HRB StatLink Series 2

NASS Intellectual Disability Supplementary Report 2020

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Table of Contents

Acknowledgements

Overview

This supplementary report presents an overview of the information recorded for service users with a primary disability of intellectual on the National Ability Supports System (NASS) for 2020. This is a supplementary report to be read in conjunction with the NASS annual report 2020.

In 2020, there were 23,673 people registered on NASS with an intellectual disability (ID). Of those, 22,746 service users had ID as their primary disability and 927 service users had intellectual listed as an additional disability. This supplementary report is based on the 22,746 people whose primary disability is intellectual.

Whilst every effort was made to ensure a comprehensive review and update of the NASS data, the information for 2020 is still incomplete due to some service providers who were unable to return data for the 2020 collection period.

The main findings of this supplementary report are:

- More males than females with ID were registered on NASS, and those in the 15-19 year age group were the greatest proportion of the overall total.

- The majority of service users had a moderate ID (43%).

- Over half of service users reported having a primary carer, the majority of whom were parents.

- In 2020, 31% of those recorded on NASS with an ID were in receipt of a residential service; 83% accessed at least one day service[1]; 1% accessed day respite; 7% accessed overnight respite; 14% were in receipt of at least one support for daily living and 63% accessed at least one specialist support.

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[1] Day services include HSE funded day services, rehabilitative training and education services provided by the Department of Education as well as employment services funded through the Department of Social Protection.

1   Introduction

1.1   Background

This is a supplementary report to be read in conjunction with the National Ability Supports System (NASS) annual report. This supplementary report provides an overview of the people on NASS whose **primary** disability is recorded as intellectual. They represent nearly two thirds of the total number of service users included in the annual report.

NASS is a national database that records information about Health Service Executive (HSE) disability-funded services[2] that are received or required as a result of an intellectual disability (ID), developmental delay, physical, sensory, neurological, learning, speech and/or language disabilities or autism. Mental health as a type of disability is also recorded on NASS where an individual is in receipt of a HSE disability-funded service. This may occur where the individual has more than one type of disability or where no suitable mental health service is available.

The purpose of NASS is to gather information to aid the planning, development, and organisation of HSE disability-funded services. A person is eligible to be registered on NASS if they receive or require (now or within the next five years) a HSE disability-funded service.

References to the last published National Intellectual Disability Database (NIDD)[3] data are given throughout this report but are provided as context only as definitions have been altered and services have changed. Comparisons are, therefore, not always like for like.

1.2   Data collection

Information on NASS for service users with ID is captured under five headings:

- Service user details

- Primary carer details

- Disability type and diagnosis

- Services; and

- Assistive products.

Within the Services section, NASS captures 86 service options across six service types:

- Residential setting

- Day services

- Day respite

- Overnight respite

- Supports for daily living

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[2] HSE disability-funded refers to the budget the HSE uses to fund services for people with disabilities. In 2020, a total of €1.9 billion was allocated by the HSE for these services.

[3] Hourigan, S., Fanagan, S. & Kelly, C. (2018). Annual report of the National Intellectual Disability Database Committee 2017: Main findings. Dublin: Health Research Board.

- Specialist supports

Service information is recorded if a service is funded by the HSE disability budget and the service is currently received or is required now or within the next five years. Provision is made to record services received via Primary Care and the Department of Education. This allows for a more holistic view of the supports provided to an individual.

This supplementary report presents information on services received in the year 2020. Service users are included in the 2020 report if they had their record reviewed by 31st of December 2020 by their main service provider. Overall, 22,746 service user records are included in this report.

1.3 Limitations of the data

Whilst every effort was made to ensure a comprehensive review and update of NASS data, the information for 2020 is still incomplete. There are gaps where data for the 2020 data collection period was not returned by some special schools, HSE disability teams and service providers.

Overall, while progress has been made in relation to NASS coverage for 2020, inconsistencies remain in the level of returns nationally. Of the Community Healthcare Organisations (CHOs) where returns were low, insufficient resources were available to NASS for much of the data collection period. It is hoped that the importance of the provision of data to NASS is recognised and that the situation will improve in 2021, as work proceeds towards achieving a full picture of HSE funded service provision.

Prior to NASS, larger service providers returned data to the National Intellectual Disability Database (NIDD) via a third-party upload from their own IT systems. However, to date it has not been possible for the majority of these service providers to update their systems to incorporate the new NASS fields due to resource constraints and the scale of the improvements required. This means that data items not previously captured by the NIDD such as occupational status, living accommodation, ethnicity or cultural background, primary carer, diagnosis information and data relating to frequency of delivery of services and the level of support provided to service users cannot be recorded on NASS by these providers. This results in the over-representation of the 'Not known' response option. The HSE are working with the larger service providers to update their IT systems to incorporate the NASS fields. It must be acknowledged that this is a large project and is currently in the initial stages.

Impact of Covid-19

The aforementioned resource issues were further compounded by Covid-19 and the redeployment of HSE staff in some areas to work on Covid-19 related work.

Information included in this report spans the entire year of 2020. Reviews of some service user records took place in early - mid 2020, before Covid-19 impacted disability service delivery. Therefore, the information in this report is a mixture of pre- and mid-Covid-19 service provision. It portrays a picture of service provision and need both in the initial wave of Covid-19 and when services were reopened in the latter part of 2020. Unfortunately, it is not possible to identify from the data the extent to which disability services were impacted by Covid-19 in 2020.

Also, as a result of Covid-19, guidance for data entry was adapted from March 2020 onwards in response to situations where it was not possible to get particular information from service users or their families. This guidance allowed the response option of 'Not known' to be used for specific NASS

questions. This primarily affected information relating to occupational status, living accommodation, self-reported ethnicity or cultural background, age of primary carer, and the WHODAS 2.0 questions.

Additionally, in some instances, the main service provider may not have had full details about services delivered by secondary service providers as opportunities for communication were limited due to Covid-19 working arrangements. This mainly affected respite and specialist support information.

1.4   Publications and analysis

This report represents an overview of available data from NASS on service users with a primary disability of intellectual. An annual report and additional supplementary reports presenting information by other disability types (autism and physical and sensory) and by CHO are also available on the Health Research Board (HRB) website https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/publications/.

