked in 2006 (6.02) (Figure 3).

FIGURE 3 NIDD: Number of Registrations and Registrations per 1,000 Population, 2006–2017



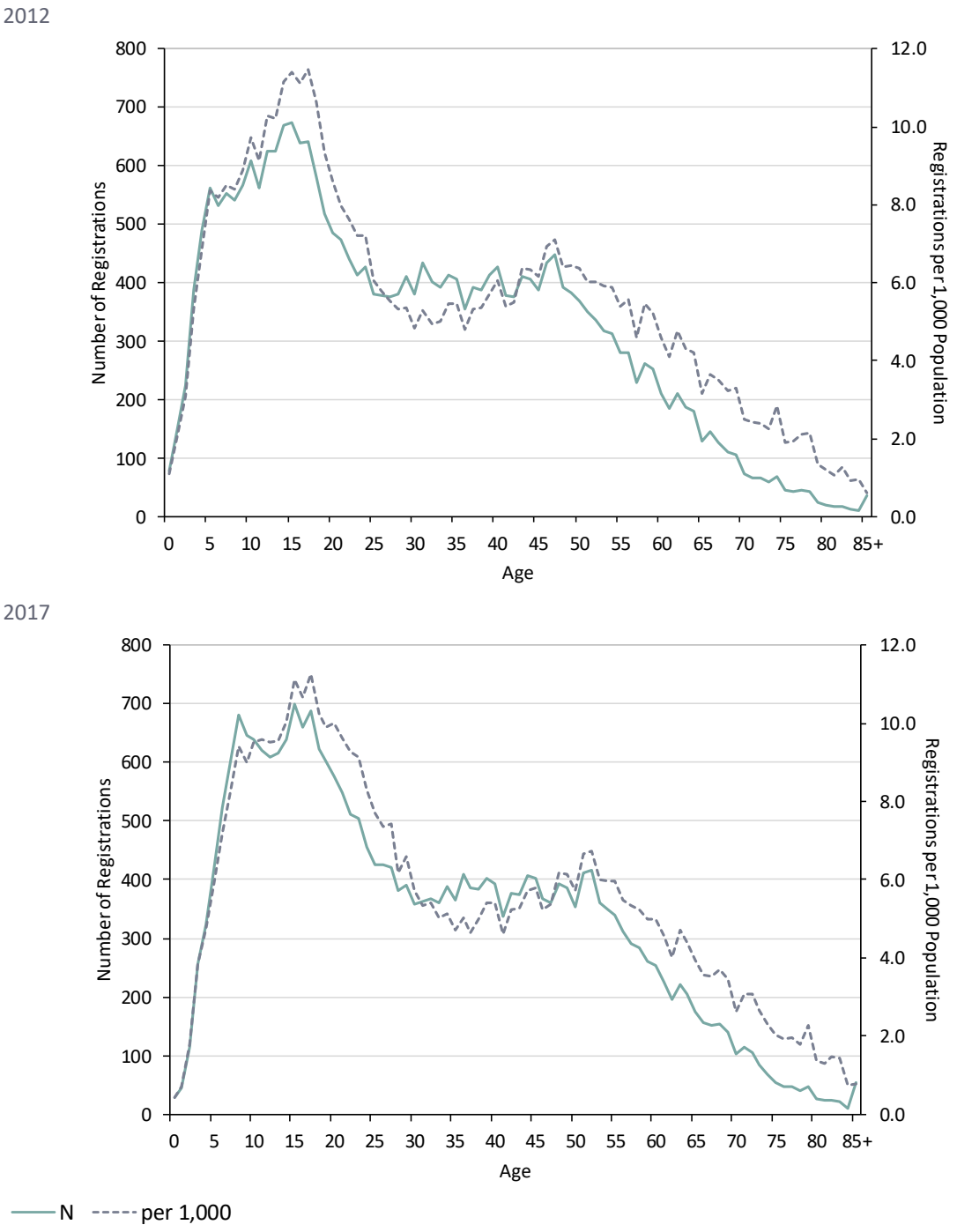
Note: Rates per 1,000 population are calculated using Census of Population figures and ESRI population estimates for non-census years.

4.2 Registrations by Age and Sex

The overall number of registrations on the NIDD has increased from 27,621 to 28,386 between 2012[8] and 2017 (Figure 4). In both years registrations peaked at 15 years of age and registrations per 1,000 population peaked at 17 years of age. There is a sharp fall in the number of people registered from these ages while from ages 25 to 49 years, registrations remain relatively stable. From age 50 and over in 2012 and 55 and over in 2017, there is a gradual fall off in the number of registrations.

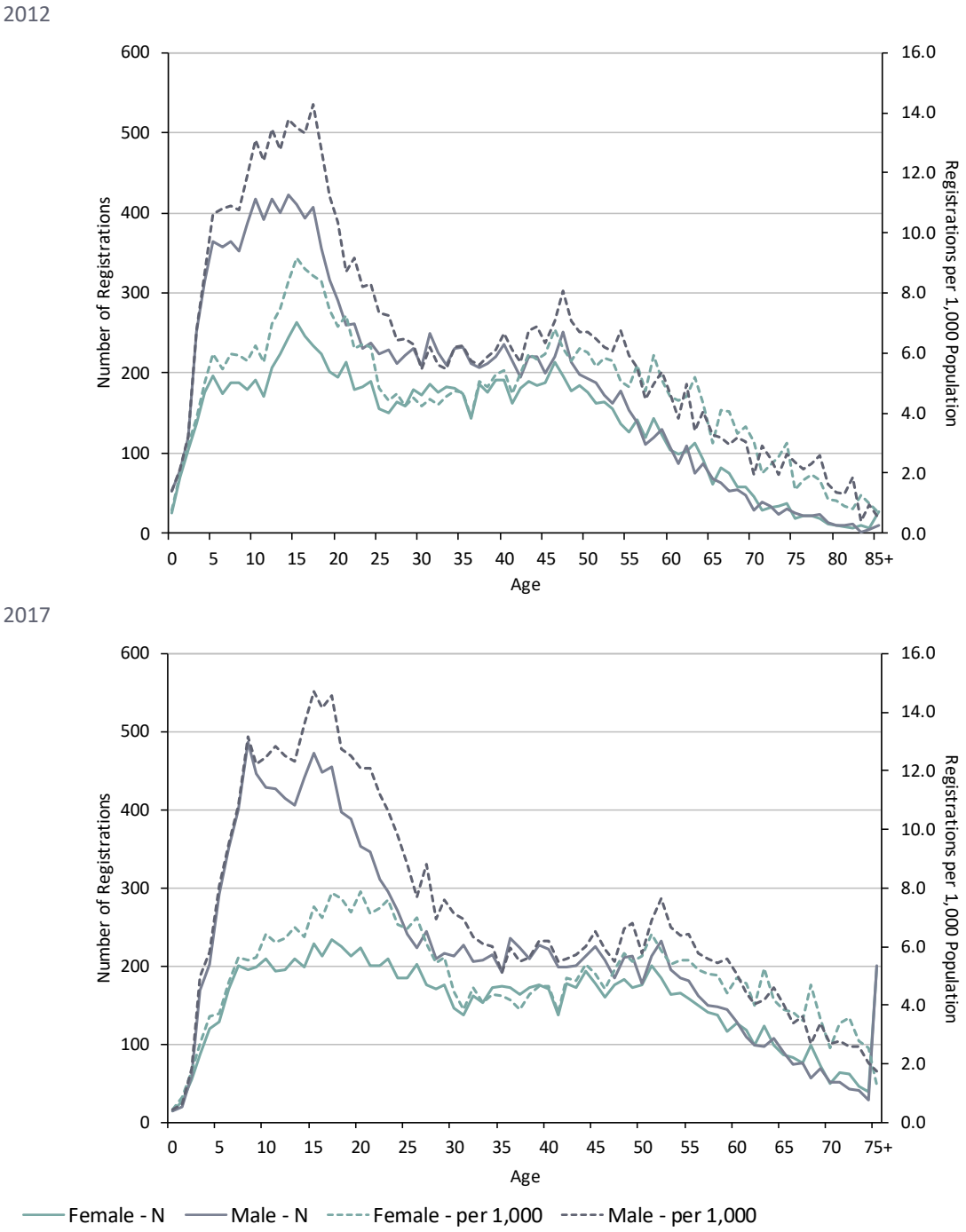
8 2012 was chosen as the comparison year as the proportion of records reviewed in that year was very high at 99.4 per cent.

FIGURE 4 NIDD: Number of Registrations and Registrations per 1,000 Population by Age, 2012 and 2017



Males accounted for 57.7 per cent (15,951) of registrations in 2012 and 59.1 per cent (16,768) in 2017. Figure 5 shows the numbers of male and female registrations and number per 1,000 population in 2012 and 2017. There were a higher number of males than females at almost all ages with the exception of the over 60s. The differential is greatest for those aged between 5 and 20 years old; the pattern is similar when examined on a population basis. This differential decreases sharply after school age.

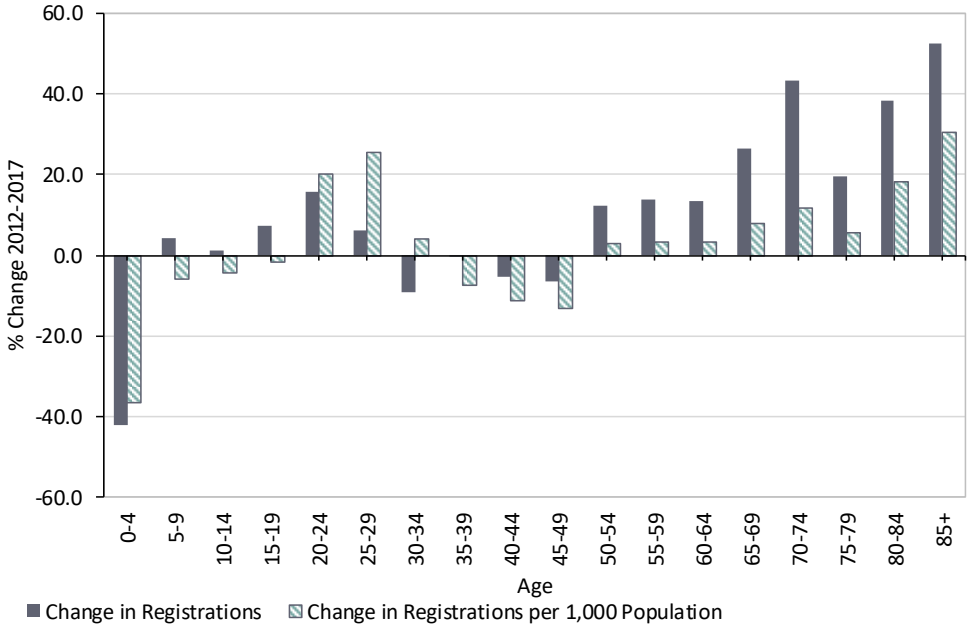
FIGURE 5 NIDD: Number of Registrations and Registrations per 1,000 Population by Age and Sex, 2012 and 2017



4.3 Changes in Registrations 2012–2017

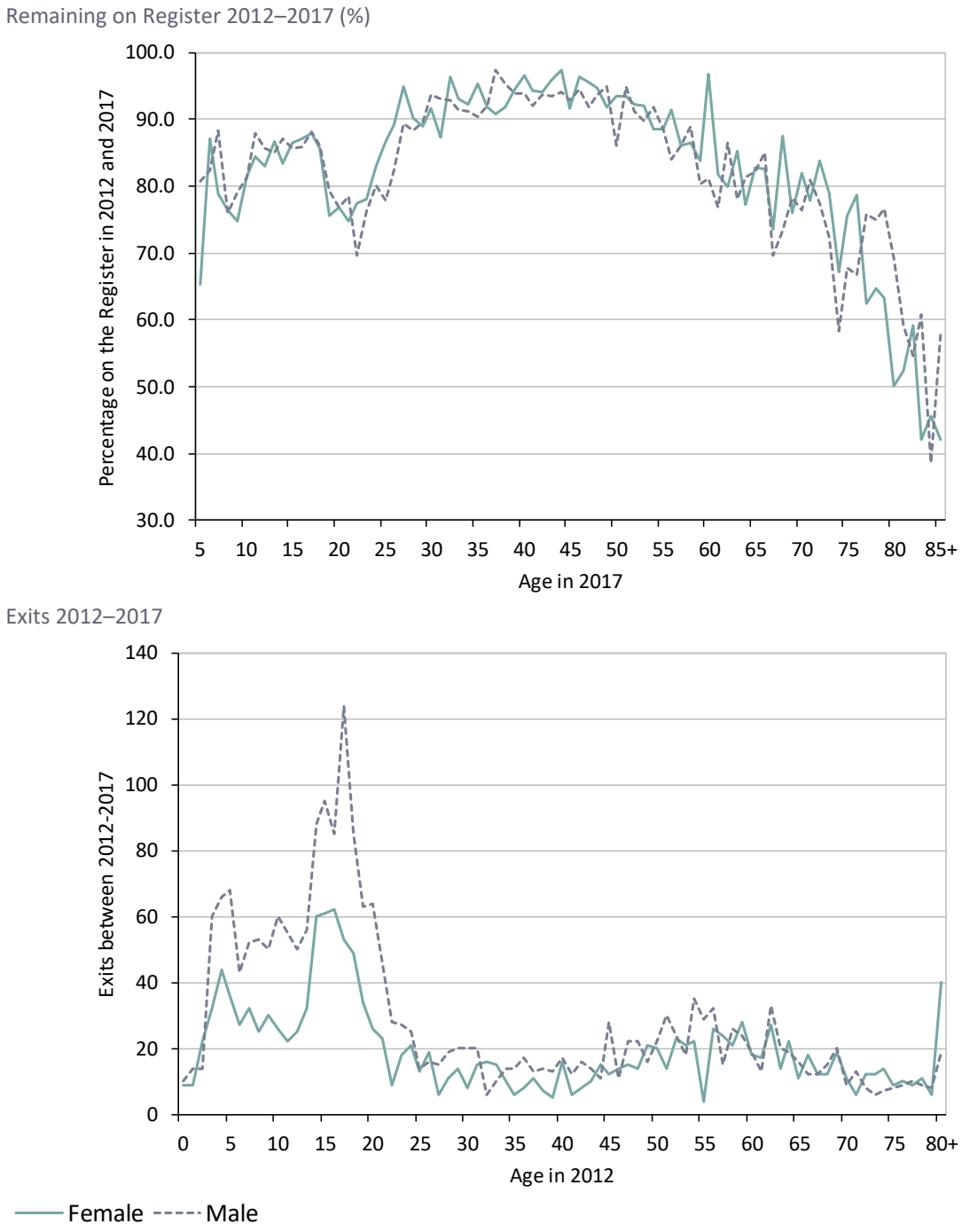
Figure 6 shows the percentage change in the numbers of registrations and registrations per 1,000 population between 2012 and 2017 by age group. For example, we see that there were 42.2 per cent fewer 0–4 year olds registered in 2017 compared to 2012, a similar decrease was observed for the number of registrations per 1,000 population. For the 70-74 years age group there was a 43.5 per cent increase in the numbers registered between 2012 and 2017 but adjusted for population the increase was much smaller with just an 11.9 per cent increase per 1,000 population over the period.

