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UTILISATION OF SPECIALIST DISABILITY SERVICES IN IRELAND – BASELINE ANALYSIS FOR THE HIPPOCRATES MODEL

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ABBREVIATIONS

HRB	Health Research Board
HSE	Health Service Executive
ID	Intellectual disability
KPI	Key Performance Indicator
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
WTE	Whole-time equivalent

EXECUTIVE SUMMARY

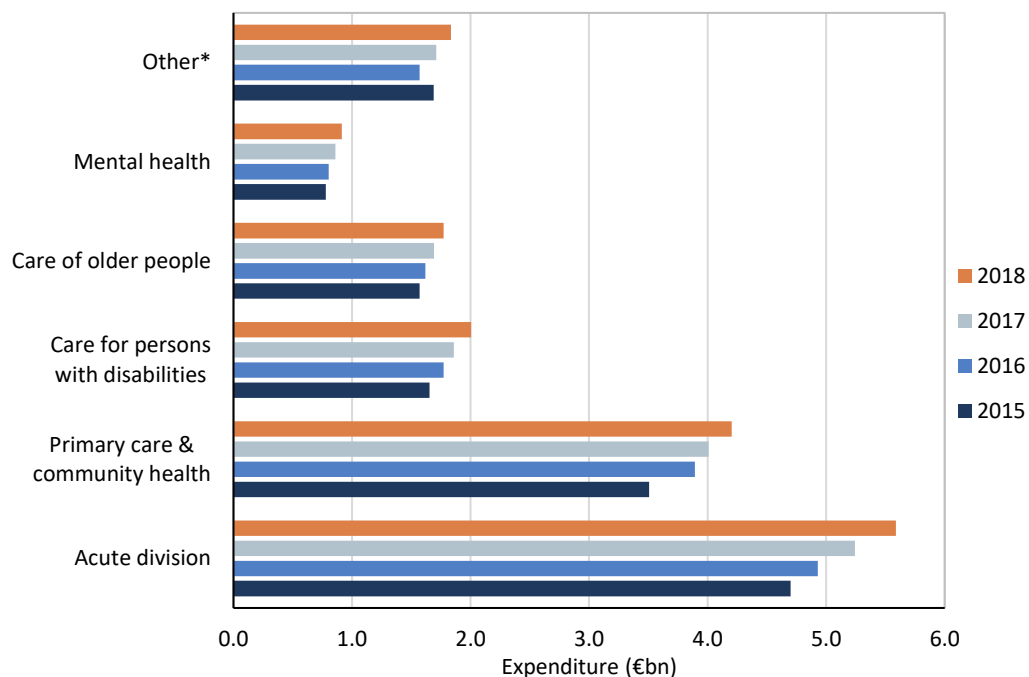
The Hippocrates model provides estimates and projections of public and private healthcare demand for a range of Irish health and social care services between 2015 and 2030. To extend the model to include specialist disability services, it was necessary to scope currently available data in Ireland. Data from a number of sources were considered. It was concluded that data on the utilisation of day and residential services for those with an intellectual disability collected by the Health Research Board are sufficiently detailed to include in the model. In addition, the model will include Health Service Executive data on those in receipt of rehabilitative training places and those waiting for day and in-patient services.

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 (Wren et al., 2017). The model continues to 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 specialist disability services.

In 2018, the Health Service Executive (HSE) gross non-capital vote allocation amounted to €16.3bn.¹ Care for Persons with Disabilities accounted for 12.3 per cent of this allocation, or €2bn (Figure 1) in 2018 (Department of Health, 2019). This was a 21 per cent increase on the 2015 allocation and the largest expenditure increase across the five main divisions.

FIGURE 1 HSE gross non-capital vote allocation, 2015–2018 (€bn)



Note: In 2015 the Vote of the HSE was disestablished and the funding transferred to Vote 38 (Office of the Minister for Health) from which Vote grants are now paid to the HSE (Department of Health, 2019).

* 'Other' includes statutory pensions, health and wellbeing, palliative and chronic illness, long-term charges repayment scheme, social inclusion, and other.

Source: Department of Health (2019), Table 6.4.

The aims of this report are to scope the types of data available on *specialist* services provided to those with an intellectual (ID) and/or physical and sensory disability (PSD) and to establish how these can be incorporated into the Hippocrates model. Services provided to those with mild levels of disability that are provided through Primary Care and Community Health are not included, to avoid double-counting in

¹ In 2015 the Vote of the HSE was disestablished and the funding transferred to Vote 38 (Office of the Minister for Health) from which Vote grants are now paid to the HSE (Department of Health, 2019).

the model. Those services provided through mainstream education are beyond the scope of this research.

The Hippocrates model employs a macro-simulation (cell-based) approach to project demand for, and expenditure on, health and social care services. A macro-simulation approach was deemed most appropriate as it offers more flexibility than standard macro-level modelling, yet is still feasible despite the considerable data constraints faced in the Irish system. In these models, individuals are grouped into cells according to age and sex, and expenditure is estimated by multiplying the number of individuals in a cell by the unit (or average) cost (Wren et al., 2017).

Where possible, the model disaggregates demand and expenditure estimates for each healthcare service by single-year-of-age (SYOA) and sex (Wren et al., 2017), and aims, where possible, to include both public and private activity and cost. The first step in the modelling is to estimate utilisation and demand in the base year. In the next step, healthcare demand will be projected based on projected population growth, with sensitivity analyses that vary 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



Source: Author representation of the 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 of the Value for Money and Policy Review of Disability Services in Ireland (Department of Health, 2012). 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 challenging data environment in this area to establish a baseline from which to estimate future

demand (Health Service Executive, 2018). The Department of Health has updated the WG1 work to examine future capacity requirements for disability services to 2032. That Disability Capacity Review is due to be published in 2020. The Hippocrates model work programme will draw on the above work to inform the establishment of scenarios for projecting demand.

The specific objective with this paper is to generate baseline utilisation data for specialist disability services that 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. The services examined include residential and respite services, home support and personal assistance, day services, multidisciplinary services, and rehabilitative training.

Section 2 describes 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 for the ID and PSD populations by age and sex. Section 6 presents utilisation data for rehabilitation training services. Section 7 outlines unmet demand in 2019 and section 8 concludes.

2 DATA SOURCES

This paper draws on several data sources 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 (HSE, 2018). 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

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.

used nationally for service planning, target setting, and tracking progress. The KPIs report on HSE-funded services only. 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.

Since there are strengths and limitations with each data source, a combination of sources will be required to create as accurate a baseline for projection as possible. 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 (NIDD)

The NIDD was a national service-planning database established in 1995 and administered by the HRB on behalf of the Department of Health. It captures data on the utilisation 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. First, 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 is taken from the database by the HRB, validated, analysed and published in the NIDD annual reports (HRB, 2012). Returns are made on a voluntary basis and those in receipt of services or their next of kin must give their written consent. In 2017, 88.4 per cent of registrations in the NIDD were reviewed (Hourigan et al., 2018).⁴

The NIDD is thought to be highly representative of the population with an ID in Ireland. The HRB estimates coverage at 95 per cent 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.⁵ The HRB acknowledges 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.

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

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, HRB, 25 July 2018.

The analysis presented in section 4 is based on validated NIDD data extracts from December 2012, 2015, 2016 and 2017 and published annual reports.⁶

2.2 National Physical and Sensory Disability Database (NPSDD)

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 with 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 annually. 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 at 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) (Gallagher, 2001). This figure was used to extrapolate the estimated national target population for a period of time, but, it has since ceased to be used due to temporal changes in demographic profile and service utilisation. In the absence of an alternative, this figure is used to estimate a target population of 44,126 for 2017, which is an increase of 6.5 per cent on 2007 (41,442).⁷ In 2017, the number of people actually registered was 20,676 (Doyle et al., 2018), implying coverage of 47.1 per cent. This is a substantial 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 be reviewed in full each year, this has not been 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 available for only 5,654 (27.3 per cent) records registered or reviewed in 2017 (Doyle et al., 2018). 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 as a measure of service utilisation for the overall population.

⁶ These data are referenced as 'NIDD' and the year to which the data relate in the figures and tables.

⁷ Using CSO Census of Population 2016 aged 65 years or less of 4,168,454, the target would be slightly less at 43,894.

The analysis presented in section 6 is based on a validated data extract from December 2017.⁸ Unlike with 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 the number of users (days and hours where relevant) of residential services, day services, respite services, home support, and personal assistant hours. Data on these services are also collected by the NIDD and NPSDD.⁹

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 thanks to the OGS case management system. This system provides comprehensive data on RT service use, measured in terms of the number of service users and the number of whole-time equivalents RT places 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.

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.

⁸ These data are referenced as 'NPSDD' and the year to which the data relate in the figures and tables.

⁹ These data are referenced as 'HSE KPI' and the year to which the data relate in the figures and tables.

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 that 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 (HSE, 2018). 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.¹⁰ NIDD registrations per 1,000 population are calculated using Census of Population figures and ESRI population estimates for intercensal years. Rates of utilisation for individual services are calculated using the number of NIDD registrations as the denominator.

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.

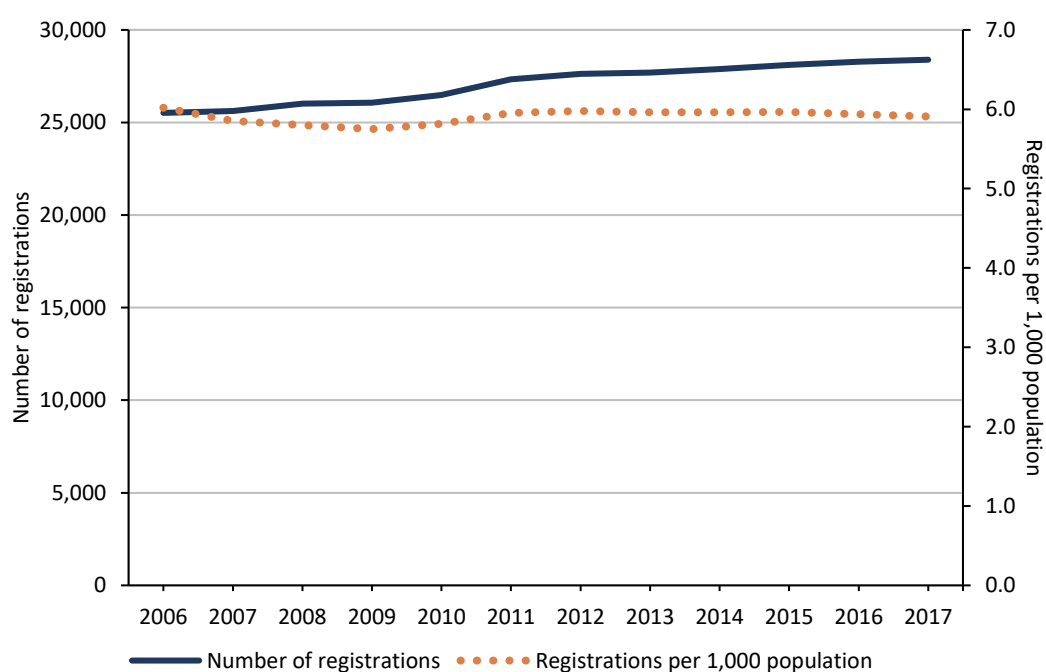
¹⁰ While privately funded service utilisation is not included in KPIs, as discussed in later sections, for most disability services private provision does not appear to be a big component of total service provision.

4 NIDD – FINDINGS

4.1 Registrations over time 2006–2017

The number of NIDD registrations 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 people registered 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 intercensal years.

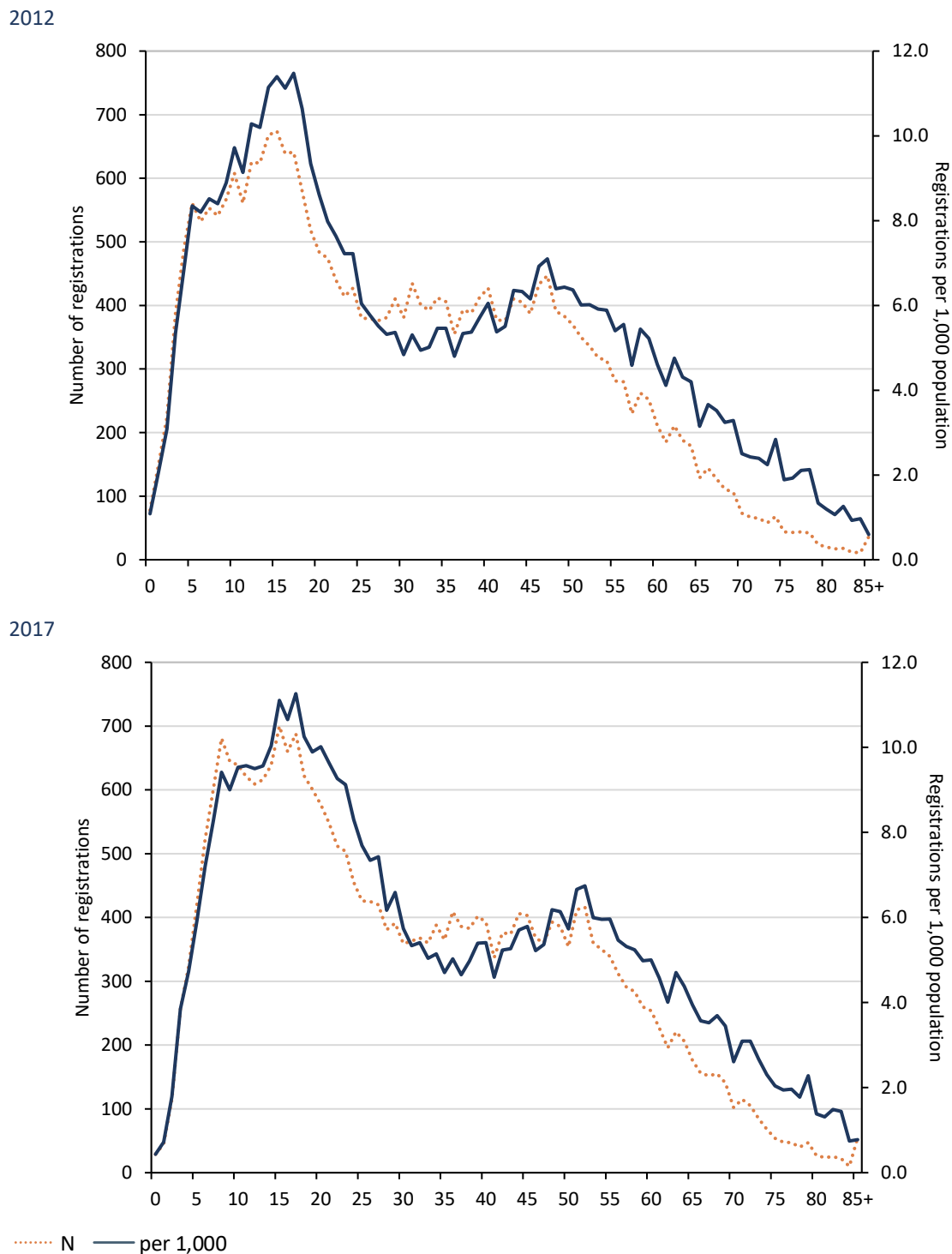
Source: NIDD, 2006–2017.

