

HRB StatLink Series 4

**NASS Autism
Supplementary
Report 2020**

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Acknowledgements.....	iv
Overview	1
1. Introduction	2
1.1 Background.....	2
1.2 Data collection.....	2
1.3 Limitations of the data	3
1.4 Publications and analysis.....	4
2 Service users with autism.....	5
2.1 Numbers registered.....	6
2.2 Demographic profile.....	7
2.3 Disability and diagnosis	13
2.4 Primary Carer.....	15
2.5 Services.....	16
2.6 Assistive products.....	27
2.7 World Health Organization Disability Assessment Schedule V.2 (WHODAS 2.0).....	28
3 Summary.....	29

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- 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 for service users with a primary disability of autism 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.

There were 5,753 people with autism registered on NASS in 2020. Of these, 3,804 had a primary disability of autism and 1,949 had autism recorded as a secondary disability. This supplementary report is based on the 3,804 people whose primary disability type is autism. This group represents one tenth of the NASS records that were reviewed in 2020 but this proportion is expected to increase considerably as the system becomes more established and new registrations continue to be added.

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 of this supplementary report are:

- Three quarters (75%) of those with a primary disability of autism were under the age of 18.
- Four times as many males have autism (79%) recorded as a primary disability compared with females (21%), and this gender disparity is more pronounced in younger ages.
- Intellectual disability was the most reported additional disability for those with autism followed by speech and/or language.
- Most service users with autism had a primary carer, almost all (99%) of whom were parents.
- In 2020, 5% of those recorded on NASS with autism as their primary disability were in receipt of a residential service; 56% accessed at least one day¹ service; 2% accessed overnight respite services; 23% were in receipt of at least one support for daily living and 63% accessed at least one specialist support.

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 autism and is based on validated data extracted from the system at the end of December 2020.

Those with a primary disability of autism represent one tenth of the total number of service users included in the annual report but this proportion is expected to continue to increase as the system becomes more established. This is the first time that a full year of data is available for those with a primary disability of autism.

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 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, 3,804 service user records with autism are included in this report. This is an increase of 108% from the 1,831 records reviewed in 2019³. Newly registered records increased by 256% accounting for the majority of the overall increase.

It is estimated that all records reviewed on NASS in 2020 reflect approximately 65% of those currently in receipt of services. It is not currently possible to estimate what proportion of remaining individuals would come under the scope of future supplementary reports on autism.

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 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

³ Health Research Board (2020). National Ability Supports System (NASS) 2019. Supplementary Bulletin – Autism Spectrum Disorder (ASD). Dublin: Health Research Board.

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, some of the restrictions for data entry were eased 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.

1.4 Publications and analysis

This report represents an overview of available data from NASS on service users with a primary disability of autism.

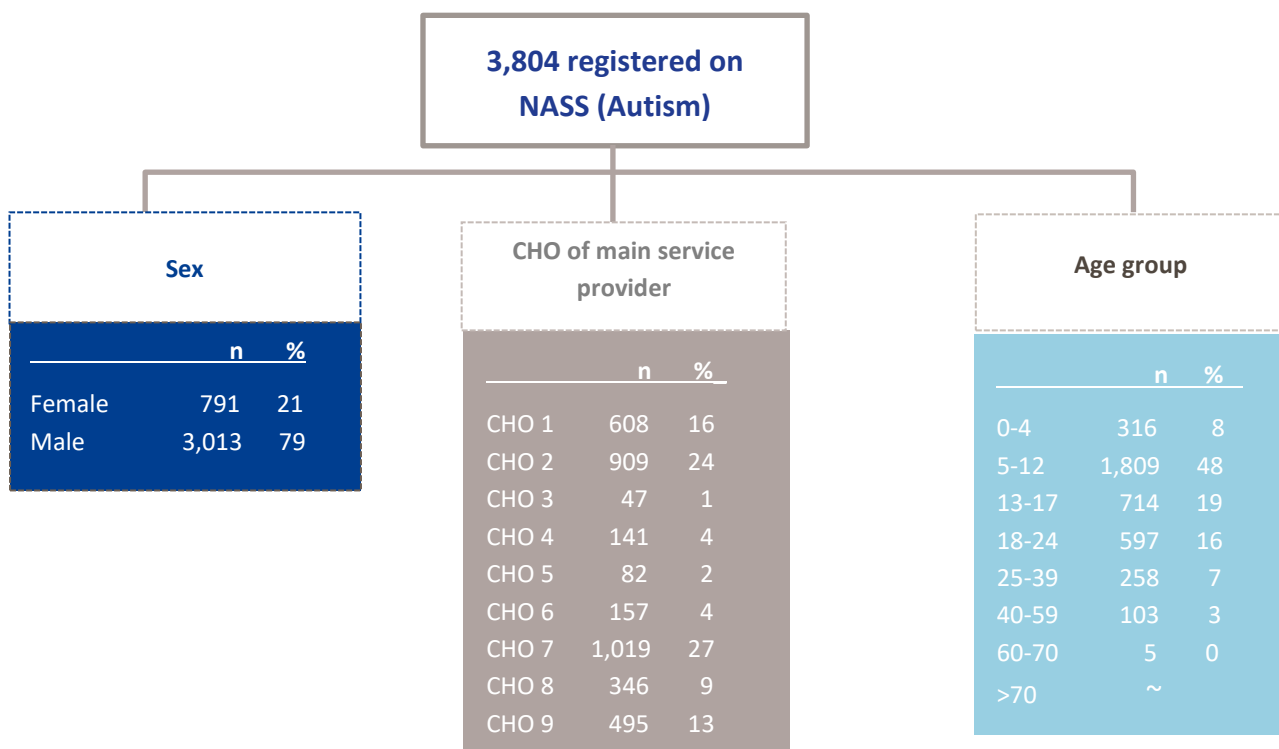
An annual report and additional supplementary reports presenting information by other disability types (intellectual and physical or sensory) and by CHO are also available on the Health Research Board (HRB) website <https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/publications/>.