FIGURE 6 Change in Registrations and Registrations per 1,000 Population by Age, 2012 and 2017



Examining the database in 2012 and 2017, we can see that of the 27,621 registered in 2012, 23,711 (83.8 per cent) remained registered in 2017. Figure 7 shows the proportion of those remaining by single year of age in 2017. For example, of those aged 17 in 2012, 69.5 per cent remain on the register when they are 22 in 2017. This appears to reflect an exodus from specialist services post-school-age. The proportions remaining on the register are reasonably stable between 25 and 50 years old but gradually reduce thereafter, as a result of people no longer receiving services or dying. The differences between males and females are relatively small with females showing a slightly higher proportion remaining on the database at older ages. However, looking at the actual numbers of people who left the database between 2012 and 2017 by sex, we see that they were predominantly young males.

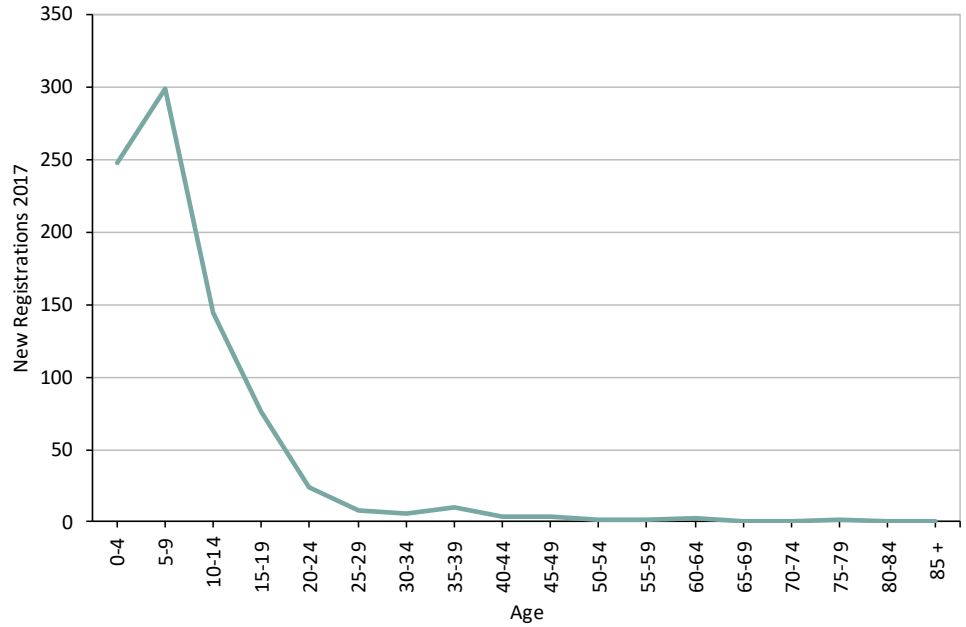
FIGURE 7 NIDD: Patterns of Registration Change, 2012–2017



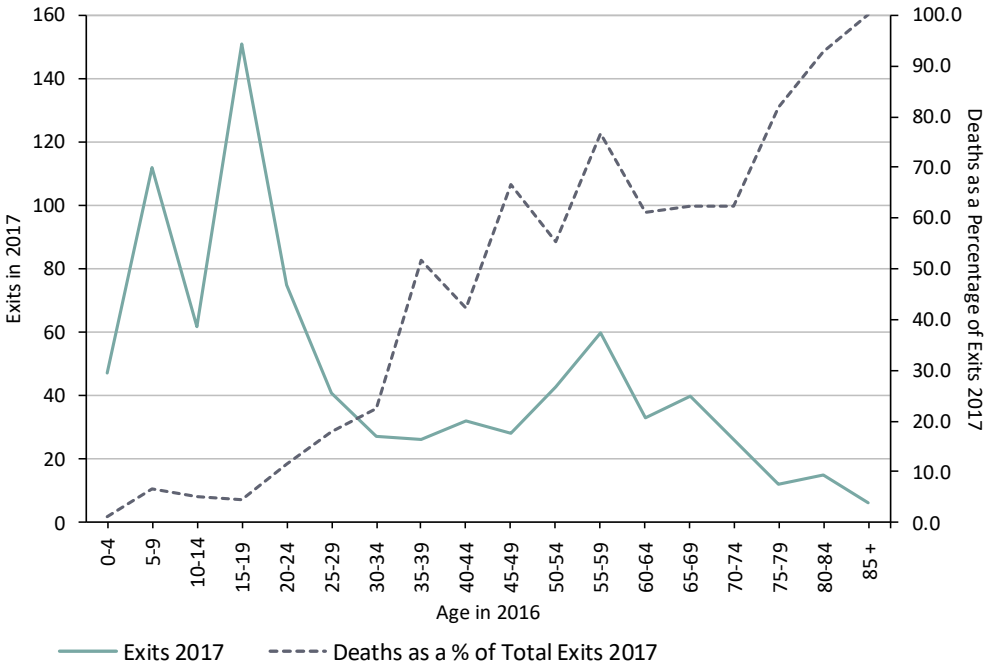
Every year there are new people registered and a number who leave the database. In 2017 there were 831 new registrations, two-thirds of whom were aged less than 9 years old. In addition, 836 people left the database, the highest number of whom were in the school-leaver age group, an age at which people may no longer require a specialist disability service (Figure 8). Of the 836 exits, 249 (27 per cent) were deaths. As expected, deaths as a proportion of total exits increased with age.

FIGURE 8 NIDD: Number of New Registrations and Exits, 2017

New Registrations 2017 (n=831)



Exits 2017 (n=836)



Note: If a person acquires a disability after the age of 65 they are not included in Disability Services but are cared for through Older Persons Services.

4.4 Degree of Intellectual Disability

The NIDD reports on the degree of ID of the people registered. The proportions in each category have changed little between 2012 and 2017 (Figure 9). Almost three-quarters (73.0 per cent in 2012 and 73.7 per cent in 2017) of those registered are assessed as having a mild or moderate degree of disability. The proportion with a severe or profound disability has fallen from 18.3 per cent to 17.1 per cent over the period. In both years a higher proportion of females with an ID (18.6 per cent and 17.8 per cent) recorded a severe or profound disability than males (18 per cent and 16.6 per cent).

FIGURE 9 NIDD: Degree of Intellectual Disability, 2012 and 2017

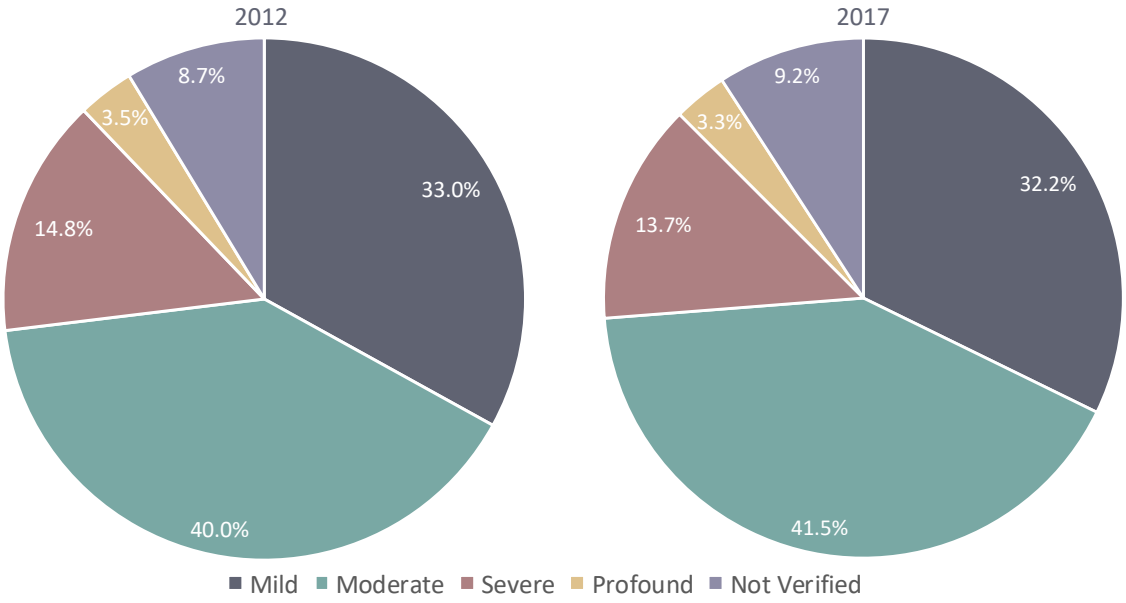
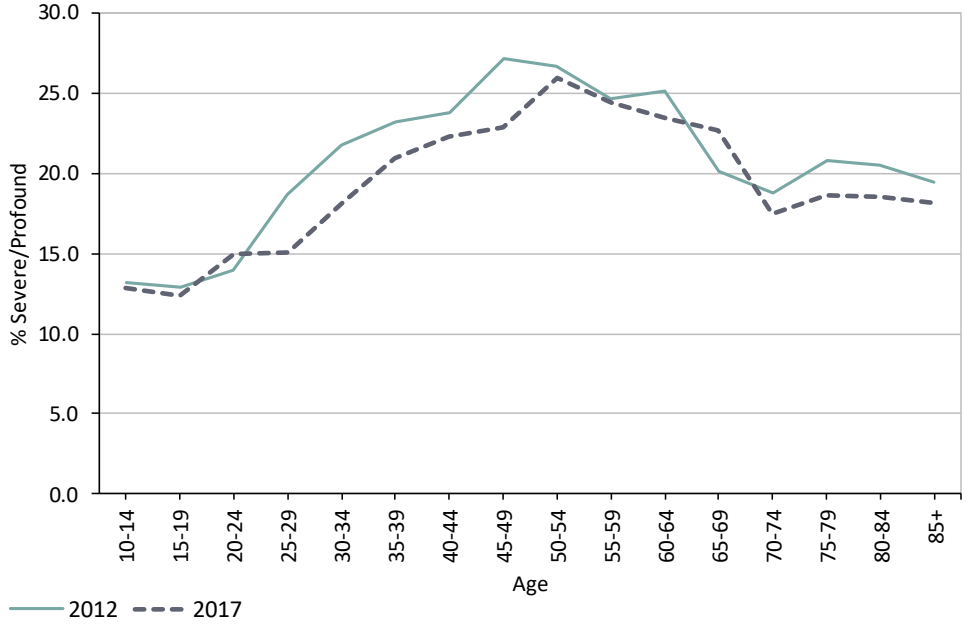


Figure 10 shows the proportion with severe and profound disability in 2012 and 2017 by age group. The degree of ID varied across age groups with over one quarter of those aged 50–54 having a severe or profound disability compared to 14 per cent in the 20–24 years group in 2017. The proportion of individuals with a severe or profound disability has decreased over time across all age groups with the exceptions of 20–24 years and 65–69 years. The majority (71.2 per cent) of those with a 'not verified' diagnosis are in the 1–9 years age group.

FIGURE 10 NIDD: Proportion of NIDD Registrations with Severe and Profound Disability by Age, 2012 and 2017



Note: Due to the large proportion of 'not verified' in the under 10 age categories they have been excluded

Of the 23,711 people who were included in the database in 2012 and in 2017, 21,872 (92.2 per cent) had a verified degree of disability in both years. Of those with a verified degree of disability in both years, approximately 5 per cent (1,012) saw a change over the period. For 614, the degree of disability became more severe, while for 398 it became less so.

4.5 Service Utilisation

4.5.1 Residential Services

Full-Time Residential Services

For the purpose of these analyses, full-time residential services include those living semi-independently, in community group homes (≥5 days), in residential centres (≥5 days), and in other full-time services.[9] Figure 11 shows the number, number per 1,000 population in 2012 and 2017, and proportion of people registered on the NIDD who were in receipt of full-time residential services in 2017 by age group and sex. The change over time varied by age group, with decreases in the number of younger people in receipt of these services and some modest increases amongst the 50 years and older age groups. There was a similar pattern for males and females.

[9] Intensive placement (challenging behaviour, profound or multiple handicap), other residential services. Places in nursing homes, mental health community residences or psychiatric hospitals are not included as they may overlap with utilisation and expenditure in other analyses being undertaken for the Hippocrates Model.

In 2012, 29.4 per cent (8,124) of people on the NIDD database were in receipt of full-time residential services, by 2017, this had decreased to 33.3 per cent (7,627).[10] In 2012, 26.6 per cent of males (4,236 – 1.9 per 1,000 population) and 33.3 per cent of females (3,888) were in receipt of full-time residential care. By 2017, this had fallen for both sexes to 23.8 per cent (3,984population) of males and 31.4 per cent (3,643) of females.

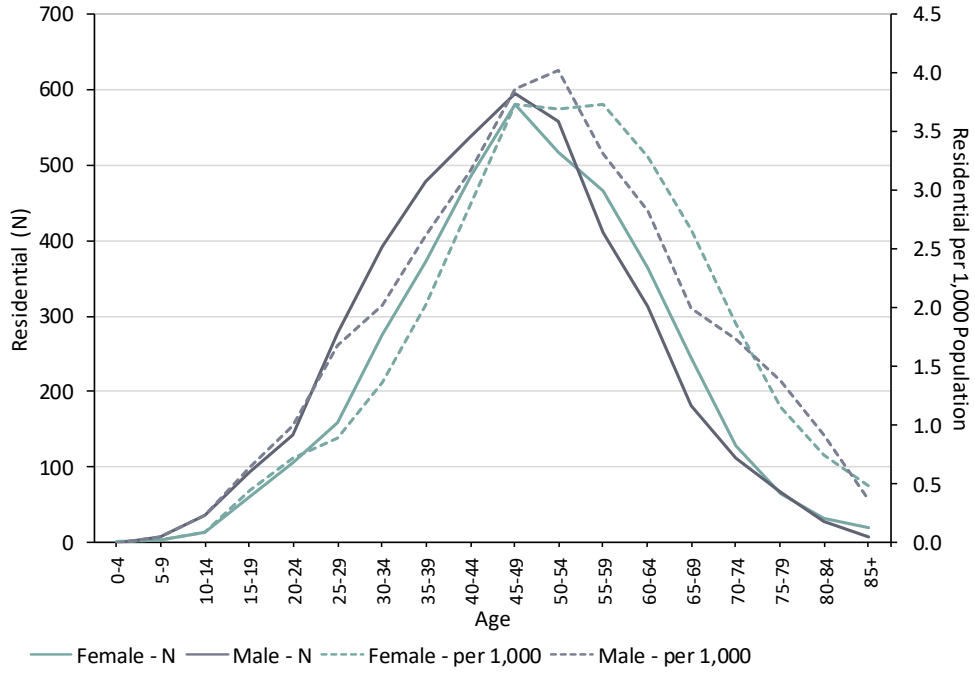
The proportion of people in each age group in receipt of full-time residential care in 2012 and 2017 increased with age for both sexes. There was a higher proportion of males in receipt of full-time residential care than females in the younger age groups; while from approximately 40 years onwards there was a higher proportion of females. For both sexes there was a decrease in the proportion of people in full-time residential care for almost all age groups over time.

The majority of people in full-time residential care in 2017 were living in a community group home or residential centre (83.8 per cent), and of those, 94.5 per cent were resident on a seven-day basis.

In 2017, 28.9 per cent of people with a moderate level of ID were in full-time residential care compared to 31.9 per cent in 2012. While 61.3 per cent of those with a profound level of ID were in full-time residential care in 2017 compared to 65.6 per cent in 2012.