4.2 Registrations by age and sex

The overall number of registrations on the NIDD increased from 27,621 to 28,386 between 2012 and 2017 (Figure 4).^{11,12} 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, whereas 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.

¹¹ Two cases had missing values for age and are excluded from the analysis in 2012.

¹² 2012 was chosen as the comparison year as the proportion of records reviewed in that year was very high at 99.4 per cent.

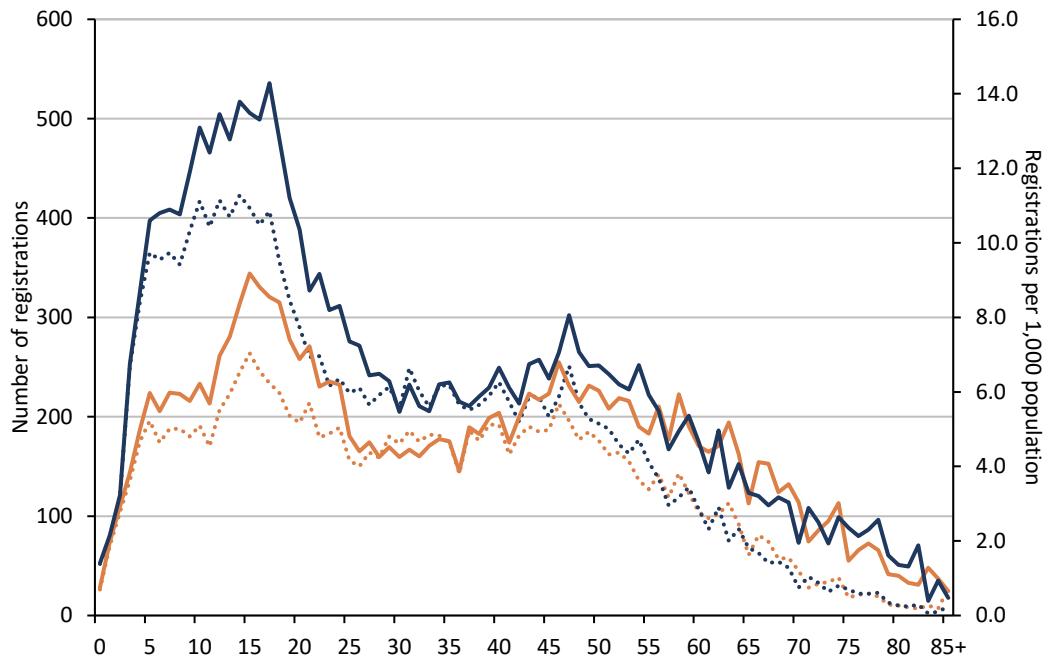
FIGURE 4 NIDD: Number of people registered and registrations per 1,000 population by age, 2012 and 2017

Source: NIDD, 2012, 2017.

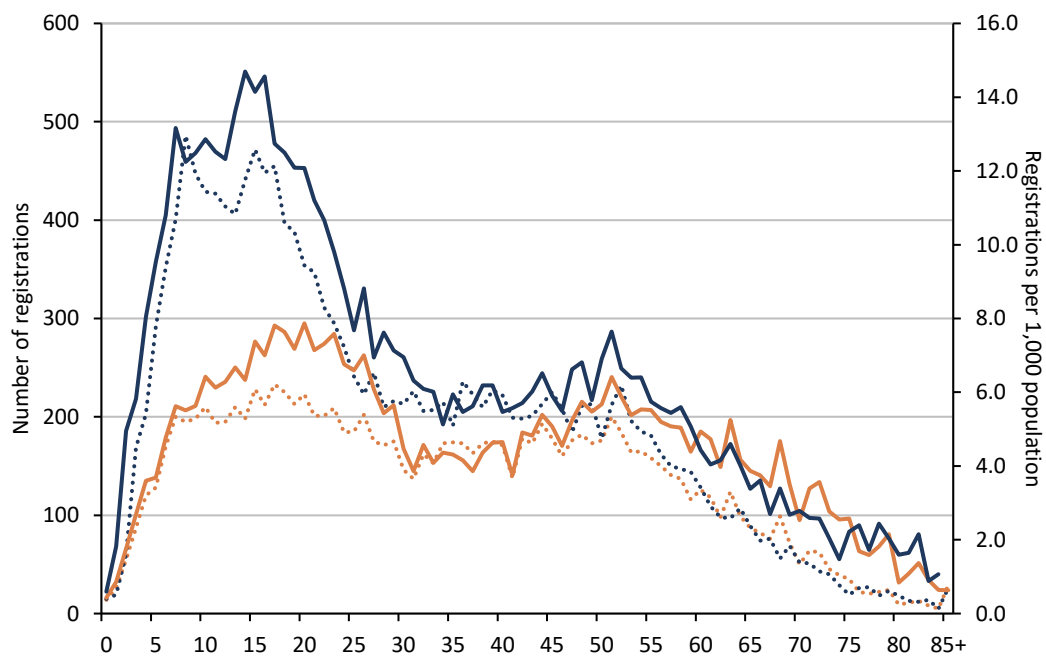
Males accounted for 57.7 per cent (15,951) of registrations in 2012 and 59.1 per cent (16,768) in 2017. Figure 5 shows the numbers of male and female registrations and number per 1,000 population in 2012 and 2017. There was a higher number of males than females at all ages with the exception of the over 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 may be due to greater service engagement at school age for boys. This differential decreases sharply after school age.

FIGURE 5 NIDD: Number of people registered and registrations per 1,000 population by age and sex, 2012 and 2017

2012



2017



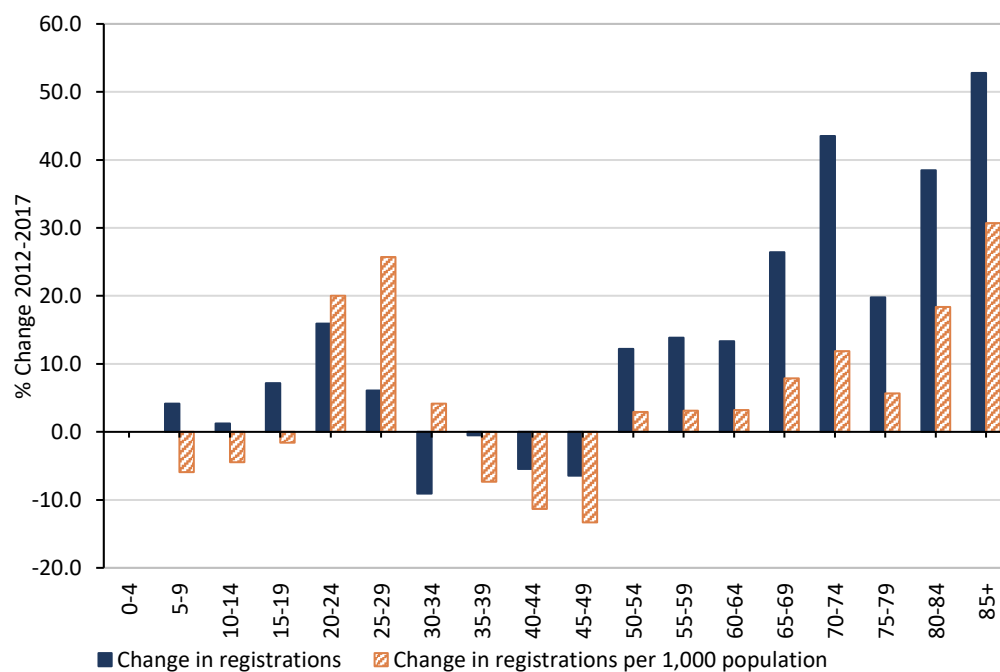
Female - N Male - N Female - per 1,000 Male - per 1,000

Source: NIDD, 2012, 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 NIDD: Change in registrations and registrations per 1,000 population by age, 2012 and 2017

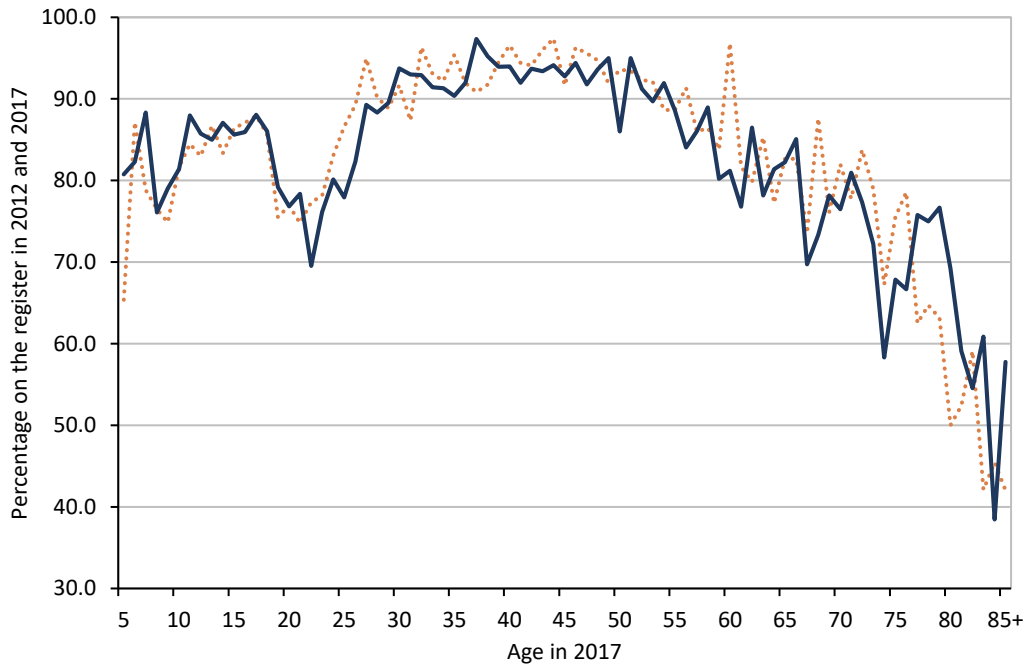


Source: NIDD, 2012, 2017.

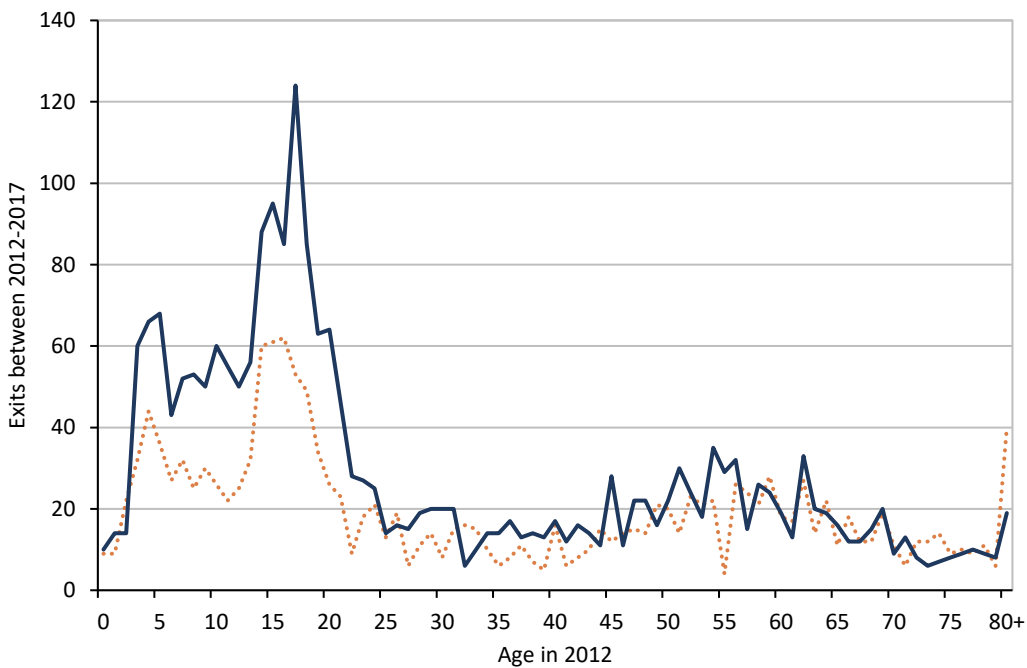
Examining the database in 2012 and 2017, we can see that, of the 27,621 registered in 2012, 23,711 (83.8 per cent) remained registered in 2017. Figure 7 shows the proportion of those remaining by single year of age in 2017. For example, of those aged 17 in 2012, 69.5 per cent remained on the register when they were 22 in 2017. This appears to reflect an exodus from specialist services after 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; females show a slightly higher proportion remaining on the database at older ages, possibly due to greater life expectancy. 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

Remaining on register 2012–2017 (%)



Exits 2012–2017



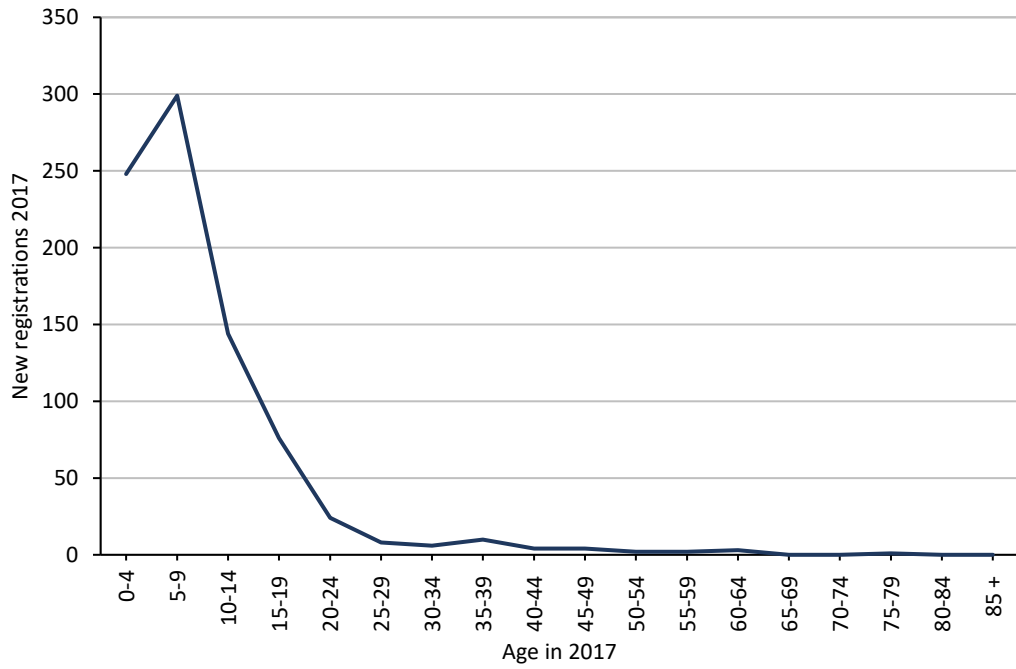
..... Female — Male

Source: NIDD, 2012, 2017.

