

HRB StatLink Series 1

Annual Report of the National Ability Supports System (NASS) 2020

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Art Competiton

The annual report art competition will return next year for the 2021 NASS annual report. See previous NIDD and NPSDD winners for some inspiration!



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Table of Contents

Acknowledgements	v
Overview	1
1 Introduction	3
1.1 Background	3
1.2 Data collection	3
1.3 Limitations of the data	5
1.4 Publications and analysis	6
2 National Overview	7
2.1 Numbers registered	7
2.2 Demographic profile	9
2.3 Disability and diagnosis	17
2.4 Primary Carer	23
2.5 Services	26
2.6 Assistive products	45
2.7 World Health Organisation Disability Assessment Schedule V.2 (WHODAS 2.0)	48
3 Summary	50
4 Appendices	52

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- Service providers;
- Representative bodies for the providers of services to people with disabilities – National Federation of Voluntary Bodies, Disability Federation of Ireland and the Not for Profit Association;
- Parents and families of people with a disability and their representative bodies; and all service users throughout Ireland.

Overview

This report presents an overview of the information recorded on the National Ability Supports System (NASS) for 2020.

A total of 36,649 service users are included in the 2020 report which is a significant increase on the 2019 figures. 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.



In 2020 the main findings were:

- More males than females were registered on NASS, and those in the 10-14 year age group were the greatest proportion of the overall total.
- Intellectual disability was the most commonly reported primary disability followed by a neurological disability and autism.
- Half of those registered on NASS reported having a primary carer, the majority of whom were parents.
- In 2020, 21% of those recorded on NASS were in receipt of a residential service; 63% accessed at least one day service¹; 5% accessed overnight respite; 17% were in receipt of at least one support for daily living; 66% were in receipt of at least one specialist support and 7% used at least one assistive product.

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.

Of those recorded on NASS in 2020:



21%

were in receipt of a residential service



63%

accessed at least one day service



5%

accessed overnight respite



17%

were in receipt of at least one support for daily living



66%

were in receipt of at least one specialist support



7%

used at least one assistive product

1 Introduction

1.1 Background

This report is based on validated data extracted from the National Ability Supports System (NASS) at the end of December 2020.

NASS is a national database that records information about Health Service Executive (HSE) disability-funded services² that are received or required as a result of an intellectual disability, 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.

1.2 Data collection

Information on NASS is captured under six headings:

- Service user details
- Primary carer details
- Disability type and diagnosis
- Services
- Assistive products; and
- WHODAS 2.0 (World Health Organisation Disability Assessment Schedule). WHODAS is only recorded for service users over the age of 16 years and for all primary disability types except intellectual disability.

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.

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
- 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 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, 36,649 service user records are included in this report. This is an increase of 64% from the 22,434 records reviewed in 2019 (Appendix A).



It is estimated that the records reviewed in 2020 reflect approximately 65% of those currently in receipt of services. This estimate is based on previous registrations on the National Intellectual Disability Database (NIDD) and National Physical and Sensory Disability Database (NPSDD) (which were replaced by NASS in 2019), as well as new registrations to capture disability types not previously registered – autism, developmental delay and mental health. The Health Research Board (HRB) will further investigate and monitor coverage so that an accurate estimate of coverage can be determined.

Appendix A and B show the comparison of service users registered and services received on NIDD and NPSDD in 2017 and on NASS in 2019 and 2020.

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 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 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, some of the 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 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 section which measures the impact that the difficulties experienced due to disability had on a person's day-to-day life in the 30 days prior to review.

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.

Publications and analysis



This report represents a national overview of available data from NASS. Additional supplementary reports presenting information by disability type (intellectual, autism, 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 National Overview

2.1 Numbers registered

A total of 36,649 service users are included in this report. Table 2.1 shows the general population distribution by CHO and registrations 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 9 had the most registered service users (5,800, 16%), followed by CHO 7 with 5,269 service users (14%).

Table 2.1 Distribution of the general population by Community Healthcare Organisation (CHO) and service users registered on NASS 2020

	Population ³	% Population distribution	NASS 2020 registrations	% NASS 2020 distribution
Total population	4,761,865	100	36,649	100
CHO 1	391,281	8.2	4,630	12.6
CHO 2	453,109	9.5	5,091	13.9
CHO 3	384,998	8.1	2,269	6.2
CHO 4	690,575	14.5	4,676	12.8
CHO 5	510,333	10.7	3,179	8.7
CHO 6	393,239	8.3	1,930	5.3
CHO 7	697,644	14.7	5,269	14.4
CHO 8	619,281	13.0	3,803	10.4
CHO 9	621,405	13.0	5,800	15.8
Outside Ireland	-	-	~	~

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

³ Central Statistics Office (2017) Census 2016 Summary Results- Part 1 Dublin: Central Statistics Office.

2.2 Demographic profile

More males (21,694, 59%) than females (14,955, 41%) were registered on NASS. Over a third of those registered during the 2020 data collection period were aged under 18 years, more than two-thirds of whom were male.

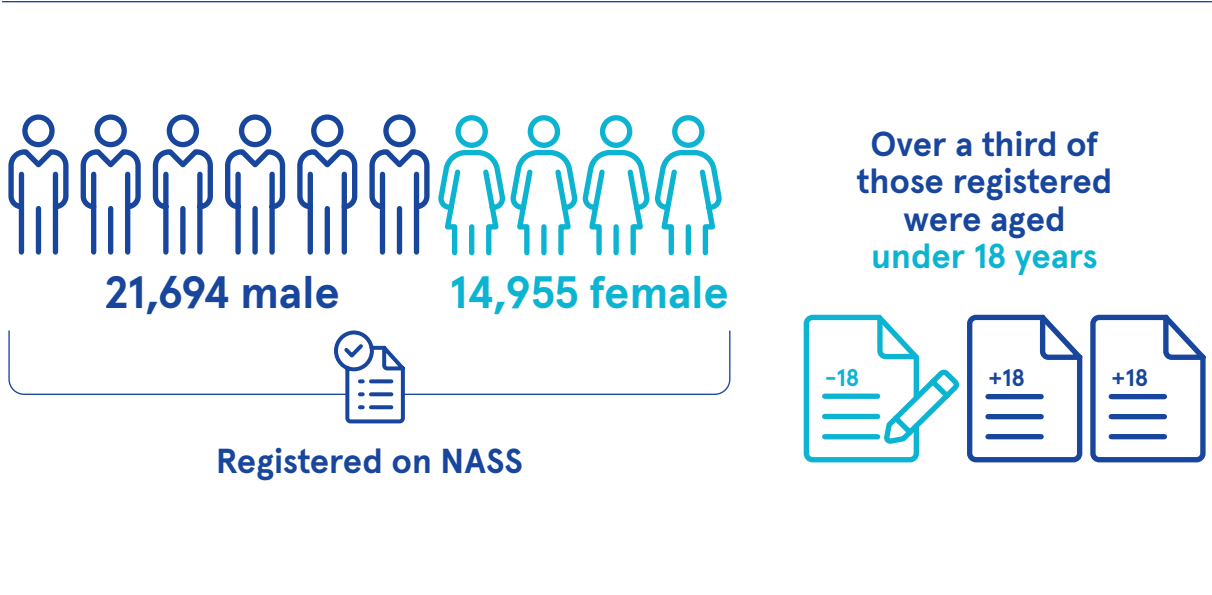
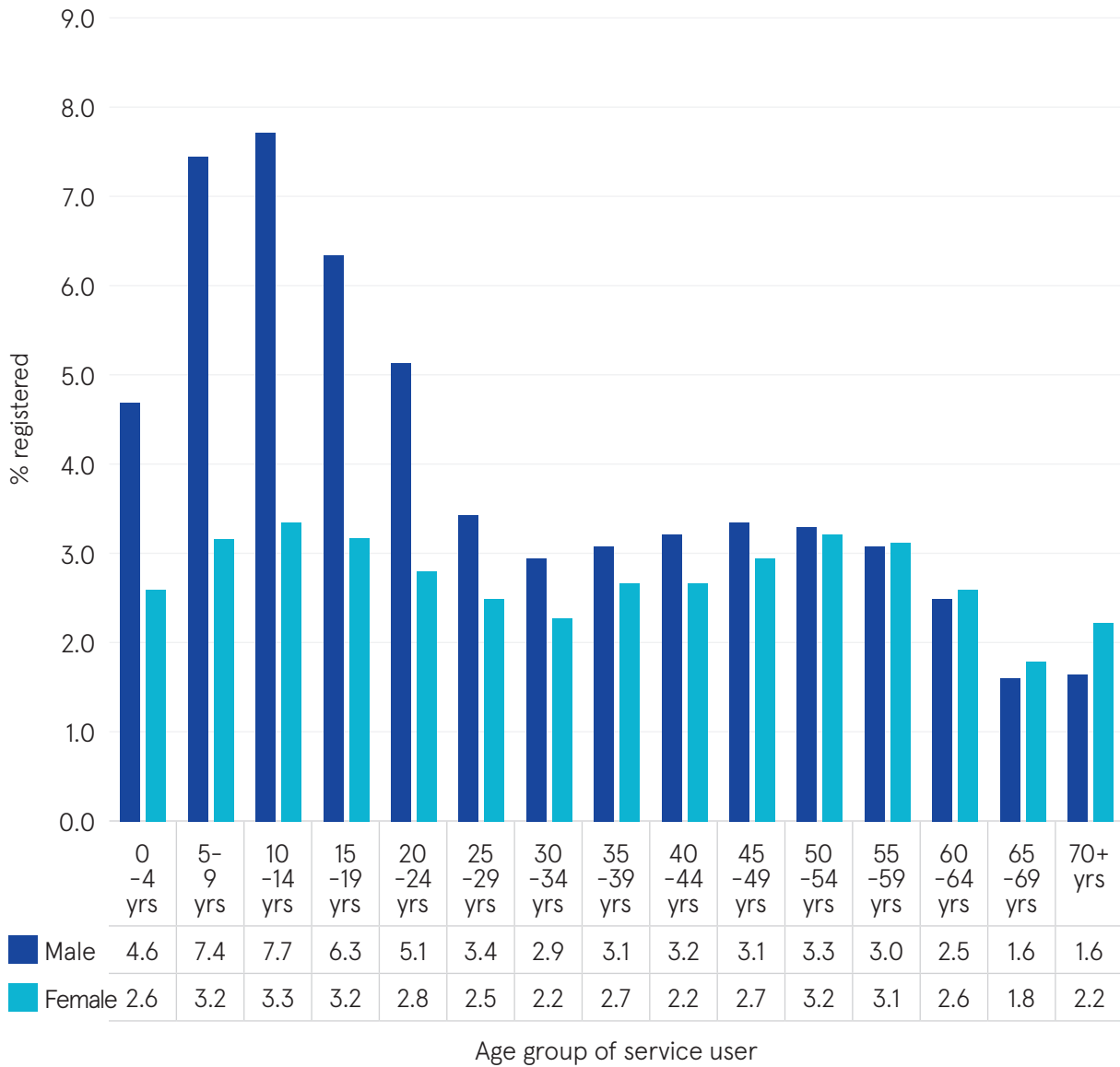


Table 2.2 and Figure 2.1 show that for both sexes, those in the 10-14 year age group were the most represented (4,045, 11%).

