National Ability Supports System (NASS) 2019

Supplementary bulletin - Autism Spectrum Disorder (ASD)

Health Research Board

Research. Evidence. Action.

Overview

This is a supplementary bulletin to be read in conjunction with the main National Ability Supports System (NASS) bulletin 2019.

The purpose of NASS is to gather information to aid the planning, development and organisation of disability-funded services. A person is eligible to be registered on NASS if they receive or require (in the next 5 years) a disability-funded service.

There were 1,831 people registered on NASS in 2019 with a primary disability of Autism Spectrum Disorder (ASD).

Those in the younger age groups, under the age of 18, make up the greatest proportion of the total. This contrasts with the overall trend whereby the majority of those registered on the system, with other primary disabilities, are in the 40-59 years age group.

Most service users with ASD had a primary carer, almost all of whom were parents.

In 2019, 4% of those recorded on NASS with ASD as their primary disability were in receipt of a residential service; 80% accessed day[1] services; 1% accessed day respite services, 6% overnight respite services; 35% were in receipt of supports for daily living and 50% accessed specialist supports.

Introduction

This supplementary bulletin provides an overview of the people recorded on NASS whose **primary** disability type is recorded as ASD (1,831, 8.2%). They represent almost one tenth of the total number of current records on NASS, but this is expected to increase over time.

NASS replaces two disability databases - the National Intellectual Disability Database (NIDD) and the National Physical and Sensory Disability Database (NPSDD). NASS has expanded the types of primary disability that can be recorded to include ASD and so this is the first time that such data on those with ASD is available.

Of the 1,831 people included in this report, 737 (40%) had newly created records while 1,079 (59%) people were previously registered on the NIDD, and 15 (1%) people were previously registered on the NPSDD.

As outlined in the main bulletin, coverage achieved in the first year of NASS is incomplete but the patterns in the data recorded give insights into the overall population of people who receive or require a disability-funded service.

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[1] Day services include non-HSE services such as Department of Education services.

Service users with ASD

Figure 1 below displays a summary profile of the people registered on NASS with ASD as their primary disability by sex, age group and CHO area of registration. Almost four times more males (1,434, 78%) than females (397, 22%) were registered and 1,238 (68%) of those with ASD were under the age of 18 years. More service users with ASD were recorded in CHO 2 (779, 43%), followed by CHO 1 (352, 19%); this reflects the early engagement of some larger service providers with NASS, along with differences in availability of resources to engage with the system across the country. Due to these variations, the emphasis of this report is at the national level.

Figure 1 Number of people with ASD as primary disability type registered on NASS in 2019 (1,831), NASS 2019

1,831 registered on NASS (ASD)

Sex

	n	(%)
Female	397	(21.7)
Male	1,434	(78.3)

CHO Area of main service provider*

	n	(%)
Area 1	352	(19.2)
Area 2	779	(42.5)
Area 3	34	(1.9)
Area 4	87	(4.8)
Area 5	24	(1.3)
Area 6	75	(4.1)
Area 7	157	(8.6)
Area 8	183	(10.0)
Area 9	140	(7.6)

Age group

	n	(%)
0-4	148	(8.1)
5-12	719	(39.3)
13-17	371	(20.3)
18-24	331	(18.1)
25-39	180	(9.8)
40-59	77	(4.2)
60-70	~	
>70	~	