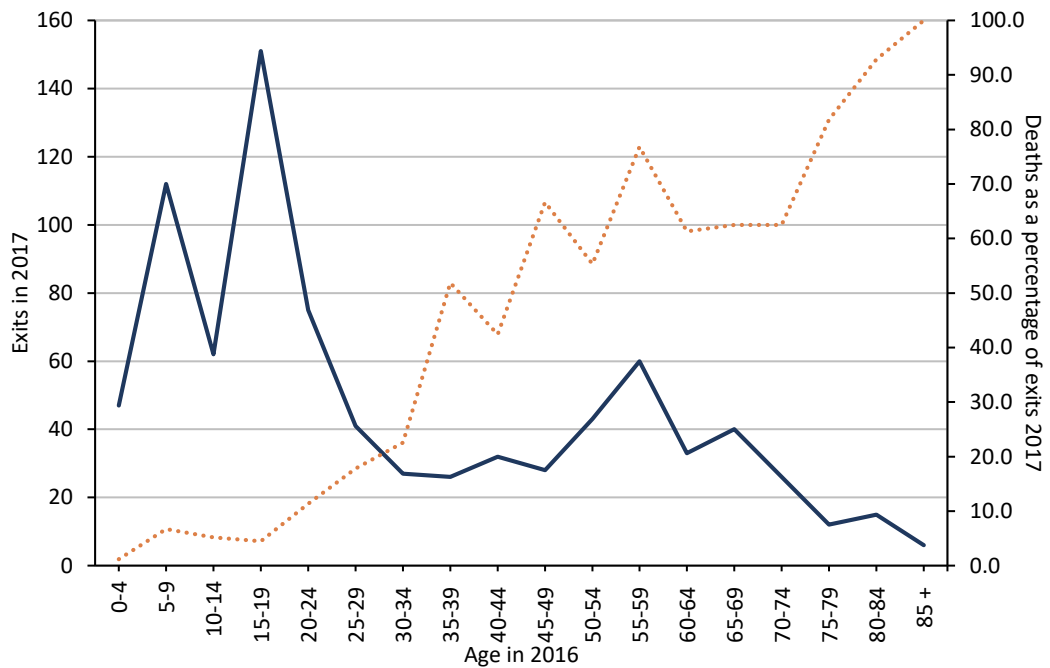
Every year, new people are registered and a number leave the database. In 2017 there were 831 new registrations, two-thirds of whom were aged under 9 years old. In addition, 836 people left the database, the highest number of whom were in the school-leaver age group, an age at which people may no longer 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, 2016–2017

New registrations 2017 (n=831)



Exits 2017 (n=836)



— Exits 2017 Deaths as a % of Total Exits 2017

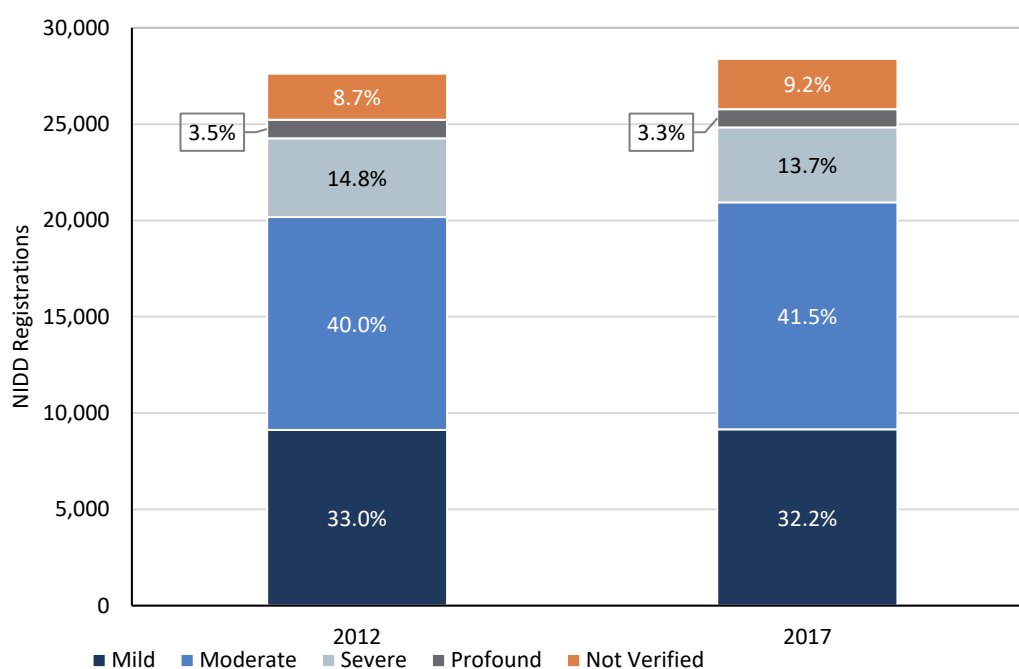
Note: If a person acquires a disability after the age of 65, they are not included in Care for Persons with Disabilities but are cared for through Care of Older People (Figure 1).

Source: NIDD 2016, 2017.

4.4 Degree of intellectual disability

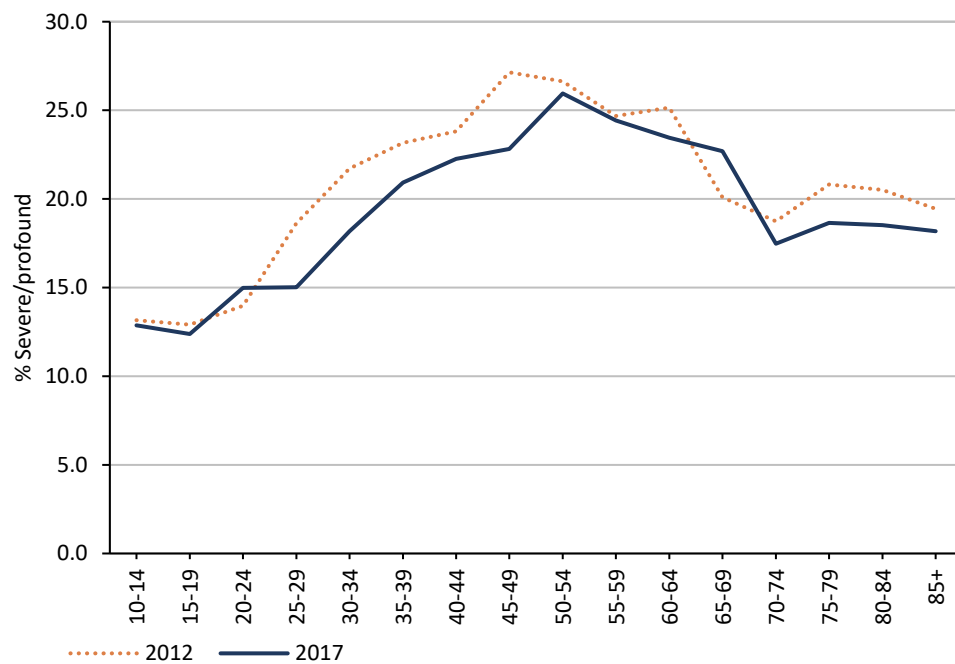
The NIDD reports on the degree of ID of the people registered. The proportions in each category changed little between 2012 and 2017 (Figure 9). Almost three-quarters (73.0 per cent in 2012 and 73.7 per cent in 2017) of those registered were assessed as having a mild or moderate degree of disability. 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) but the absolute numbers of males with a severe or profound disability is higher than that for females.

FIGURE 9 NIDD: Degree of intellectual disability, 2012 and 2017



Source: NIDD, 2012, 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. Over one-quarter of those aged 50–54 had a severe or profound disability compared to 14 per cent in the 20–24 age group in 2017. The proportion of individuals with a severe or profound disability 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 were in the 1–9 years age group.

FIGURE 10 NIDD: Proportion of people registered 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.
Source: NIDD, 2012, 2017.

Of the 23,711 people 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, users of 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.¹³ Figure 11 shows, by age group and sex, the number and proportion of people registered on the NIDD in 2012 and 2017 who were in receipt of full-time residential services. 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 among the 50-year and older age groups. There was a similar pattern for males and females.

¹³ Intensive placement (challenging behaviour, profound or multiple handicap), other residential services. Places in nursing homes, mental health community residences and 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 26.9 per cent (7,627).¹⁴ In 2012, 26.6 per cent of males (4,236) 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 (3,984) of males and 31.4 per cent (3,643) of females.

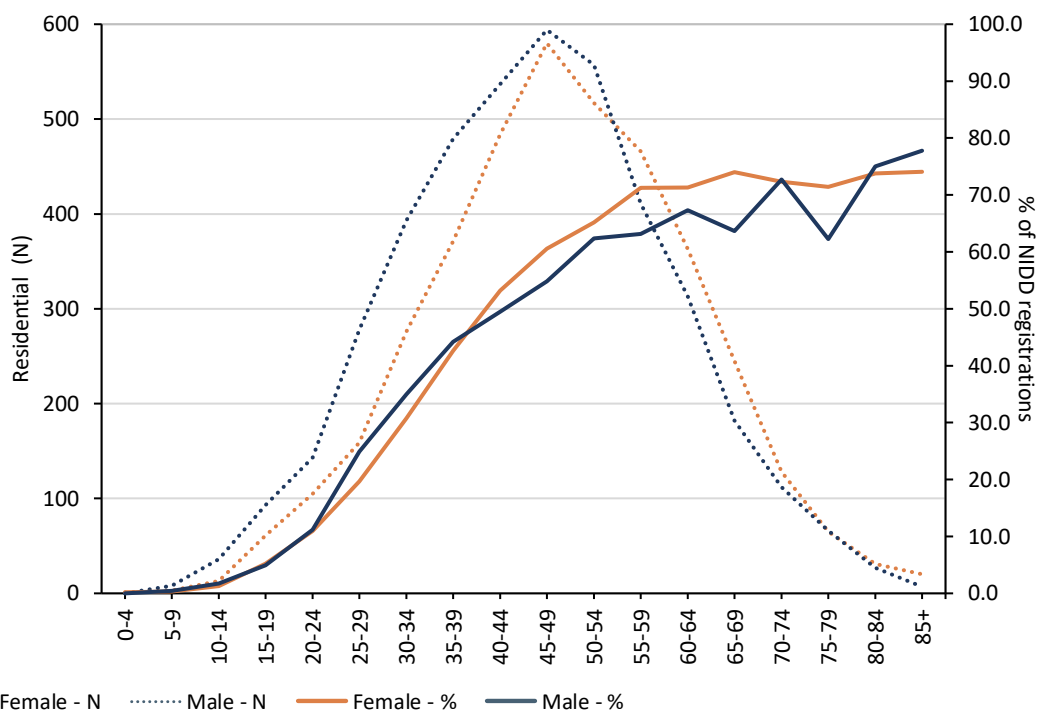
The proportion of people in each age group in receipt of full-time residential care in 2012 and 2017 increased with age for both sexes. There was a higher proportion of males in receipt of full-time residential care than females in the younger age groups; from approx. 40 years onwards there was a higher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

Most people in full-time residential care in 2017 were living in a community group home or residential centre (83.8 per cent). 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; 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.

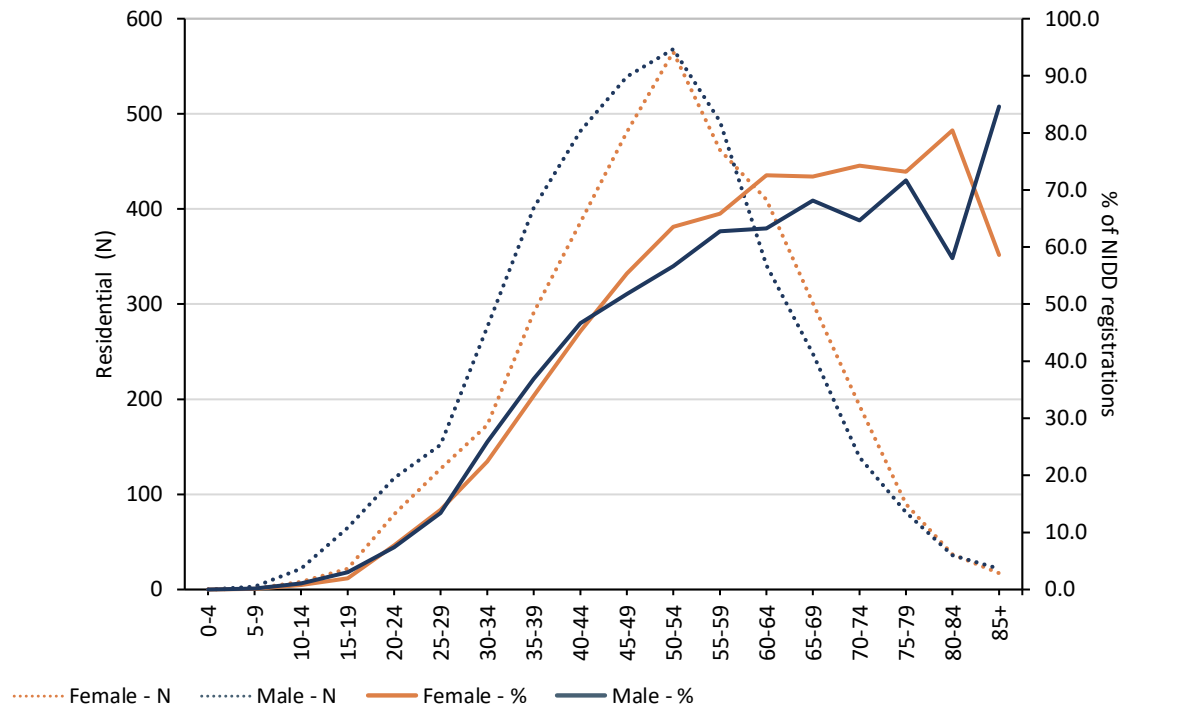
FIGURE 11 NIDD: Number and proportion of people in receipt of full-time residential care, by age and sex, 2012 and 2017

2012



¹⁴ Of the individuals in full-time residential care in 2012 and 2017, 0.2 per cent were recorded as privately funded.