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

	Male	Female	Total
0-4 years	1,703	936	2,639
5-9 years	2,728	1,156	3,884
10-14 years	2,819	1,226	4,045
15-19 years	2,319	1,156	3,475
20-24 years	1,870	1,023	2,893
25-29 years	1,247	914	2,161
30-34 years	1,074	822	1,896
35-39 years	1,126	973	2,099
40-44 years	1,175	974	2,149
45-49 years	1,222	1,074	2,296
50-54 years	1,196	1,170	2,366
55-59 years	1,117	1,137	2,254
60-64 years	911	938	1,849
65-69 years	586	645	1,231
≥ 70 years	601	811	1,412
Total	21,694	14,955	36,649

Figure 2.1 Percentage of service users registered by age group and sex, NASS 2020



Occupational status⁴

For service users under the age of 18 years (12,571), the majority were students/pupils (5,676, 45%). Of service users who are aged over 18 years (24,078), the majority were unable to work due to a disability (6,164, 26%) followed by attending a training/day programme (4,262, 18%) (Table 2.3).

Table 2.3 Occupational status of service users, NASS 2020

	Less than 18 years		18 years and over		Total	
	n	%	n	%	n	%
Total population	12,571	100	24,078	100	36,649	100
Unable to work due to disability	39	0.3	6,164	25.6	6,203	16.9
Student/pupil	5,676	45.2	422	1.8	6,098	16.6
Training/day programme	10	0.1	4,262	17.7	4,272	11.7
Other	1,307	10.4	345	1.4	1,652	4.5
In paid employment	0	0.0	1,365	5.7	1,365	3.7
Unemployed	~	~	1,151	4.8	1,154	3.1
Retired	0	0.0	877	3.6	877	2.4
Housewife/husband	~	~	194	0.8	195	0.5
Not known	5,535	44.0	9,298	38.6	14,833	40.5

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

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

Ethnic or cultural background

The ethnic or cultural background question on NASS is based on a question from the Central Statistics Office 2016 national census form which measures ethnicity or cultural background. The service user's ethnic or cultural background is self-determined.

The most frequently self-reported ethnicity or cultural background was Irish (17,063, 47%) (Table 2.4).

Table 2.4 Ethnic or cultural background of service users, NASS 2020

	n	%
Total population	36,649	100
Irish	17,063	46.6
Any other white background	574	1.6
Irish Traveller	159	0.4
Any other Asian background	146	0.4
Black African	120	0.3
Any other black background	49	0.1
Asian-Chinese	23	0.1
Do not wish to answer this question	909	2.5
Not known	17,606	48.0

Living accommodation

Living accommodation refers to the service user's living accommodation for the majority of the week, that is, where the service user resides an average of 4 or more nights per week.

For the purpose of this section, residential setting includes residential care facilities that are HSE disability-funded such as congregated settings, group homes and houses in the community as well as those that are not funded from the HSE disability budget such as nursing homes under the Fair Deal scheme or paid for privately. HSE disability-funded residential settings are described in more detail in section 2.5.

A total of 9,371 (26%) service users were living in private accommodation that was owner occupied and 2,723 (7%) were living in rented accommodation. A total of 7,621 (21%) were residing in a residential setting and 70 service users (<1%) were residing in unstable accommodation (Table 2.5).

Table 2.5 Living accommodation of service users, NASS 2020

	n	%
Total population	36,649	100
Private accommodation-owner occupied	9,371	25.6
Residential setting*	7,621	20.8
Rented from county council/public authority/service provider	1,833	5.0
Rented on open market	890	2.4
Unstable accommodation	70	0.2
Not known	16,864	46.0

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

Living arrangements

For the purpose of this section, residential setting includes residential care facilities that are HSE disability-funded such as congregated settings, group homes and houses in the community as well as those that are not funded from the HSE disability budget such as nursing homes under the Fair Deal scheme or paid for privately. HSE disability-funded residential settings are described in more detail in section 2.5.

Most service users registered on NASS were residing with family members [23,058 (63%)] and 1,704 (5%) service users were living alone. The living arrangements of 3,814 (10%) service users were not known (Table 2.6).

The remaining 22% described their living arrangements as living with non-family or living in a residential service.

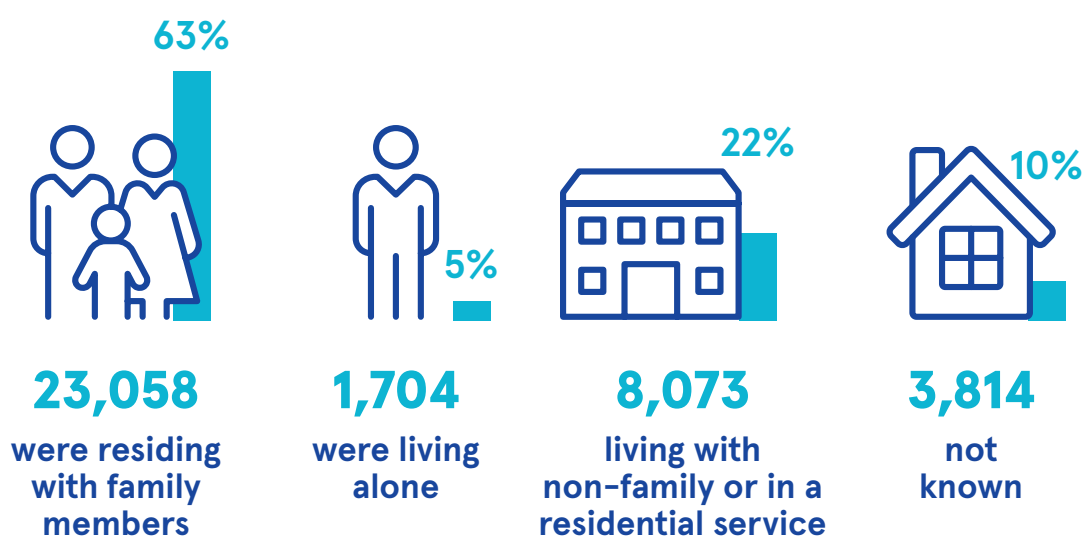


Table 2.6 Living arrangements of service users, NASS 2020

	n	%
Total population	36,649	100
Living with family	23,058	62.9
Both parents	12,234	33.4
One parent	4,695	12.8
Parent(s) and sibling(s)	2,612	7.1
Wife/husband/partner, no children	1,040	2.8
Sibling(s)	1,028	2.8
Wife/husband/partner and children	994	2.7
Daughter(s)/ son(s)	286	0.8
Other relative(s)	169	0.5
Residential setting*	7,608	20.8
Residential setting	7,608	20.8
Living alone	1,704	4.6
Alone	1,704	4.6
Living with non-family	465	1.3
Foster family	305	0.8
Non-relatives	160	0.4
Not known	3,814	10.4
Not known	3,814	10.4

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

2.3 Disability and diagnosis

Primary disability

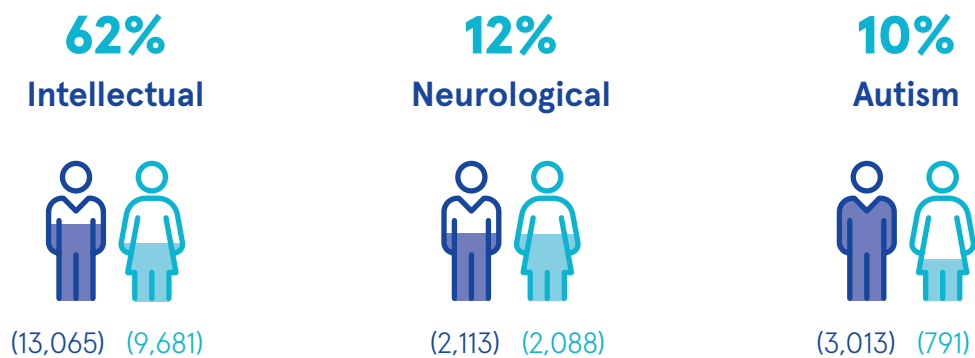


Table 2.7 and Figure 2.2 show primary disability type by sex.

The most frequently reported primary disability was intellectual (22,746, 62%), followed by neurological (4,201, 12%). Amongst those whose primary disability was intellectual, their level of intellectual disability was:

- Borderline (396, 2%)
- Mild (6,825, 30%)
- Moderate (9,760, 43%)
- Severe (3,222, 14%)
- Profound (810, 4%)
- Not verified (1,702, 7%)

Level of intellectual disability was missing for 31 service users.