*** The 9 Community Health Organisations (CHOs) are:**

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

Area 2 - Galway, Roscommon, Mayo

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

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

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

Area 6 - Wicklow, Dun Laoghaire, Dublin South East

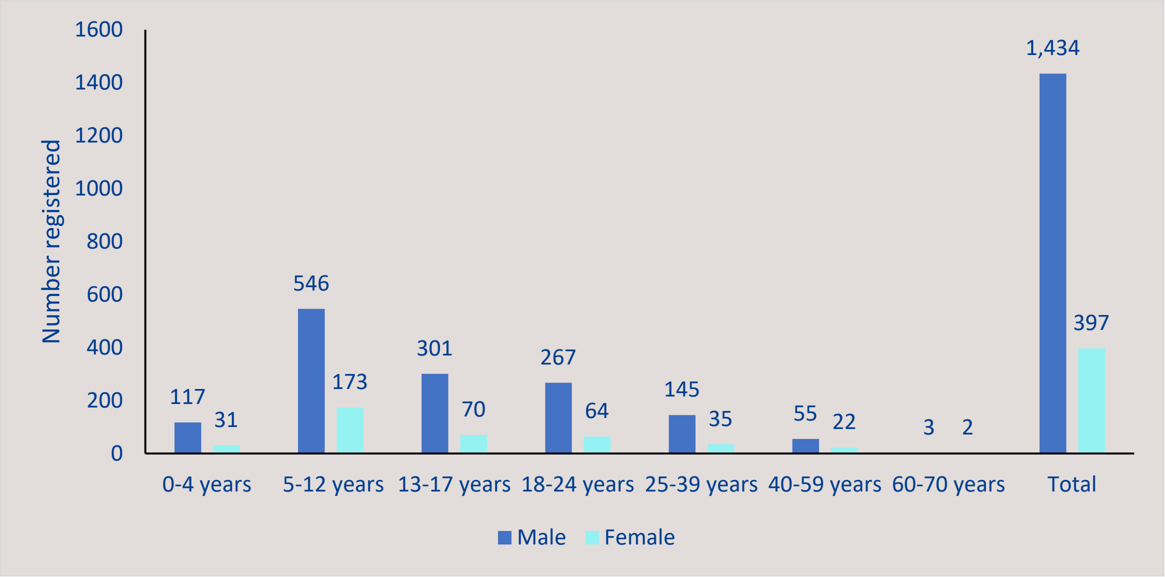
Area 7 - Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West

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

Area 9 - Dublin North, Dublin North Central, Dublin North West

Figure 2 shows that there were more males than females registered in all age groups with the most pronounced differences in the younger age groups, up to the age of 39 years.

Figure 2 Number of people with ASD registered by age group and gender, NASS 2019



Employment status

The employment status of those registered on NASS shows that, where known, the majority were students or pupils (954, 52%), followed by those who are unable to work due to their disability[2] (167, 9.1%) and those attending a training/day programme (122, 6.7%).

The ‘not known’ response option was used where this information could not be acquired in the review period.

Table 1 Employment status of service users with ASD, NASS 2019

	n (%)
Student/Pupil	954 (52.1)
Unable to work due to disability	167 (9.1)
Training/day programme	122 (6.7)
Other	54 (2.9)
Unemployed	38 (2.1)
In paid employment	20 (1.1)
Retired	0
Housewife/ husband	0
Not known	476 (26.0)
Total	**1,831 (100.0)**

Ethnic/cultural background

The ethnic/cultural background is based on the response options for the same question on the Central Statistics Office national census form. Ethnic/cultural background is self-reported by the service user. Ethnicity is an important indicator of potential barriers to social participation and this information is useful to ensure that health services are as inclusive as possible.

The most frequently self-reported ethnicity/cultural background was Irish (841, 46%). As with ‘employment status’, the ‘not known’ response option is over-represented due to this information not being readily available to service providers in the review period.

Table 2 Ethnic/cultural background of service users with ASD, NASS 2019

	n (%)
Irish	841 (45.9)
Any other white background	42 (2.3)
Any other Asian background	20 (1.1)
Black African	13 (0.7)
Irish Traveller	6 (0.3)
Any other black background	~
Asian-Chinese	~
Do not wish to answer this question	366 (20.0)
Not known	537 (29.3)
Total	**1,831 (100.0)**

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

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[2] Receiving benefits for people who are sick or have a disability (e.g. disability allowance, illness benefit)

Living accommodation

Living accommodation refers to the service user's living situation for the majority of the week. A total of 813 (44%) people recorded on NASS were living in private accommodation (i.e. owner occupied) and 279 people (15%) were in rented accommodation. 117 people (6%) were residing in residential services and < 5 people reported living in unstable accommodation.