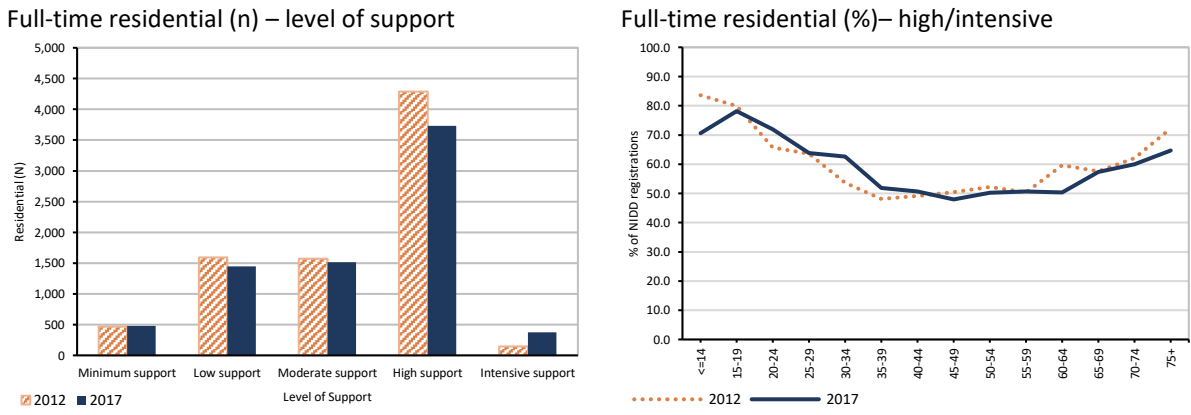
2017



Source: NIDD, 2012, 2017.

Figure 12 illustrates the support level required by those in full-time residential care in 2012 and 2017. Approx. 54 per cent of those in residential care in both years required a high or intensive level of support. The only support category that 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 2017.¹⁵ When examined as a proportion of NIDD registrations, the rate of use of high-or-intensive-support full-time residential care increased for almost all age groups under 50 years and decreased for those over 50 years.

FIGURE 12 NIDD: Number and proportion of people in receipt of full-time residential care by level of support required, 2012 and 2017

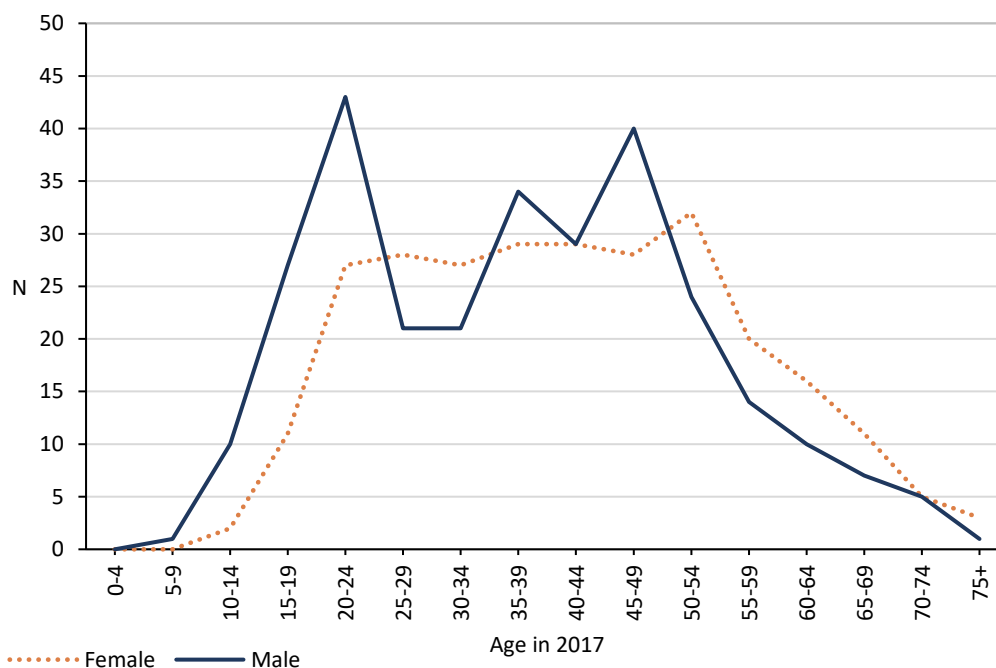


Source: NIDD, 2012, 2017.

¹⁵ The intensive category was a recent introduction in 2012, so the change here may be as a result of an adjustment from high support.

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. In the younger age groups, more males than females entered.

FIGURE 13 NIDD: Number of people who entered full-time residential care between 2012 and 2017 by age and sex



Source: NIDD, 2012, 2017.

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.¹⁶ 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.

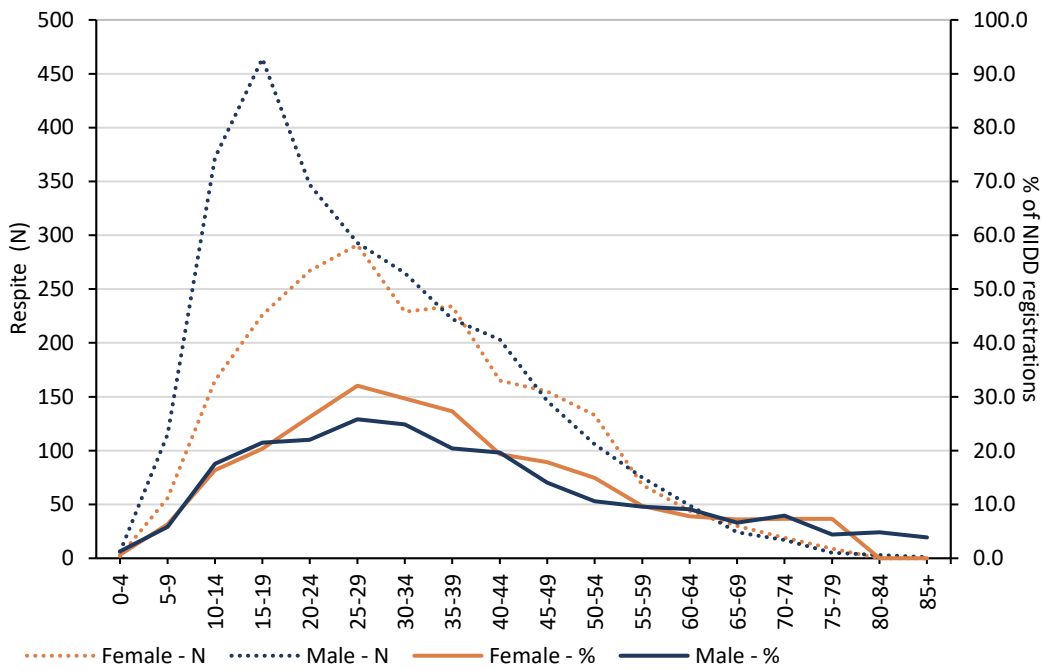
¹⁶ This KPI was not collected in 2012 so is not available for comparison.

Respite services

A number of different respite services are 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 and proportion of individuals in receipt of any respite, by age and sex, 2017

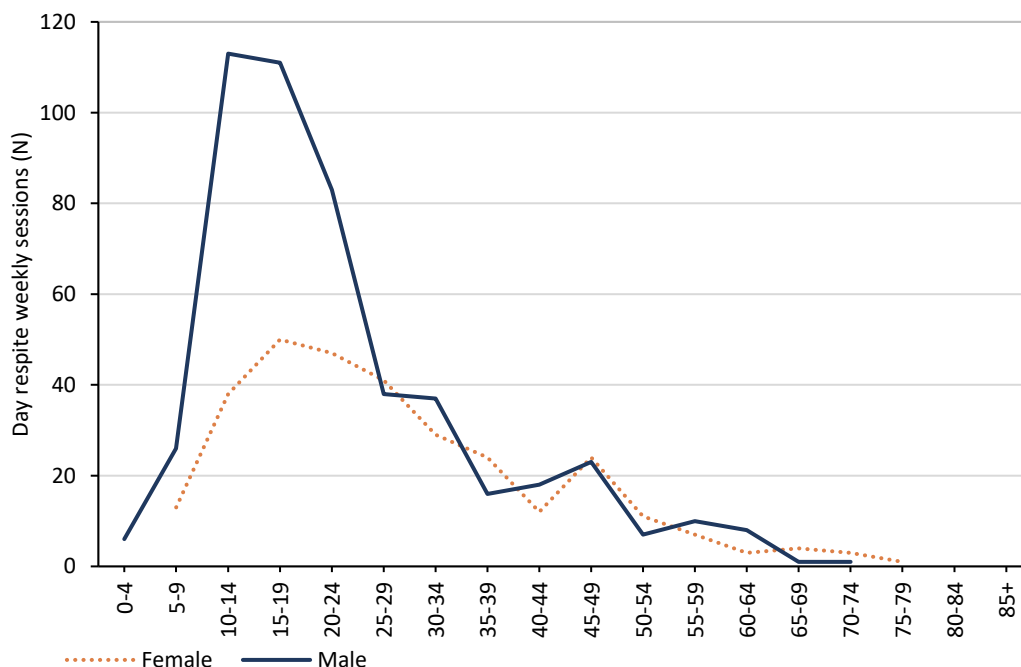


Source: NIDD, 2012, 2017.

Day respite

Over the period 2012–2017, there was a 26.8 per cent decrease in the number of individuals in receipt of day respite (2012, 888; 2017, 650). Of those availing of day respite in 2017 (2.3 per cent), the majority (68.8 per cent) reported using the service for one half-day per week, while a further 18.0 per cent recorded one day per week. Almost 80 per cent of those using day respite services were under 35 years old. A total of 806 day respite sessions per week was reported for 2017 (Figure 15); multiplying this by 50 gives an estimated 40,300 in the year.¹⁷ The majority of users (87.0 per cent) had one session per week. There is a large gender difference in usage in the younger age groups, with males using more sessions than females.

FIGURE 15 NIDD: Number of day respite weekly sessions by age and sex, 2017



Source: NIDD, 2012, 2017.

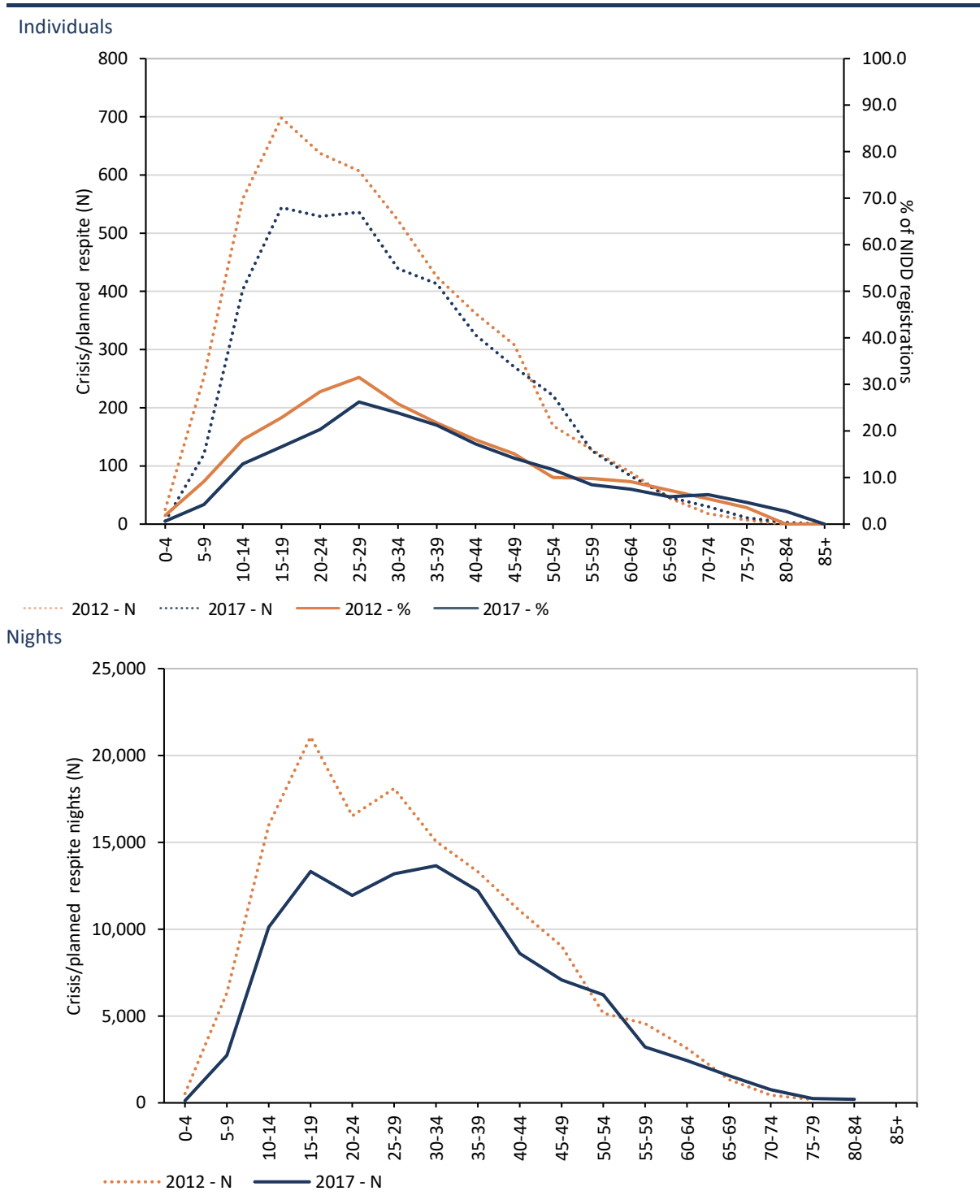
Crisis/planned respite

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 median number of nights decreased from 20 nights in 2012 to 18 nights in 2017.¹⁸ The overall number of respite nights recorded in the NIDD decreased from 141,815 in 2012 to 107,644 in 2017.

¹⁷ To calculate the number of sessions, both one half day and one day are counted as one session.

¹⁸ Fewer than five individuals were recorded as privately funded in 2012; no individuals were recorded as privately funded in 2017.