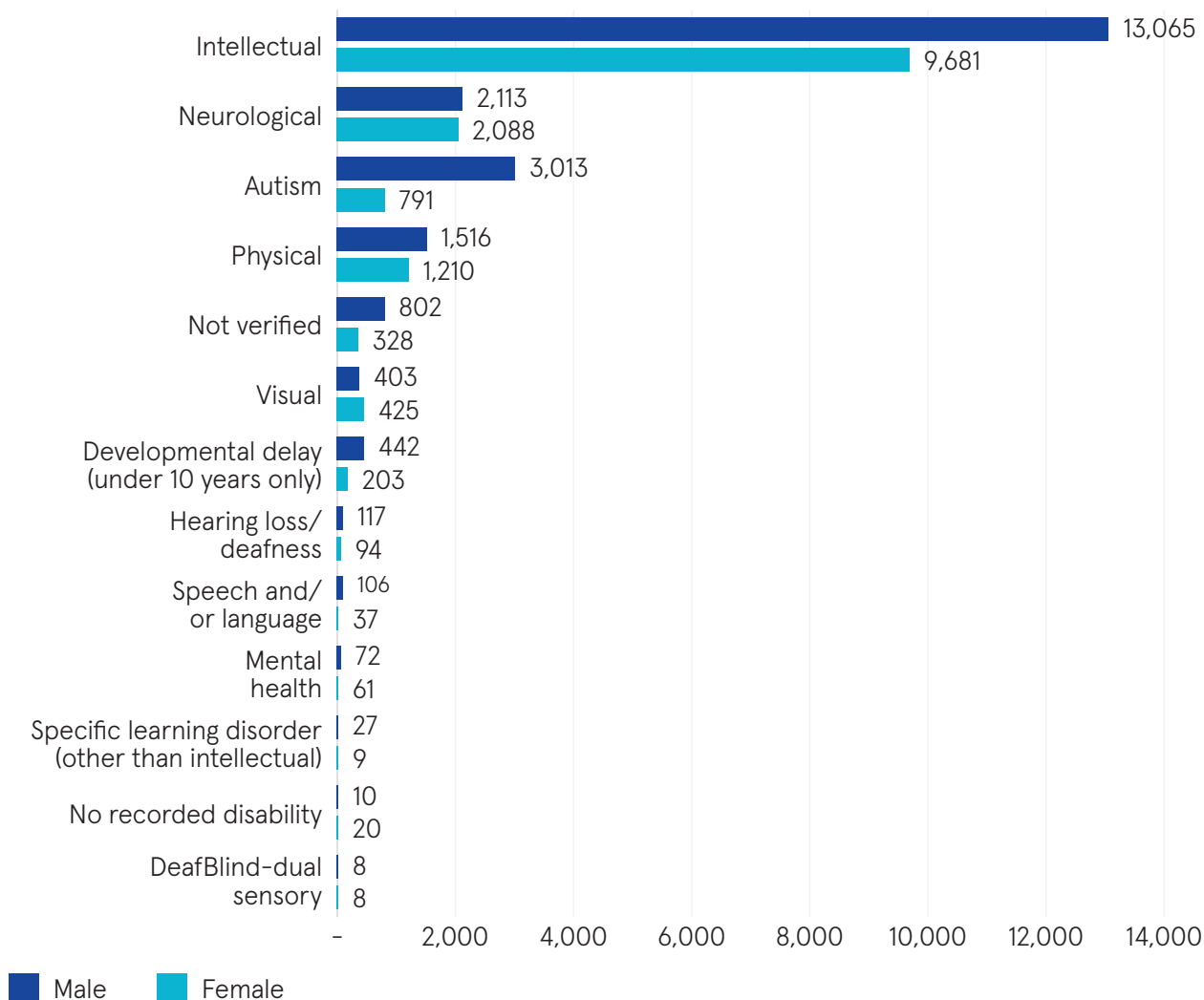
Almost four out of five of those whose primary disability was autism were male.

Table 2.7 Primary disability type by sex based on total population of 36,649, NASS 2020

	Male		Female		Total	
	n	%	n	%	n	%
Intellectual	13,065	35.6	9,681	26.4	22,746	62.1
Neurological	2,113	5.8	2,088	5.7	4,201	11.5
Autism	3,013	8.2	791	2.2	3,804	10.4
Physical	1,516	4.1	1,210	3.3	2,726	7.4
Not verified*	802	2.2	328	0.9	1,130	3.1
Visual	403	1.1	425	1.2	828	2.3
Developmental delay	442	1.2	203	0.6	645	1.8
Hearing loss/deafness	117	0.3	94	0.3	211	0.6
Speech and/or language	106	0.3	37	0.1	143	0.4
Mental health	72	0.2	61	0.2	133	0.4
Specific learning disorder	27	0.1	9	0.0	36	0.1
DeafBlind-dual sensory	8	0.0	8	0.0	16	0.0
No recorded disability	10	0.0	20	0.1	30	0.1
Total	21,694	59.2	14,955	40.8	36,649	100.0

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

Figure 2.2 Primary disability type by sex, NASS 2020



Additional disabilities⁵

A total of 14,629 (40%) service users had at least one additional disability recorded (Table 2.8). The most commonly reported additional disability was physical (6,225, 17%), followed by speech and/or language (5,082, 14%).

Those with an intellectual disability most commonly had an additional physical disability, followed by a speech and/or language disability. Those with autism most commonly had an additional intellectual disability recorded.

⁵ Additional disabilities were captured as ‘secondary disabilities’ on NASS.

Table 2.8 Additional disabilities by primary disability, NASS 2020

Additional disability	Primary disability categories									
	Intellectual disability		Autism		Physical/sensory*		Other**		Total population	
	n	%	n	%	n	%	n	%	n	%
Total population	22,746	100	3,804	100	8,125	100	1,944	100	36,649	100
Physical	4,951	21.8	50	1.3	1,196	14.7	28	1.4	6,225	17.0
Speech and/or language	4,676	20.6	139	3.7	230	2.8	37	1.9	5,082	13.9
Visual	2,037	9.0	28	0.7	239	2.9	8	0.4	2,312	6.3
Autism	1,876	8.2	0	0.0	52	0.6	21	1.1	1,949	5.3
Hearing loss/deafness	1,351	5.9	16	0.4	99	1.2	~	~	1,470	4.0
Neurological	633	2.8	57	1.5	694	8.5	11	0.6	1,395	3.8
Intellectual	0	0.0	721	19.0	184	2.3	22	1.1	927	2.5
Mental health	466	2.0	95	2.5	164	2.0	~	~	726	2.0
Specific learning disorder	75	0.3	61	1.6	25	0.3	~	~	164	0.4
Developmental delay	28	0.1	49	1.3	31	0.4	~	~	110	0.3
Not verified	23	0.1	11	0.3	44	0.5	6	0.3	84	0.2
DeafBlind- Dual sensory	26	0.1	~	~	5	0.1	0	0.0	32	0.1
No additional disability	12,038	52.9	2,701	71.0	5,448	67.1	1,811	93.2	22,028	60.1

* Physical/sensory includes: DeafBlind (dual sensory), hearing loss and/or deafness, neurological, physical, speech and/or language and visual.

** Other includes: Developmental delay (under 10 years only), specific learning disorder (other than intellectual), mental health and not verified.

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

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

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.

NASS uses the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) to code these diagnoses. The exact ICD-10 code is captured on NASS but for the purposes of reporting, the higher-level grouping code is presented in tabular format below using ICD-10 terminology (Table 2.9).

There were 6,587 diagnoses recorded for 5,287 service users during the 2020 data collection period. The most frequently reported ICD-10 diagnosis category on NASS was diseases of the nervous system (G00–G99) which includes conditions such as multiple sclerosis, cerebral palsy, and Parkinson’s disease. Mental and behavioural disorders was the second most frequently reported ICD-10 diagnosis category which includes intellectual disabilities, dementia, and attention deficit hyperactivity disorder.

It should be noted that as it is optional to record diagnosis on NASS, information on diagnosis is not necessarily reflective of those registered on the system. Diagnosis information was not captured on the NIDD and 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.

Table 2.9 ICD-10 diagnostic category, NASS 2020

ICD-10 diagnostic category	n	%
Total population	36,649	100
Diseases of the nervous system (G00–G99)	1,858	5.1
Mental and behavioural disorders (F00–F99)	1,479	4.0
Congenital malformations, deformations, and chromosomal abnormalities (Q00–Q99)	1,371	3.7
Diseases of the eye and adnexa (H00–H59)	437	1.2
Diseases of the circulatory system (I00–I99)	253	0.7
Endocrine, nutritional, and metabolic diseases (E00–E90)	251	0.7

ICD-10 diagnostic category	n	%
Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	195	0.5
Diseases of the musculoskeletal system and connective tissue (M00-M99)	187	0.5
Injury, poisoning and certain other consequences of external causes (S00-T98)	141	0.4
Diseases of the ear and mastoid process (H60-H95)	123	0.3
Diseases of the respiratory system (J00-J99)	79	0.2
Factors influencing health status and contact with health services (Z00-Z99)	36	0.1
Neoplasms (C00-D48)	34	0.1
Diseases of the digestive system (K00-K93)	29	0.1
Certain conditions originating in the perinatal period (P00-P96)	29	0.1
Diseases of the genitourinary system (N00-N99)	26	0.1
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50-D89)	24	0.1
Mental, behavioural or neurodevelopmental disorders (ICD-11)	15	0.0
Diseases of the skin and subcutaneous tissue (L00-L99)	12	0.0
Certain infectious and parasitic diseases (A00-B99)	8	0.0
Total	6,587	

Note that more than one diagnosis may be recorded for an individual.

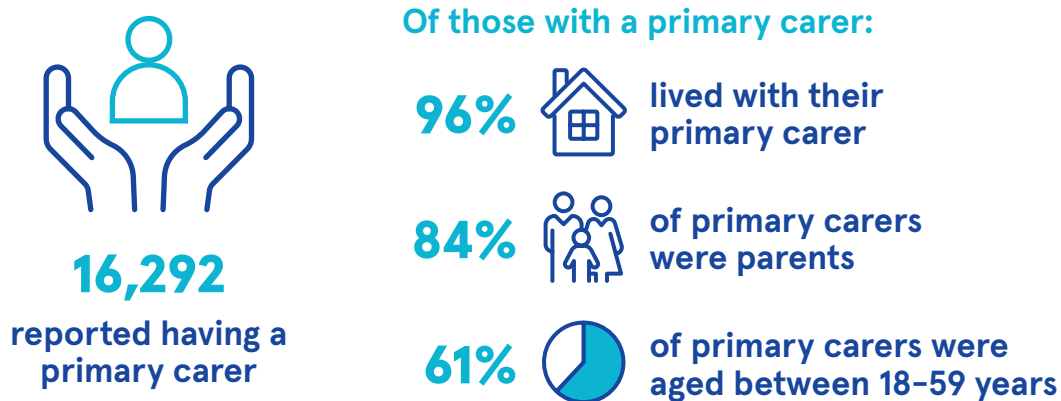
2.4 Primary Carer

For the purposes of NASS, a primary carer is defined as someone who has been identified as providing regular and sustained care and assistance (also referred to as an informal carer). Primary carers can include a family member, friend or neighbour.