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 autism

A total of 3,804 service users are included in this report. A summary profile of the people registered on NASS with autism as their primary disability by sex, age group and CHO area⁴ of registration is shown in Figure 2.1 below. An additional 1,949 recorded autism as a secondary disability and these are reported on the intellectual⁵ (1,876 service users) and physical and sensory⁶ supplements to the annual report.

Figure 2.1 Number of people with autism as primary disability type registered on NASS in 2020 (3,804), NASS 2020



⁴ 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

⁵ Casey, C., O’Sullivan, M., Fanagan, S. & Flanagan N. (2021). NASS Intellectual Disability Supplementary Report 2020. HRB Statlink Series 2. Dublin: Health Research Board.

⁶ Flanagan N., O’Sullivan, M., Fanagan, S. & Casey, C. (2021). NASS Physical and Sensory Disability Supplementary Report 2020. HRB Statlink Series 3. Dublin: Health Research Board.

2.1 Numbers registered

Table 2.1 shows the registration of service users on NASS by CHO. Overall, CHO 7 had the most service users registered (1,019, 27%), followed by CHO 2 with 909 service users (24%).

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

	n	%
Total population	3,804	100
CHO 1	608	16.0
CHO 2	909	23.9
CHO 3	47	1.2
CHO 4	141	3.7
CHO 5	82	2.2
CHO 6	157	4.1
CHO 7	1,019	26.8
CHO 8	346	9.1
CHO 9	495	13.0

2.2 Demographic profile

More males (3,013, 79%) than females (791, 21%) were registered on NASS. During the 2020 data collection period, 3,086 (81%) of those registered were aged under 19 years, four fifths (79%) of whom were male.

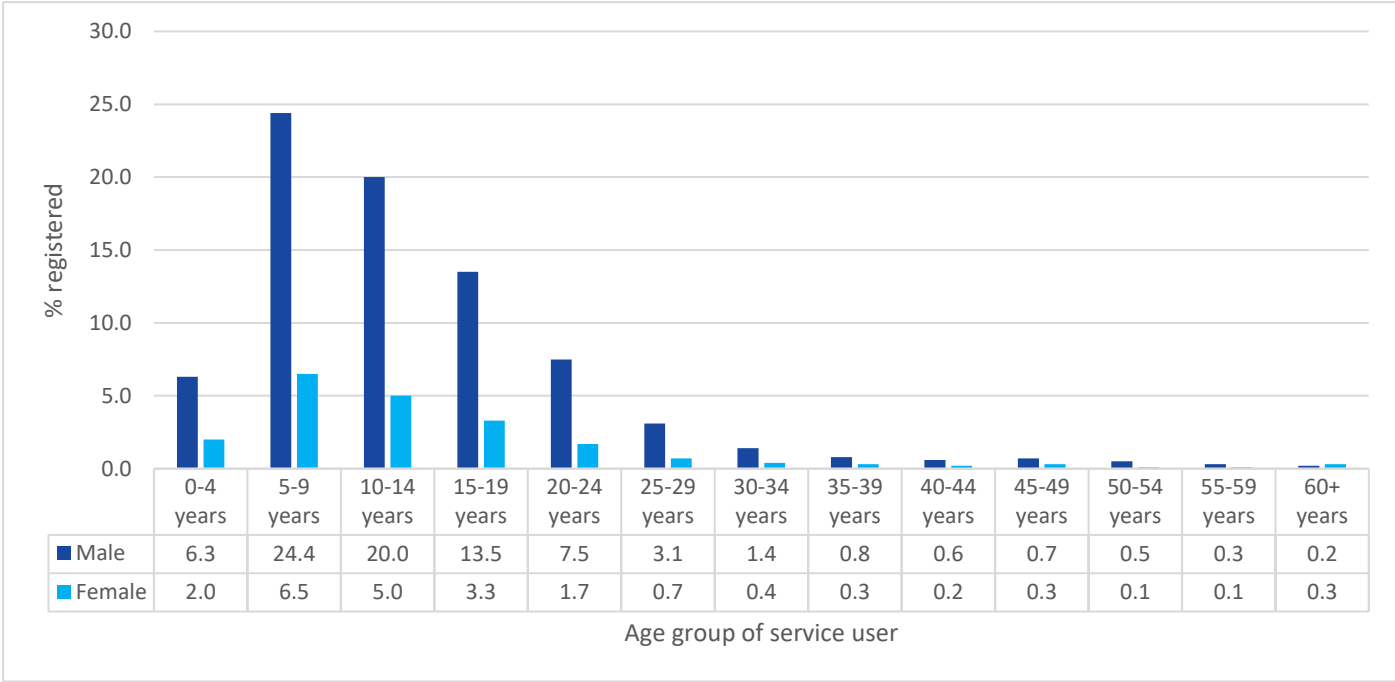
Table 2.2 and Figure 2.1 show that for both sexes, those in the 5-9 year age group were the most represented (1,179, 31%).