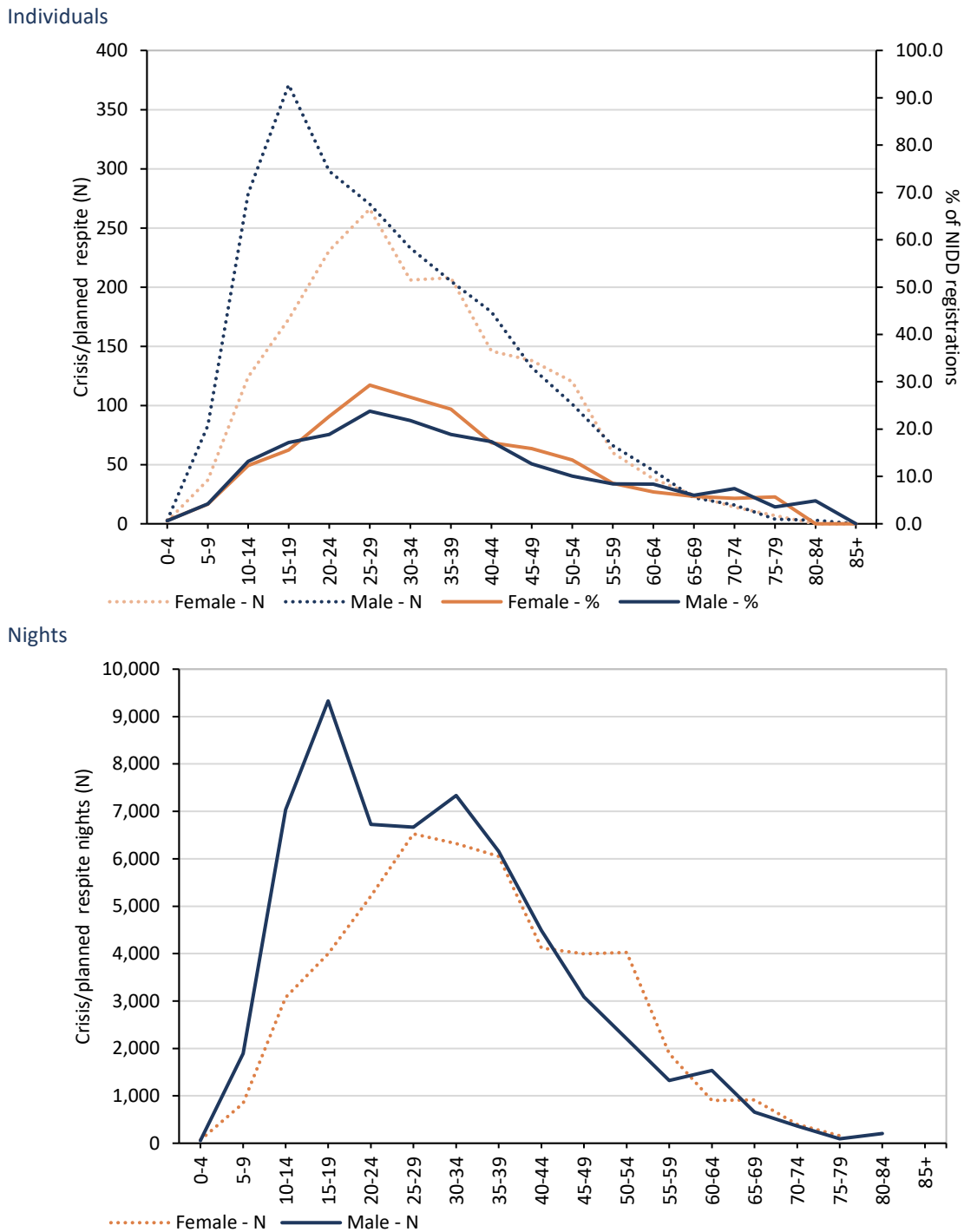
FIGURE 16 NIDD: Number and proportion of individuals and nights of crisis/planned respite by age, 2012 and 2017



Source: NIDD, 2012, 2017.

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

FIGURE 17 NIDD: Number and proportion of individuals and nights of crisis/planned respite, by age and sex, 2017



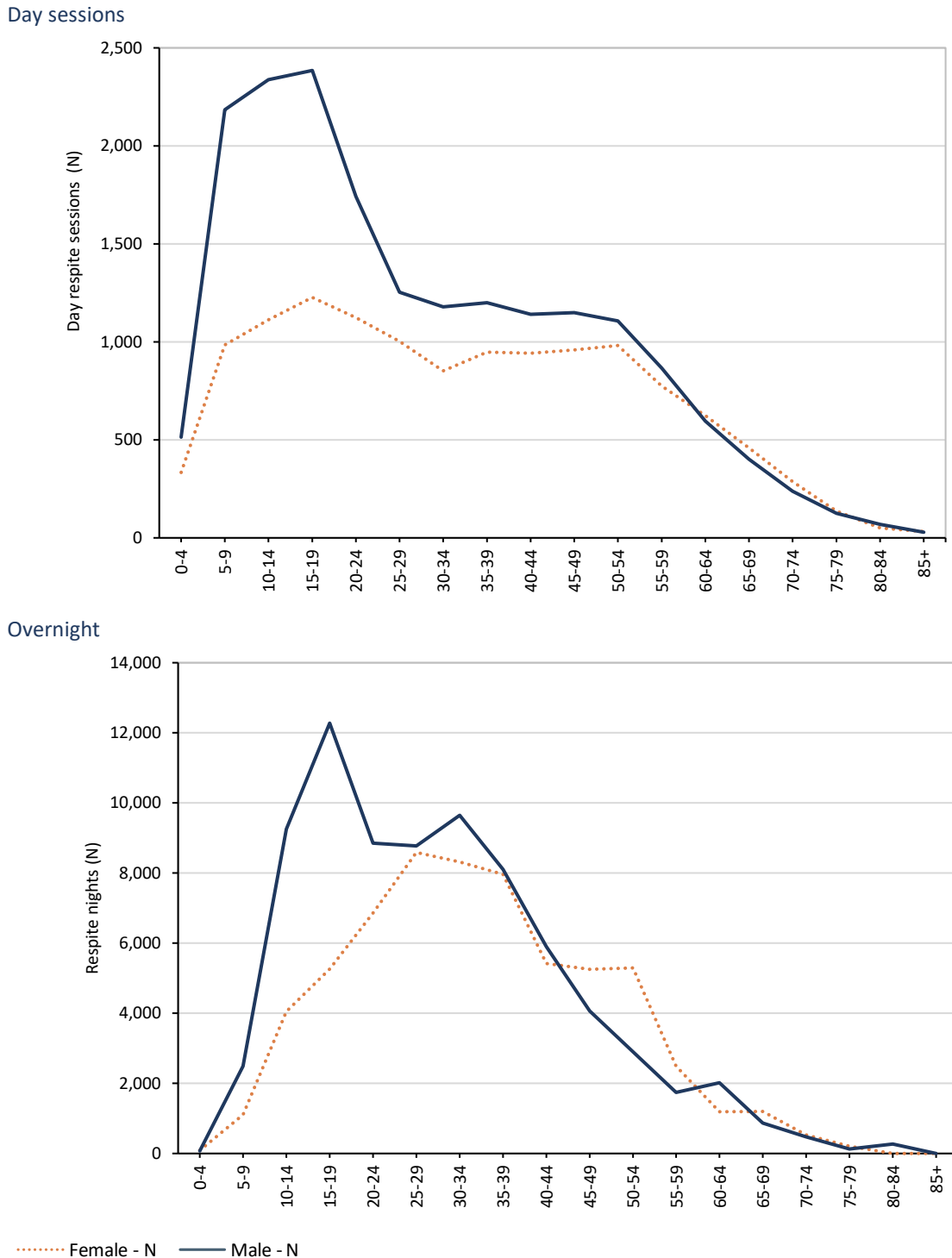
Source: NIDD, 2012, 2017.

Application of NIDD age and sex profile to KPI

There are three relevant KPIs relating to respite services: the number of individuals 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) (Figure 14). For day sessions, the age and sex profile 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 using 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



Source: NIDD, 2017; HSE KPI, 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 the NIDD.^{19,20} This was an increase of 2.6 per cent on 2012 (27,190). The categories of day services captured by the NIDD are broad. They 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. The NIDD captures the use of up to three-day support services per individual and the intensity of the usage measured in number of days per week.

The HSE KPIs report on two categories of day services.²¹ These are the number of individuals with ID and/or autism doing 'work/work-like activity' and the number in receipt of 'other day services'.²² 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, 14,755²³ 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 and proportion of individuals on the NIDD register in receipt of these services, disaggregated by sex, in 2012 and 2017. A higher proportion of males were 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, decreased over the period for those aged 30–50 and increased slightly in older age groups.

¹⁹ Excludes 'not applicable', 'no day service' and 'full-time resident with no formal day programme'.

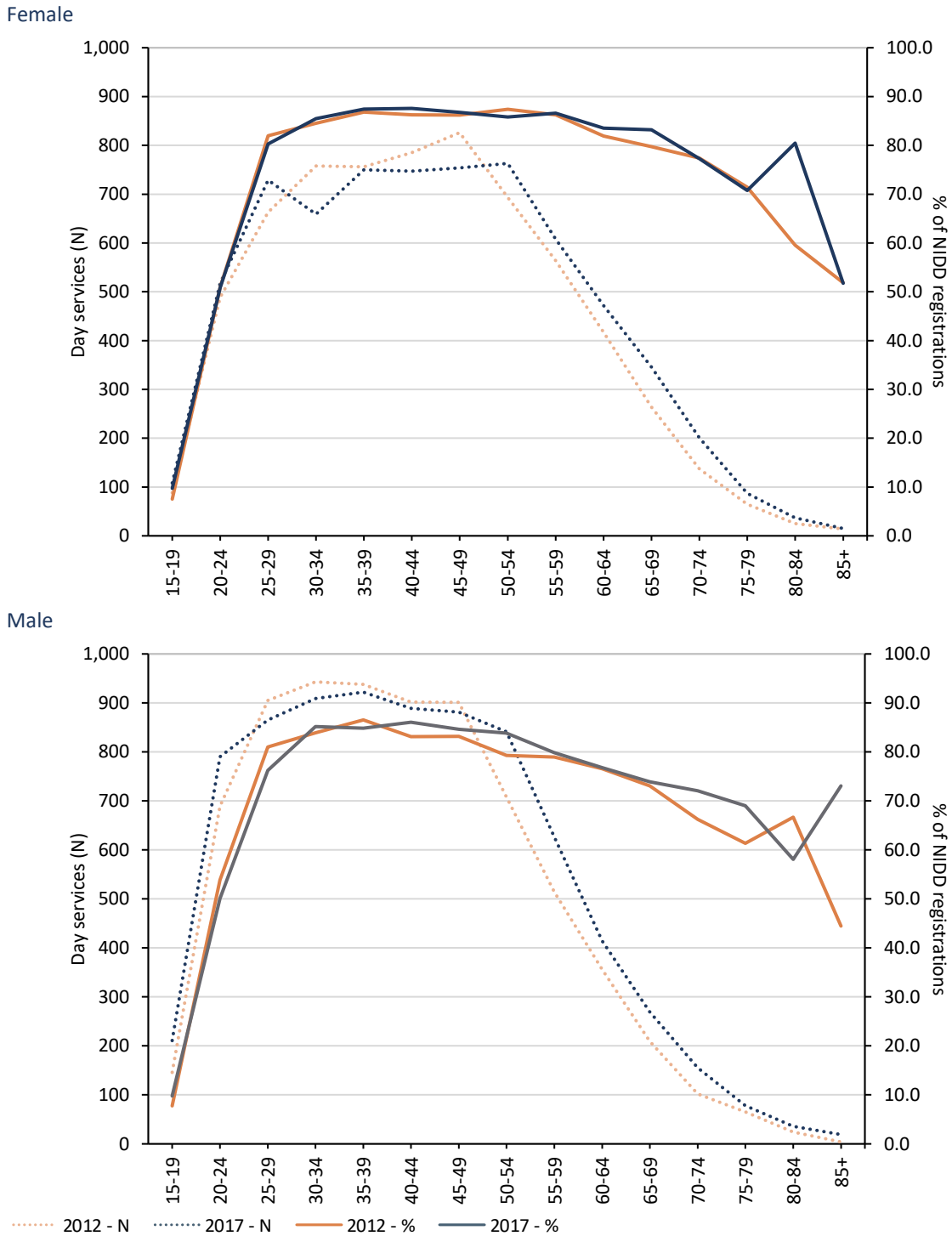
²⁰ Total day services include day respite; they are discussed along with respite services earlier in the paper to allow for comparison with the HSE KPIs.

²¹ Rehabilitative training is examined separately in section 7.

²² 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'.

²³ 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 and proportion of individuals in receipt of selected day services, by age and sex, 2012 and 2017



Source: NIDD, 2012, 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 (HSE Working Group, 2012). In the subsequent *Comprehensive Employment Strategy for People with a Disability, 2015–2024*, a goal was set out to ensure that individuals with disabilities who are able to and want to work are enabled to do so (Department of Justice and Equality, 2015).

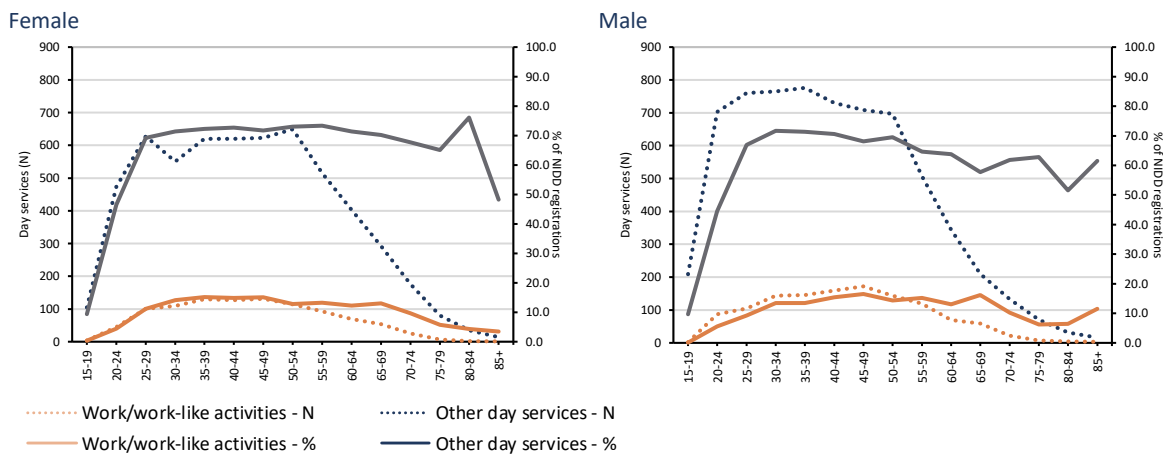
While 12,500 individuals in 2017 were in receipt of ‘other day services’, this was an increase of 16.2 per cent since 2012.²⁴ The majority (72 per cent) of individuals availing of ‘work and work/like activities’ and ‘other day services’ received the service five days per week.