Primary carers include those who are unpaid for this role and also those who receive an allowance or benefit for their caring role. The care is provided on an ongoing basis. For the purposes of NASS, primary carers do not include paid or volunteer carers organised by formal services, such as host families or foster families where the family is paid to care for the service user.

Of those registered on NASS who do not live in a residential setting (28,606), 16,292 (57%) reported having a primary carer. Most of those with a primary carer lived with their primary carer (15,647, 96% of those who reported having a primary carer) (Figure 2.3).

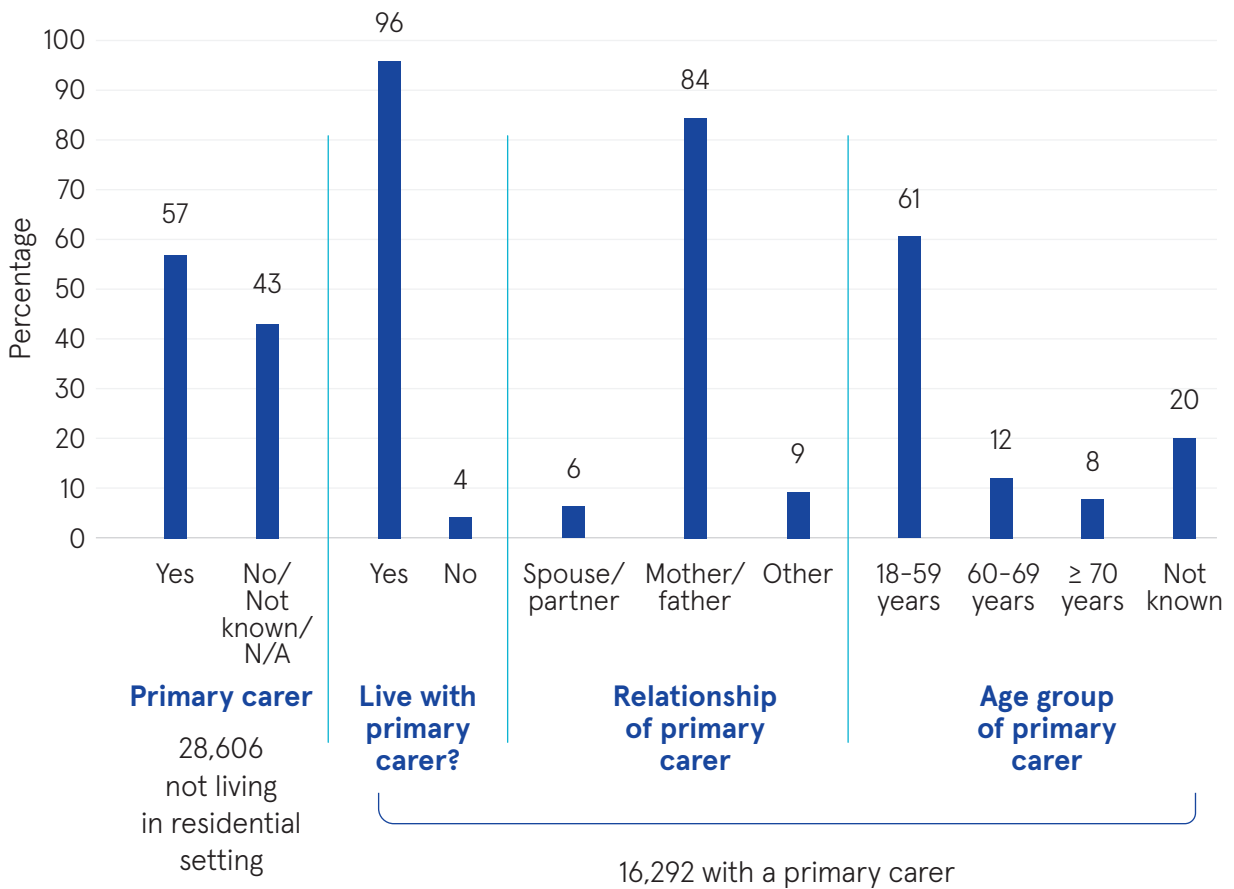
The majority (13,729, 84%) of primary carers were parents and 1,005 (6%) were a spouse/partner. Primary carers were mostly aged between 18–59 years (9,889, 61%), 1,942 (12%) were aged between 60 and 69 years and 1,282 (8%) were aged 70 years and over.



Parents made up the majority of primary carers for all disability types. A notable number of siblings were reported as the primary carer of those with an intellectual disability (751, 5% of primary carers of service users with intellectual disability).

In terms of service user age, 62% (7,837) of those aged 18 years or less had a primary carer, 57% (6,950) of those aged 19–54 years had a primary carer, and 42% (1,506) of service users aged 55 years and over had a primary carer.

Figure 2.3 Primary carer information, NASS 2020



The proportion of service users who do not live in a residential setting and have a primary carer is shown below by their primary disability type:

- Intellectual (9,062, 58%)
- Autism (2,447, 72%)
- Neurological (1,740, 45%)
- Physical (1,022, 39%)
- Not verified (867, 82%)
- Developmental delay (565, 89%)
- Visual (370, 46%)
- Speech and/or language (115, 84%)
- Hearing loss/deafness (46, 22%)
- Mental health (33, 30%)
- Specific learning disorder (other than intellectual) (17, 57%)
- DeafBlind- dual sensory (6, 55%)

2.5 Services

As outlined earlier, 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.

Residential services

Residential services include HSE disability-funded accommodation and services that provide support to enable people with disabilities to remain in their existing accommodation or to move to more suitable or appropriate accommodation.

The HSE report, *Time to Move On from Congregated Settings (2011)*⁶, recommended that traditional types of residential settings with 10 or more people should be phased out and service users facilitated to move to settings with a maximum of four people. Service providers have been working to implement this policy with service users but due to constraints in the availability of suitable accommodation and supports, some service users are still living in larger congregated settings and their information is shown in the table below.

There were 7,535 (21%) people registered on NASS accessing 7,601 HSE disability-funded residential services in 2020 (as some service users accessed more than one residential service). The majority of residential services were provided to those reporting intellectual disability as their primary disability (7,046, 93%) and those aged ≥40 years (5,949, 79%).

⁶ Time to Move On from Congregated Settings. Report of the Working Group on Congregated Settings. Health Service Executive, 2011.

A community group home (5-9 residents sharing) was the most common residential circumstance, followed by a house in the community (1-4 residents sharing) (Table 2.10).

Of those accessing residential services and where information on support was available (6,491):

- 3,257 (50%) had 24/7 staff and awake cover at night
- 1,730 (27%) had 24/7 staff and sleepover cover at night
- 601 (9%) had less than 24/7 staff and sleepover cover at night
- 403 (6%) had 1 to 1 support
- 326 (5%) had less than 24/7 care
- 174 (3%) 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 (6,637), 6,379 (96%) availed of their residential service 7 nights per week.

As shown in Table 2.10, 1,366 (18%) residential places require an enhancement to the current residential service. Of these, 535 were places in a community group home (18% of current places), 382 were places in a residential centre/on campus (26% of current places) and 381 were places in a house in the community (16% of current places).

Although NASS does not yet have complete capture of residential service use and need (HSE estimates that 8,139 residential places were funded from the disability budget in December 2020), the 2020 data suggests that at least 1,000 residential places are required now or within the next five years, an increase of 13% on the current level of provision (Table 2.10). Almost nine out of ten (89%) of the residential placements required are for those who reported an intellectual disability as their primary disability.



**Residential
places**

7,601
**Currently
accessed**

1,366
**Enhancement
required**

1,000
**New places
required**

Table 2.10 Residential services; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020

Residential service	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	36,649	100		
Community group home (5-9 residents)	3,035	8.3	535	9
House in community (1-4 residents)	2,419	6.6	381	877
Residential centre/on campus (10+ residents)	1,452	4.0	382	0
Specialist facility – challenging behaviour¥	303	0.8	47	17
Nursing home	199	0.5	0	19
Psychiatric hospital	86	0.2	~	0
Specialist facility – neurological	34	0.1	12	21
Home sharing – shared living family	33	0.1	~	37
Specialist facility – mental health co-morbidity	28	0.1	~	5
Specialist facility – physical	8	0.0	~	~
Specialist facility – dementia	~	~	~	8
Other hospital	~	~	0	0
Hospice	0	0.0	0	~
Total	7,601		1,366	1,000

¥ This includes intensive placements for challenging behaviour as previously recorded on the National Intellectual Disability Database (NIDD).

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

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

Day Services

Although the remit for NASS is to capture HSE disability-funded services nationally, the data also include services which are funded by the Department of Education, Tusla and the Department of Employment Affairs and Social Protection. This is to facilitate the HSE and service providers in planning for those service users navigating key transition points such as those transitioning from primary to secondary level education and school leavers. Day services cover a broad range of activities including day programmes, rehabilitative training, supported employment and education.

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 model⁷ 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 23,194 (63%) service users accessed at least one day service in 2020 accounting for 24,644 day service places (service users can attend more than one day service) (Table 2.11). The most frequently accessed day service reported on NASS was a day programme (14,036, 38% of the total NASS population). Of these day programmes, 2,553 enhancements were required to the existing service. Day programmes also had the highest proportion of unmet need of all day services with 532 new day programme places required now or within the next five years.

In the 2020 data collection period, the level of support was recorded for 18,126 (78%) of service users who received a day service and was as follows:

- 4,298 (24%) had a staff to service user ratio of between 1-to-6 and 1-to-9.
- 4,181 (23%) had a staff to service user ratio of between 1-to-4 and 1-to-5.
- 2,768 (15%) had a staff to service user ratio of 1-to-1.
- 2,214 (12%) had a staff to service user ratio of 1-to-2.
- 2,182 (12%) had a staff to service user ratio of 1-to-3.
- 2,112 (12%) had a staff to service user ratio of 1-to-10+.
- 371 (2%) had a staff to service user ratio of greater than 1-to-1.