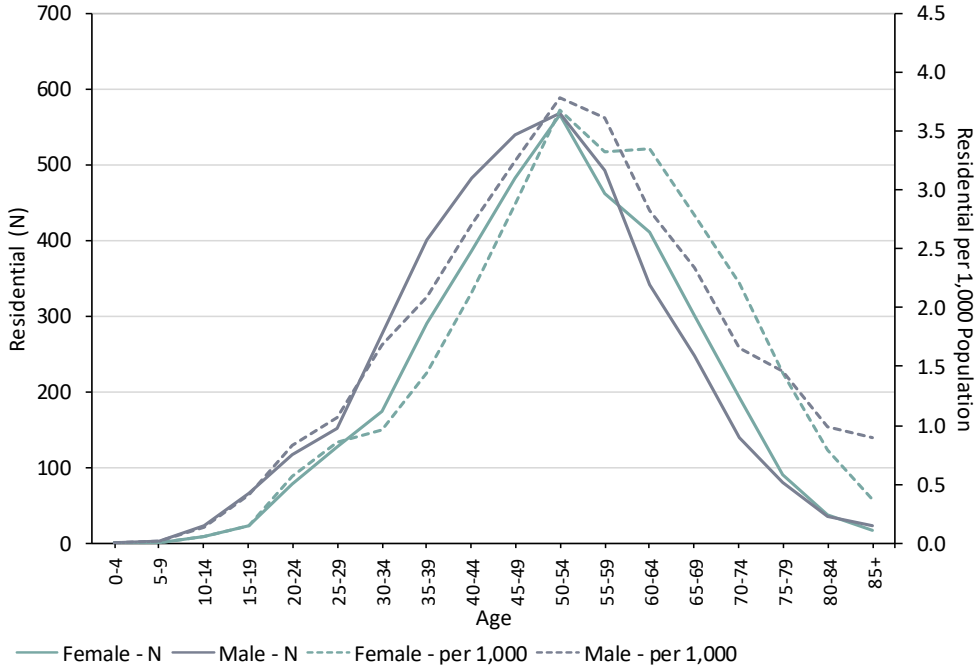
FIGURE 11 NIDD: Number of People in Receipt of Full-Time Residential Care, Rate per 1,000 population in 2012 and 2017, and Proportion of NIDD Registrations in 2017, by Age and Sex

2012



[10] Of the individuals in full-time residential care in 2012 and 2017 0.2 per cent were recorded as privately funded.

2017



Proportion in Receipt of Full-Time Residential Care, 2017

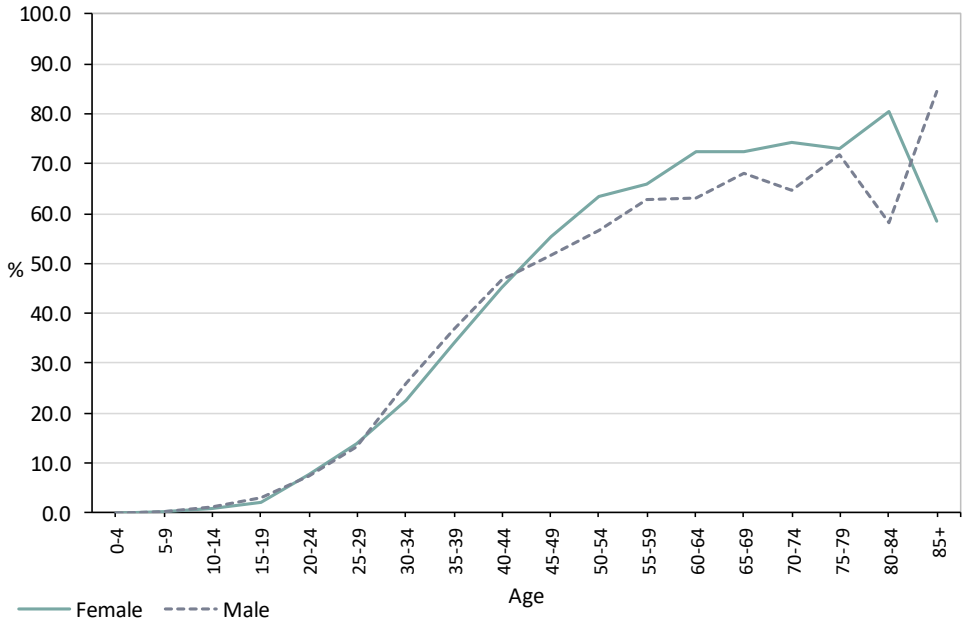
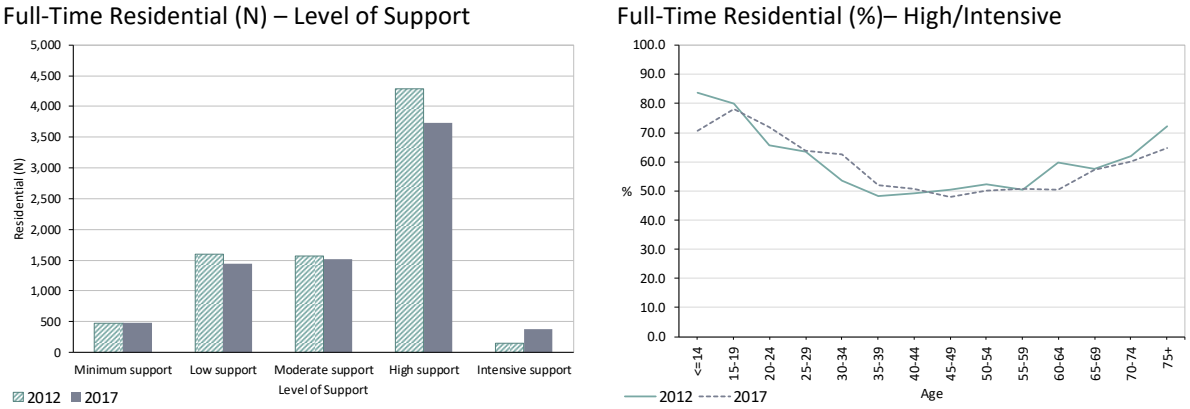


Figure 12 illustrates the support level required by those in full-time residential care in 2012 and 2017. Approximately 54 per cent of those in residential care in both years required a high or intensive level of support. The only support category which experienced an increase over the period was intensive support which increased from 143 (1.8 per cent) in 2012 to 383 (5.1 per cent) in 2017.[11] However, when examined as a proportion of NIDD registrations, the rate of use of full-time residential care with high or intensive support has decreased for almost all age groups.

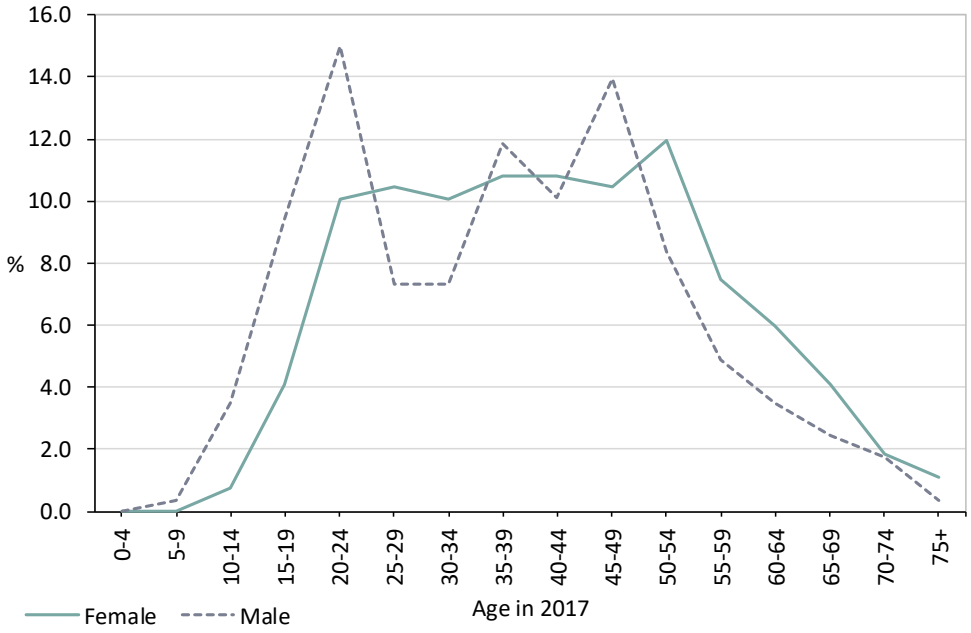
[11] The intensive category was a recent introduction in 2012 so the change here may be as a result of an adjustment from high support.

FIGURE 12 NIDD: Number of People in Receipt of Full-Time Residential Care by Level of Support Required, 2012 and 2017



Of the 23,711 individuals who were on the database in 2012 and remained on the database in 2017, 555 entered full-time residential care over the period while 189 left. Those who entered full-time residential care were not concentrated in the older age groups (Figure 13), three out of four had a mild to moderate degree of disability, and 52.5 per cent were male.

FIGURE 13 NIDD: Proportion of People Who Entered Full-Time Residential Care between 2012 and 2017 by Age and Sex (N=555)



Application of NIDD Age and Sex Profile to KPI

The HSE reported that 7,424 people were in receipt of residential services in 2017, 203 fewer than reported in the NIDD.[12] As there is such a small difference between the KPI and NIDD figures, in the age and sex profile presented in Figure 11 for 2017, the age and sex adjusted KPI figure is not presented.

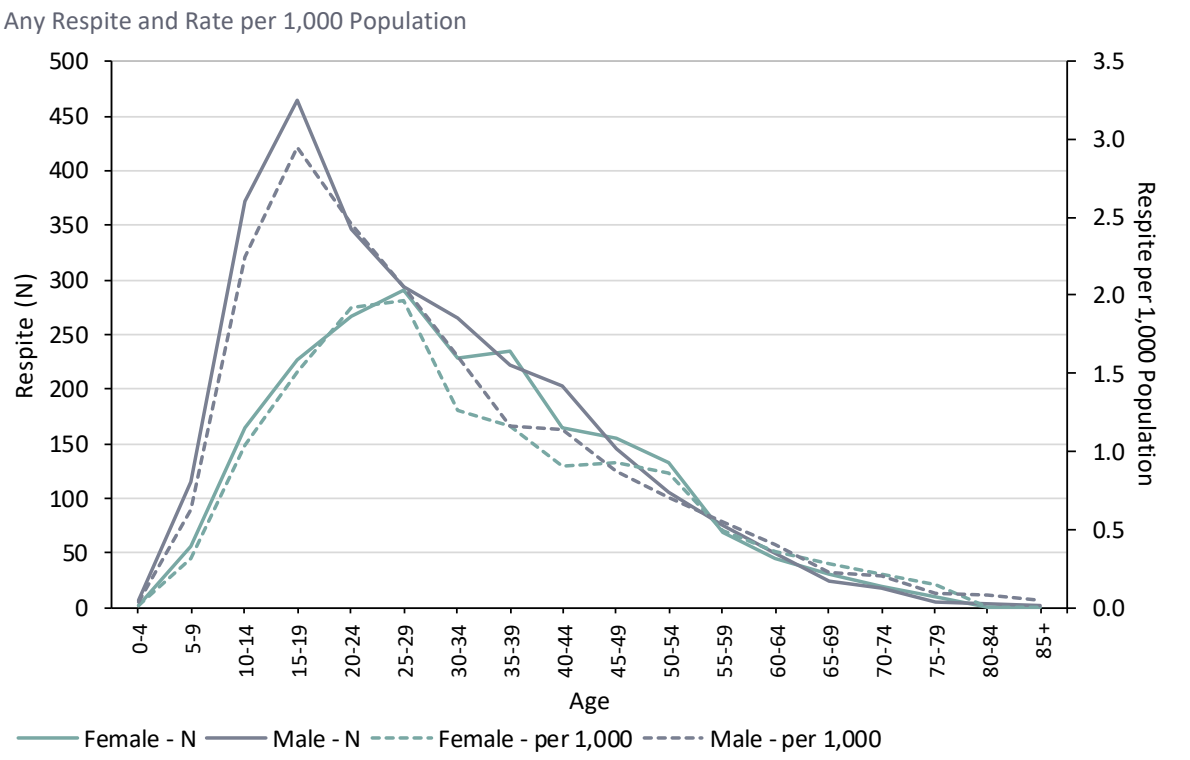
12 This KPI was not collected in 2012 so is not available for comparison.

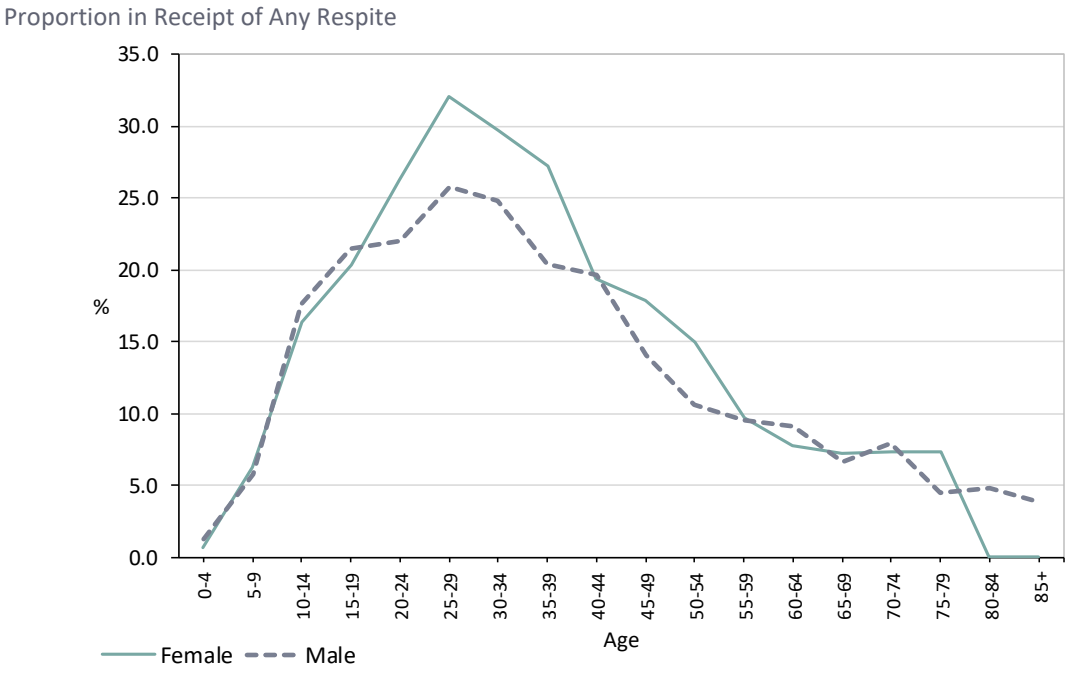
Respite Services

There are a number of different respite services captured in the NIDD. These include crisis and planned respite, occasional respite with host family, overnight respite in the home, day respite in the home, and centre-based day respite. In addition to the numbers availing of the services, the number of crisis and planned respite nights are also captured.

In 2012, 5,541 (20.1 per cent) individuals were in receipt of respite (day and/or overnight) services compared to 4,806 (16.9 per cent) in 2017. In 2017, there were more males in receipt of respite services and the majority of users were in the younger age groups (Figure 14).