Requests for further analysis with more detailed or different breakdowns are welcomed. Please visit https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/request-data/ to access a data request form and return it to nass@hrb.ie.

2   Service users with an intellectual disability

There were 23,673 people registered on NASS with an ID. Of those, 22,746 service users listed intellectual as their primary disability and 927 service users had intellectual listed as an additional disability. There are fewer registrations of service users with ID on NASS than were previously recorded on NIDD (28,388 registrations in 2017).

This supplementary report is based on the 22,746 service users who have ID listed as their primary disability. The degree of ID among these service users is shown in Figure 2.1

Figure 2.1 Degree of intellectual disability, NASS 2020
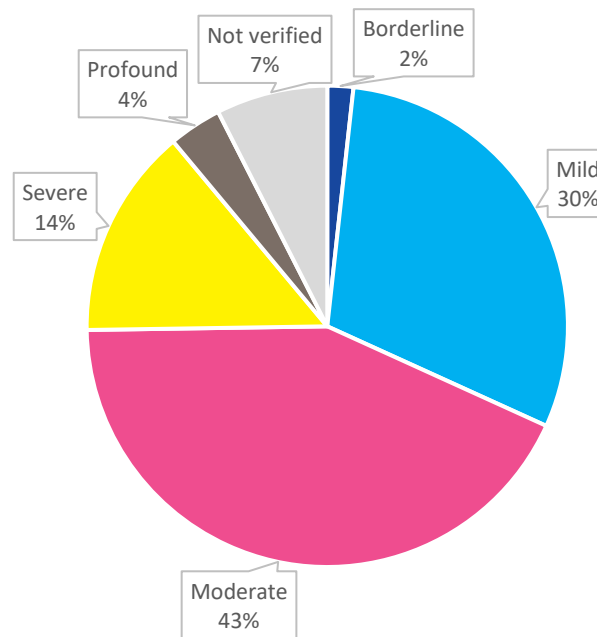
The degree of ID was missing for 31 service users

2.1   Numbers registered

Table 2.1 shows the registration of service users on NASS by CHO.

The nine CHOs and the areas they cover are as follows:

CHO 1 - Donegal, Sligo/ Leitrim/West Cavan, Cavan/Monaghan

CHO 2 - Galway, Roscommon, Mayo

CHO 3 - Clare, Limerick, North Tipperary/East Limerick

CHO 4 - Kerry, North Cork, North Lee, South Lee, West Cork

CHO 5 - South Tipperary, Carlow/Kilkenny, Waterford, Wexford

CHO 6 - Wicklow, Dun Laoghaire, Dublin South East

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

CHO 8 - Laois/Offaly, Longford/West Meath, Louth/Meath

CHO 9 - Dublin North, Dublin North Central, Dublin North West

Overall, CHO 4 had the most registered service users (3,786, 17%), followed by CHO 7 with 3,319 service users (15%).

Table 2.1 Distribution of service users with an ID registered on NASS by Community Healthcare Organisation (CHO), NASS 2020

	n	%
Total population	**22,746**	**100**
CHO 1	2,154	9.5
CHO 2	2,442	10.7
CHO 3	1,705	7.5
CHO 4	3,786	16.6
CHO 5	2,422	10.6
CHO 6	1,408	6.2
CHO 7	3,319	14.6
CHO 8	2,307	10.1
CHO 9	3,202	14.1
Outside Ireland	~	~

~To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

2.2 Demographic profile

More males (13,065, 57%) than females (9,681, 43%) with an ID were registered on NASS.

Table 2.2 and Figure 2.2 show that overall, those in the 15-19 year age group were the most represented (2,281, 10%).

Table 2.2 Number of service users with an ID registered on NASS by age and sex, NASS 2020

	Male	Female	Total
0-4 years	340	231	**571**
5-9 years	855	472	**1,327**
10-14 years	1,365	684	**2,049**
15-19 years	1,494	787	**2,281**
20-24 years	1,426	844	**2,270**
25-29 years	1,016	792	**1,808**
30-34 years	871	672	**1,543**
35-39 years	934	764	**1,698**
40-44 years	941	739	**1,680**
45-49 years	925	787	**1,712**
50-54 years	885	813	**1,698**
55-59 years	758	732	**1,490**
60-64 years	556	517	**1,073**
65-69 years	346	378	**724**
≥ 70 years	353	469	**822**
Total	**13,065**	**9,681**	**22,746**

Figure 2.2 Percentage of service users with an ID by age group and sex, NASS 2020

	0-4 years	5-9 years	10-14 years	15-19 years	20-24 years	25-29 years	30-34 years	35-39 years	40-44 years	45-49 years	50-54 years	55-59 years	60-64 years	65-69 years	70+ years
Male	1.5	3.8	6.0	6.6	6.3	4.5	3.8	4.1	4.1	4.1	3.9	3.3	2.4	1.5	1.6
Female	1.0	2.1	3.0	3.5	3.7	3.5	3.0	3.4	3.2	3.5	3.6	3.2	2.3	1.7	2.1

Age group of service user
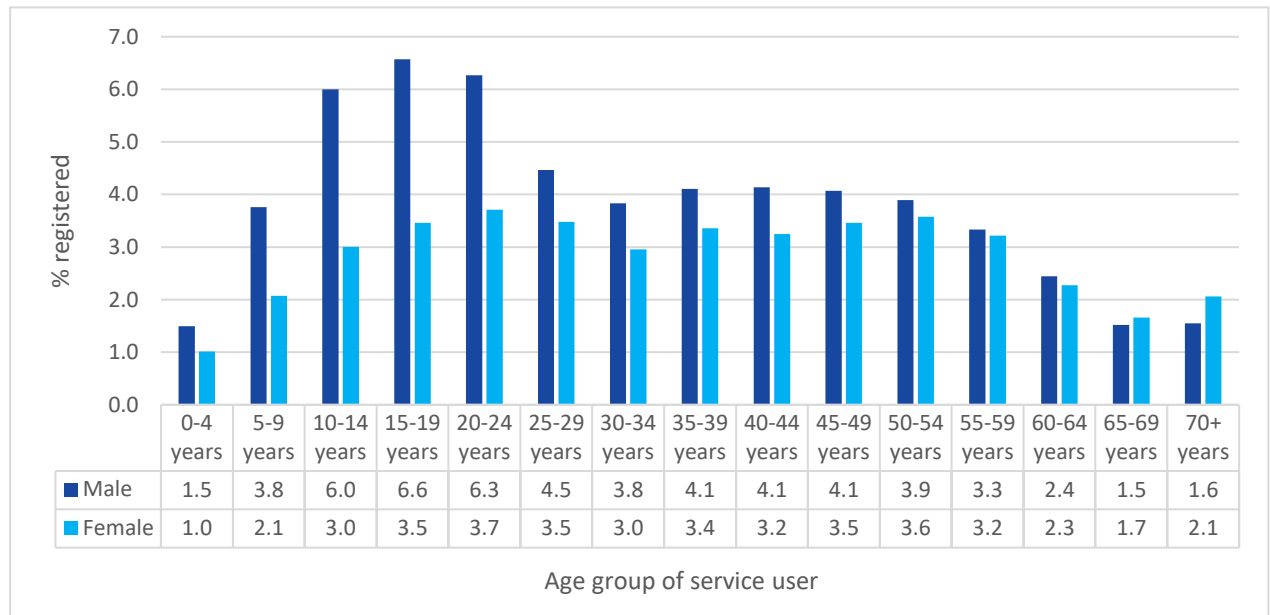
Occupational status[4]