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

	Male	Female	Total
0-4 years	239	77	316
5-9 years	930	249	1,179
10-14 years	762	189	951
15-19 years	513	127	640
20-24 years	284	66	350
25-29 years	119	28	147
30-34 years	54	17	71
35-39 years	30	10	40
40-44 years	21	6	27
45-49 years	26	10	36
50-54 years	18	5	23
55-59 years	12	5	17
≥60 years	5	~	7
Total	3,013	791	3,804

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

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



Occupational status⁷

Most service users (1,921 50%) recorded student/pupil as their occupational status followed by 'unable to work due to disability' (274, 7%) (Table 2.3)

Table 2.3 Occupational status of service users with autism, NASS 2020

	n	%
Total population	3,804	100
Student/pupil	1,921	50.5
Unable to work due to disability	274	7.2
Training/day programme	256	6.7
Other	146	3.8
Unemployed	69	1.8
In paid employment	24	0.6
Not known	928	24.4

Note: No service users identified as retired or housewife/househusband.

⁷ Occupational status information was captured as 'employment status' on NASS in 2020.

Ethnic or cultural background

The most frequently self-reported ethnicity or cultural background was Irish (1,568, 41%) (Table 2.4).

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

	n	%
Total population	3,804	100
Irish	1,568	41.2
Irish Traveller	80	2.1
Asian-Chinese	38	1.0
Any other Asian background	22	0.6
Any other white background	14	0.4
Black African	10	0.3
Any other black background	8	0.2
Do not wish to answer this question	420	11.0
Not known	1,644	43.2

Living accommodation

A total of 1,128 (30%) service users were living in private accommodation that is owner occupied and 432 (10%) were living in rented accommodation. A total of 205 (5%) were residing in a residential setting and 7 service users (<1%) were residing in unstable accommodation (Table 2.5).

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

	n	%
Total population	3,804	100
Private accommodation-owner occupied	1,128	29.7
Rented on open market	222	5.8
Rented from county council/public authority/service provider	210	5.5
Residential setting*	205	5.4
Unstable accommodation	7	0.2
Not known	2,032	53.4

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

Living arrangements

Most service users resided with family members (2,906, 76%), with the majority of those living with parents (Table 2.6). Five percent of people (205) resided in a residential setting and 52 (1%) lived alone.

Table 2.6 Living arrangement of service users with Autism, NASS 2020

	n	%
Total population	3,804	100
Living with family	2,906	76.4
Both parents	1,678	44.1
One parent	577	15.2
Parent(s) and sibling(s)	628	16.5
Sibling(s)	11	0.3
Other relative(s)	11	0.3
Daughter(s)/ son(s)	~	0
Residential setting	205	5.4
In a residential service*	205	5.4
Living alone	52	1.4
Alone	52	1.4
Living with non-family	20	0.5
Foster family	16	0.4
Non-relatives	~	0.1
Not known	621	16.4
Not known	621	16.4

*Includes those that are not funded from the disability budget

2.3 Disability and diagnosis

Additional disabilities^a

A total of 1,103 (30%) service users with autism had at least one additional disability recorded (Table 2.7). The most commonly reported additional disability was intellectual (721, 19%), followed by speech and/or language (139, 4%).

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

	n	%
Total population	3,804	100
Intellectual	721	19.0
Speech and/or language	139	3.7
Mental health	95	2.5
Specific learning disorder (other than intellectual)	61	1.6
Neurological	57	1.5
Physical	50	1.3
Developmental delay (under 10 years only)	49	1.3
Visual	28	0.7
Hearing loss/deafness	16	0.4
Not verified*	11	0.3
DeafBlind- Dual sensory	~	~
No additional disability	2,701	71.0

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

*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.

^a 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 319 diagnoses recorded for service users with autism during the 2020 data collection period. The most frequently reported ICD-10 diagnosis category on NASS was Mental and behavioural disorders (F00-F99) which includes intellectual disability and autism (293, 92%).

Diseases of the nervous system (G00-G99) was the second most frequently reported ICD-10 diagnosis category this includes conditions such as multiple sclerosis, cerebral palsy, and Parkinson's disease (21, 7%).