Figure 20 shows how the numbers of individuals in receipt of day services varied by age and sex. 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 numbers using the services increase sharply between 15–20 years and remain relatively flat until there is a sharp and continuous decline at 50–55 years. The proportion of individuals receiving services is relatively constant for both services across the age distribution. The proportions of male and female users is similar across the age distribution, with a higher absolute number of male users.

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

²⁴ 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.

FIGURE 20 NIDD: Number and proportion of individuals in receipt of selected day services, 2017



Source: NIDD, 2012, 2017.

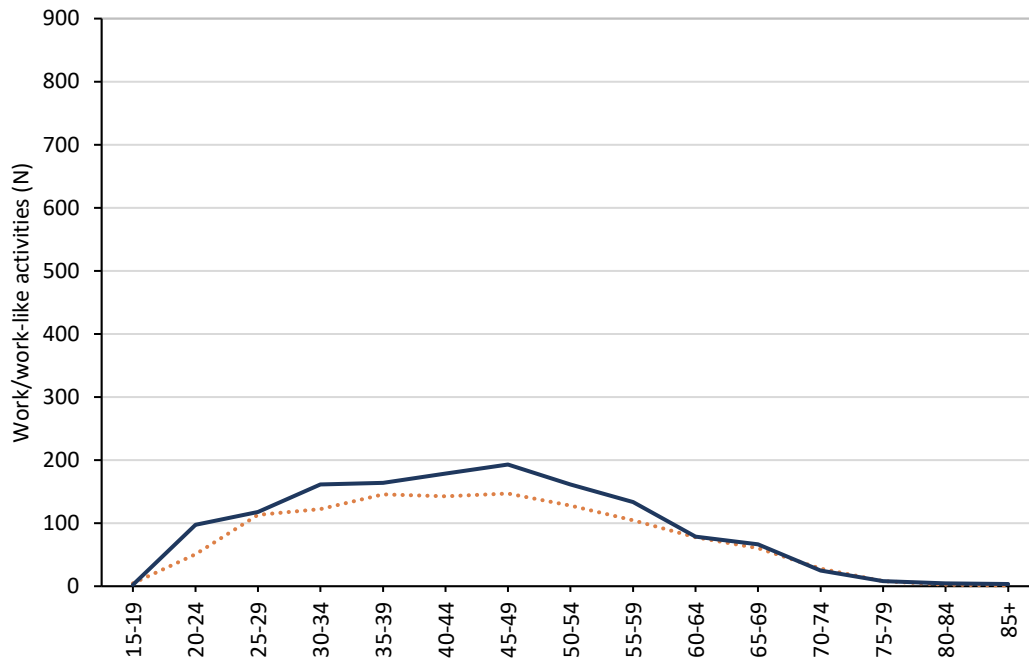
Application of NIDD age and sex profile to KPI

The number of users reported by the NIDD matches reasonably well to that reported in the KPIs for 2017 at an aggregate level, 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).²⁵ Applying the age profile of users from the NIDD to the total number of users reported in the KPIs would, therefore, seem reasonable (Figure 21). Higher numbers of males than females use day services.

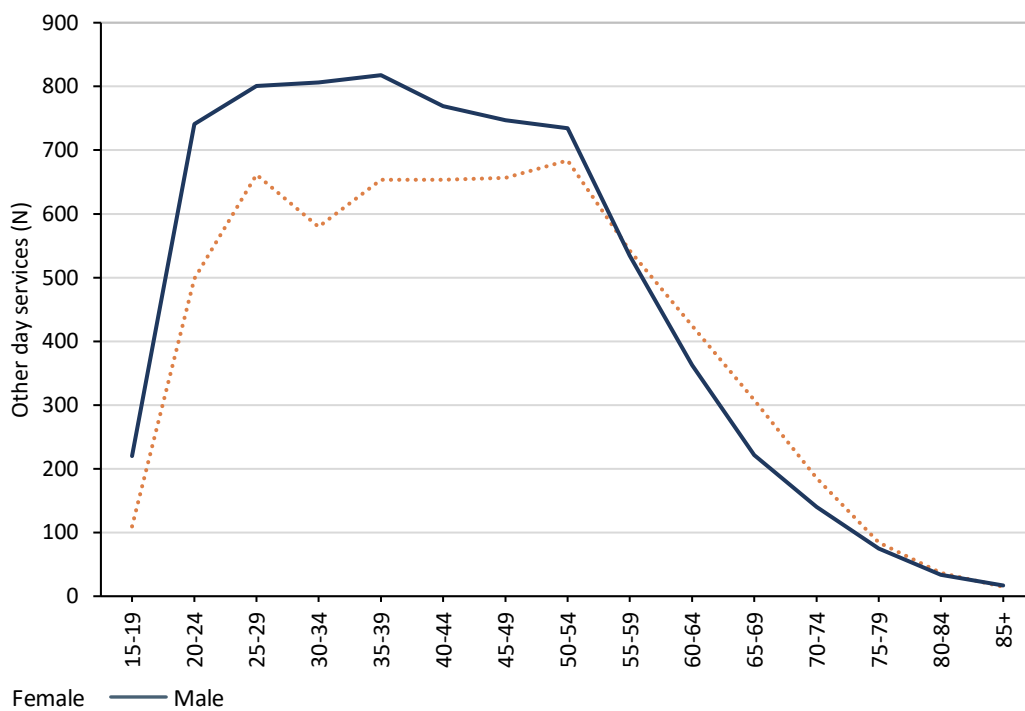
²⁵ There are no KPI data currently available on the numbers availing of individual services; for example, activation centres. If this level of data becomes available at a later date, the model can be updated accordingly.

FIGURE 21 KPI: Number of individuals in receipt of day services by age and sex, 2017

Work and work-like activities



Other day services



..... Female — Male

Source: NIDD, 2017; HSE KPI, 2017.

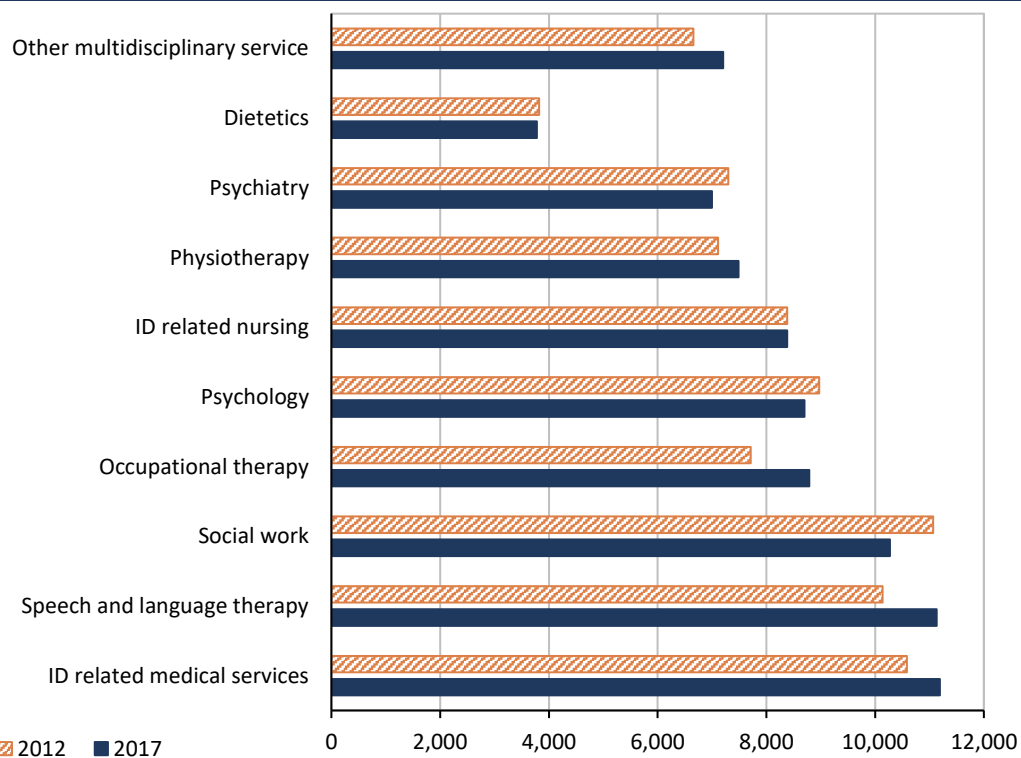
4.5.3 Multidisciplinary support services

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 that year (Kelly et al., 2013). Therefore, the following estimates may underestimate the number of users of multidisciplinary services by the NIDD population and do 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) were in receipt of one or more multidisciplinary support services.^{26,27} This was a slight decrease on the proportion in receipt of these services in 2012 (84.5 per cent).²⁸ Similar proportions of males and females in both years were in receipt of 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 registered in receipt of multidisciplinary services, 2012 and 2017



Source: NIDD, 2012, 2017.

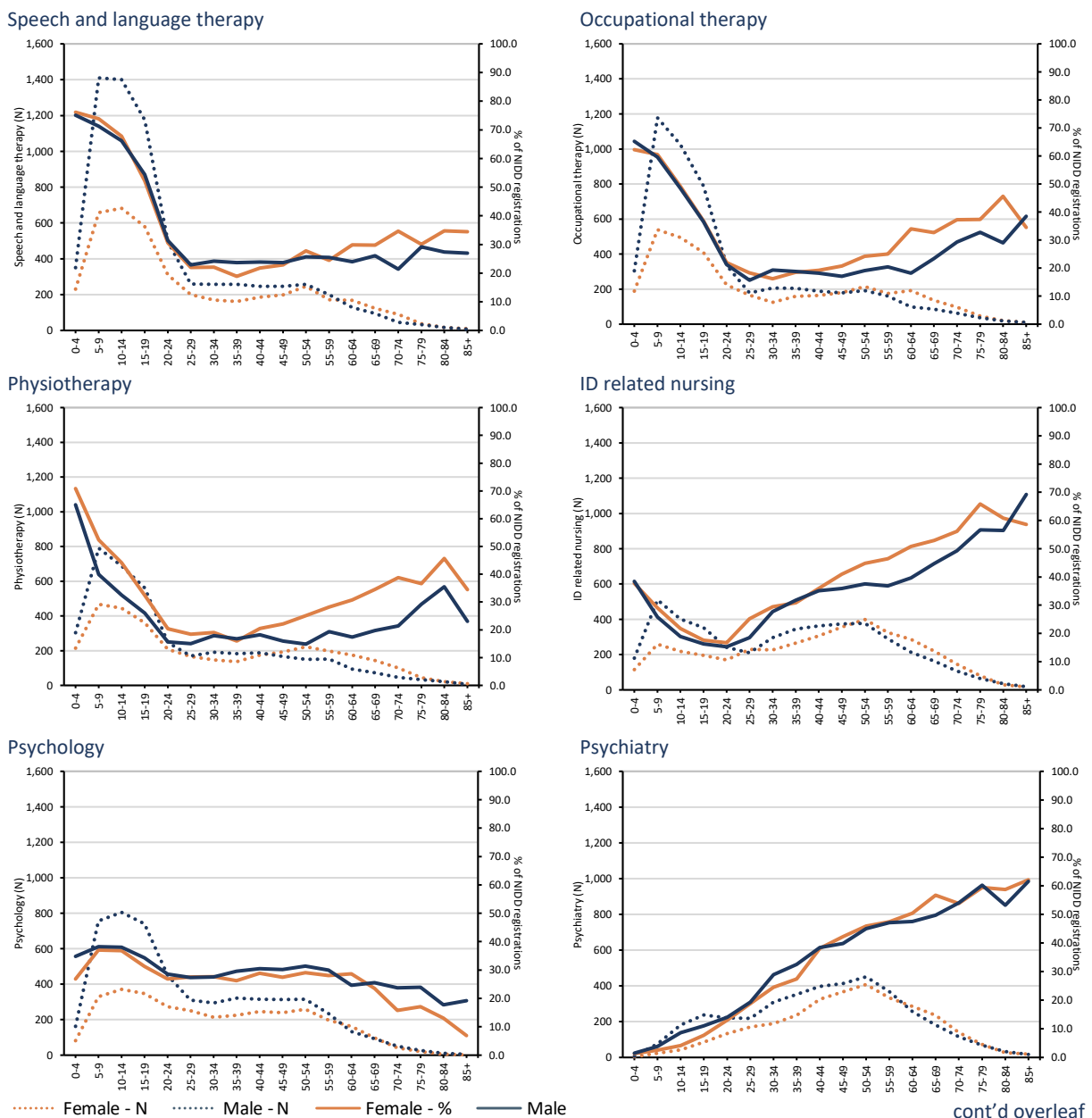
²⁶ A tiny proportion of multidisciplinary services were recorded as privately funded in 2017; for example, of the 11,193 individuals in receipt of physiotherapy services, just 0.5 per cent were recorded as privately funded.

²⁷ '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).

²⁸ The HSE KPIs do not include any information on the use of multidisciplinary services, so there is no basis for comparison.

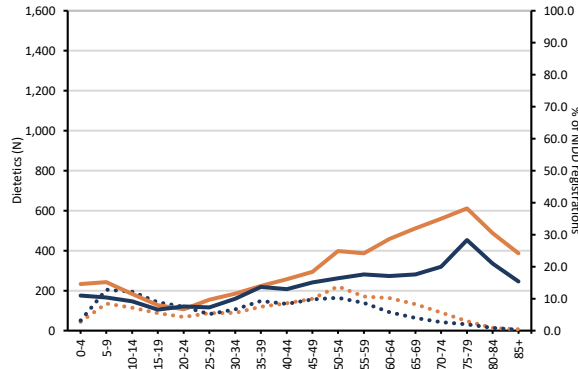
Figure 23 shows how the numbers and proportion of individuals in receipt of multidisciplinary services vary by age and sex. Services such as speech and language therapy, occupational therapy, physiotherapy, psychology, and social work were more commonly used by those under 20 years old. Services such as nursing and psychiatry were more commonly used by those over 20 years old. The pattern of utilisation is similar for males and females for most services.