For service users under the age of 18 years (5,205), the majority were students/pupils (2,318, 45%). Of service users who were aged 18 years and over (17,541), the majority were unable to work due to a disability (4,252, 24%) followed by attending a training/day programme (3,534, 20%) (Table 2.3).

Table 2.3 Occupational status of service users with an ID, NASS 2020

	Less than 18 years		18 years and over		Total	
	n	**%**	**n**	**%**	**n**	**%**
Total population	**5,205**	**100**	**17,541**	**100**	**22,746**	**100**
Unable to work due to disability	12	0.2	4,252	24.2	4,264	18.7
Training/day programme	2	0.0	3,534	20.1	3,536	15.5
Student/pupil	2,318	44.5	202	1.2	2,520	11.1
In paid employment	0	0.0	913	5.2	913	4.0
Unemployed	2	0.0	622	3.5	624	2.7
Other	186	3.6	283	1.6	469	2.1
Retired	0	0.0	263	1.5	263	1.2
Housewife/husband	1	0.0	5	0.0	6	0.0
Not known	2,684	51.6	7,467	42.6	10,151	44.6

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[4] Occupational status information was captured as 'employment status' on NASS in 2020.

Ethnic or cultural background

The most frequently self-reported ethnicity/cultural background was Irish (10,454, 46%), followed by any other white background (219, 1%) (Table 2.4).

Table 2.4 Ethnicity or cultural background of service users with an ID, NASS 2020

	n	%
Total population	**22,746**	**100**
Irish	10,454	46.0
Any other white background	219	1.0
Irish Traveller	113	0.5
Any other Asian background	54	0.2
Black African	59	0.3
Any other black background	20	0.1
Asian-Chinese	9	0.0
Do not wish to answer this question	468	2.1
Not known	11,350	49.9

Living accommodation

Service users with an ID most frequently resided in a residential setting (7,016, 31%), followed by living in private accommodation (4,605, 20%). (Table 2.5).

Table 2.5 Living accommodation situation of service users with an ID, NASS 2020

	n	%
Total population	**22,746**	**100**
Residential setting*	7,016	30.8
Private accommodation-owner occupied	4,605	20.2
Rented from county council/public authority/service provider	899	4.0
Rented on open market	342	1.5
Unstable accommodation	19	0.1
Not known	9,865	43.4

* includes those that are not funded by the HSE disability budget

Living arrangements

Most service users resided with family members (14,126, 62%), with the majority of those living with parents (Table 2.6). Thirty one percent of people resided in a residential setting and 584 (3%) lived alone.

Table 2.6 Living arrangement of service users with an ID, NASS 2020

	n	%
Total population	**22,746**	**100**
Living with family	**14,126**	**62.1**
Both parents	8,501	37.4
One parent	3,481	15.3
Parent(s) and sibling(s)	1,050	4.6
Sibling(s)	895	3.9
Other relative(s)	124	0.5
Wife/husband/partner, no children	42	0.2
Wife/husband/partner and children	24	0.1
Daughter(s)/ son(s)	9	0.0
Residential setting	**7,006**	**30.8**
In a residential service	7,006	30.8
Living alone	**584**	**2.6**
Alone	584	2.6
Living with non-family	**350**	**1.5**
Foster family	245	1.1
Non-relatives	105	0.5
Not known	**680**	**3.0**
Not known	680	3.0

2.3   Disability and diagnosis

Additional disabilities[5]

A total of 10,708 service users with an ID recorded at least one additional disability (Table 2.7). A total of 16,142 additional disabilities were recorded for these service users. The most commonly reported additional disability was physical (4,951, 22%), followed by speech and/or language (4,676, 21%).

Table 2.7 Additional disabilities of those whose primary disability is intellectual, NASS 2020

	n	%
Total population	**22,746**	**100**
Physical	4,951	21.8
Speech and/or language	4,676	20.6
Visual	2,037	9.0
Autism	1,876	8.2
Hearing loss/deafness	1,351	5.9
Neurological	633	2.8
Mental health	466	2.0
Specific learning disorder (other than intellectual)	75	0.3
Developmental delay (under 10 years only)	28	0.1
DeafBlind - dual sensory	26	0.1
Not verified*	23	0.1
No additional disability	12,038	52.9

*Not verified - where the type of disability has not been verified for an individual.

Note more than one additional disability may be recorded for a person and as a result, total percentages add up to more than 100.

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[5] Additional disabilities were captured as 'secondary disabilities' on NASS in 2020.

Diagnostic category

In addition to disability type, information on any diagnoses received from a healthcare professional can also be recorded on NASS. It is optional to record this information.

There were 3,114 diagnoses recorded for 2,337 service users during the 2020 data collection period. The most frequently reported ICD-10 diagnostic category was congenital malformations, deformations and chromosomal abnormalities (1,107, 36%), which includes Down's Syndrome. Mental and behavioural disorders was the second most frequently reported ICD-10 diagnostic category (780, 25%), which includes intellectual disability and autism.