⁷ 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 2.11 Day services; 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	36,649	100		
Day programme [†]	14,036	38.3	2,553	532
Supported employment	1,413	3.9	171	167
Rehabilitative training	1,471	4.0	192	80
Neuro-rehabilitative training	60	0.2	10	6
Mainstream early childhood education and care	319	0.9	15	70
Special early childhood education and care	408	1.1	57	26
Mainstream primary/secondary school	2,398	6.5	132	133
Special primary/secondary school	3,142	8.6	330	60
Special class/unit in mainstream primary/secondary school	986	2.7	232	83
Home tutor	80	0.2	5	~
Vocational training	198	0.5	15	39
Third level education	133	0.4	8	14
Total	24,644		3,720	1,214

† 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.



26,644
Currently accessed

3,720
Enhancement required

1,214
New places required

Tables 2.12 and 2.13 present a breakdown of day services by age - under 18 years old and over 18 years old, respectively.

Table 2.12 shows that most services accessed in 2020 by those aged under 18 years old were educational services (6,879, 55%). 712 enhancements were required to existing educational services, with the majority of enhancements (301) required in special primary/secondary school settings. Of those service users aged under 18 years old, 483 individuals had an unmet need for a total of 521 day service places. Of these, the highest proportion of unmet need was for educational places (383), in particular, places in a mainstream primary/secondary school (133).

 **12,571** under 18 years old



6,963
Currently accessed

714
Enhancement required

521
New places required

Table 2.12 Day services for service users aged under 18 years; 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	12,571	100		
Day programme	84	0.7	~	99
Supported employment	0	0.0	0	~
Rehabilitative training	0	0.0	~	37
Mainstream early childhood education and care	319	2.5	15	70
Special early childhood education and care	408	3.2	57	26
Mainstream primary/secondary school	2,272	18.1	116	133
Special primary/secondary school	2,843	22.6	301	60
Special class/unit in mainstream primary/secondary school	924	7.4	218	83
Home tutor	80	0.6	5	~
Vocational training	32	0.3	0	7
Third level education	~	~	0	~
Total	6,963		714	521

~ 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.

Table 2.13 shows that a day programme was the most frequently accessed day service by those aged 18 years and over (13,952, 58%), and 2,552 enhancements were required to existing day programmes in this cohort. Of those service users aged 18 years and over, 675 individuals had an unmet need for a total of 693 day service places. Of these, the highest proportion of unmet need was for a day programme placement (433).

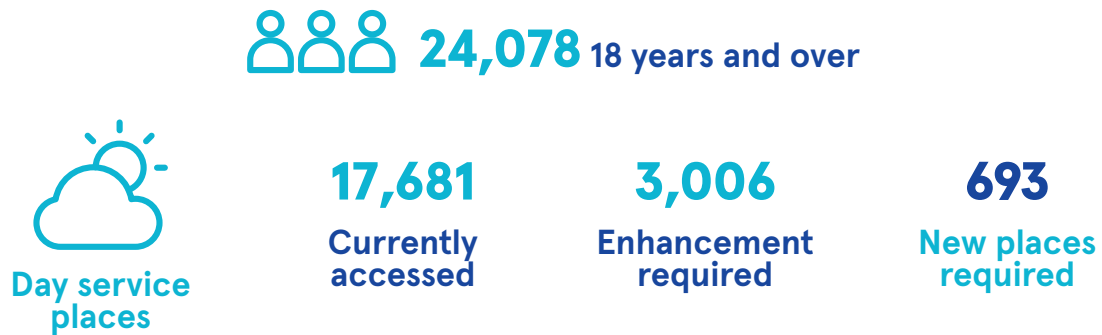
Table 2.13 Day services for service users aged 18 years and over; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	24,078	100		
Day programme [†]	13,952	57.9	2,552	433
Supported employment	1,413	5.9	171	165
Rehabilitative training	1,471	6.1	191	43
Neuro-rehabilitative training	60	0.3	10	6
Mainstream primary/secondary school	126	0.5	16	0
Special primary/secondary school	299	1.2	29	0
Special class/unit in mainstream primary/secondary school	62	0.3	14	0
Home tutor	0	0.0	0	~
Vocational training	166	0.7	15	32
Third level education	132	0.5	8	13
Total	17,681		3,006	693

† 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.



Of all those accessing day services, and where information was available (22,942):

- 17,447 (76%) accessed their day service five days per week.
 - Of these service users accessing their day service five days per week, 6,063 were aged 18 years and under and 11,384 were aged 18 years and over.
- 1,301 (6%) service users accessed their day service three days per week.
 - Of these service users, 154 were aged 18 years and under and 1,147 were aged 18 years and over.
- 969 (4%) service users accessed their day service two days per week.
 - Of these service users, 111 were aged 18 years and under and 858 were aged 18 years and over.

Respite services

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

Day respite consists of short-term care in the local community. It may also be provided in the service user's own home for a number of hours, a centre-based facility or a contract or host family arrangement.

Overall, 210 people (<1%) accessed 217 disability-funded day respite services in 2020. In total, 2,420 days of respite were received. The most commonly reported service was centre-based respite (177, <1%). The level of support was recorded for 96 day respite services, with 58 (60%) receiving between 1 to 4 and 1 to 5 support and 9 (9%) receiving 1 to 1 support. A total of 120 day respite services were recorded as required now or within the next five years, 77 of which are centre-based respite places.

Overnight Respite

Overnight respite consists of temporary residential care in the local community. Overnight respite care may involve providing alternative family or residential care for a person with a disability in order to enable the carer to take a short break, a holiday or a rest. It can cover short-term respite such as a weekend, or a longer arrangement, for example, to cover a holiday or a hospital stay for the primary carer.

There were 1,742 people (5%) registered on NASS accessing 1,771 disability-funded overnight respite services. The most availed of overnight respite service was in a house in the community/centre-based (1,590, 4%) (Table 2.14).

Of those accessing overnight respite services and where information on support was available (1,218):

- 727 (60%) had 24/7 staff and awake cover at night
- 308 (25%) had 24/7 staff and sleepover cover at night
- 97 (8%) had 1-to-1 support
- 50 (4%) had less than 24/7 staff and sleepover cover at night
- 25 (2%) had greater than 1-to-1 support
- 11 (1%) had less than 24/7 staff support.

In 2020, 30,094 nights of respite were recorded on NASS with the majority recorded as house in the community/centre-based respite (26,278 nights), an average of 16.5 nights per person. 597 current overnight respite service recipients require an enhancement. Of these, 567 got overnight respite services received in a house in the community/centre-based.

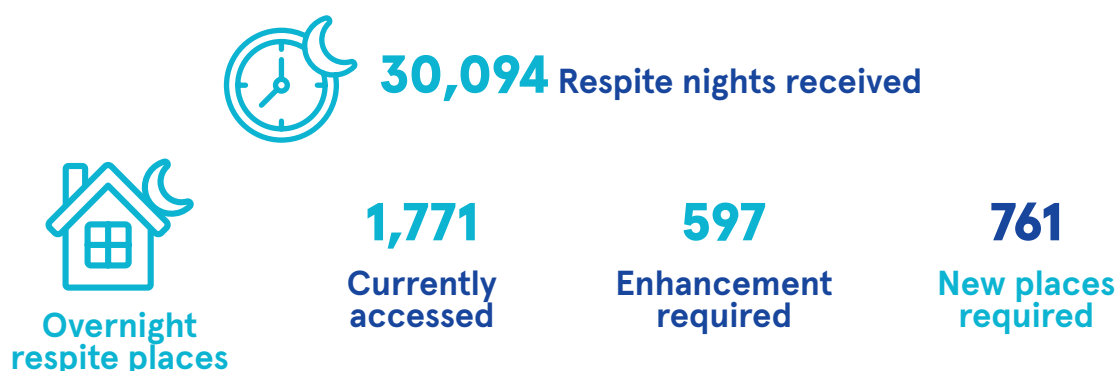
761 overnight respite places are required in the next 5 years, the majority of which are for house in the community/centre-based respite (512 places) (Table 2.14).

Table 2.14 Overnight respite; number of nights accessed, places currently being accessed, enhancement required to current places and unmet need for places, 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		36,649	100		
House in the community/centre-based respite	26,278	1,590	4.3	567	512
Holiday respite (residential/centre-based/summer camp)	1,033	103	0.3	25	85
Home sharing short breaks family	1,809	52	0.1	0	21
Holiday Respite (hotel/B&B/hostel)	244	15	0.0	~	108
Own home respite	660	7	0.0	0	15
Home sharing contract family	54	~	~	~	15
Nursing home respite	16	~	~	~	5
Total	30,094	1,771		597	761

~ 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

Supports for daily living are services and supports that enable a person with a disability to live more independently and participate more effectively in the community.

In total, 6,235 (17%) of service users registered on NASS were in receipt of at least one support for daily living in 2020. A total of 7,471 supports for daily living were accessed in the data collection period.

The most frequently accessed supports for daily living were home support (2,584, 7%) and community support (2,183, 6%) (Table 2.15).

Overall, 4,181 (56%) of supports for daily living places were accessed by service users whose primary disability was intellectual, 2,291 (31%) were accessed by those who had a physical and/or sensory disability and 893 (12%) were accessed by those who had autism.

The majority of supports for daily living places were accessed by those aged 50 years or over (2,593, 35%), 2,158 (29%) were accessed by those aged 30-49 years, 1,384 (19%) were accessed by those aged 18-29 years and 1,336 (18%) services were accessed by those aged less than 18 years.

A total of 800 support for daily living places are required now or within the next five years, of which home support is the most commonly required (251 places). This represents a 10% increase in home support places.



7,471
Currently accessed

1,095
Enhancement required

800
New places required

Table 2.16 shows supports for daily living by service users aged less than 18 years and those 18 years and over.