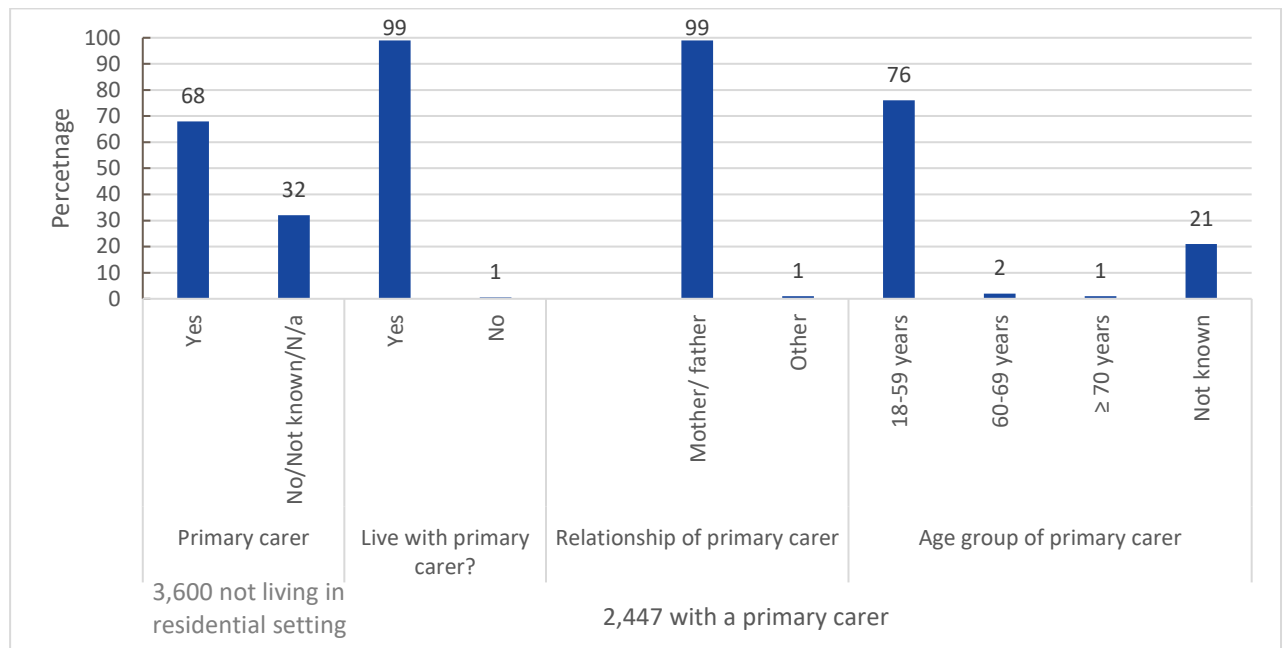
It should be noted that as it is optional to record diagnosis on NASS, information on diagnosis is not necessarily reflective of those registered on the system. Diagnosis information was not captured on the NIDD and is a new field for most service providers completing NASS. The importance of completing diagnosis information will continue to be highlighted to service providers for 2021.

2.4 Primary Carer

Of those registered on NASS, 2,447 (68%) reported having a primary carer. Most of those with a primary carer lived with their primary carer (2,432, 99% of those who reported having a primary carer) (Figure 2.3).

The majority (2,413, 99%) of primary carers were parents. Primary carers were mostly aged between 18-59 years (1,861, 76%), 52 (2%) were aged between 60 and 69 years and 23 (1%) were aged 70 years and over.

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



2.5 Services

The service use and services needed now or within the next five years for those with a primary disability of autism registered on NASS is displayed in the following tables and figures.

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 were received by 204 (5%) people whose primary disability is autism. An enhancement to their existing residential service was required by 21 people (10%). A total of 47 new residential places were reported as required now or within the next five years, most of which were unmet need for house in the community (Table 2.8).

Of those accessing residential services (204):

- 88 (43%) had 24/7 staff and awake cover at night
- 51 (25%) had 24/7 staff and sleepover cover at night
- 27 (13%) had greater than 1 to 1 support
- 25 (12%) had 1 to 1 support
- 7 (3%) had less than 24/7 care
- 6 (3%) had less than 24/7 staff and sleepover cover at night

Nine out of ten those accessing residential services availed of their residential place 7 nights per week (183, 90%).

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

Residential service	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	3,804	100		
House in community (1-4 residents)	151	4.0	11	42
Community group home (5-9 residents)	31	0.8	6	0
Residential centre/on campus (10+ residents)	14	0.4	~	0
Specialist facility – challenging behaviour¥	8	0.2	~	~
Specialist facility – mental health co-morbidity	0	0.0	0	~
Home sharing – shared living family	0	0.0	0	~
Total	204		21	47

¥ 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. Services with no recorded current use or unmet need include nursing home, specialist facilities for neurological, dementia and physical disabilities, hospice, psychiatric hospital and other hospital.

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 model⁹ 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 2,147 (56%) service users accessed at least one day service in 2020 accounting for 2,188 day service places (service users can attend more than one day service) (Table 2.9). The most frequently accessed day service reported on NASS was Mainstream primary/secondary school (814, 21%). The largest unmet need was for Special class/unit in mainstream primary/secondary school (54 places required now or in the next five years) and those already accessing special classes/units in mainstream school require the greatest number of enhancements (181). Of those accessing HSE funded day programmes 423 (11%), 82 required an enhancement. A further 25 places are required in the coming five years.