It should be noted that diagnosis is optional to record on NASS and therefore information on diagnosis is not necessarily reflective of those registered on the system. Diagnosis information is a new field for most service providers completing NASS. The importance of completing diagnosis information will continue to be highlighted to service providers for 2021.
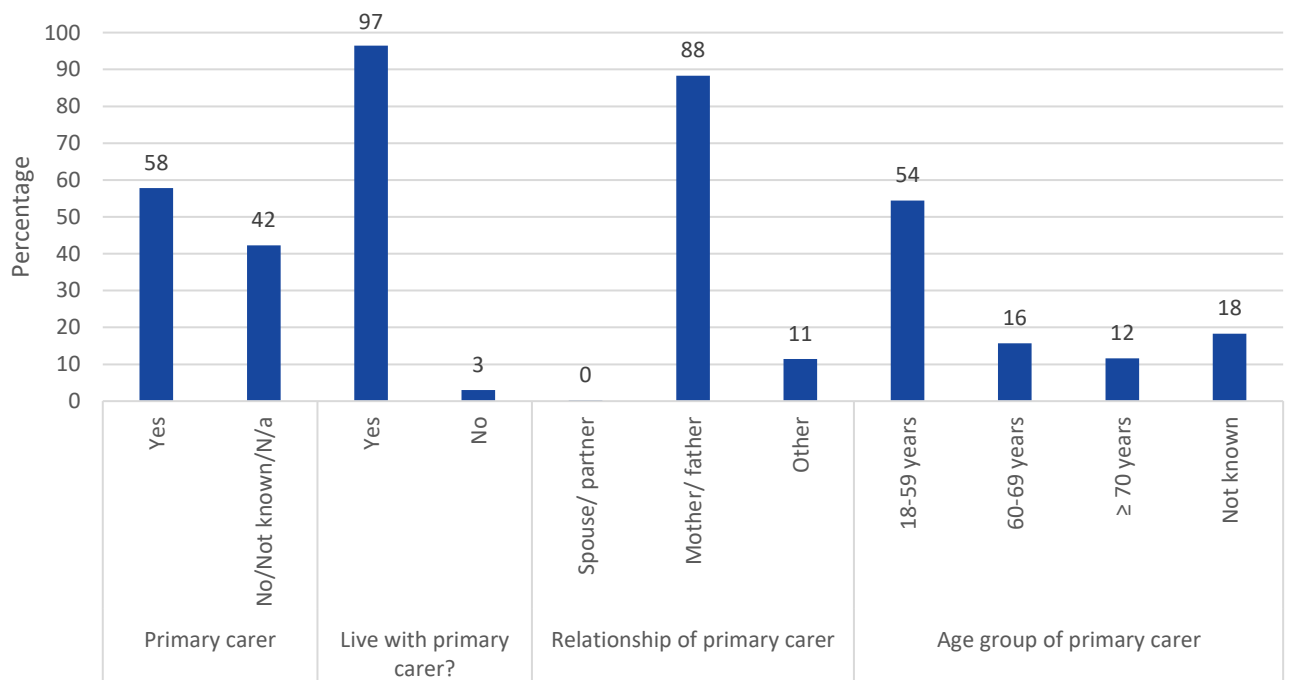
2.4 Primary Carer

Of those service users with ID who do not live in a residential setting (15,686), 58% (9,062) have a primary carer. Of these, 97% live with their primary carer and the majority of carers are a parent (Figure 2.3). Notably, 751 (8%) of primary carers were siblings of service users.

Primary carers were mostly aged between 18-59 years (4,925, 54%). Sixteen percent (1,427) were aged between 60 and 69 years and 12% (1,054) were aged 70 years and over.

In terms of service user age, 54% (3,012) of those aged 18 years or less had a primary carer, 61% (5,502) of those aged 19-54 years had a primary carer, and 47% (548) of service users aged 55 and over had a primary carer.

Figure 2.3 Primary carer information for service users with an ID, NASS 2020

2.5 Services

The service use in 2020 and the service need now or within the next five years for those with an ID registered on NASS are displayed in the following tables and figures.

NASS collects information on the HSE disability-funded services people with disabilities use and/or require in the next five years in the following categories:

- Residential

- Day

- Respite (day and overnight)

- Supports for daily living

- Specialist supports

The service tables presented in this section represent whether a service was recorded as:

- **Places currently being accessed:** The number of places accessed in the reporting year.

- **Enhancement required to current places:** The number of places accessed which require an enhancement for example, additional hours/days or additional support.

- **Unmet need for places:** The number of additional places required for those not in receipt of that service but who require it now or within the next five years.

References are made to the NIDD 2017 data for context. It is important to note that comparisons are a guide only as definitions have been altered and services have changed. Comparisons, therefore, are not always like for like.

Residential services

Overall, 6,981 (31% of ID population) service users were in receipt of at least one residential service in 2020. A total of 7,046 residential places were accessed in 2020, of which community group home (5-9 residents sharing) was the most common circumstance (2,964, 13%) followed by a house in the community (1-4 residents sharing) (2,173, 10%) (Table 2.8). In 2017, as captured on the NIDD, 27% (7,530) of service users were in receipt of a residential service, of which community group homes were the most common (4,389, 16%), followed by residential centres (2,005, 7%).

Of those accessing residential services and where information on support was available (5,944):
- 2,994 (50%) had 24/7 staff and awake cover at night

- 1,590 (27%) had 24/7 staff and sleepover cover at night

- 580 (10%) had less than 24/7 staff and sleepover cover at night

- 354 (6%) had 1 to 1 support

- 301 (5%) had less than 24/7 care

- 125 (2%) had greater than 1 to 1 support.

Of service users about whom information was recorded on the number of nights per week on which a residential service was accessed (6,084), 5,868 (96%) availed of their residential service 7 nights per week.

In 2020, an unmet need for 891 residential places now or within the next five years has been reported, an increase of 13% on the current level of provision (Table 2.8). 795 of these places are a house in the community.