Table 2.15 Supports for daily living; 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	36,649	100		
Home support	2,584	7.1	397	251
Community support	2,183	6.0	240	142
Personal assistant	923	2.5	188	99
Transport services	917	2.5	139	129
Peer support	396	1.1	50	62
Advocacy services	367	1.0	56	73
Voluntary work	90	0.2	25	34
Guide dog/Assistance dog	11	0.0	0	10
Total	7,471		1,095	800

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

Table 2.16 Supports for daily living; places currently being accessed, enhancement required to current places and unmet need for places broken down by under 18 and 18 years and over, NASS 2020

	Places currently being accessed				Enhancements required to current places		Unmet need for places	
	Under 18 years		18 years and over		Under 18 years	18 years and over	Under 18 years	18 years and over
	n	%	n	%	n	n	n	n
Total population	12,571	100	24,078	100				
Home support	530	4.2	2,054	8.5	102	295	29	222
Community support	597	4.7	1,586	6.6	24	216	13	129
Personal assistant	69	0.5	854	3.5	~	184	8	91
Transport services	125	1.0	792	3.3	11	128	46	83
Peer support	7	0.1	389	1.6	~	49	25	37
Advocacy services	0	0.0	367	1.5	0	56	0	73
Voluntary work	~	~	89	0.4	0	25	0	34
Guide dog/Assistance dog	7	0.1	~	~	0	0	5	5
Total	1,336		6,315		142	953	126	674

~ 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

Specialist support services including multidisciplinary therapies are those which aim to develop or restore a person’s capabilities and provide support to a person. Specialist support services are provided by a trained professional and are delivered via the HSE. These services include health services in addition to assessment, rehabilitation, and community care.

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 teams’ 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.

Two-thirds of service users (66%, 24,309) registered on NASS availed of one or more specialist support services in 2020. Of these 24,309 service users, 41% (9,899) availed of one specialist support service, 20% (4,930) availed of two specialist support services and 14% (3,509) availed of three specialist support services.

In total, 61,039 specialist support services were availed of in 2020 (Table 2.17). The most received specialist support services were speech and language therapy (8,531, 23%), occupational therapy (8,108, 22%), social work (7,467, 20%), physiotherapy (7,298, 20%) and nursing (5,780, 16%). Additionally, 2,981 service users require at least one specialist support service now or within the next five years that they are not currently receiving. This equates to 4,886 requirements for specialist supports of which occupational therapy (836 places), speech and language therapy (787 places) and clinical psychology (728 places) are the most required services.



Table 2.17 Specialist supports; 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	36,649	100		
Speech and language therapy	8,531	23.3	3,486	787
Occupational therapy	8,108	22.1	3,011	836
Social work	7,467	20.4	3,042	415
Physiotherapy	7,298	19.9	2,270	535
Nursing	5,780	15.8	2,147	75
Key worker	4,792	13.1	816	54
Psychiatry	4,025	11.0	1,586	53
Case manager	3,005	8.2	92	21
Clinical psychology	2,450	6.7	557	728
Dietetic services	2,294	6.3	991	167
Behaviour therapy	801	2.2	138	178
Chiropody	790	2.2	126	142
Dentistry/orthodontic	749	2.0	190	61
Children's Disability Network Team (CDNT)	723	2.0	560	26
Vision rehabilitation	697	1.9	107	45
Special Needs Assistant (SNA)	651	1.8	89	85
Assistive technology/client technical service	571	1.6	101	100
Orthotics/prosthetics	444	1.2	83	27
Educational psychology	401	1.1	113	205

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Complementary therapy	306	0.8	40	67
Resource teacher	286	0.8	32	20
Counselling psychology	172	0.5	33	69
Creative therapy	153	0.4	24	53
Neurorehabilitation	146	0.4	7	10
Neuropsychology	127	0.3	9	37
Vision communication-IT/AT and alternative formats	107	0.3	34	24
Aural rehabilitation services	50	0.1	6	~
Palliative care	45	0.1	5	~
Play therapy	39	0.1	16	47
Aural communication-IT/AT and alternative format services	23	0.1	11	~
Animal assisted therapy	8	0.0	~	12
Total	61,039		19,724	4,886

~ 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 (5,117, 41%), occupational therapy (4,310, 34%) and physiotherapy (3,351, 27%). The specialist supports most availed of by those service users aged 18 years and over were social work (4,850, 20%), nursing (4,494, 19%) and physiotherapy (3,947, 16%). 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.

Most commonly accessed specialist supports for those aged under 18 years old



Speech and language therapy

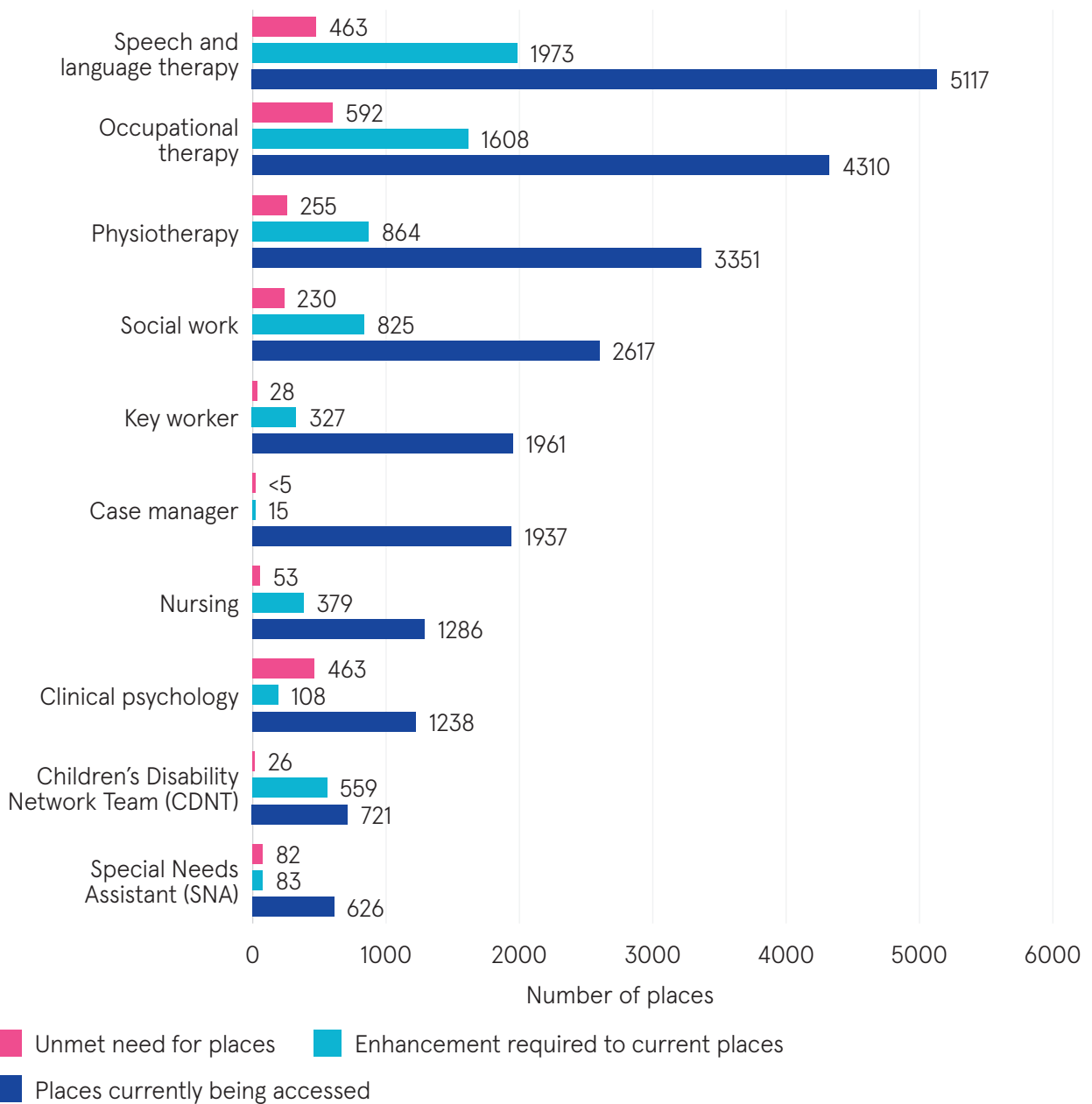


Occupational therapy



Physiotherapy

Figure 2.4 Specialist supports for those aged under 18 years old; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020