FIGURE 14 NIDD: Number of People in Receipt of Any Respite, Rate per 1,000 population and Proportion of NIDD Registrations by Age and Sex, 2017

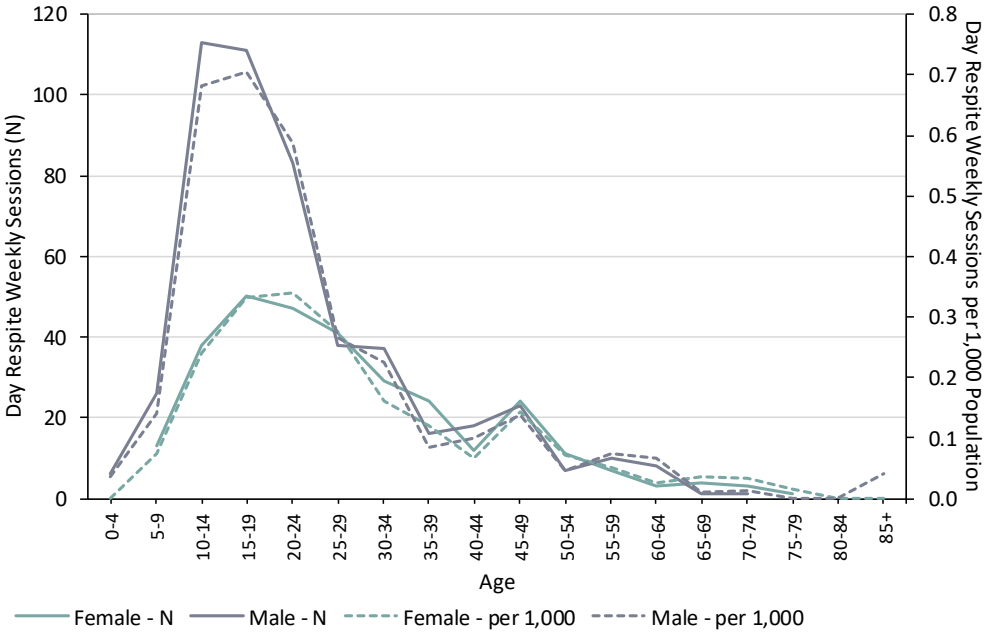




Day Respite

Over the period 2012–2017, there was a 26.8 per cent decrease in the number in receipt of day respite (2012 – 888; 2017 – 650). Of those availing of day respite in 2017, the majority (68.8 per cent) report using the service for one-half day per week, while a further 18.0 per cent record one day per week. Almost 80 per cent of those utilising day respite services are under 35 years old. There were a total of 806 day respite sessions per week reported for 2017, multiplying this by 50 gives an estimated 40,300 in the year.[13] The majority of users (87.0 per cent) had one session per week.

FIGURE 15 NIDD: Day Respite Weekly Sessions and Rate per 1,000 Population by Age and Sex, 2017

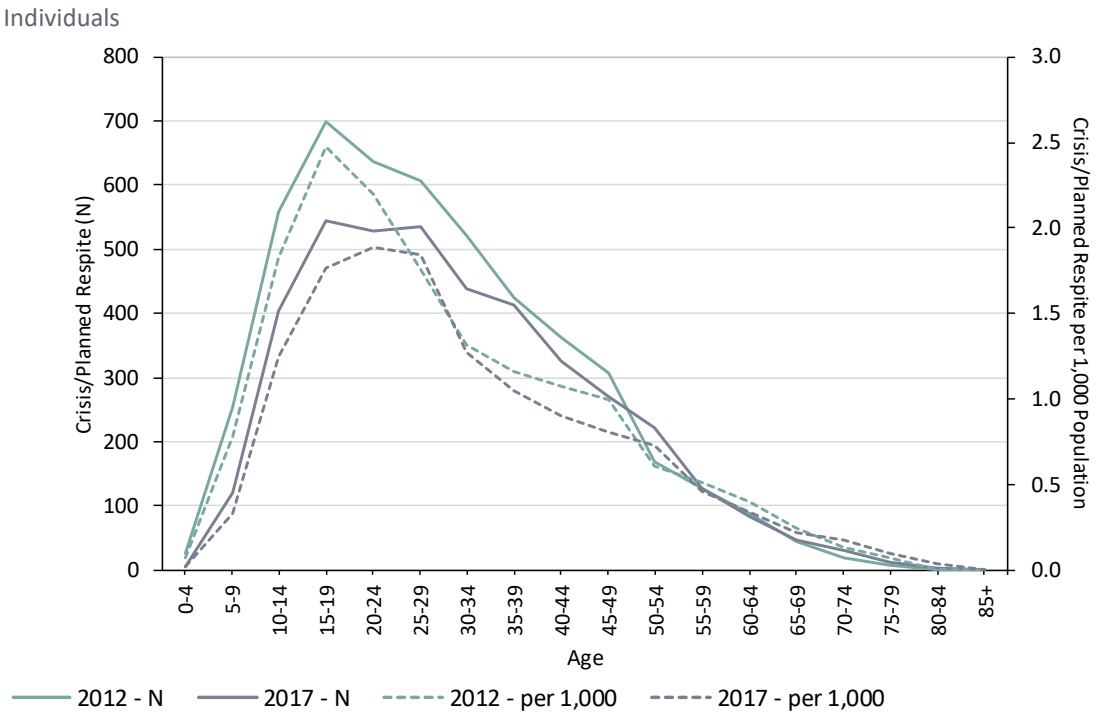


[13] To calculate the number of sessions, both one half day and one day is counted as one session.

Crisis/Planned Respite

There was a 13.8 per cent decrease in the number availing of overnight respite (2012 – 5,204; 2017 – 4,488) and a 15.4 per cent decrease in the number receiving crisis/planned respite in particular (2012 – 4,852; 2017 – 4,104). Of those in receipt of crisis/planned respite both the number of individuals using the service and the intensity of use peaks at 10–14 years in both years and gradually decreases with age thereafter (Figure 16). The rates per 1,000 population follow a similar pattern. The median number of nights decreased from 20 nights in 2012 to 18 nights in 2017.[14] The overall number of respite nights recorded in the NIDD decreased from 141,815 in 2012 to 107,644 in 2017.

FIGURE 16 NIDD: Users and Nights of Crisis/Planned Respite and Rate per 1,000 Population by Age, 2012 and 2017



[14] Less than 5 individuals were privately funded in 2012, no individuals were privately funded in 2017.

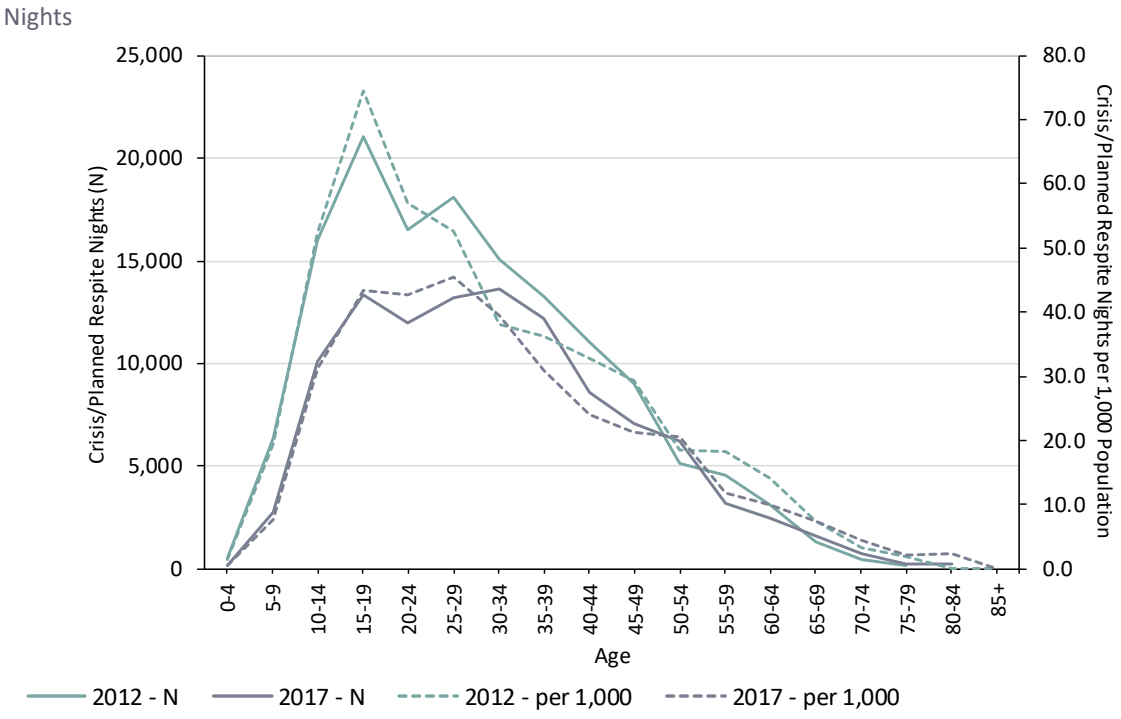
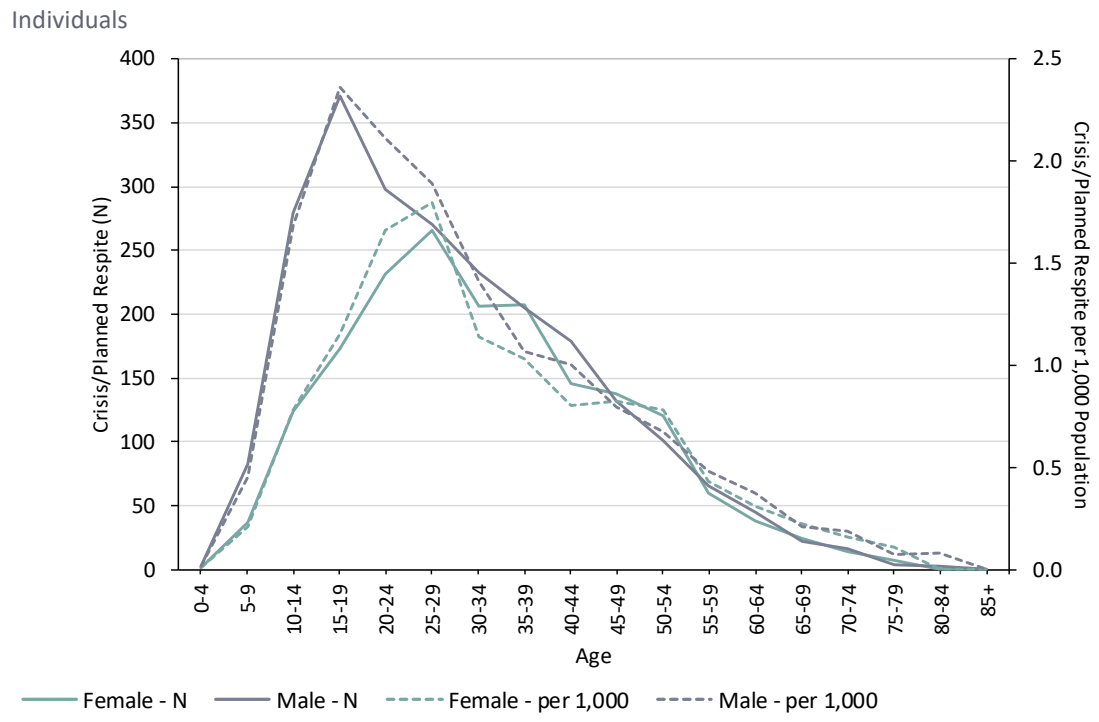
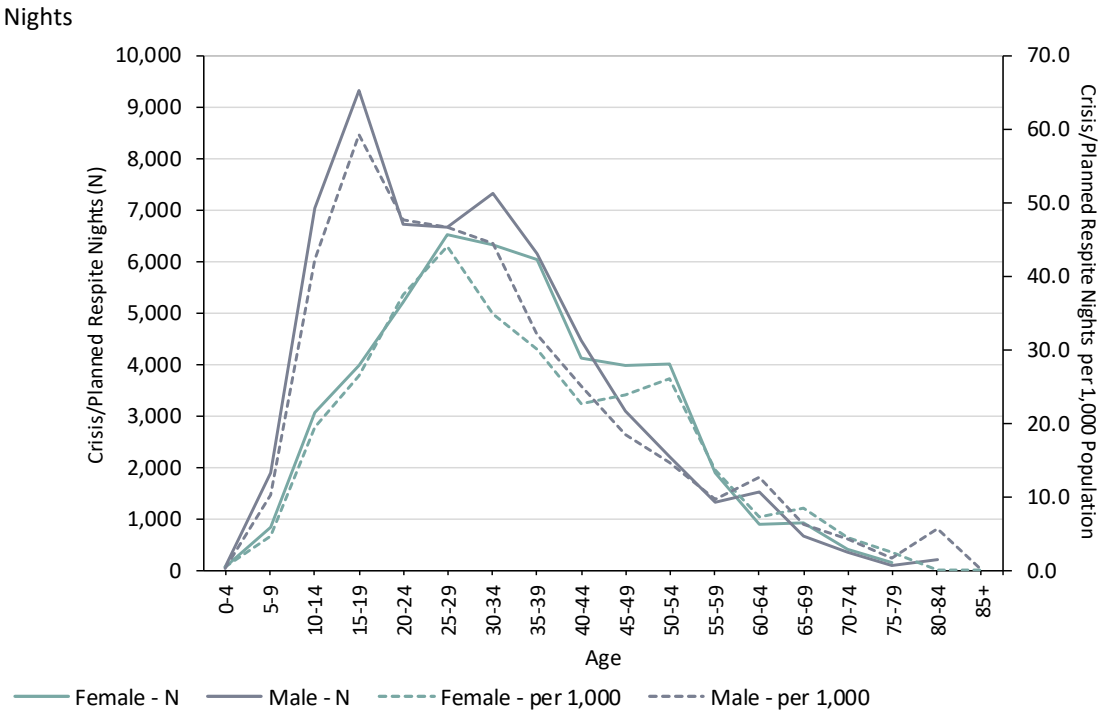


Figure 17 shows utilisation of respite services in 2017 by sex. The pattern of utilisation varied with a higher number of males using the service. Also, the peak in utilisation for males is younger (10-14 years) than that for females (25-29 years). There was no variation in the median number of nights by sex.