Table 2.8 Residential services; places currently being accessed, enhancement required to current places and unmet need for places for service users with an ID, NASS 2020

Residential service	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	**22,746**	**100**		
Community group home (5-9 residents)	2,964	13.0	523	9
House in community (1-4 residents)	2,173	9.6	359	795
Residential centre/on campus (10+ residents)	1,379	6.1	370	0
Specialist facility-challenging behaviour†	292	1.3	46	13
Nursing home	89	0.4	0	14
Psychiatric hospital	86	0.4	~	0
Home sharing-shared living family	32	0.1	~	35
Specialist facility-mental health comorbidity	26	0.1	~	~
Specialist facility-dementia	~	~	~	8
Specialist facility-physical	~	~	0	~
Other hospital	~	~	0	0
Specialist facility-neurological	0	0.0	0	10
Hospice	0	0.0	0	~
Total	**7,046**		**1,306**	**891**

† This includes intensive placements for challenging behaviour as previously recorded on the NIDD.

Note that more than one residential service may be recorded for a person within a year.

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

Day Services

Day services recorded on NASS in 2020 were selected from 23 service options. Some of the data recorded in 2020 used the following codes: day activation/activity, high support day service, sheltered work-therapeutic, sheltered work-commercial, sheltered work-like work, sheltered employment and external work. In keeping with service providers transitioning to the New Directions model[6] of day service provision, these codes have been rolled up to 'day programme' for reporting purposes. Educational services have also been rolled up so that primary and secondary options are reported together. Baby and toddler groups and pre-schools have been rolled up to "early childhood education and care". These groupings will apply in the future from the NASS 2021 data collection period onwards.

A total of 18,873 (83%) service users were in receipt of one or more day services. This is lower than what was reported on the NIDD in 2017, where 27,902 (100%) of service users accessed at least one day service. There are marked differences in how day services are captured on NASS in comparison to the NIDD, so comparisons should be used as a guide only.

Table 2.9 shows that a day programme was the most frequently accessed day service (12,452, 55%), followed by a special primary/secondary school (2,822, 12%).

In 2020 data collection period, the level of support was recorded for 15,287 of service users who received a day service and was as follows:

- 3,765 (25%) had a staff to service user ratio of between 1-to-4 and 1-to-5.

- 3,604 (24%) had a staff to service user ratio of between 1-to-6 and 1-to-9.

- 2,259 (15%) had a staff to service user ratio of 1-to-1.

- 1,829 (12%) had a staff to service user ratio of 1-to-3.

- 1,797 (11%) had a staff to service user ratio of 1-to-10+.

- 1,726 (11%) had a staff to service user ratio of 1-to-2.

- 307 (2%) had a staff to service user ratio of greater than 1-to-1.

An enhancement is required for 3,074 services with almost one in five-day programmes needing an enhancement. Day programmes also had the highest proportion of unmet need of all day services with 452 new day programmes required now or within the next five years, this is an increase of 4% to current service provision.

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[6] New Directions: review of HSE day services and implementation plan 2012-2016: personal support services for adults with disabilities. Naas: Health Service Executive, 2012.

Table 2.9 Day services; places currently being accessed, enhancement required to current places and unmet need for places for service users with an ID, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	**22,746**	**100**		
Day programme†	12,452	54.7	2,337	452
Supported employment	1,377	6.1	170	147
Rehabilitative training	1,199	5.3	159	63
Mainstream early childhood education and care	150	0.7	~	36
Special early childhood education and care	218	1.0	14	22
Mainstream primary/secondary school	1,198	5.3	84	58
Special primary/secondary school	2,822	12.4	242	38
Special class/unit in mainstream primary/secondary school	541	2.4	50	25
Home tutor	68	0.3	~	0
Vocational training	150	0.7	11	33
Third level education	79	0.3	~	~
Total	**20,254**		**3,074**	**878**

† A day programme aims to provide a supportive environment which addresses the service user's needs. Service users may be aged under 18 years or above 18 years old. For those service users aged above 18 years old, day programmes provide, or are moving towards providing, the 12 supports outlined in the New Directions Model.

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

Note that an individual may be in receipt of more than one day service

Services with no recorded current or unmet need include neuro-rehabilitative training.

Tables 2.10 and 2.11 present a breakdown of day services by age - under 18 years old and 18 years and over, respectively.

Table 2.10 shows that most services accessed in 2020 by those aged under 18 years old were educational services (4,594, 99%). 355 enhancements were required to existing educational services, with the majority of enhancements (219) required in special primary/secondary school settings. Of those service users aged under 18 years old, 283 individuals had an unmet need for 319 day service places. Of these, the highest proportion of unmet need was for a day programme (94).

Table 2.10 Day services for service users aged under 18 years with an ID; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	**5,205**	**100**	-	
Day programme	53	1.0	0	94
Supported employment	0	0.0	0	~
Rehabilitative training	0	0.0	~	37
Mainstream early childhood education and care	150	2.9	~	36
Special early childhood education and care	218	4.2	14	22
Mainstream primary/secondary school	1,095	21.0	70	58
Special primary/secondary school	2,538	48.8	219	38
Special class/unit in mainstream primary/secondary school	495	9.5	46	25
Home tutor	68	1.3	~	0
Vocational training	30	0.6	0	6
Third level education	0	0.0	0	~
Total	**4,652**		**355**	**319**

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

Note that an individual may be in receipt of more than one day service

Services with no recorded current or unmet need include neuro-rehabilitative training.

Table 2.11 shows that a day programme was the most frequently accessed day service by those aged 18 years and over (12,399, 71%), and 2,337 enhancements were required to the existing day programme service in this cohort. Of those service users aged 18 years and over, 546 individuals had an unmet need for a total of 559 day service places. Of these, the highest proportion of unmet need was for a day programme placement (358).

Table 2.11 Day services for service users aged 18 years and over with an ID; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	**%**	**n**	**n**
Total population	**17,541**	**100**		
Day programme†	12,399	70.7	2,337	358
Supported employment	1,377	7.9	170	145
Rehabilitative training	1,199	6.8	158	26
Mainstream primary/secondary school	103	0.6	14	0
Special primary/secondary school	284	1.6	23	0
Special class/unit in mainstream primary/secondary school	46	0.3	~	0
Vocational training	120	0.7	11	27
Third level education	79	0.5	~	3
Total	**15,602**		**2,719**	**559**

† A day programme aims to provide a supportive environment which addresses the service user's needs. These day programmes provide, or are moving towards providing, the 12 supports outlined in the New Directions Model, for adult service users.