Most commonly accessed specialist supports for those aged 18 years old and over



Social work

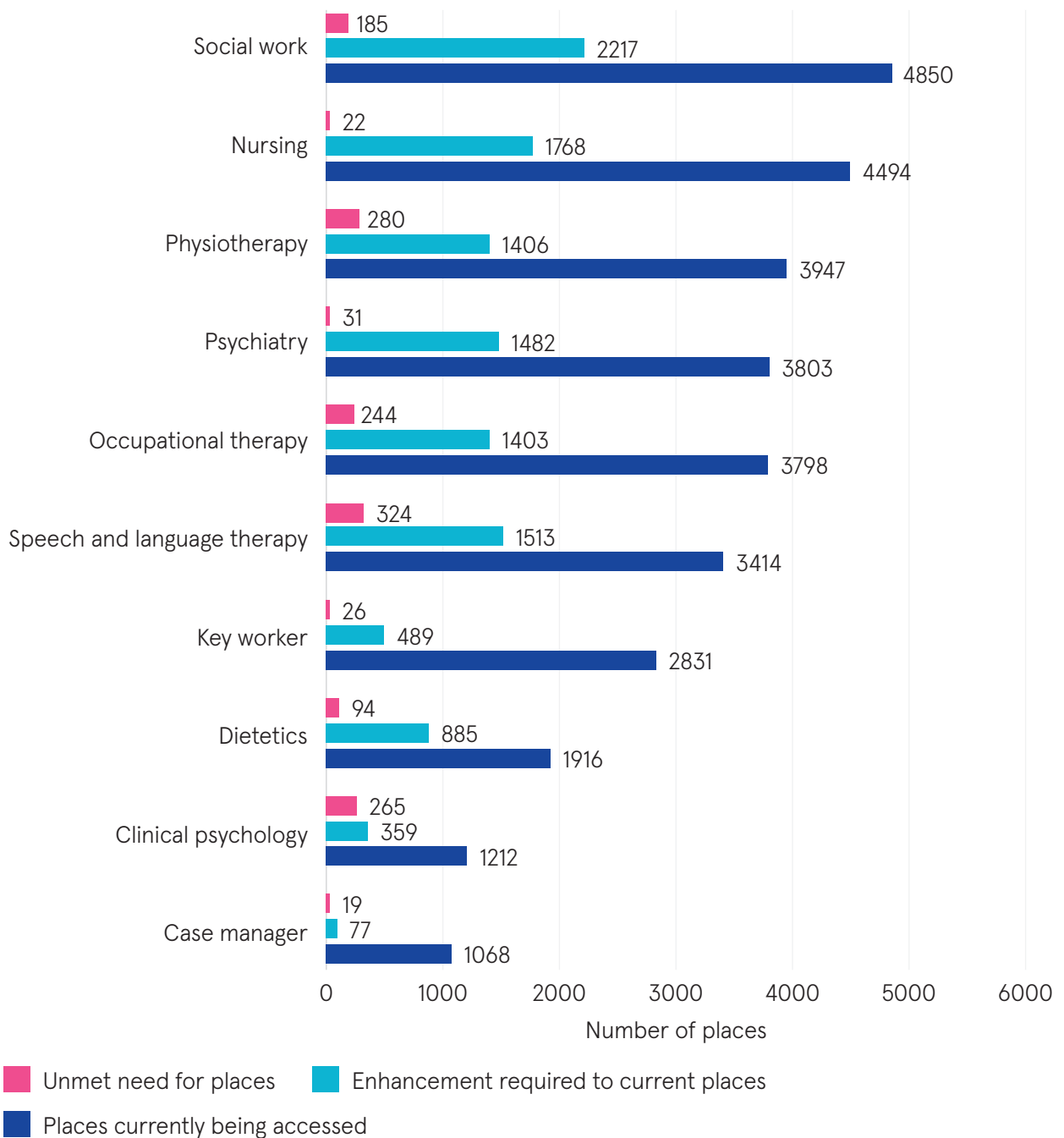


Nursing



Physiotherapy

Figure 2.5 Specialist supports for those aged 18 years old and over; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020



2.6 Assistive products

Assistive products refer to products that a person uses to support living with their disability. They include devices, equipment, instruments and software, especially produced or generally available, used by or for persons with a disability:

- for participation
- to protect, support, train, measure or substitute for body functions/structures and activities; or
- to prevent impairments, activity limitations or participation restrictions.

NASS uses the National Standards Authority of Ireland (NSAI) assistive products for persons with disability – classification and terminology (ISO 9999:2016). Only assistive products that are HSE disability-funded are recorded on NASS. In addition, people may receive assistive technology via primary care, or may purchase it privately.

Assistive products were used by 2,575 (7%) people registered on NASS and 5,655 assistive products were used by these service users. Table 2.18 shows the breakdown of currently accessed assistive product classes and those that are required.

The most commonly used product groups and products were:

- Assistive products for activities and participation relating to personal mobility and transportation (2,191). Of these, manual wheelchairs (633) and powered wheelchairs (367) were the most commonly used products.
- Assistive products for communication and information management (1,076). Of these, assistive products for seeing (459) and assistive products for hearing (216) were the most commonly used.
- Furnishings and adaptations to homes (916). Of these, beds and bed equipment (331) and seating (221) were the most commonly used.

The most commonly used assistive product groups and products were:



Assistive products for activities and participation



Assistive products for communication and information management



Furnishings and adaptations to homes

Overall, 1,231 service users had an unmet need for at least one assistive product, and 2,177 assistive products were reported as being required now or within the next five years. The most frequently required assistive product groups and products were:

- Furnishings and adaptations to homes (770). Of these, supporting handrails and grab rails (317) and seating (205) were the most commonly required.
- Assistive products for communication and information management (420). Of these, assistive products for seeing (153) and computers (116) were the most commonly required.
- Assistive products for personal mobility and transportation (361). Of these, assistive products for walking (using both arms) for example, walking sticks, crutches, rollators or frames (167); and powered wheelchairs (62) were the most commonly required.

Table 2.18 Assistive product classes; currently being accessed and unmet need for assistive products, NASS 2020

	Assistive products currently accessed		Unmet need for assistive products
	n	%	n
Total population	36,649	100	
Assistive products for activities and participation relating to personal mobility and transportation	2,191	6.0	361
Assistive products for communication and information management	1,076	2.9	420
Furnishings, fixtures, and other assistive products for supporting activities in indoor and outdoor human-made environments	916	2.5	770
Assistive products for self-care activities and participation in self-care	728	2.0	168
Assistive products for supporting neuromusculoskeletal or movement-related functions (orthoses) and replacing anatomical functions	276	0.8	157

	Assistive products currently accessed		Unmet need for assistive products
	n	%	n
Assistive products for measuring, supporting, training or replacing body functions	189	0.5	153
Assistive products for education and for training in skills	173	0.5	94
Assistive products for domestic activities and participation in domestic life	63	0.2	20
Assistive products for controlling, carrying, moving and handling objects and devices	30	0.1	30
Assistive products for work activities and participation in employment	7	0.0	0
Leisure/recreation	~	~	~
Assistive products for controlling, adapting or measuring elements of physical environments	~	~	0
Total number of assistive products	5,655		2,177

~ 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 have more than one assistive product.

2.7 World Health Organisation Disability Assessment Schedule V2.0 (WHODAS 2.0)

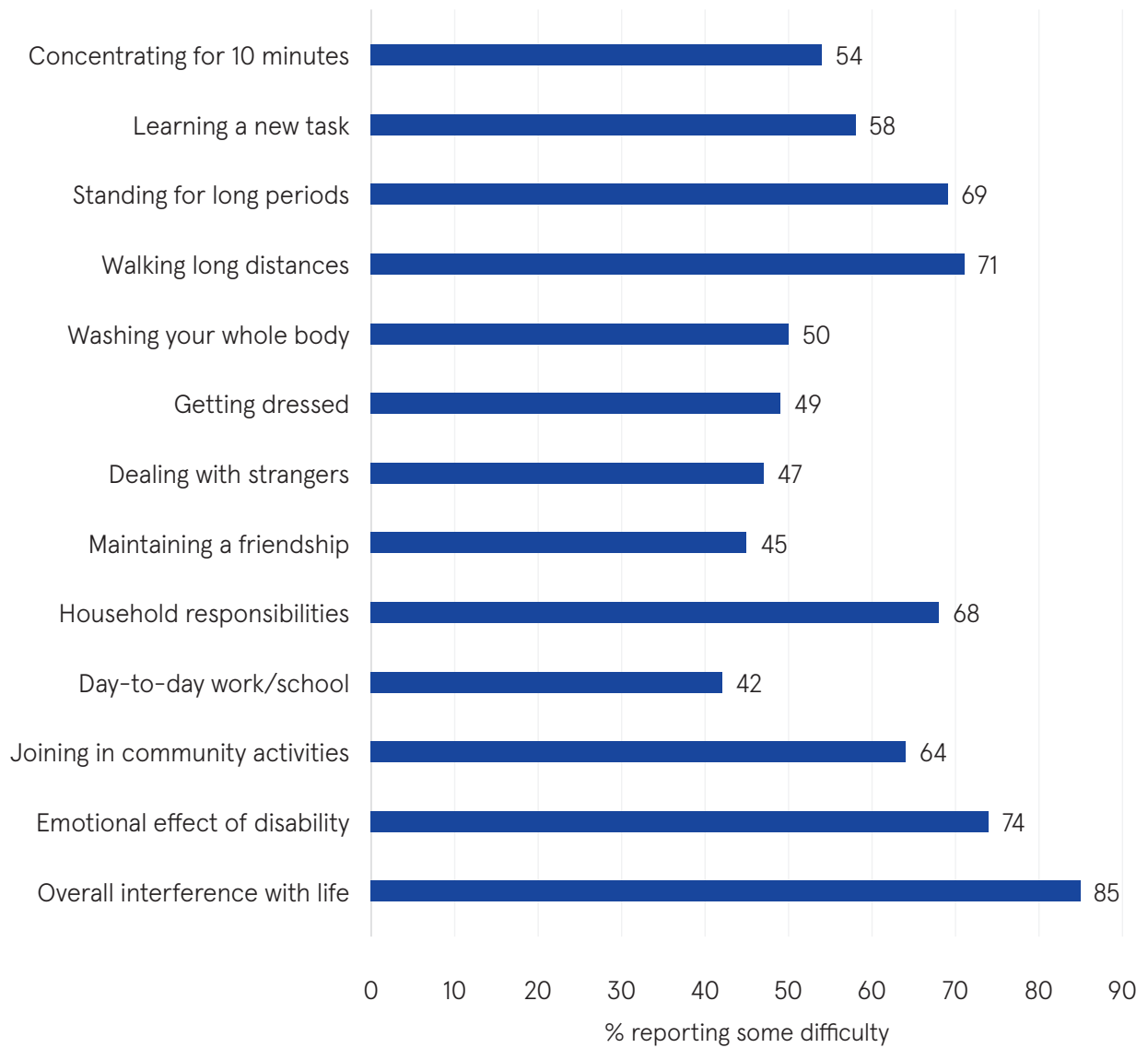
The WHODAS 2.0 captures information on the extent of difficulty an individual has with functioning in daily activities in the previous thirty days that is due to their disability. The extent of difficulty can be recorded as mild, moderate, severe, extreme/cannot do. The data presented below groups these four categories into one category of 'some' difficulty. The WHODAS questions are not completed by those aged under 16 years or those whose primary disability type is intellectual.

The percentages presented are based on those who completed WHODAS (4,821 people out of 7,043 eligible). The majority of those who completed WHODAS had a neurological condition (2,578, 54%), followed by those with autism (913, 19%) and a physical disability (666, 14%). In 1,917 (40%) cases the answers were provided by the service user and the remainder were provided by a proxy.

As shown in Figure 2.6, the areas of greatest difficulty were the emotional effects of disability (3,560, 74%), walking long distances (3,407, 71%), standing for long periods (3,349, 69%) and household responsibilities (3,297, 68%). For the majority (4,088, 85%), difficulties due to their disability resulted in an overall interference with their life.