FIGURE 17 NIDD: Individuals and Nights in Receipt of Crisis/Planned Respite and Rate per 1,000 Population by Age and Sex, 2017



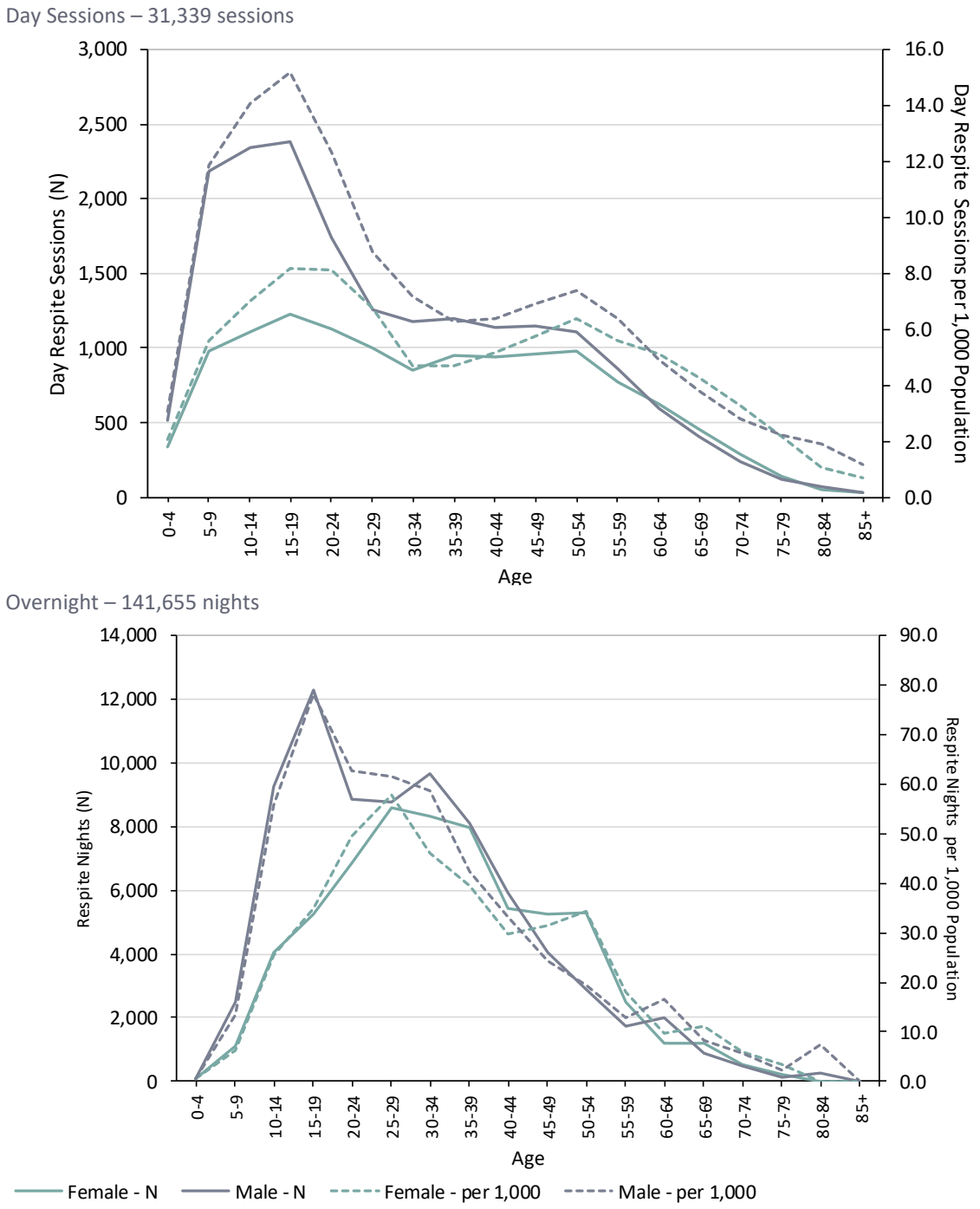


Application of NIDD Age and Sex Profile to KPI

There are three relevant KPIs relating to respite services. The number of people in receipt of respite (day and overnight) and the number of day and overnight sessions. In 2017, the KPIs report 4,798 users of respite services, 31,339 day sessions, and 141,655 overnights used.

For total users, the age and sex profile from NIDD (4,806) was applied to the almost identical number of users reported in the KPI (4,798), see Figure 14. For day sessions, the age and sex profiles of the number of weekly sessions in NIDD was applied to the total number of annual day respite sessions reported by the KPI (Figure 18). For the number of overnights, the age and sex profile of those in the NIDD utilising crisis and planned nights was applied to the total nights reported in the KPI.

FIGURE 18 KPI: Day Respite and Overnight Sessions Estimates by Age and Sex, 2017



4.5.2 Day Services

In 2017, 27,902 (98.3 per cent) individuals were in receipt of one or more day services as defined in NIDD.[15,16] This was an increase of 2.6 per cent on 2012 (27,190). The categories of day services captured by the NIDD are broad and include education services provided to children in mainstream schools and special schools. Such services would not be provided through HSE Disability Services but rather by the Department of Education. The figures also include those in receipt of multidisciplinary services only and day respite. NIDD captures the utilisation of up to three-day support services per individual and the intensity of the utilisation measured in number of days per week.

The HSE KPIs report on two categories of day services.[17] These are the number of people with ID and/or autism in receipt of 'work/work-like activity' and the number in receipt of 'other day services'.[18] This covers the majority of day services available to adults with specialist disability requirements. The remainder of the analysis will focus on these aggregated categories.

In total, 14,755[19] individuals were in receipt of the above defined day services as their main day service in 2017, this was a 5.2 per cent increase from 2012. Figure 19 shows the number of people in receipt of these services and the rate per 1,000 population disaggregated by sex in 2012 and 2017. There were a higher proportion of males in receipt of services than females in both years (2012 – 53.2 per cent; 2017 – 53.8 per cent). The numbers in receipt of these services, across males and females, has decreased over the period for those aged 30–50 and increased slightly in older age groups, a similar picture emerges when examined on a population basis.

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15 Excludes 'not applicable', 'no day service' and 'full-time resident with no formal day programme'.

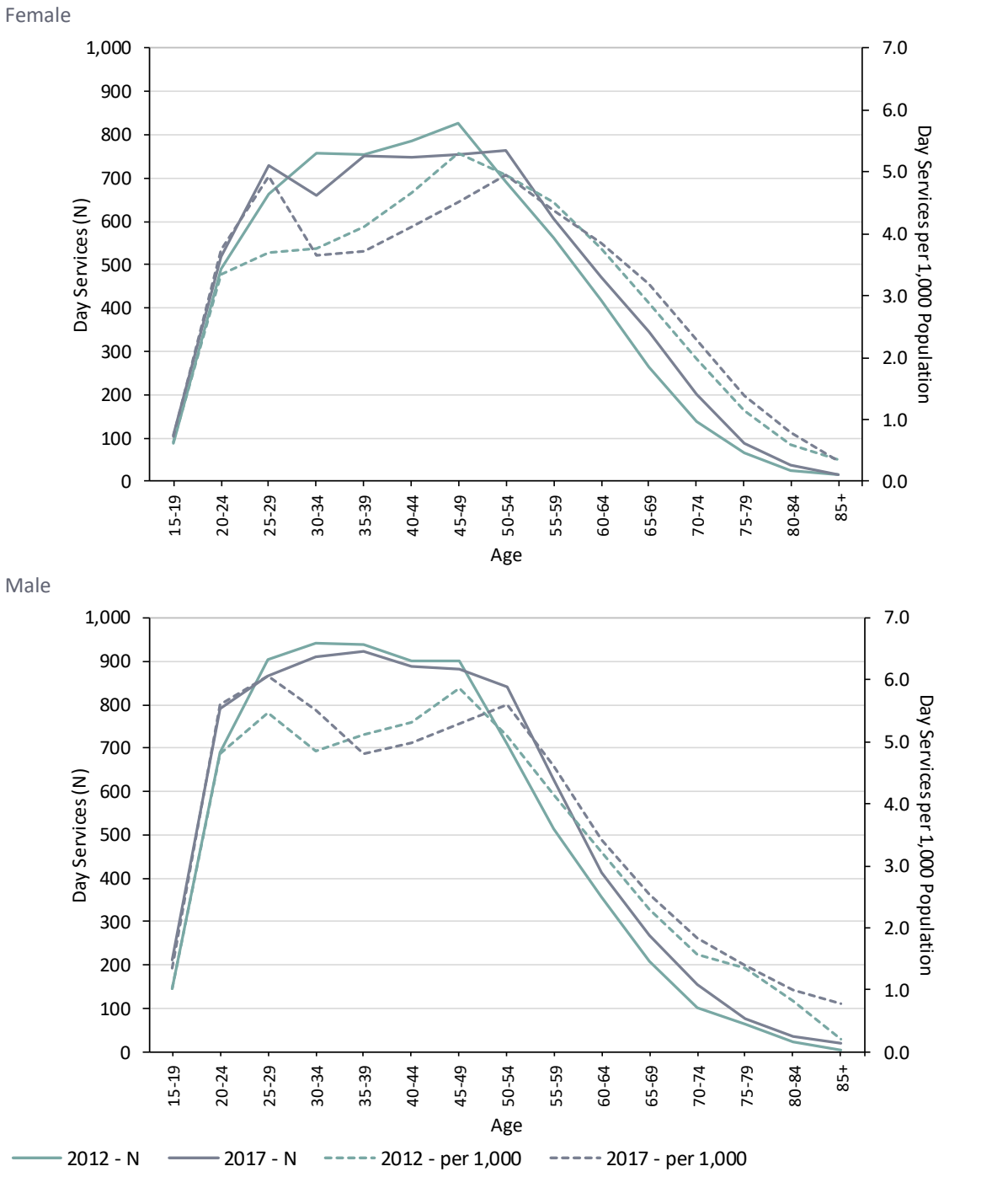
16 Total day services include day respite which are discussed along with respite services earlier in the paper to allow for comparison with the HSE KPIs.

17 Rehabilitative training is examined separately in section 7.

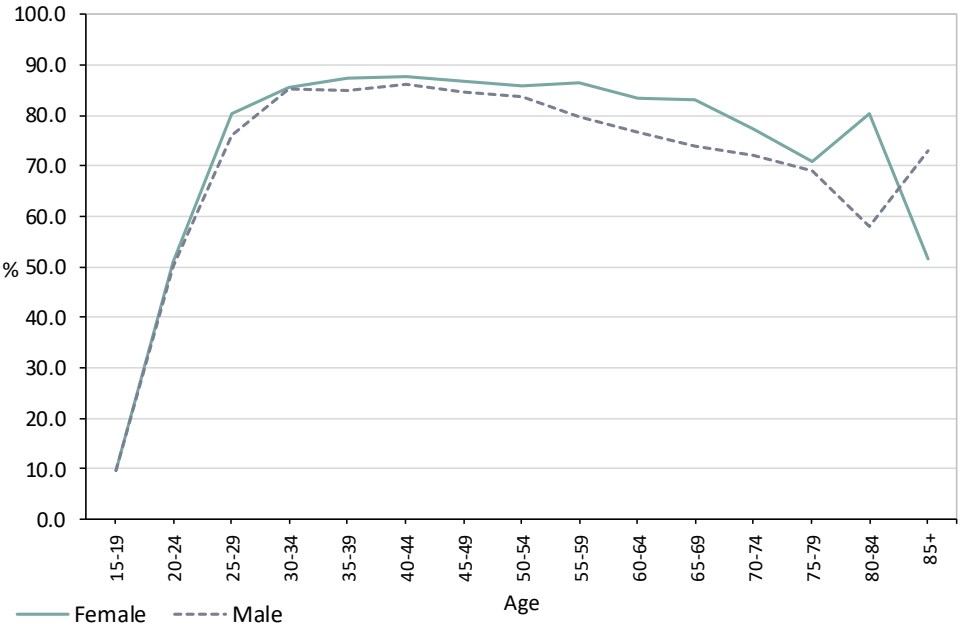
18 This includes 'activation centre', 'programme for the older person', 'special high support day service', 'special intensive day service', 'sheltered employment centre', 'supported employment', 'open employment', 'generic day services', 'outreach services', and 'other day services'.

19 Of the individuals in receipt of these selected day services in 2017, less than 0.5 per cent were recorded as privately funded in both years.

FIGURE 19 NIDD: Number of People in Receipt of Selected Day Services, Rate per 1,000 population in 2012 and 2017, and Proportion of NIDD Registrations in 2017, by Age and Sex



Proportion in Receipt of Selected Day Services, 2017



Of the 14,755 receiving selected day services in 2017, 20 per cent received two services and a further 2.3 per cent received three.

Work and work-like activities includes sheltered work centres and enclaves within open employment. In 2017, 2,255 individuals were reported to engage in these day service activities as their main service (Figure 20), a 31.3 per cent decrease from 2012. It should be noted that while individuals continue to engage in work/work-like activities and the HSE continue to report a KPI, they are in the process of being phased out. One of the key policy documents in the area of disability services, New Directions, proposed a new approach to the provision of adult day services that envisaged all services being integrated in the local community (10). In the subsequent Comprehensive Employment Strategy for People with a Disability, 2015–2024, a goal was set out to ensure that people with disabilities who are able to and want to work are enabled to do so (11).

While 12,500 individuals in 2017 were in receipt of 'other day services', this was an increase of 16.2 per cent since 2012.[20] The majority (72 per cent) of individuals availing of work and work/like activities and other day services receive the service five days per week.

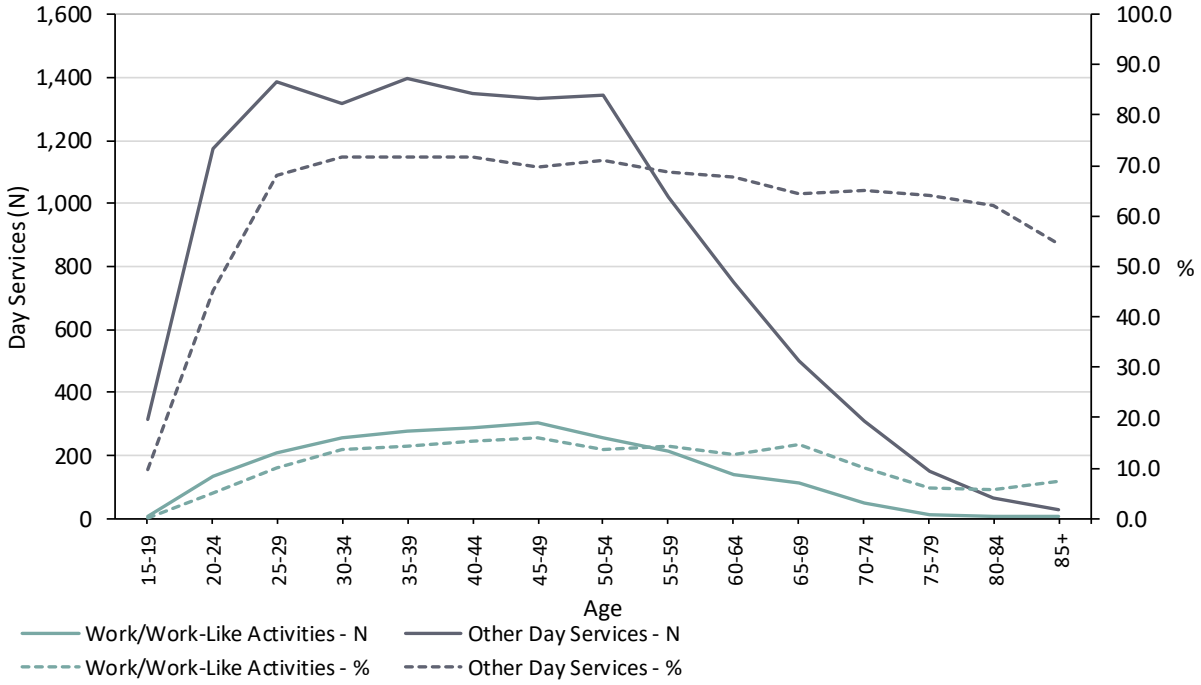
Figure 20 shows how the numbers of individuals in receipt of day services varied by age. For work/work like activities, utilisation is distributed relatively evenly across age groups, with almost no change in the numbers receiving services between 25–54 years and gradually falling thereafter. For other day services, the

[20] As per New Directions it appears as if individuals have moved between the categories of 'sheltered work centre' and 'activation centre' in particular over the period.

numbers utilising the services increases sharply between 15–20 years and remains relatively flat until there is a sharp and continuous decline at 55 years. The proportion of people receiving services is relatively constant for both services across the age distribution.