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed

Note that an individual may be in receipt of more than one day service

Services with no recorded current or unmet need include neuro-rehabilitative training, mainstream early childhood education and care, special early childhood education and care and home tutor.

Respite

The reporting of respite data on NASS in 2020 has been greatly improved since 2019 by HRB processes so that each service must be closed out by recording an end date and verified by the service provider at the end of the reporting period. As a result, some verified respite data applies to service users who are not included in any other section of the 2020 annual report. Since some service providers are not returning data, we know that respite data recorded is incomplete. Additionally, the impact of COVID-19 on respite service provision and the recording of respite data on NASS cannot be quantified for 2020.

Day respite

Overall, 209 people (1%) accessed 216 disability-funded day respite places in 2020. Overall, 2,419 days of respite were received. The most commonly reported day respite service was centre-based respite (176, 1%).

The level of support was recorded for 95 day respite services, with 58 (61%) receiving between 1 to 4 and 1 to 5 support and 9 (9%) receiving 1 to 1 support. A total of 88 day respite services were recorded as required now or within the next five years, 58 of which are centre-based respite places.

Overnight respite

There were 1,582 people (7%) registered on NASS with an ID accessing 1,611 disability-funded overnight respite services. The most availed of overnight respite service was in a house in the community/centre-based (1,444, 6%) (Table 2.12). In 2020, 26,946 nights of respite were recorded on NASS for people with an ID. The majority were recorded as house in the community/centre-based respite (23,838).

Of those accessing overnight respite and where information on support was available (1,076):

- 650 (60%) had 24/7 staff and awake cover at night

- 279 (26%) had 24/7 staff and sleepover cover at night

- 73 (7%) had 1 to 1 support

- 45 (4%) had less than 24/7 staff and sleepover cover at night

- 20 (2%) had greater than 1 to 1 support

- 9 (1%) had less than 24/7 care

A total of 526 current overnight respite services required an enhancement, of these 498 were overnight respite services received in a house in the community/centre-based respite.

621 overnight respite places are required now or within the next five years, the majority of which are for house in the community/centre-based respite (431 places) (Table 2.12).

Table 2.12 Overnight respite; number of respite nights accessed, places currently being accessed, enhancement required to current places and unmet need for places for service users with an ID, NASS 2020

	Respite nights accessed in 2020	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	n	%	n	n
Total population		**27,746**	**100**		
House in the community/centre-based respite	23,838	1,444	6.3	498	431
Holiday respite (residential/centre-based/summer camp)	1,002	98	0.4	24	65
Home sharing short breaks family	1,679	48	0.2	0	15
Holiday Respite (hotel/B&B/hostel)	238	14	0.1	~	86
Own home respite	135	~	~	0	9
Home sharing contract family	54	~	~	~	11
Nursing home respite	0	0	0.0	0	4
Total	**26,946**	**1,611**		**526**	**621**

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

Note that an individual may be in receipt of more than one overnight respite service.

Supports for Daily Living

Overall, 3,225 (14%) service users were in receipt of at least one support for daily living in 2020. A total of 4,181 supports for daily living were accessed by service users with a primary disability of intellectual.

The most frequently accessed supports for daily living were home support (1,339, 6%) and community support (1,303, 6%) (Table 2.13). Comparable data on supports for daily living is not available from NIDD, however NIDD did report on home support services in 2017, with 2,050 (7%) people accessing this service .

The 2020 data shows that there is an unmet need for 513 supports for daily living now or within the next five years. Home support is the most commonly required service (164), with a 12% increase on current service provision required.

Table 2.13 Supports for daily living; places currently being accessed, enhancement required to current places and unmet need for places for service users with an ID, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	**22,746**	**100**		
Home support	1,339	5.9	236	164
Community support	1,303	5.7	176	104
Transport services	829	3.6	129	60
Advocacy services	296	1.3	55	58
Personal assistant	210	0.9	67	63
Peer support	116	0.5	27	28
Voluntary work	82	0.4	22	32
Guide dog/Assistance dog	6	0.0	0	~
Total	**4,181**		**712**	**513**

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed

Note that an individual may be in receipt of more than one support for daily living

Specialist supports

Almost two thirds of service users with ID (14,363) accessed at least one specialist support in 2020. Of these 14,363 service users, 33% (4,764) availed of one specialist support service, 20% (2,917) availed of two specialist support services and 16% (2,292) availed of three specialist support services. The remaining 31% (4,390) availed of four or more specialist support services.

A total of 40,741 specialist supports were received by these service users (Table 2.14). The most received specialist support services were social work (6,229, 27%), speech and language therapy (5,721, 25%), occupational therapy (4,909, 22%), nursing (4,885, 22 %), and physiotherapy (4,531, 20%).

 Of the 40,741 specialist supports that were received in 2020, 16,322 (40% of services currently accessed) require an enhancement to the current service.

Additionally, there is an unmet need for 2,581 specialist supports, of which speech and language therapy (470 places) and clinical psychology (393) are the most required now or within the next five years.

Comparisons to the NIDD, 2017 are limited as only a number of specified multidisciplinary services were recorded on the NIDD. Comparisons, however, can be made directly to services, for example, social work was accessed by 10,275 (36%) service users in comparison to 6,229 (27%) on NASS. In addition, speech and language therapy was accessed by 11,193 service users on NIDD, 2017 compared to 5,721 on NASS, 2020. Occupational therapy was accessed by 8,791 (31%) service users on NIDD, 2017 compared to 4,909 (22%) on NASS, 2020.

It is clear that in relation to specialist supports, the data available on NASS is not yet in line with what was previously recorded on NIDD. As outlined earlier, the 2020 NASS data is incomplete and there are people with disabilities whose service use and needs are not recorded. For example, several Children's Disability Network Team's (CDNT) data are not captured which means that the data presented is an under-representation of the actual use of and need for specialist support services. Every effort is being made to ensure that future datasets provide more comprehensive coverage.