In the 2020 data collection period, the level of support was recorded for 1,265 (33%) of service users who were receiving a day service, and was as follows:

- 367 (29%) had a staff to service user ratio of 1-to-1.
- 357 (28%) had a staff to service user ratio of 1-to-2.
- 184 (15%) had a staff to service user ratio of between 1-to-6 and 1-to-9.
- 174 (14%) had a staff to service user ratio of between 1-to-4 and 1-to-5.
- 170 (13%) had a staff to service user ratio of 1-to-3.
- 79 (6%) had a staff to service user ratio of 1-to-10+.
- 34 (3%) had a staff to service user ratio of greater than 1-to-1.

Of those accessing day services and where information was available (2,154), 2,004 (93%) accessed their day service five days per week.

⁹ 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 autism, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	3,804	100		
Day programme	423	11.1	82	25
Supported employment	10	0.3	0	6
Rehabilitative training	116	3	10	~
Mainstream early childhood education and care	56	1.5	~	5
Special early childhood education and care	52	1.4	11	~
Mainstream primary/secondary school	814	21.4	45	24
Special primary/secondary school	247	6.5	87	9
Special class/unit in mainstream primary/secondary school	415	10.9	181	54
Home tutor	12	0.3	~	~
Vocational training	9	0.2	~	~
Third level education	34	0.9	6	~
Total	2,188		431	135

† 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.

The category Neuro-rehabilitative training had no recorded use or unmet need.

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

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

No provision of day respite services or unmet need were recorded for those with autism in 2020.

Overnight respite

In 2020, 78 (2%) people received overnight respite services. Of these, 73 received respite in a house in the community or a centre for a total of 1,431 nights, 38 requiring an enhancement to their current service. In addition, home sharing with short breaks family and own home respite were recorded as currently being accessed by a combined total of five individuals.

Unmet need for overnight respite was recorded for 63 people as follows: house in the community/centred based (38), holiday respite residential/centre-based/summer camp (7), holiday respite Hotel/ B&B/Hostel (7) and home sharing with short breaks family (6). Home sharing with contract family and own home respite unmet need were recorded as less than 5.

Supports for daily living

In 2020, 893 supports for daily living were accessed by 866 (23%) people with autism as a person may access more than one of these services. Community support was the most frequently accessed support for daily living and was accessed by 18% of the total population with autism (685 places), with 43 of these services requiring an enhancement (6%). By contrast, 153 home support places were accessed, 47 (31%) of which require an enhancement to the existing service. A total of 66 supports for daily living were reported as required now or within the next 5 years, with peer support (16 places), community support (12 places) and home support (12 places) the most commonly required supports (Table 2.10).

Table 2.10 Supports for daily living; places currently being accessed, enhancement required to current places and unmet need for places for service users with autism, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	3,804	100		
Community support	685	18.0	43	12
Home support	153	4.0	47	12
Transport services	28	0.7	~	6
Personal assistant	15	0.4	~	9
Participation in voluntary work	6	0.2	~	~
Peer support	~		0	16
Advocacy services	~		0	9
Guide dog/assistance dog	~		0	0
Total	893		97	66

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

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

Specialist supports

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 team's 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.

Nearly two-thirds of service users with a primary disability of autism (63%, 2,378) registered on NASS availed of one or more specialist support services in 2020. Of these 2,378 service users, 50% (1,184) availed of one specialist support service, 21% (493) availed of two specialist support services and 13% (302) availed of three specialist support services. In total, 4,960 specialist support services were availed of in 2020 (Table 2.11).

Table 2.11 Specialist supports; places currently being accessed, enhancement required to current places and unmet need for places for service users with autism, NASS 2020

	Places currently being accessed		Enhancement required to current places	Unmet need for places
	n	%	n	n
Total population	3,804	100		
Speech and language therapy	1,044	33.9	454	124
Occupational therapy	1,010	32.7	432	144
Social work	527	17.1	87	72
Key worker	502	16.3	130	6
Clinical psychology	384	12.5	84	113
Children's Disability Network Team (CDNT)	336	10.9	247	10
Physiotherapy	300	9.7	51	41
Psychiatry	175	5.7	59	14
Behaviour therapy	147	4.8	10	35
Nursing	131	4.2	37	7
Special Needs Assistant (SNA)	120	3.9	13	19
Case manager	93	3	6	~
Resource teacher	61	2	8	5
Educational psychology	57	1.8	21	29
Dietetic services	33	1.1	~	~
Counselling Psychology	11	0.4	0	8
Chiropody	5	0.2	~	~
Vision rehabilitation	5	0.2	0	0
Creative therapy	~	0.1	0	5
Others	17	0.6	~	12
Total	4,960		1,645	650

~ 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

Others includes Dentistry/orthodontic, Assistive technology/client technical service, Orthotics/prosthetics, Complementary therapy, Neurorehabilitation, Neuropsychology, Vision communication-IT/AT and alternative formats, Aural rehabilitation services, Palliative care, Play therapy, Aural communication-IT/AT and alternative format services, Animal assisted therapy.