Of the 14,755 people with one of these services as their main day service in 2017, one-third required high or intensive levels of support.

FIGURE 20 NIDD: Number and Proportion of People in Receipt of Selected Day Services, 2017

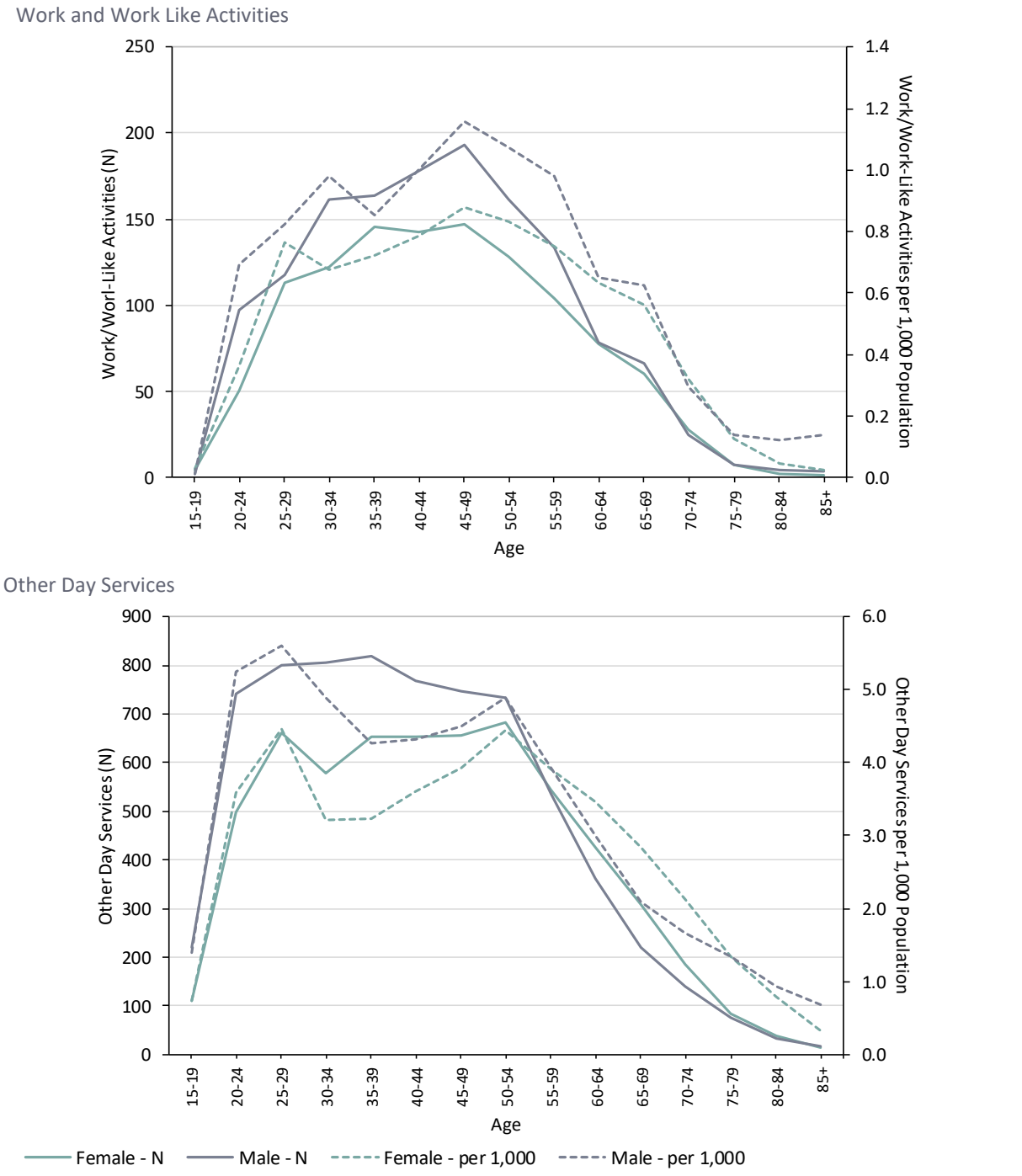


Application of NIDD Age and Sex Profile to KPI

The number of users reported by the NIDD matches reasonably well to that reported in the KPIs for 2017 at an aggregate level[21], 89.1 per cent of the work and work-like activities (2,530) and 94.9 per cent of the other day services (13,171). Applying the age profile of users from the NIDD to the total number of users reported in the KPIs would seem reasonable (Figure 21).

[21] There are no KPI data currently available on the numbers availing of individual services e.g. activation centre. If this level of data become available at a later date the model can be updated accordingly.

FIGURE 21 KPI: Number of People in Receipt of Day Services and Rate per 1,000 Population by Age and Sex, 2017



4.5.3 Multidisciplinary Support Services

The NIDD collects data on the use of a variety of multidisciplinary support services. An individual is counted as having received a service in a given year if they have had four or more inputs in the given year (12). Therefore, it must be noted that the following estimates may underestimate the number of users of multidisciplinary services by the NIDD population and does not capture the actual level of service use. This will, however, be captured in the new NASS system.

In 2017, 23,583 individuals (83.1 per cent)[22] were in receipt of one or more multidisciplinary support services[23], this was a slight decrease on the proportion in receipt of these services in 2012 (84.5 per cent).[24] Similar proportions of males and females in both years were in receipt of services.

The NIDD collects data on a wide variety of multidisciplinary services. Figure 22 shows the numbers of individuals in receipt of each service in 2012 and 2017. Over the period there have been small changes in the numbers of individuals in receipt of services with small decreases observable in the utilisation of dietetics, social work, psychology, and psychiatry services and small increases in the remainder.

FIGURE 22 NIDD: Individuals in Receipt of Multidisciplinary Services, 2012 and 2017

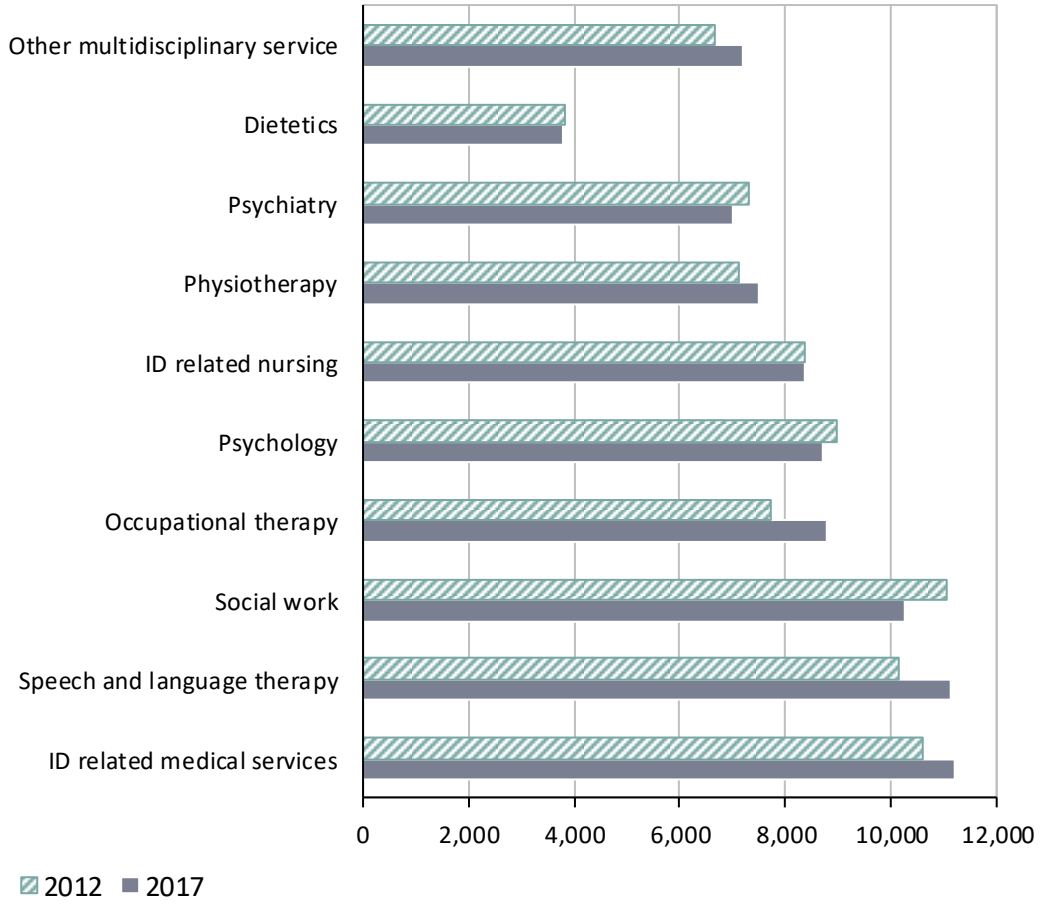


Figure 23 shows how the numbers of individuals in receipt of multidisciplinary services and the rate of use per 1,000 population vary by age and sex. Services such as speech and language therapy, occupational therapy, physiotherapy, psychology, and social work are more commonly used by those under 20 years old. Services

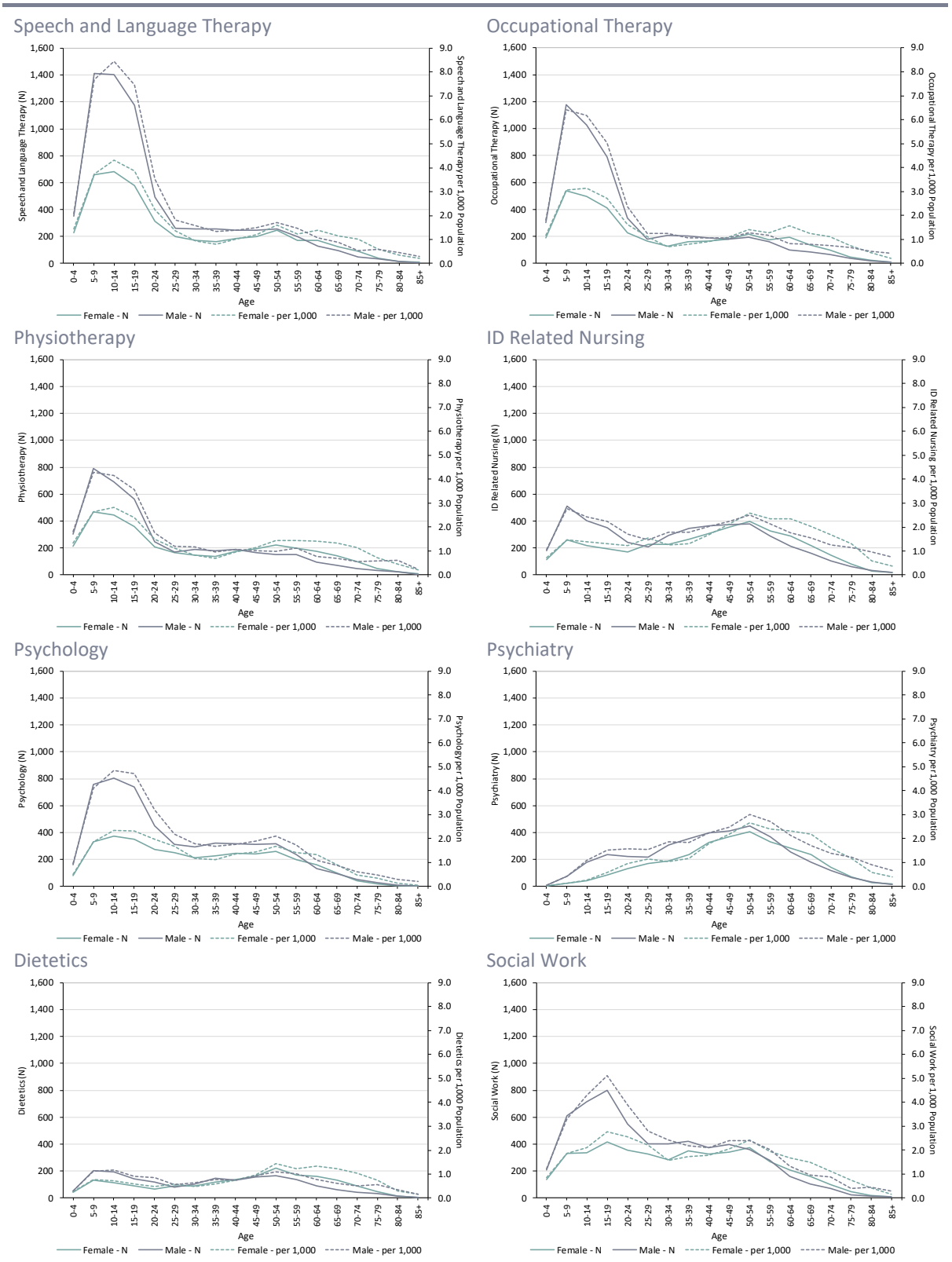
22 A very small proportion of multidisciplinary services were privately funded in 2017, for example, of the 11,193 individuals in receipt of physiotherapy services, just 0.5 per cent were privately funded.

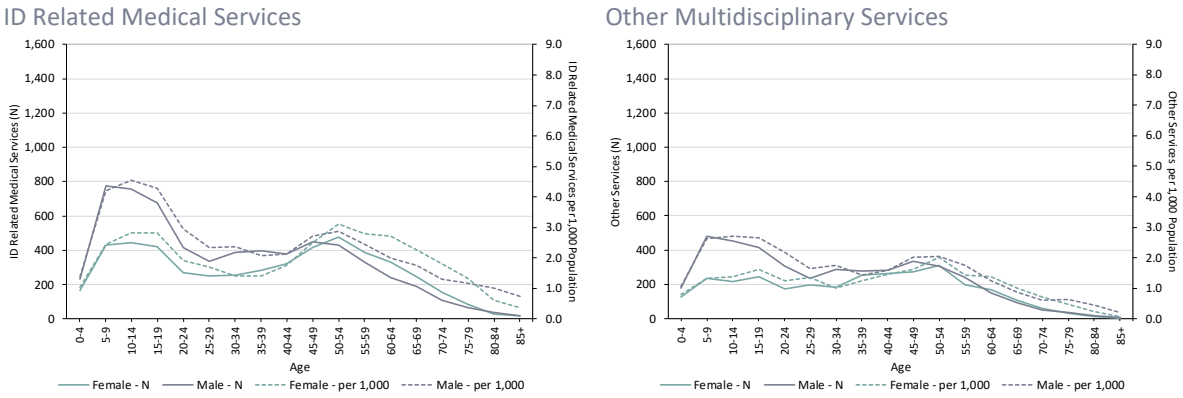
23 'Specific inputs are only recorded if the individual has received, or will receive, at least four inputs of that service in a 12-month period' Kelly et al (2013) p 52.