Table 2.14 Specialist supports; places currently being accessed, enhancement required to current places and unmet need for places for service users with an ID, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	**22,746**	**100**		
Social work	6,229	27.4	2,918	273
Speech and language therapy	5,721	25.2	2,694	470
Occupational therapy	4,909	21.6	2,210	381
Nursing	4,885	21.5	2,042	35
Physiotherapy	4,531	19.9	1,969	192
Psychiatry	3,743	16.5	1,516	34
Key worker	2,888	12.7	627	14
Dietetic services	2,027	8.9	974	131
Clinical psychology	1,496	6.6	426	393
Dentistry/orthodontic	719	3.2	186	49
Chiropody	702	3.1	116	53
Behaviour therapy	626	2.8	126	132
Case manager	547	2.4	23	~
Special Needs Assistant (SNA)	387	1.7	65	24
Orthotics/prosthetics	280	1.2	61	18
Educational psychology	200	0.9	87	121
Children's Disability Network Team (CDNT)	151	0.7	113	~
Complementary therapy	118	0.5	33	36
Resource teacher	118	0.5	20	5
Assistive technology/client technical service	112	0.5	45	67
Counselling	102	0.4	23	43
Creative therapy	74	0.3	22	43
Vision rehabilitation	55	0.2	5	5

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Palliative care	42	0.2	~	~
Neuropsychology	30	0.1	6	~
Aural rehabilitation services	15	0.1	~	0
Vision communication-IT/AT and alternative formats	14	0.1	5	6
Neurorehabilitation	13	0.1	~	~
Play therapy	~	~	~	32
Aural communication-IT/AT and alternative format services	~	~	~	~
Animal assisted therapy	~	~	0	9
Total	**40,741**		**16,322**	**2,581**

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed

Note that an individual may be in receipt of more than one specialist support

The specialist supports most availed of by service users under 18 years were speech and language therapy (2,538, 49%), occupational therapy (1,846, 36%) and social work (1,621, 31%). The specialist supports most availed of by service users aged 18 years and over were social work (4,608, 26%), nursing (4,040, 23%) and psychiatry (3,617, 21%). A breakdown of the top ten most received specialist support services by age (under 18 years and 18 years and over) is provided in Figures 2.4 and 2.5.

Figure 2.4 Specialist supports for service users with an ID aged under 18 years; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020
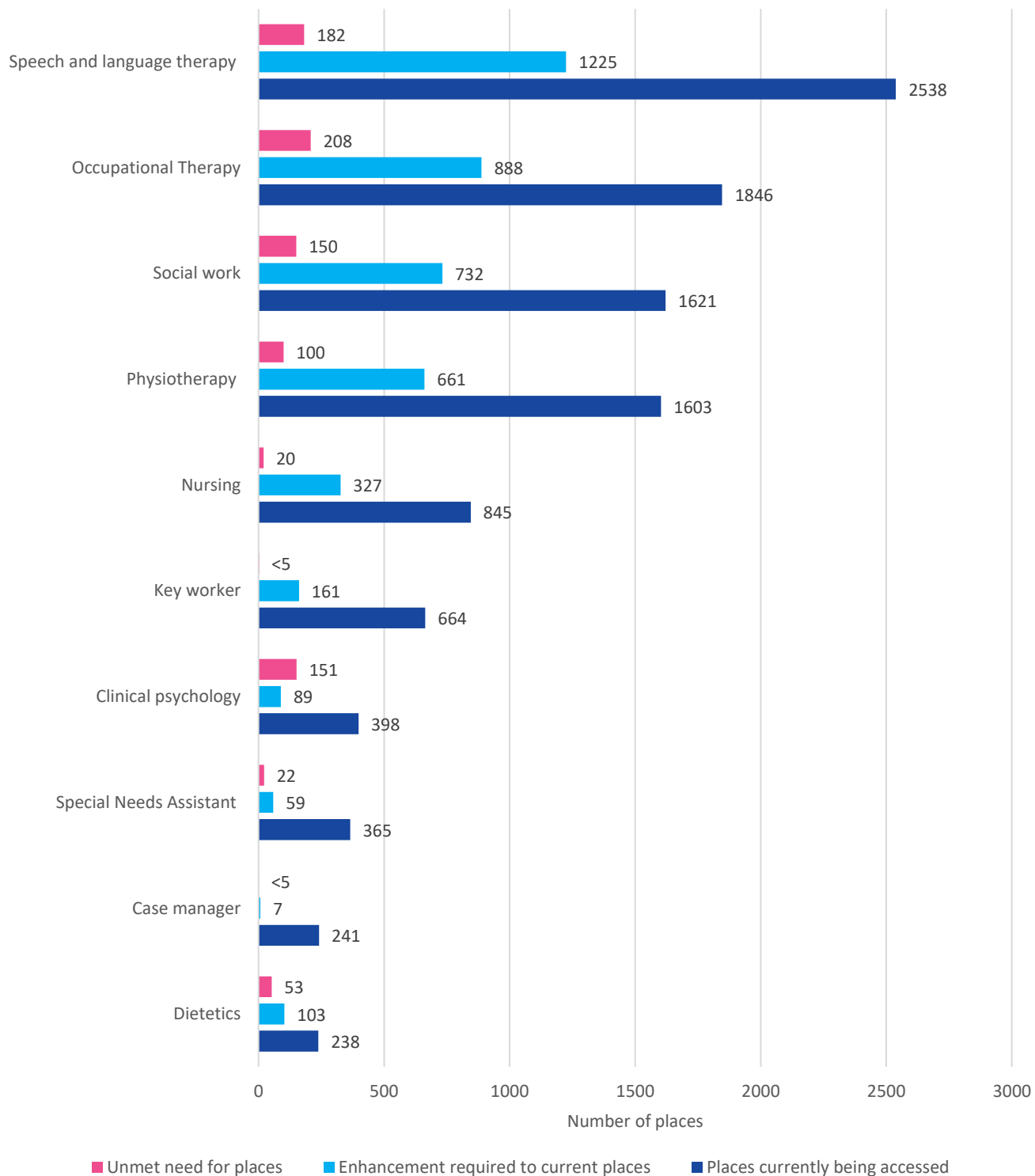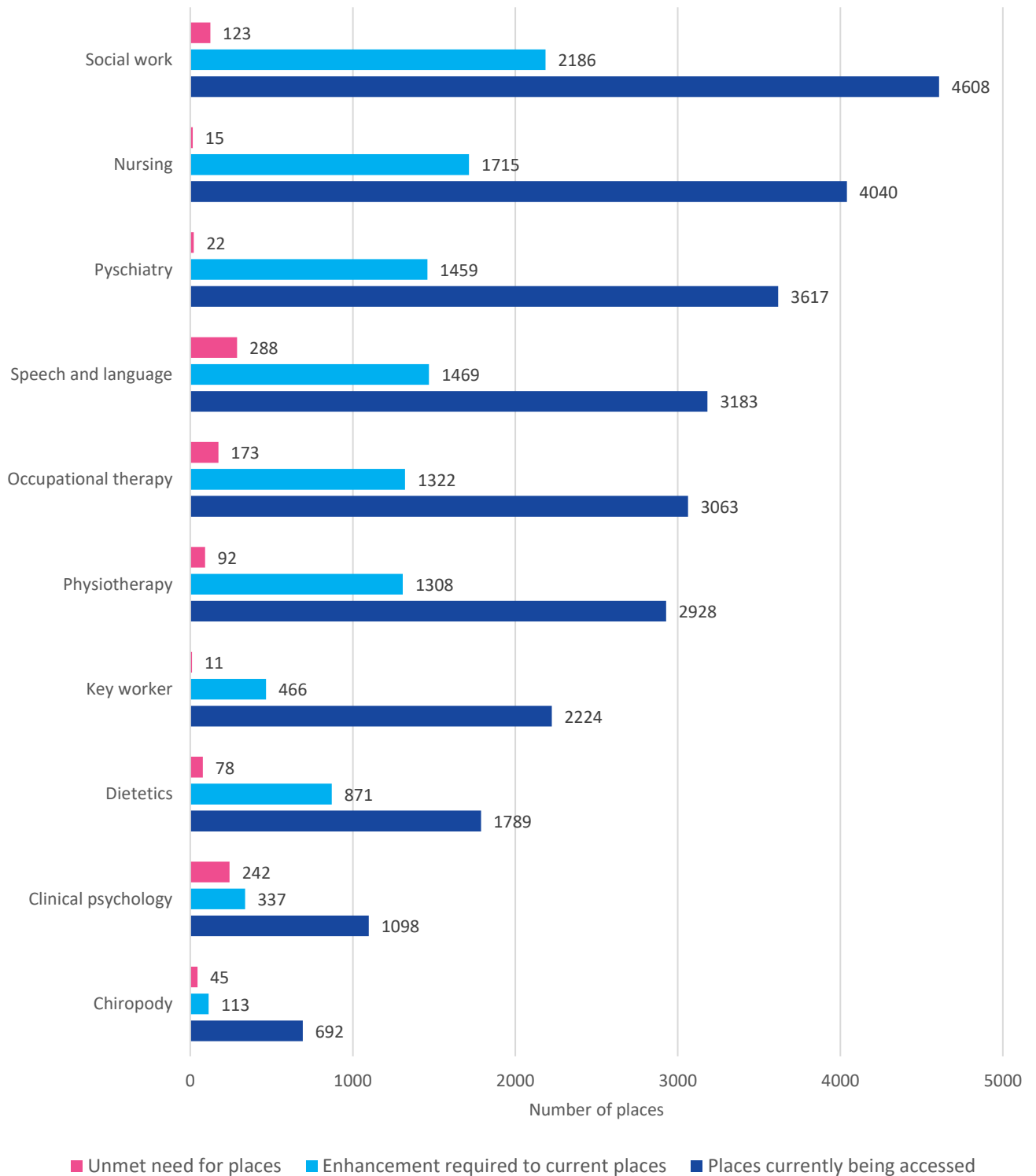
Figure 2.5 Specialist supports for service users with an ID aged 18 years and over; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020