Figure 2.6 WHODAS 2.0 – World Health Organisation Disability Assessment Schedule, NASS 2020



3 Summary

This report is based on information collected from 36,649 service users registered on NASS at the end of December 2020. It represents the recorded service use and needs of people accessing HSE disability-funded services in 2020.

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 current 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 accurately assessed.

Despite Covid-19 and its ongoing challenges, more service providers were recruited to update their records on NASS in 2020 compared to 2019. This can particularly be seen among the number of the physical and sensory service providers now updating data on NASS, and this is clearly reflected in the total number of service users and proportion of disability types now captured on NASS.

In 2019, service data was reported for 22,434 service users. In 2020, this increased to 36,649 service users – an increase of over 14,000 records. NASS now reports on a similar number of service users as were reported on from the NIDD and NPSDD combined. However, this number is less than the expected full capture of disability service users, and efforts will continue to increase the number of service users registered in the next data collection period.

The proportion of service users with an intellectual disability registered on NASS has decreased since 2019. While the number of service users with an intellectual disability is lower than in the 2017 NIDD report⁸, it is positive that there are higher numbers of people with physical/sensory disabilities being recorded, and that NASS has expanded to record people with a primary disability of autism. The number of service users registered on NASS with a primary disability of physical has increased from 665 in 2019 (3% of total number registered) to 2,726 in 2020 (7% of total number registered). This is a direct consequence of an increase in those service providers providing services to people with physical disabilities updating the records of their service users on NASS. It is encouraging to see this progress reflected in the data.

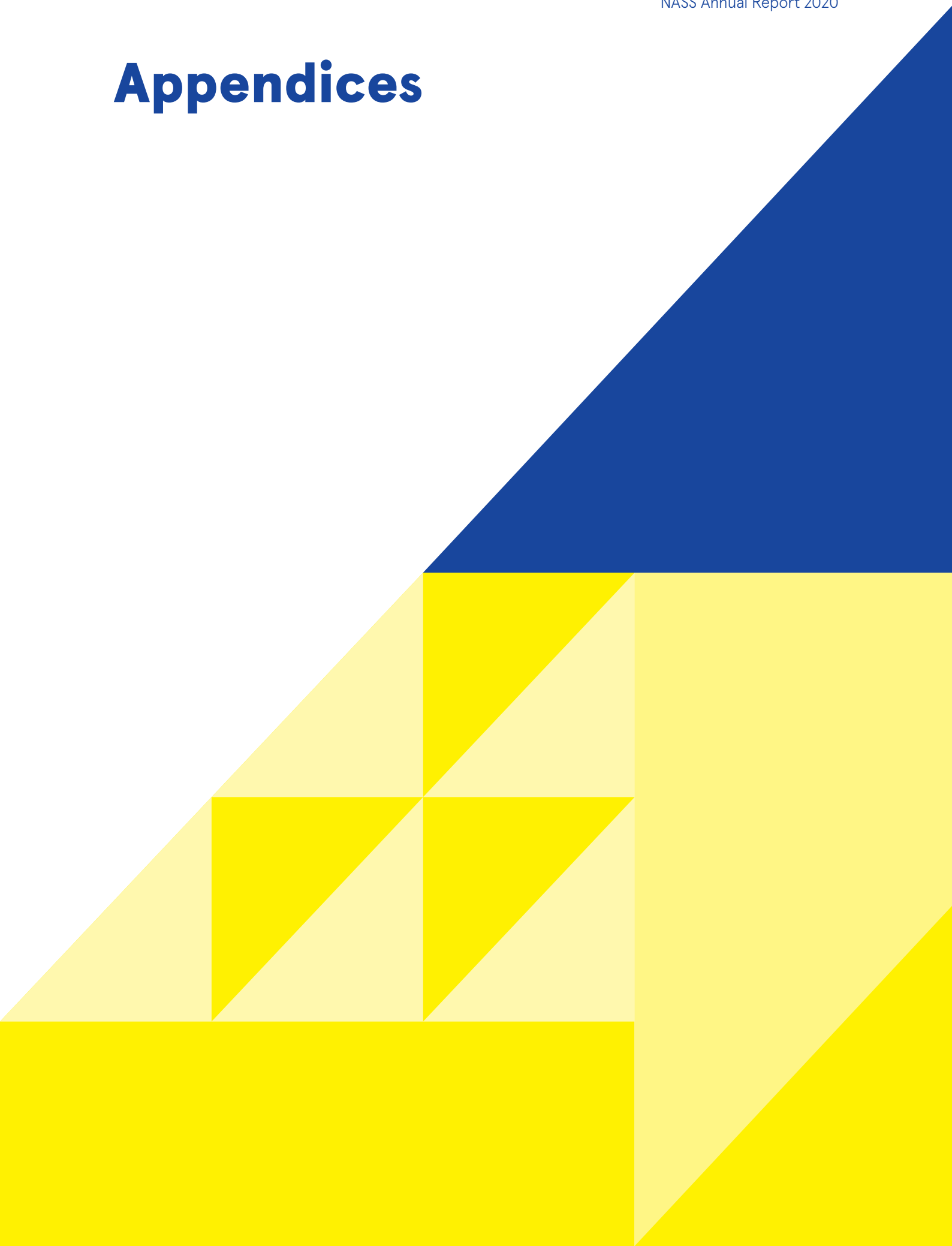
⁸ Hourigan, S., Fanagan, S., & Kelly, C. (2018). Annual Report of the National Intellectual Disability Database Committee 2017: Main Findings. Dublin: Health Research Board.

The number of people recorded as accessing residential services has increased from 5,297 in 2019 to 7,535 in 2020. Although it is still below the HSE estimate of 8,139 residential places funded from the HSE disability budget in December 2020, this represents a marked improvement. A community group home was the most frequently accessed residential setting followed by a house in the community. The greatest unmet need for residential services was for a house in the community. This is in line with the HSE report, *Time to Move On from Congregated Settings* (2011)⁹ which recommends that traditional types of residential settings should be phased out, such as residential settings with 10 or more residents and service users are facilitated to move to settings with a maximum of 4 people. Service providers have been working to implement the policy with service users but due to constraints in the availability of suitable accommodation and supports, progress has been slow. In future reports, the number of service users in houses in the community is expected to increase, as the number of residents in community group homes and residential centres on campus decreases.

Separate supplementary reports have been developed for those recorded on NASS with an intellectual disability, 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.

⁹ *Time to Move On from Congregated Settings*. Report of the Working Group On Congregated Settings. Health Service Executive, 2011.

Appendices



Appendix A

Table A Demographic information: NIDD 2017; NPSDD 2017; NASS 2019 and NASS 2020

	NIDD ¹⁰ 2017		NPSDD ¹¹ 2017		NASS ¹² 2019		NASS 2020	
	n	%	n	%	n	%	n	%
Number registered	28,388	100	9,956	100	22,434	100	36,649	100
CHO*								
CHO 1	2,582	9.1	1,314	13.2	2,873	12.8	4,630	12.6
CHO 2	3,277	11.5	2,259	22.7	2,772	12.4	5,091	13.9
CHO 3	2,390	8.4	1,081	10.9	915	4.1	2,269	6.2
CHO 4	4,148	14.6	207	2.1	3,765	16.8	4,676	12.8
CHO 5	3,527	12.4	753	7.6	1,488	6.6	3,179	8.7
CHO 6	1,473	5.2	268	2.7	1,629	7.3	1,930	5.3
CHO 7	3,770	13.3	709	7.1	3,056	13.6	5,269	14.4
CHO 8	3,855	13.6	2,359	23.7	2,536	11.3	3,803	10.4
CHO 9	3,366	11.9	1,006	10.1	3,400	15.2	5,800	15.8
Sex								
Male	16,768	59.1	4,984	50.1	12,857	57.3	21,694	59.2
Female	11,620	40.9	4,972	49.9	9,577	42.7	14,955	40.8
Age								
0-4	768	2.7	184	1.8	1,006	4.5	2,639	7.2
5-12	4,738	16.7	1,757	17.6	3,274	14.6	6,439	17.6
13-17	3,303	11.6	1,045	10.5	2,172	9.7	3,493	9.5
18-24	3,819	13.5	879	8.8	2,742	12.2	4,365	11.9
25-39	5,826	20.5	1,395	14.0	4,395	19.6	6,156	16.8
40-59	7,174	25.3	3,292	33.1	6,150	27.4	9,065	24.7
60+	2,760	9.7	1,404	14.1	2,695	12.0	4,492	12.3

*NIDD 2017 and NASS 2019 and 2020 CHO data is based on CHO of service.
NPSDD 2017 CHO data is based on CHO of residence.

¹⁰ Hourigan, S., Fanagan, S., & Kelly, C. (2018). Annual Report of the National Intellectual Disability Database Committee 2017: Main Findings. Dublin: Health Research Board.

¹¹ Doyle, A., Carew, AM. (2018). Annual Report of the National Physical and Sensory Disability Database Committee 2017: Main Findings. Dublin: Health Research Board.

¹² Casey, C., O'Sullivan, M., Fanagan S., Doyle A. (2019). HRB Bulletin, National Ability Supports System. Dublin: Health Research Board.

Appendix B

Table B Summary service information: NIDD 2017; NPSDD 2017*; NASS 2019 and NASS 2020

	NIDD 2017		NPSDD 2017*		NASS 2019		NASS 2020	
	n	%	n	%	n	%	n	%
Number registered	28,388	100	5,654	100	22,434	100	36,649	100
Services								
Residential	7,530	26.5	172	3.0	5,297	23.6	7,535	20.6
Day services	27,793	97.9	3,276	57.9	16,805	74.9	23,194	63.3
Day respite	654	2.3	Not available	Not available	516	2.3	210	0.6
Overnight respite	4,104	14.4	443	7.8	2,834	12.6	1,742	4.8
Supports for daily living	Not available	Not available	1,520	26.9	3,892	17.3	6,235	17.0
Specialist supports	23,583	83.1	4,986	88.2	15,270	68.0	24,309	66.3

* Service information only available from NPSDD on records reviewed in 2017.



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