FIGURE 23 NIDD: Number and proportion of individuals in receipt of multidisciplinary services by age and sex, 2017

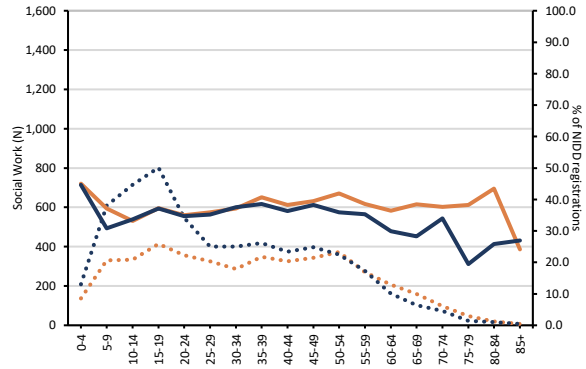


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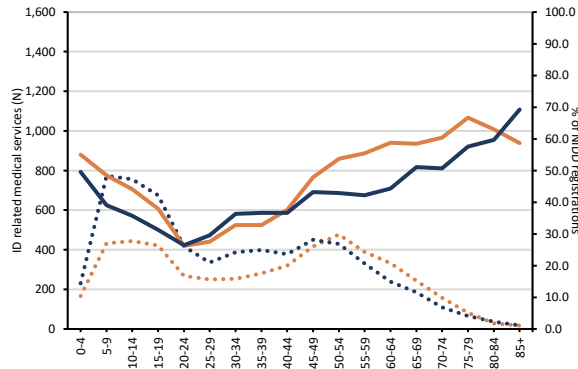
Dietetics



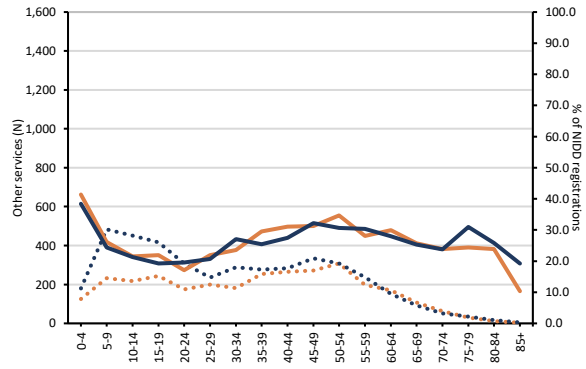
Social work



ID related medical services



Other multidisciplinary services



Female - N Male - N Female - % Male - %

Source: NIDD, 2012, 2017.

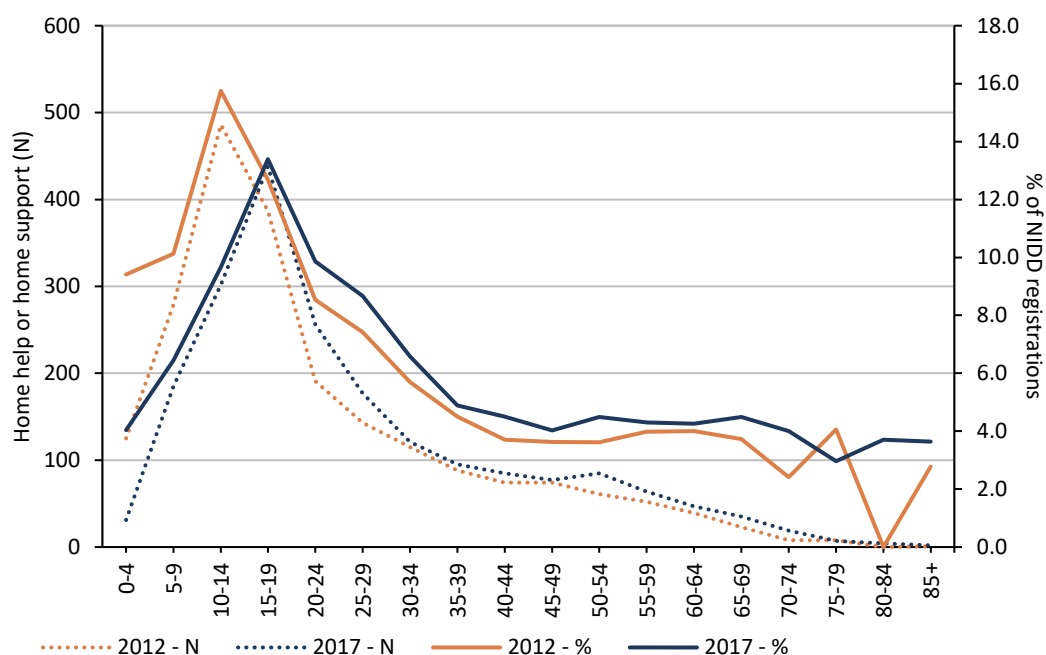
Addition of multidisciplinary services to the model

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 means that multidisciplinary services will not 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 at 5–9 years in 2012 but at 15–19 years in 2017.

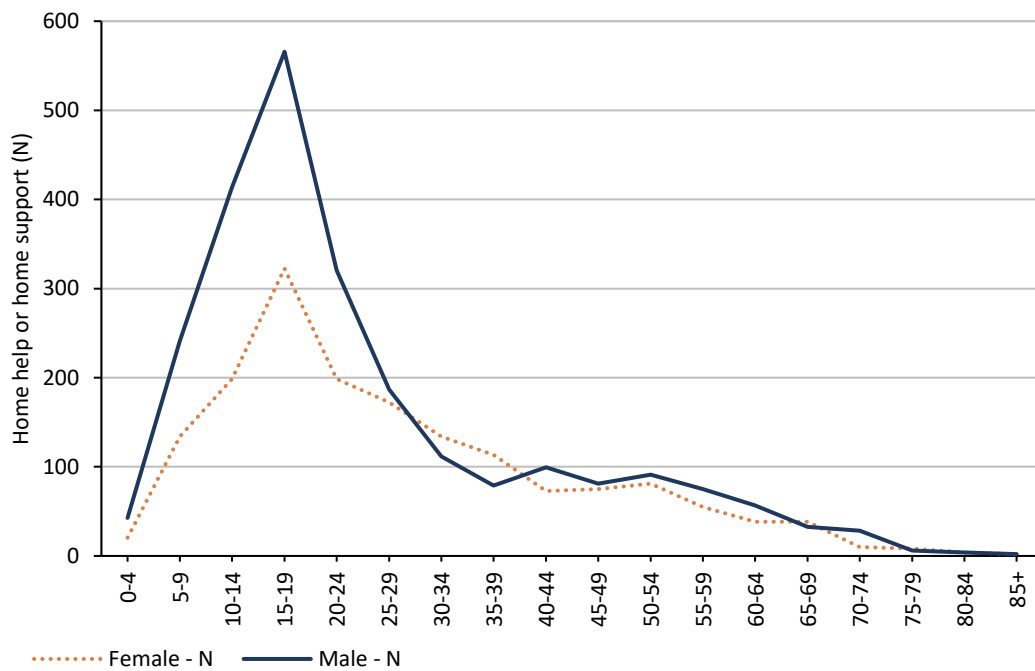
FIGURE 24 NIDD: Number and proportion of individuals in receipt of home help or home support services, 2012 and 2017



Source: NIDD, 2012, 2017.

Application of NIDD age and sex profile to KPI

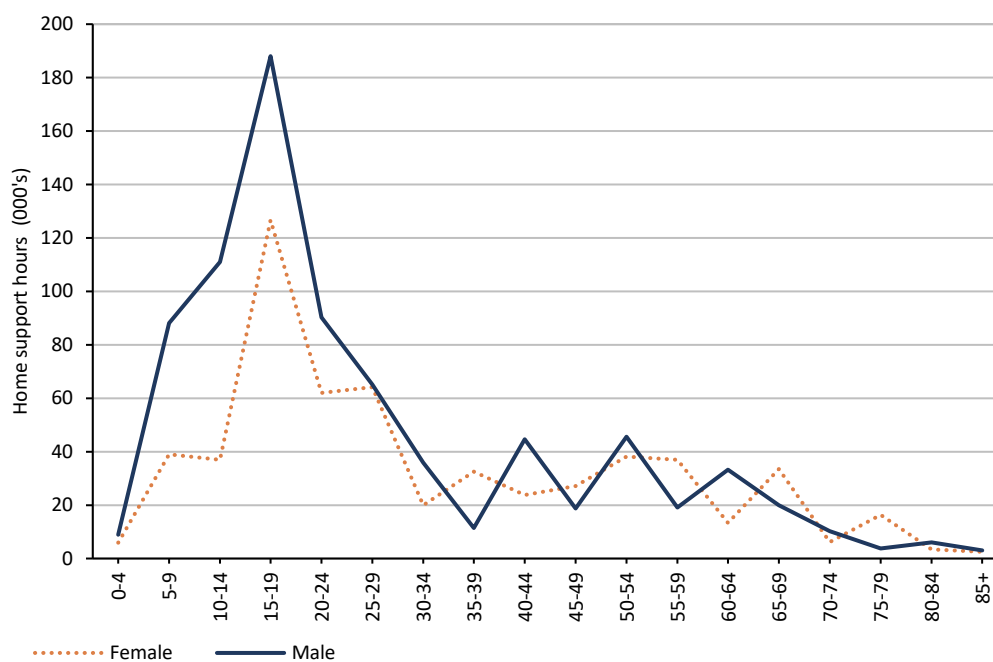
The number of individuals recorded by the NIDD as having received home help or home support in 2017 (2,030) is far fewer than reported in the HSE KPIs (4,116). It has not been possible to ascertain why there is such a discrepancy between the NIDD and KPI figures. A clearer picture may emerge when the 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 the figures reported by the HRB are closer to those reported by the HSE KPIs.

FIGURE 25 KPI: Number of individuals in receipt of home help or home support services by NIDD age and sex profile, 2017

Source: NIDD, 2012, 2017; HSE KPI, 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 (for example, 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).²⁹ 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 number of hours reported by the KPIs to give an estimate of the total number of hours used by age and sex (Figure 26).

²⁹ The KPIs report 4,116 users but record hours for only 3,348. The data on number of users by hours used are not currently validated.

FIGURE 26 KPI: Hours of home help or home support services by NIDD age and sex profile, 2017

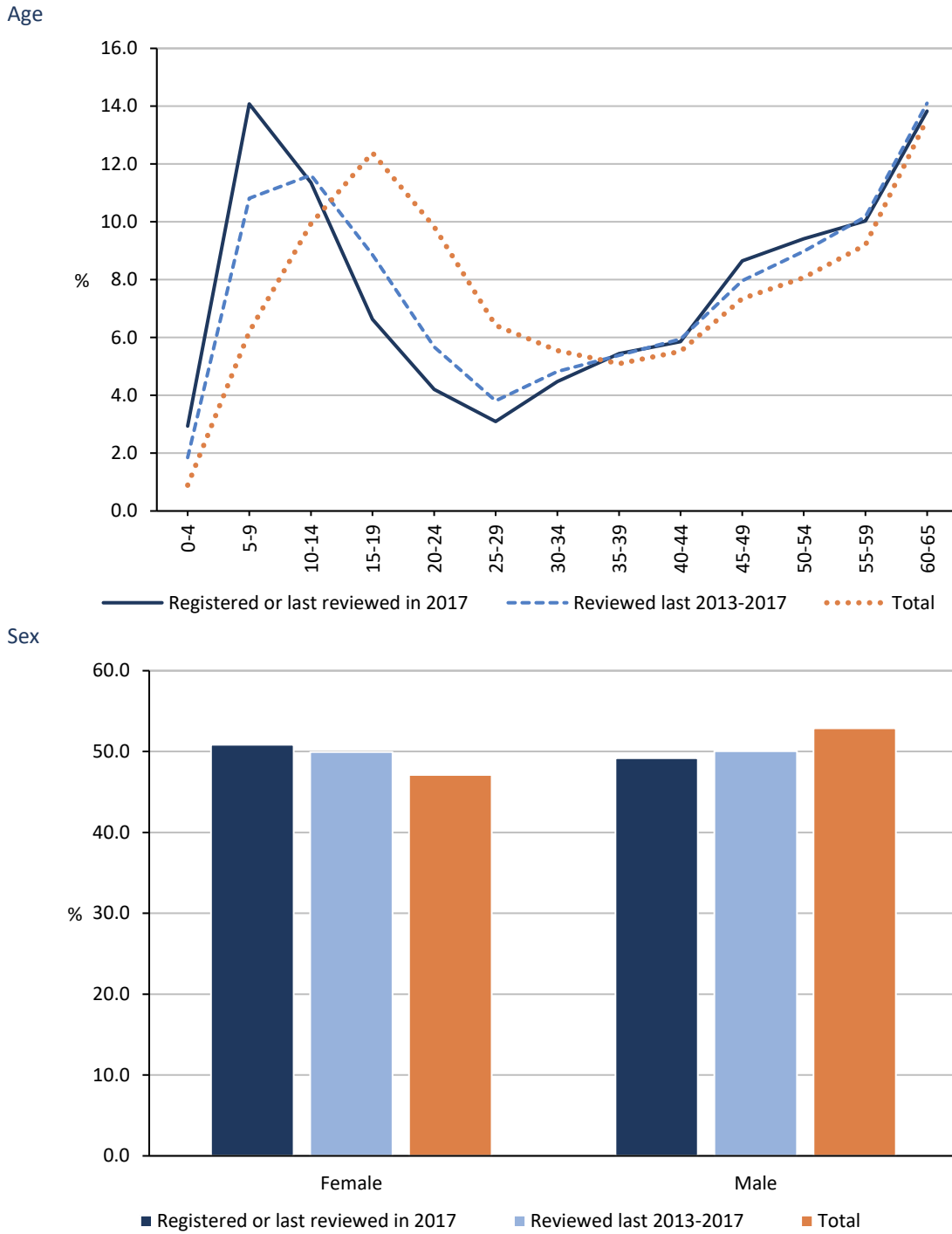
Source: NIDD, 2017; HSE KPI, 2017.

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 and 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. 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. Due to the data quality issues with NPSDD, these services will not be included in the Hippocrates model. This will be revisited when NASS data become available.