2.6 Assistive products

Assistive products were used by 775 (3%) service users and a total of 1,768 assistive products were accessed. The most commonly used product groups and products were:

- Assistive products for activities and participation relating to personal mobility and transportation (647). Of these, manual wheelchairs (273) and assistive products for walking (using both arms) for example, walking sticks, crutches, rollators, or frames (112) were the most commonly used products.

- Furnishings and adaptions to homes (290). Of these, beds and bed equipment (133) and sitting furniture (99) were the most frequently used.

- Assistive products for personal care and protection (268). Of these, assistive products for washing, bathing, and showering (120) and assistive products for absorbing urine and faeces (50) were the most commonly used products.

Overall, 124 service users had an unmet need for at least one assistive product, and 200 assistive products were reported as being required now or within the next five years. The most frequently required assistive product groups and products were:

- Assistive products for personal mobility and transportation (51). Of these, manual wheelchairs (18) and diverse human powered vehicles (11) were the most commonly required.

- Furnishings and adaptions to homes (45). Of these, sitting furniture (19) and beds and bed equipment (8) were the most frequently required.

- Assistive products for communication and information management (44). Of these, assistive products for face-to-face communication (16) and interactive devices for computers (11) were the most commonly required.

3   Summary

This is a supplementary report to be read in conjunction with the NASS annual report. This report is based on information collected from 22,746 service users registered on NASS with ID at the end of December 2020. It represents the recorded service use and needs of people with ID accessing HSE disability-funded services in 2020.

As outlined in the annual report, information included in this report spans the entire year of 2020. Some reviews of service user records took place in early - mid 2020, before Covid-19 had impacted service delivery. Therefore, the information in this report is a mixture of pre- and mid-Covid-19 service provision. It is difficult to identify and quantify the extent to which Covid-19 impacted the delivery of services and the ability of service providers to update NASS in this challenging year. This is unfortunate as 2020 is the first full data collection year for NASS and uncertainty remains around a benchmark of disability service use and need and the variation in service provision attributable to Covid-19. Going forward for 2021 data collection, a mechanism for service providers to identify services which are impacted by Covid-19 has been included. Use of this marker will be encouraged so that the impact of Covid-19 on the delivery of HSE disability-funded services can be more accurately assessed.

Although gaps exist in the data overall, this cohort of the NASS population provides a snapshot of service provision and need for 2020 for service users with ID. Efforts to increase the levels of return will be undertaken by the Health Research Board for future data collections.

Separate supplementary reports have been developed for those recorded on NASS with autism and for those with a physical and sensory disability. Additional breakdowns of NASS 2020 data are available on request from the Health Research Board. Please visit https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/request-data/ to access a data request form and return it to nass@hrb.ie.