Over two thirds of service users aged 18 years and over (673, 70%) did not record attendance with any specialist support while in the under 18 years age group less than one third (753, 27%) recorded no specialist supports (Table 2.12). Those receiving 3 or more specialist supports made up 7% (64) of the 18 years and over group and 22% (637) of the under 18 years group.

Table 2.12 Number of specialist supports received by age group for service users with autism, NASS 2020

Number of Specialist Supports	Under 18 years		18 years and over	
	n	%	n	%
Total population	2,839	100	965	100
No Specialist Support	753	27	673	70
1 Specialist Support	1046	37	138	14
2 Specialist Supports	403	14	90	9
3 or more Specialist Supports	637	22	64	7

The specialist supports most availed of by service users under 18 years were speech and language therapy (996, 35%), occupational therapy (964, 34%) and key worker (433, 15%). The specialist supports most availed of by service users aged 18 years and over were social work (99, 10%), psychiatry (97, 10%) and key worker (69, 7%). 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 autism aged under 18 years; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020

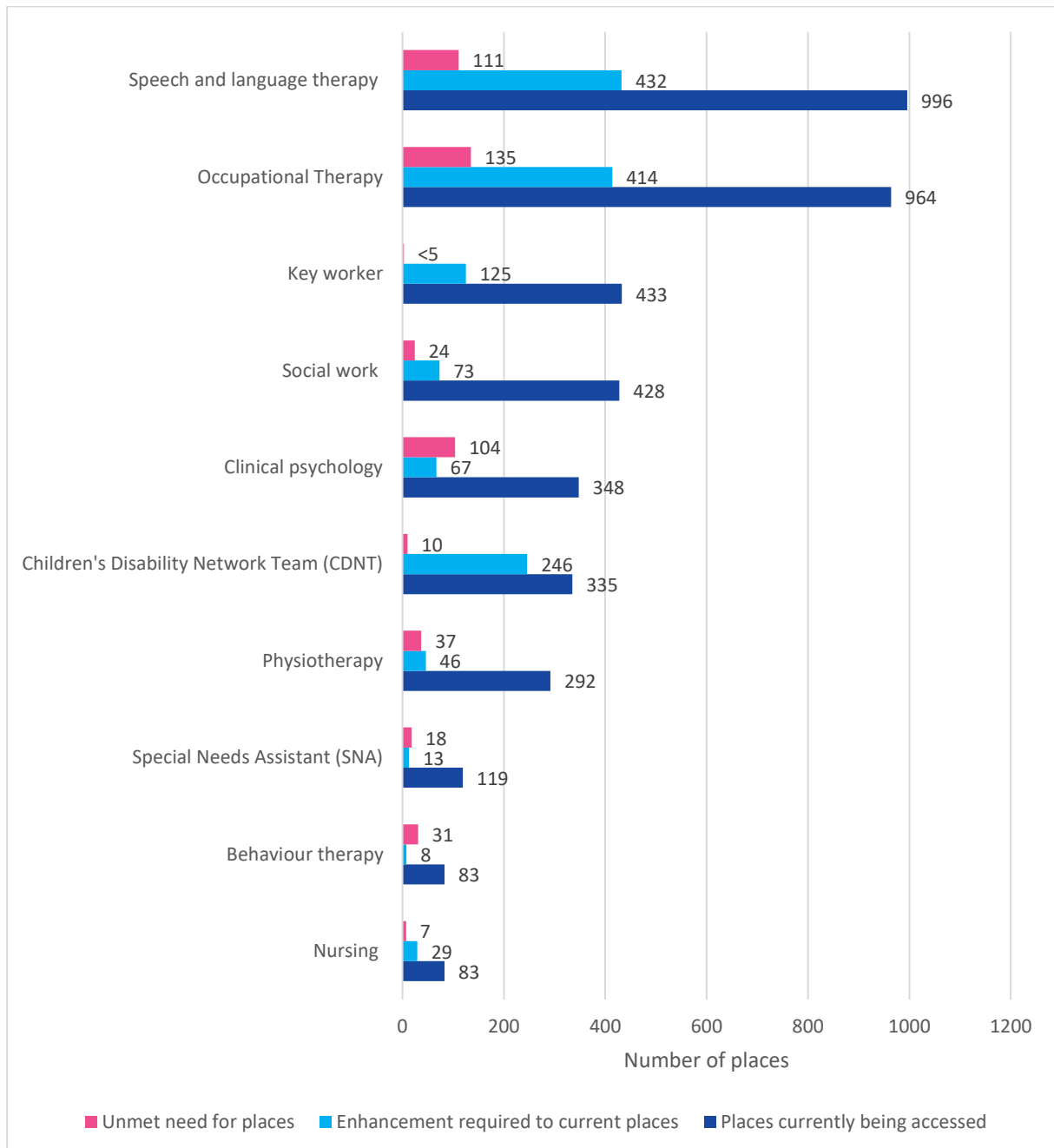
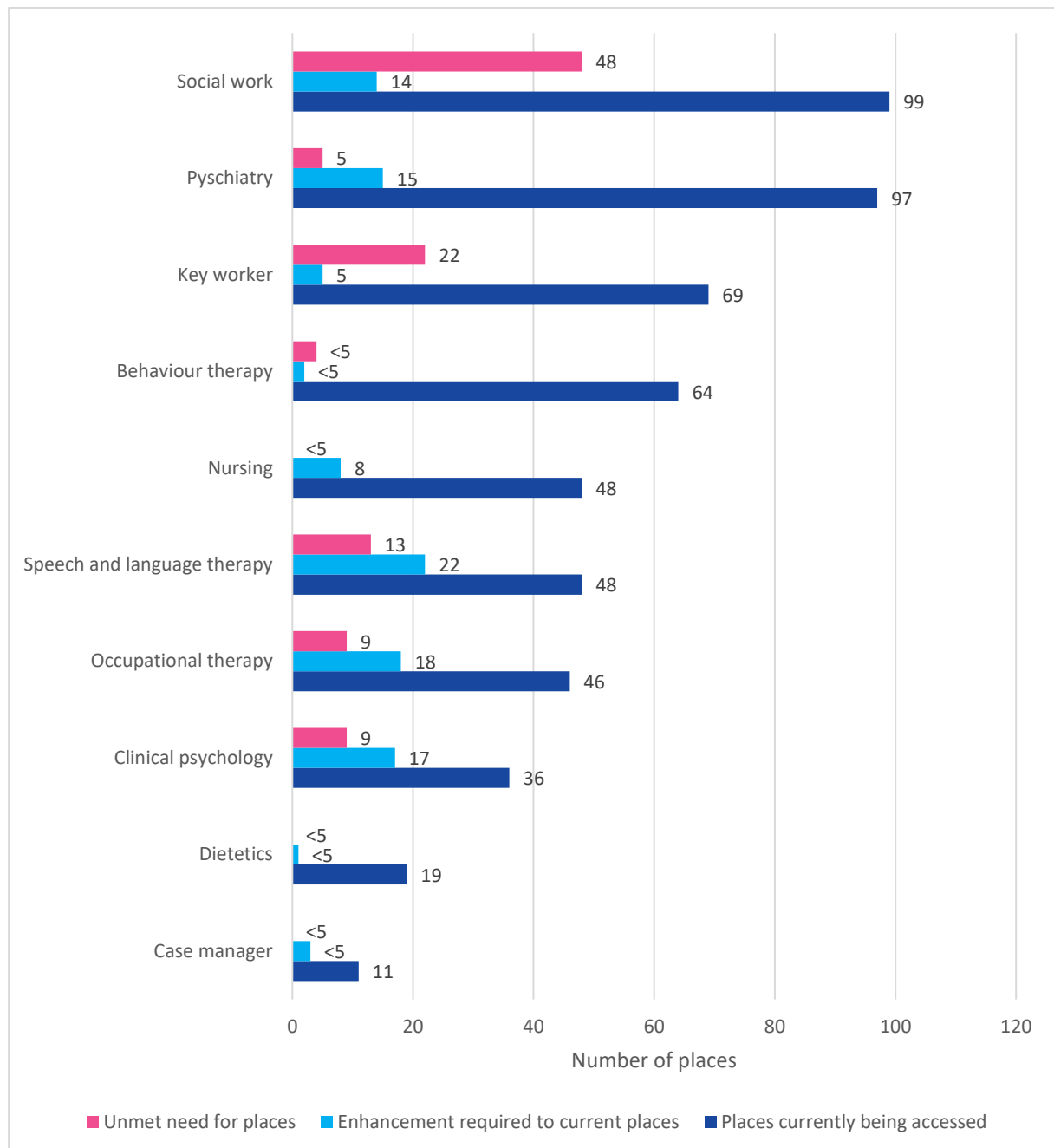