FIGURE 27 NPSDD: Age and sex profile, 2017



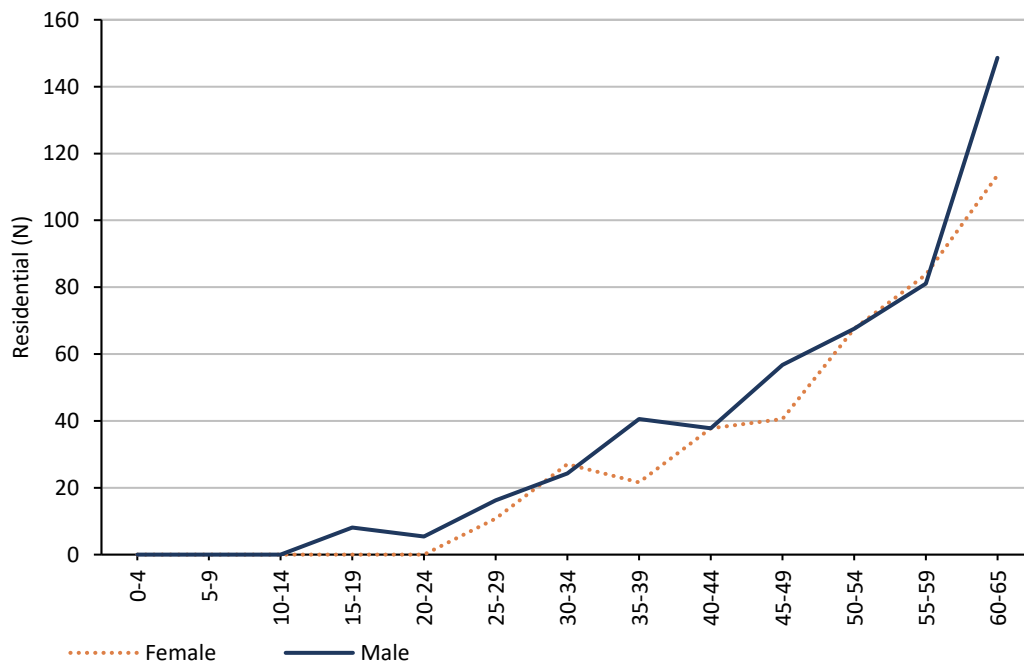
Source: NPSDD, 2017.

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 329 residential care users in NPSDD records updated between 2013 and 2017. Use of residential services increases with age, peaking between 60 and 65 years.

FIGURE 28 KPI: Number of individuals in receipt of residential services, 2017



Source: NPSDD, 2017; HSE KPI, 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 NPSDD³⁰ records updated between 2013 and 2017. Use of respite services is high among those aged 10 to 19, at which point it falls significantly only to increase gradually with age from 30 onwards.

FIGURE 29 KPI: Number of individuals in receipt of respite services, 2017



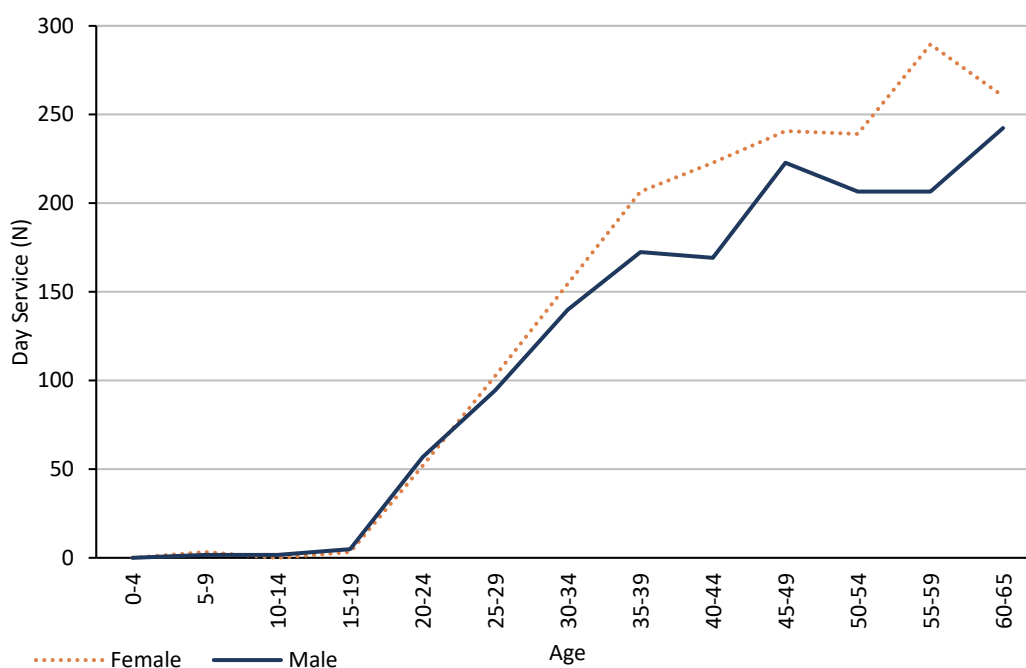
Source: NPSDD, 2017; HSE KPI, 2017.

³⁰ 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 2,025 day service users in NPSDD records updated between 2013 and 2017. Use of day services increases gradually with age, peaking between 55 and 59 years for females and 60–65 years for males. Most 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 individuals in receipt of day services, 2017



Source: NPSDD, 2017; HSE KPI, 2017.

5.2.4 Multidisciplinary services

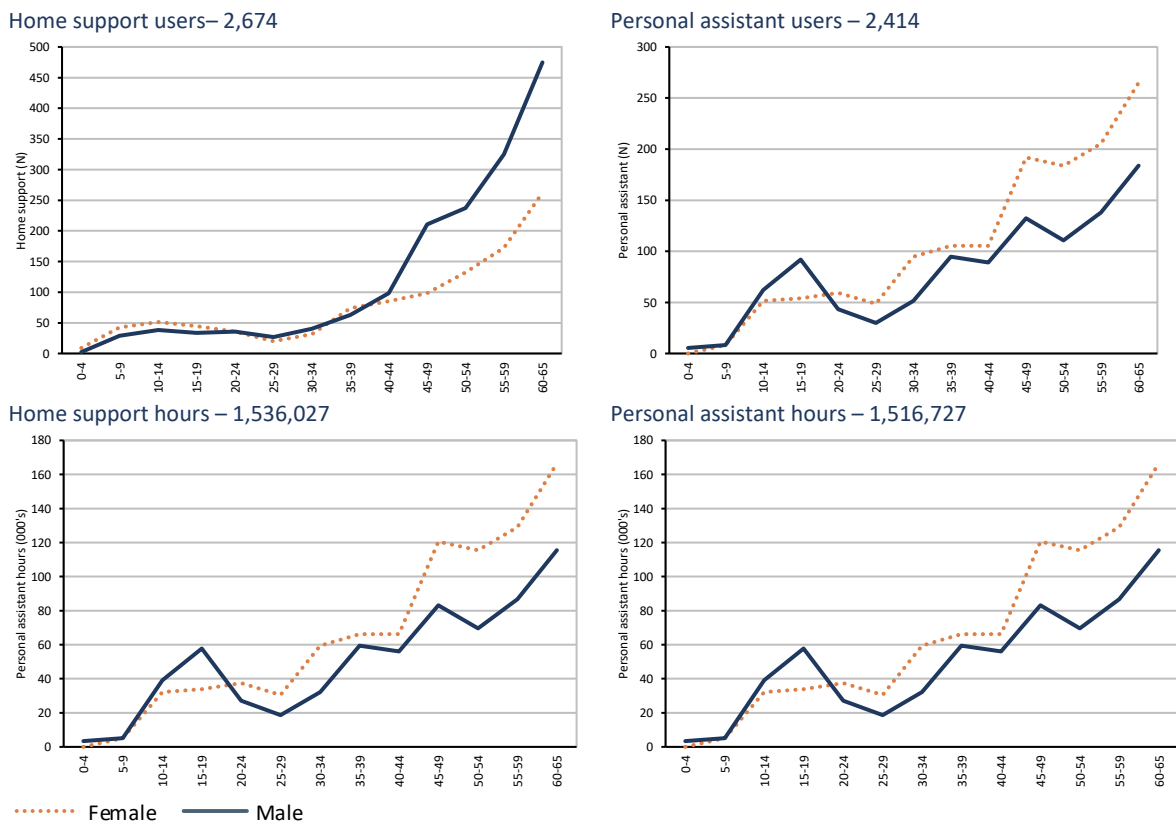
As with multidisciplinary services for the ID population, there are no KPIs available for these services for the PSD population. The NPSDD can provide an age and sex profile of multidisciplinary support users, but the number of users reported cannot be used to impute the utilisation rate for the entire NPSDD population because of the limited coverage of the database.

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 users (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 assistants are included in one KPI, that is how they are presented.

Unlike with 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 individuals in receipt of home support or personal assistance, 2017

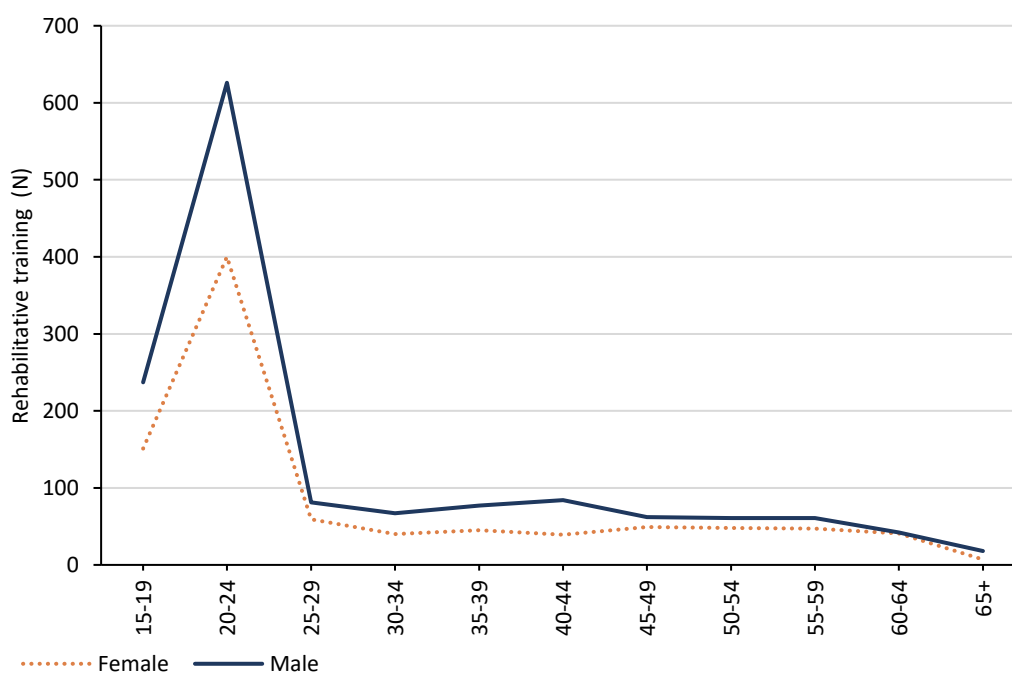


Source: NPSDD, 2017; HSE KPI, 2017.

6 REHABILITATIVE TRAINING – FINDINGS

The total number of RT places fell 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 whole-time equivalents (WTEs). In 2017, there were on average 1.1 individuals per WTE. This varied by age group, with 1.03 individuals 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 individuals in receipt of an RT place. There was a higher proportion of males than females in all age groups.

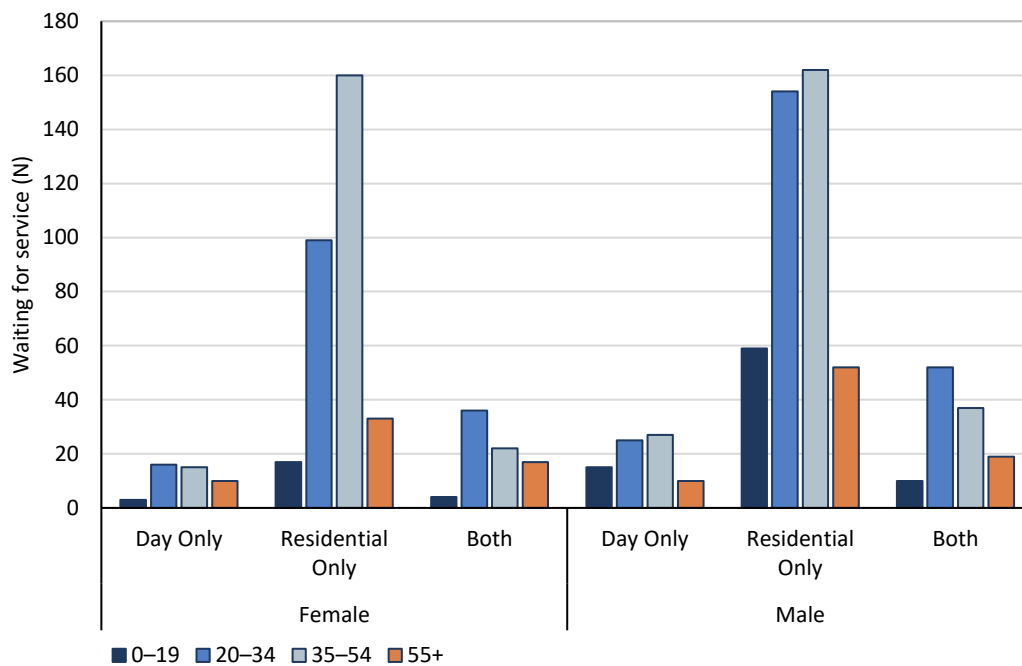
FIGURE 32 OGS: Number of individuals in receipt of a rehabilitative training place, 2017



Source: Personal communication, HSE, 5 November 2019.

7 UNMET DEMAND

In recent years, HSE Disability Services have maintained a database of those individuals waiting for a new or enhanced day or residential services. In June 2019 there were 1,054 individuals waiting for a service, 80 per cent of whom had a primary intellectual disability. Of the 1,054, 736 (69.8 per cent) were awaiting a residential service, 121 (11.5 per cent) a day service and 197 (18.7 per cent) a combination of the two. The majority of those waiting for a service were aged 35–54 years.

FIGURE 33 Number of individuals waiting for day and residential services by age and sex, June 2019

Source: Personal communication, HSE, 16 October 2019.

8 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 individuals with ID and PSD in receipt of specialised services. This analysis, designed to inform projections of service demand for the Hippocrates model, 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 individuals 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 data on services for individuals 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 will be updated to reflect this. The work ongoing in HSE Disability Services to improve data on day services provision will be particularly important.

Despite data deficiencies, this paper has combined the available data sources to generate estimates of baseline utilisation profiles 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. The first iteration of the inclusion of disability services in Hippocrates will focus on day and residential

services for ID only. We estimate that the services covered will account for approximately 80 per cent 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 individuals in receipt of work / work-like activity services	2,255	2,530	12.2
No. of individuals in receipt of other day services (excl. RT and work / work-like activities)	12,500	13,171	5.4
Rehabilitative training services			
No. of individuals in receipt of rehabilitative training	1,441 ^a	-	-
Residential services			
No. of individuals with a disability in receipt of residential services	7,530	7,424	-2.7
Respite services			
Total no. of individuals in receipt of respite services	4,806 ^b	4,798	-0.2
No. of overnights (with or without day respite) accessed by individuals 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 individuals 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 reports 650 individuals 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, 2017; HSE KPI, 2017.

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