24 The HSE KPIs do not include any information on the use of multidisciplinary services so there is no basis for comparison.

such as nursing and psychiatry are more common used by those over 20 years old. The patterns of utilisation are similar for males and females with higher utilisation by males in younger age groups reflecting relatively higher numbers in these age groups.

FIGURE 23 NIDD: Individuals in Receipt of Multidisciplinary Services and Rate per 1,000 Population by Age and Sex, 2017





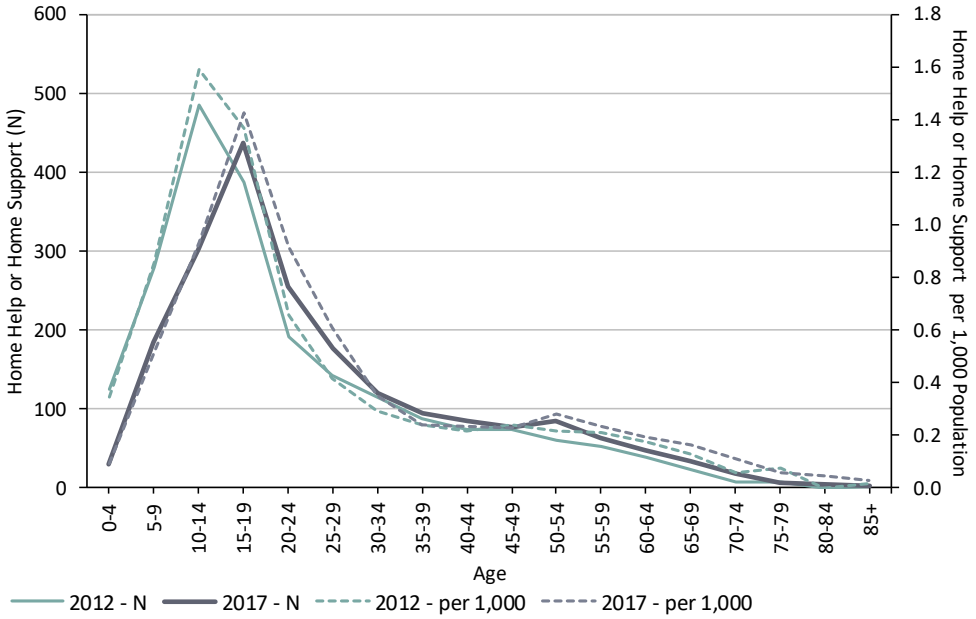
Addition of Multidisciplinary Services to the Model

In the absence of relevant KPIs, the NIDD is the only source of utilisation data available for multidisciplinary services. The lack of a visiting rate makes it unlikely that multidisciplinary services will be included in the Hippocrates model. This will be revisited when NASS data become available.

4.5.4 Home Support

The NIDD recorded that 2,154 individuals received home help or home support services in 2012, this decreased by six per cent (2,030) in 2017. Figure 24 shows the distribution of utilisation by age group. Utilisation peaked in 2012 at 5–9 years and moved to 15–19 years in 2017.

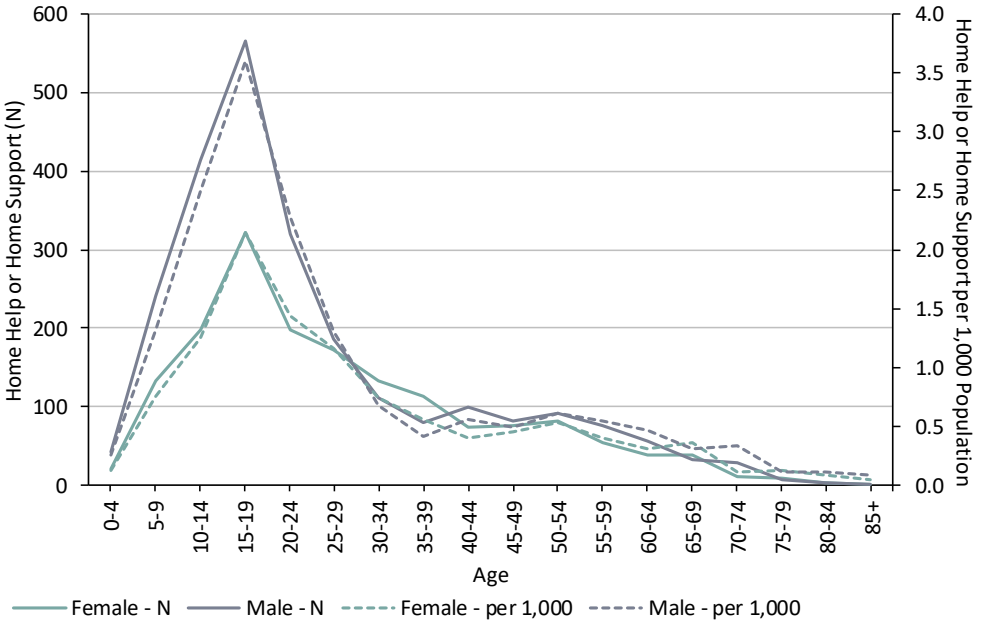
FIGURE 24 NIDD: Individuals in Receipt of Home Help or Home Support Services and Rate per 1,000 Population, 2012 and 2017



Application of NIDD Age and Sex Profile to KPI

The numbers of individuals recorded by the NIDD as having received home help or home support in 2017 (2,030) is far fewer than reported in the HSE KPIs (4,116). It has not been possible to ascertain why there is such a discrepancy between the NIDD and KPI figures. A clearer picture may emerge when the number of hours of home support are collected in NASS. In the absence of an alternative data source, the age and sex profile for home support users in NIDD 2017 is applied to the total number of users reported in the KPIs, the results of this imputation are presented in Figure 25. While these figures are presented here this service will not be included in the Hippocrates model until a time that the figures reported by the HRB are closer to those reported by the HSE KPIs.

FIGURE 25 KPI: Individuals in Receipt of Home Help or Home Support Services and Rate per 1,000 Population by NIDD Age and Sex Profile, 2017

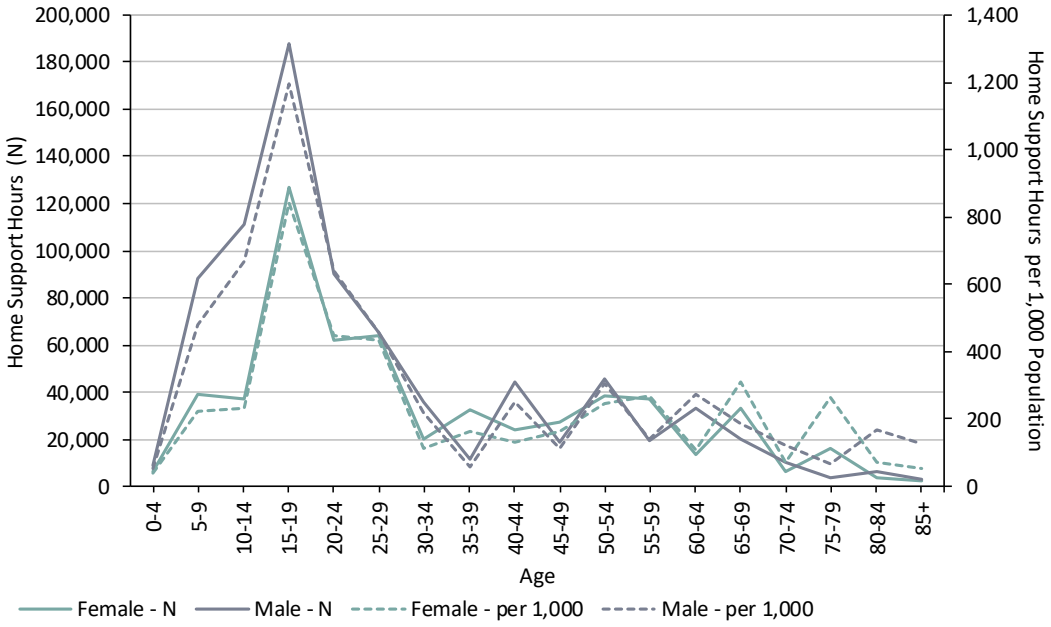


The NIDD does not record the exact number of hours of home help and home support used but it does have an intensity measure in the form of number of days per week used. It is planned that a greater level of detail will be captured in the new NASS system. The HSE KPIs categorise users into six groups by their intensity of use per week[25] (e.g. between one and five hours per week to more than 60 hours per week) and also report the total number of hours per year for all users (1,391,621). To apply an age and sex profile to the KPI figures the data on days reported in the NIDD are also grouped into six levels of intensity mirroring the KPIs. This method generates an age and sex profile for differing levels of home support users from low level users to high level users. Once the number of users in each category has been established, the age and sex profile can be applied to the total

[25] The KPIs report 4,116 users but only records hours for 3,348. The data on number of users by hours used are not currently validated.

number of hours reported by the KPIs to give an estimate of the total number of hours used by age and sex (Figure 26).

FIGURE 26 KPI: Hours of Home Help or Home Support Services and Rate per 1,000 Population by NIDD Age and Sex Profile, 2017



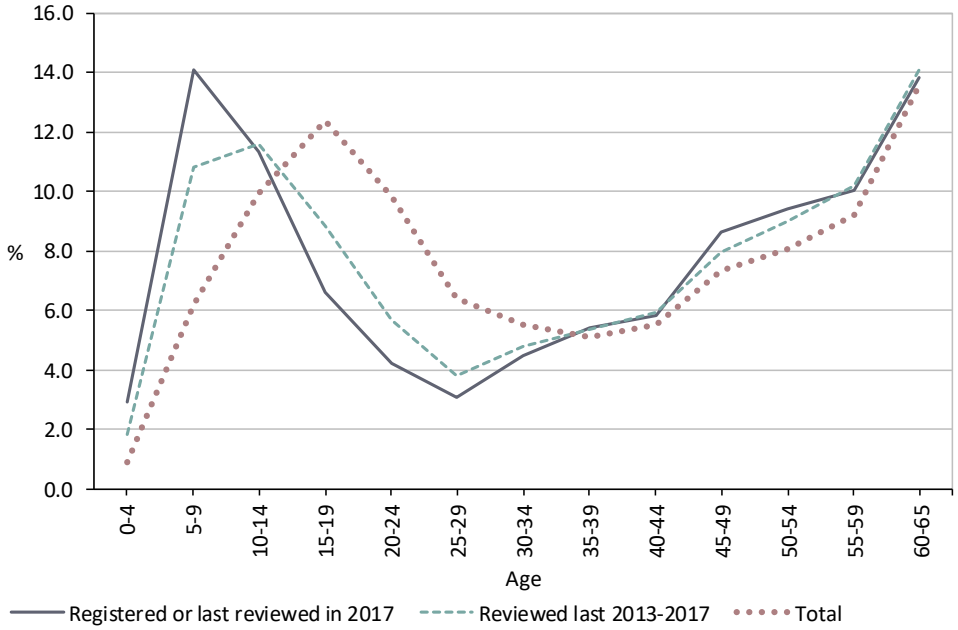
5 NPSDD – Findings

5.1 Registrations Profile 2017

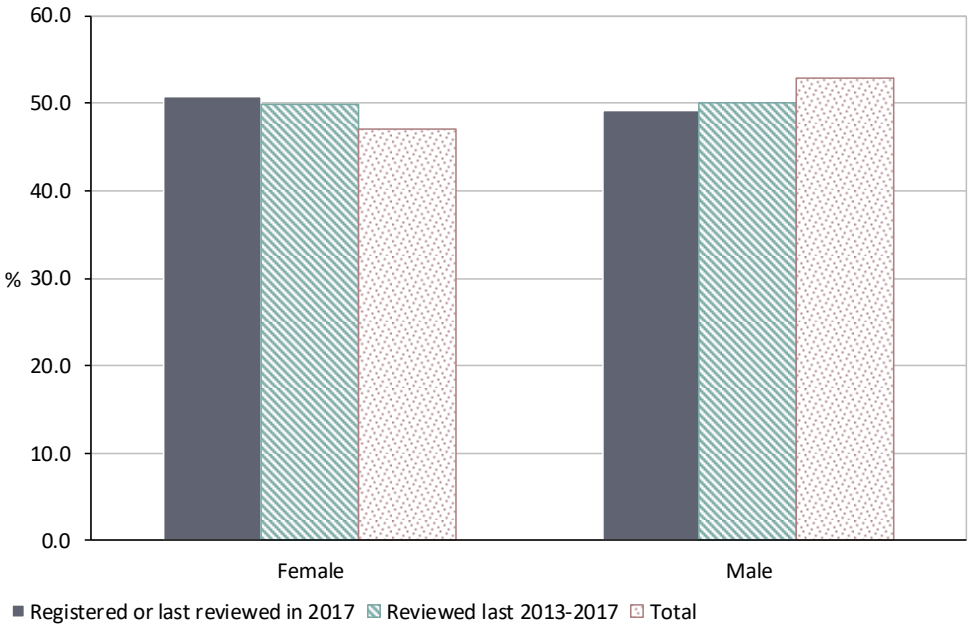
Figure 27 outlines the age profile of those registered in 2017, disaggregated by when the record was reviewed. The age and sex profile of those last reviewed in 2017 and those last reviewed between 2013-2017 inclusive are reasonably similar and this is the group on which service utilisation age profiles will be based, a total of 9,956 records. It must be emphasised that data on those registered on the NPSDD will not be included in the Hippocrates model for any services at the present time, due to the data limitations discussed in section 2.2 above. However, the age and sex profile of users from the NPSDD is applied to the HSE KPI data on service use to generate an age-sex profile of utilisation, in the absence of more representative data.

FIGURE 27 NPSDD: Age and Sex Profile, 2017

Age



Sex

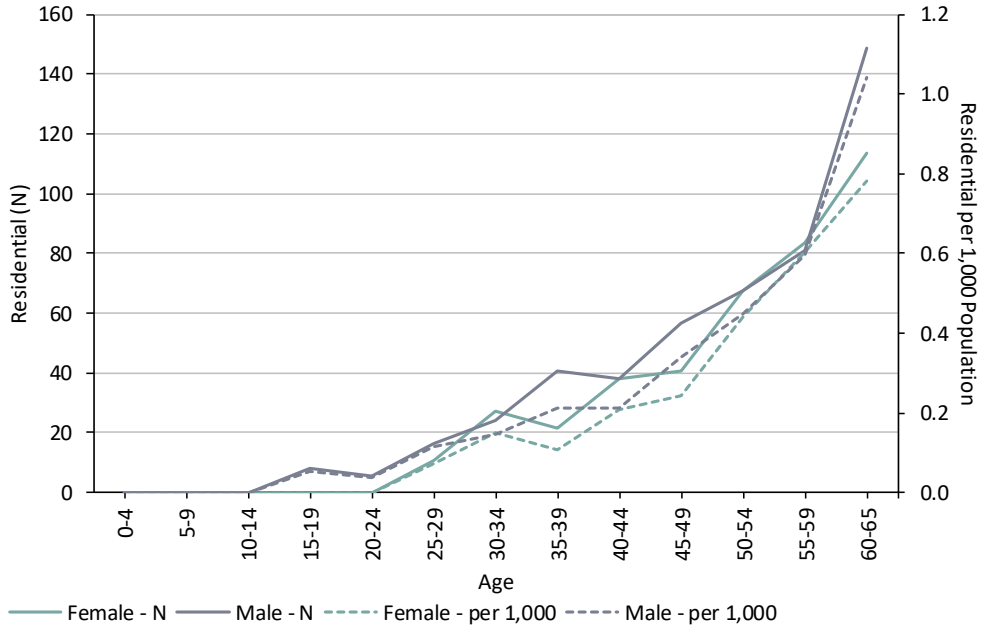


5.2 Service Utilisation

5.2.1 Residential Services

The HSE KPI reports 889 users of residential services in 2017. Figure 28 presents an estimate of the age and sex disaggregation of the 889 based on the age and sex profile of 564 residential care users in NPSDD records updated between 2013 and 2017. Utilisation of residential services increases with age peaking between 60 and 65 years.