Figure 2.5 Specialist supports for service users with autism aged 18 years and over; places currently being accessed, enhancement required to current places and unmet need for places, NASS 2020



2.6 Assistive products

Assistive products were used by 66 (2%) people registered on NASS with a primary disability of autism and 82 assistive products were used by these service users. The most commonly used product groups and products were:

- Assistive products for communication and information management (25, 31%)
- Assistive products for self-care activities and participation in self-care (23, 28%)
- Furnishings, fixtures, and other assistive products for supporting activities in indoor and outdoor human-made environment (14, 17%)

Overall, 17 service users had an unmet need for at least one assistive product, and 23 assistive products were reported as being required now or in the next five years. The most frequently required assistive product groups and products were:

- Assistive products for supporting neuromusculoskeletal or movement-related functions (orthoses) and replacing anatomical structures (Prostheses) (6, 35%)
- Assistive products for self-care activities and participation in self-care (6, 35%)

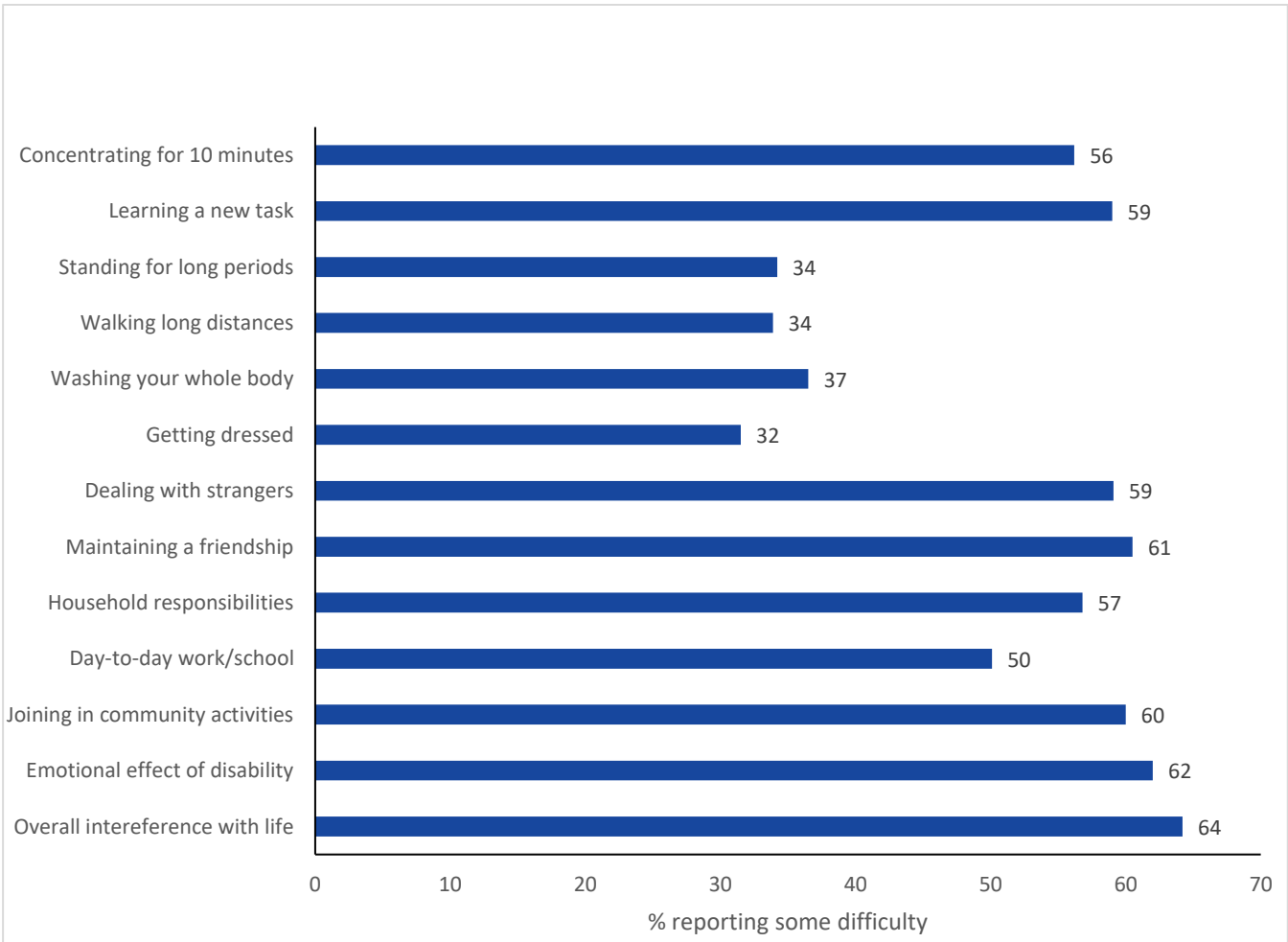
2.7 World Health Organization Disability Assessment Schedule V.2 (WHODAS 2.0)

The WHODAS 2.0 captures information on the extent of difficulty an individual has with functioning in daily activities in the previous thirty days. 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.

The percentages shown are based on those who completed WHODAS (913 people out of 1,231 eligible). In 833 (91%) cases the answers were provided by proxy and the remainder were provided by the service user.

Of the service users with autism who completed WHODAS, 587 people (64%) reported that their disability had an overall interference with their life (Figure 2.6). The areas where people reported the most difficulty were the emotional effects of their disability (567, 62%), maintaining a friendship (553, 60%) and joining in community activities (548, 60%); with 59% reporting some difficulty with dealing with strangers and /or learning a new task.

Figure 2.6 WHODAS 2.0 – World Health Organisation Disability Assessment Schedule for those with a primary disability of autism, NASS 2020



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 3,804 service users registered on NASS with autism at the end of December 2020. It represents the recorded service use and needs of people with autism 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 autism. There are 3,804 service users with autism included in this report. This is an increase of 108% from the 1,831 service user records reviewed in 2019. New registrations for those with a primary disability of autism increased by 256% accounting for the majority of the overall increase.

The number of registrations of those with autism is expected to increase considerably as the system becomes more established and new registrations continue to be added. The roll out of Children's Disability Network Teams is expected to continue this year and when they are in place it will facilitate greater return of data for those under 18 years, who already comprise the largest age group for those with Autism. 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 intellectual disability 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.