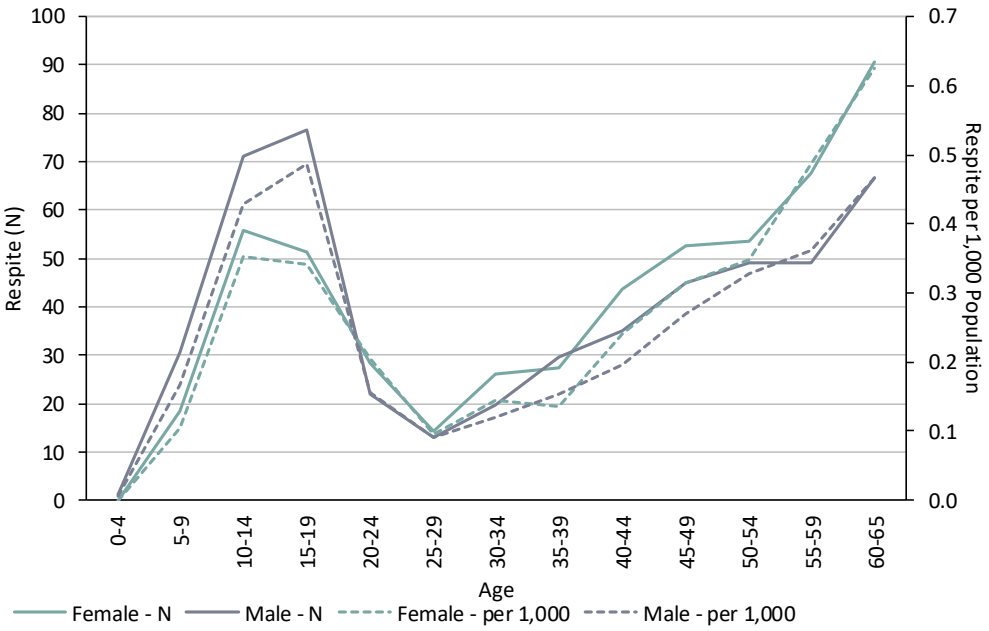
FIGURE 28 KPI: Number of People in Receipt of Residential Services and per 1,000 Population, 2017



5.2.2 Respite Services

The HSE KPI reports 1,038 users of respite services in 2017. Figure 29 presents an estimate of the age and sex disaggregation based on the age and sex profile of 950 respite users in the NPSDD[26] records updated between 2013 and 2017. Utilisation of respite services is high amongst those aged 5 to 25 at which point it falls significantly only to increase gradually with age from 25 onwards.

FIGURE 29 KPI: Number of People in Receipt of Respite Services and per 1,000 Population, 2017

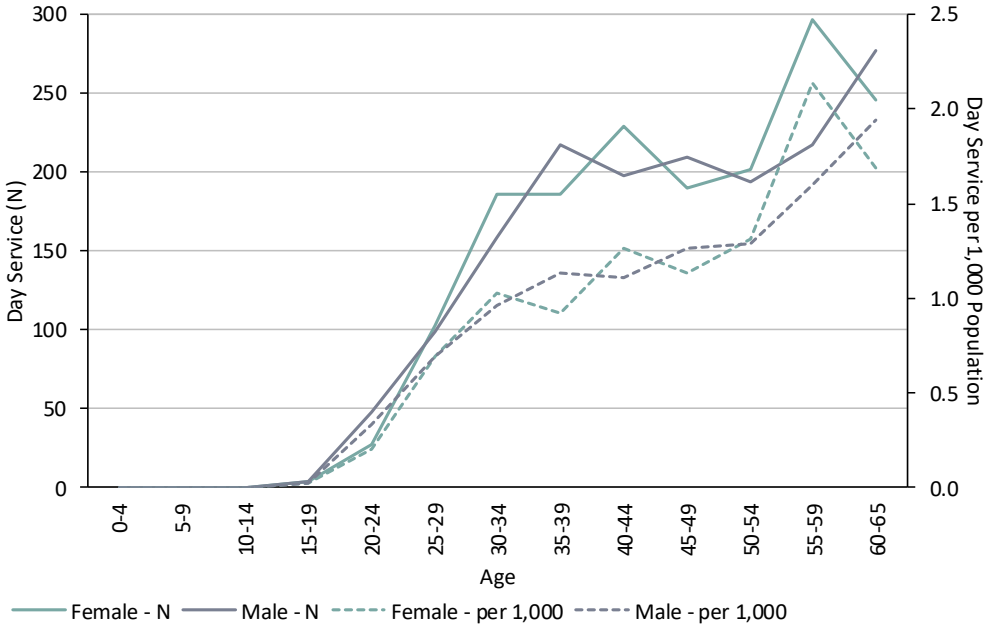


[26] Includes planned residential respite with high support, planned residential respite with low support, planned home based respite, summer camp residential, summer camp day, breakaway and befriending scheme, holiday respite placement, emergency residential respite with low support, emergency residential respite with high support, and emergency home-based respite.

5.2.3 Day Services

The HSE KPI reports 3,294 users of day services in 2017. Figure 30 presents an estimate of the age and sex disaggregation of the 3,294, based on the age and sex profile of 832 day service users in NPSDD records updated between 2013 and 2017. Utilisation of day services increases gradually with age, peaking between 55 and 59 years for females and 60-65 years for males. The majority of the day services used by those registered in the NPSDD and reviewed in the last five years were open employment and day activation services.

FIGURE 30 KPI: Number of People in Receipt of Day Services and per 1,000 Population, 2017



5.2.4 Multidisciplinary Services

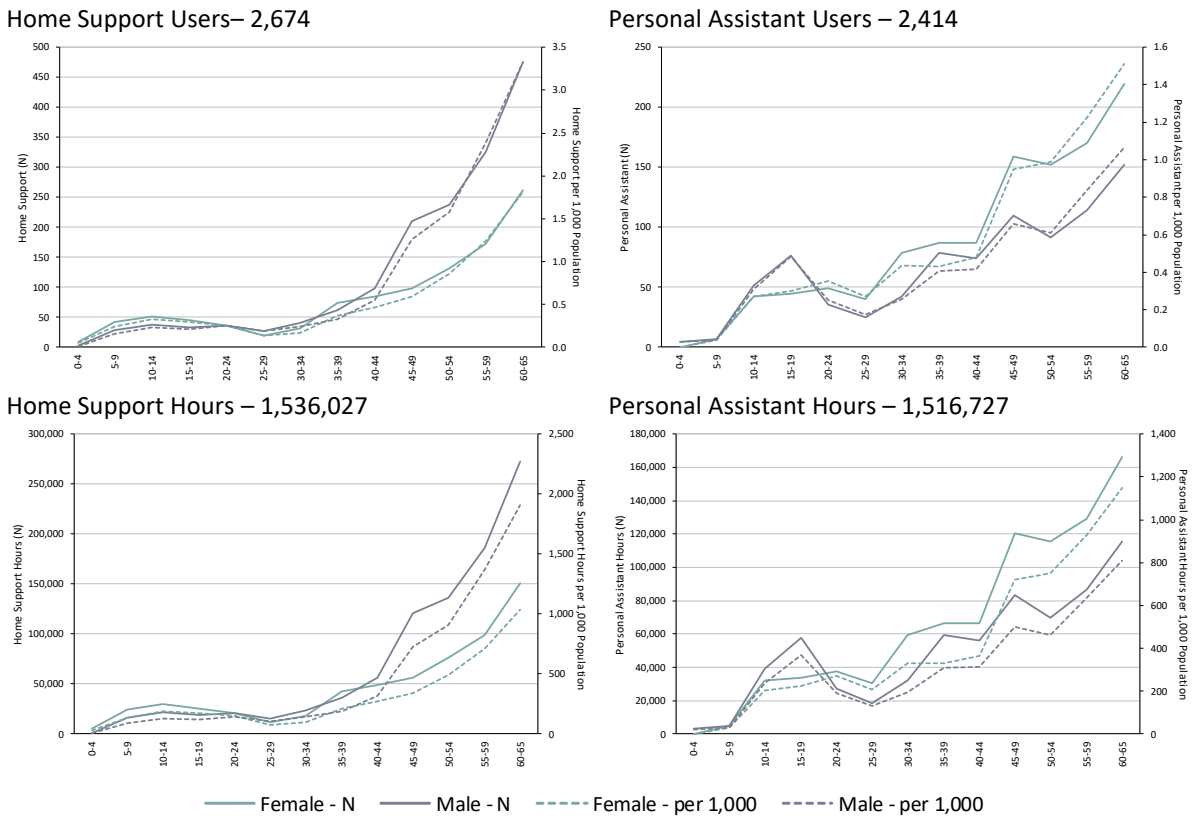
As with multidisciplinary services for the ID population, there are no KPIs available for these services for the PSD population. The NPSDD can provide an age and sex profile of multidisciplinary support users but the number of users reported cannot be used to impute the utilisation rate for the entire population because of the limited coverage of the database. It is deemed prudent to exclude these data from the model until a more comprehensive source becomes available.

5.2.5 Personal Assistance and Home Support

The number of users of personal assistance and home support (home help and home care assistant) is collected in the NPSDD. As with residential and day services, the age and sex profile of home support users (1,194) and personal assistance (893) reviewed in the last five years was applied to the number of users reported in the KPIs (Figure 31). As home help and home care assistant are included in one KPI, that is how they are presented.

Unlike the NIDD no indicator for intensity of use is collected in the NPSDD. While the age/sex profile of users can be applied to the total number of hours reported in the KPI, no adjustment can be made for intensity by age.

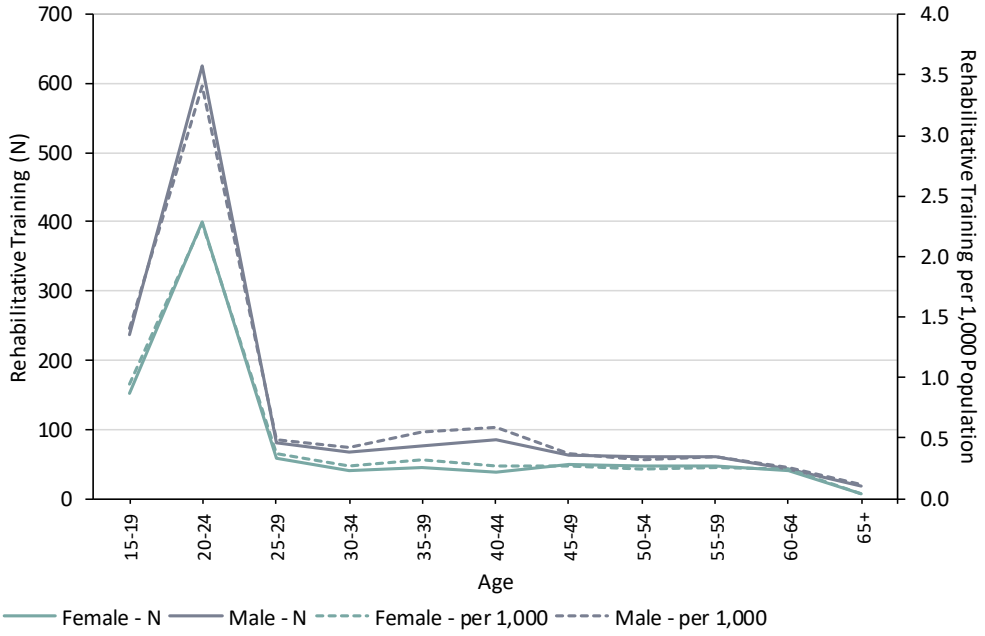
FIGURE 31 KPI: Number of People in Receipt of Home Support or Personal Assistant and per 1,000 Population, 2017



6 Rehabilitative Training – Findings

The total number of RT places has fallen from 3,023 in 2012 to 2,342 in 2017 a reduction of 22.5 per cent, with a similar fall (23.8 per cent) in the number of WTEs. In 2017, there was on average 1.1 people per WTE. This varied by age group with 1.03 people per WTE in the 20–24 years age group compared to 1.36 in the 60–64 years group. School leavers represent the majority of people in receipt of an RT place with a higher proportion of males than females in all age groups.

FIGURE 32 OGS: Number of People in Receipt of a Rehabilitative Training Place and per 1,000 Population, 2017



7 Conclusion

It is clear that there are significant data deficits in the area of specialist disability services provision. This paper has developed and applied methods to generate baseline estimates of service utilisation for people with ID and PSD in receipt of specialised services. This analysis is designed to inform projections of service demand for the Hippocrates model and uses the best data currently available. However, it will be subject to substantial revision when more comprehensive data become available, which is unlikely to be before 2021. It is intended that the coverage of people with PSD will improve under the new NASS database as resources are being made available to support data collection. It is also an objective that services for people with autism will be more comprehensively collected.

In addition to NASS, HSE Disability Services are in the process of reviewing the suite of KPIs and the data provided by service providers. Over time as data and coverage improve, the Hippocrates model can be updated to reflect this. The work ongoing in HSE Disability Services to improve data on day services provision will be particularly important.

Notwithstanding data deficiencies, this paper has combined the available data sources to generate estimates of baseline utilisation rates by age and sex for a wide range of specialised disability services, which will inform the development of projections of demand and expenditure using the Hippocrates model. We estimate that the services covered in the baseline utilisation analysis in this paper account for at least 85% of public spending on specialist disability services.

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Appendix

TABLE A.1 Comparison of KPI to NIDD for Key Services, 2017

	NIDD	KPI – ID	% Difference
Day Services			
No. of people in receipt of work / work-like activity services	2,255	2,530	12.2
No. of people in receipt of Other Day Services (excl. RT and work / work-like activities)	12,500	13,171	5.4
Rehabilitative Training Services			
No. of people in receipt of Rehabilitative Training (RT)	1,441[a]	-	-
Residential Services			
No. of people with a disability in receipt of residential services	7,530	7,424	-2.7
Respite Services			
Total no. of people in receipt of respite services	4,806[b]	4,798	-0.2
No. of overnights (with or without day respite) accessed by people with a disability	107,644[c]	141,655	31.6
No. of day only respite sessions	40,300[d]	31,339	-22.2
Home Support			
No. of people with a disability in receipt of Home Support Services	2,030	4,116	102.8
No. of Home Support Hours delivered to persons with a disability	856,674[e]	1,391,621	62.4

Note:
a Data provided by the Occupational Guidance Service was not available by disability type.
b Includes day, overnight and crisis or planned respite
c Includes crisis or planned respite only
d NIDD report 650 people per week in receipt of 806 day only respite sessions. Multiplying the number of weekly sessions by 50 gives an estimate of the number of sessions per annum.
e Estimate

Source: NIDD and Health Service Executive (2018)