Unstable accommodation refers to situations where an individual may be homeless, living in temporary accommodation such as a B&B/guesthouse/hostel/hotel, staying with friends on a temporary basis; or in Direct Provision accommodation.

Table 3 Living accommodation of service users with ASD, NASS 2019

	n (%)
Private accommodation (owner occupied)	813 (44.4)
Rented on open market	144 (7.9)
Rented from county council/public authority/service provider	135 (7.4)
Residential service*	117 (6.4)
Unstable accommodation	~
Not known	619 (33.8)
Total	**1,831 (100.0)**

*Includes those that are not disability-funded.
~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

Living arrangements

Most people registered on NASS were residing with family members (1,647, 90%). 117 people (6%) were living in a residential service, 32 people (2%) were living alone and 14 people (<1%) were living with a foster family or non-relatives. The living arrangements for 21 people (1%) were recorded as 'not known'.

Table 4 Living arrangements, NASS 2019

	n (%)
Living with family	**1,647 (90.0)**
Both parents	996 (54.4)
One parent	328 (17.9)
Parent(s) and sibling(s)	308 (16.8)
Sibling(s)	9 (0.5)
Other relative(s)	5 (0.3)
Daughter(s)/son(s)	~
Wife/husband/partner and children	0
Wife/husband/partner, no children	0
Residential	**117 (6.4)**
In a residential service*	117 (6.4)
Living alone	**32 (1.7)**
Alone	32 (1.7)
Living with non-family	**14 (0.8)**
Foster family	11 (0.6)
Non-relative(s)	~
Not known	**21 (1.1)**
Not known	21 (1.1)
Total	**1,831 (100.0)**

*Includes those that are not disability-funded.

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

Additional disabilities

A total of 606 (33%) people with ASD also recorded at least one additional disability (Table 5).

The most commonly reported additional disability was intellectual (418, 23%) followed by speech and/or language (64, 4%).

ASD was recorded as a secondary disability by those with a primary disability type of intellectual disability (1,387, 7.9%), physical/sensory (44, 1.6%) and those with other disability types which include developmental delay/specific learning difficulty/mental health/not verified (8, 2.1%).

The recording of some of the disability types not previously available on the NIDD or NPSDD - including ASD - is lower than anticipated most likely due to the limited resources and the challenges faced during the data collection period, as outlined in the main bulletin.

Table 5 Additional disabilities¥ of those whose primary disability is ASD, NASS 2019

Additional disability¥	n (%)
Intellectual	418 (22.8)
Speech and/or language	64 (3.5)
Mental health	44 (2.4)
Specific learning disorder (other than intellectual)	33 (1.8)
Neurological	32 (1.7)
Developmental delay (under 10 years only)	24 (1.3)
Physical	16 (0.9)
Visual	15 (0.8)
Hearing loss/deafness	11 (0.6)
DeafBlind - dual sensory	0
Not verified	8 (0.4)

¥ More than one additional disability may be recorded for a person.

Diagnostic category

It is optional to record information on the diagnosis(es) of those registered on NASS.

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

There were 172 service users with ASD registering 222 individual diagnoses during this data collection period.

When grouped to higher level ICD-10 Diagnostic Codes (see Table 6) there were 197 diagnostic codes recorded.

The most frequently reported ICD-10 diagnosis on NASS is 'mental and behavioural disorders' - this includes childhood Autism, ASD, intellectual disabilities, dementia and attention deficit hyperactivity disorder, followed by 'diseases of the nervous system' which include conditions such as multiple sclerosis, cerebral palsy and Parkinson's disease.

Table 6 ICD-10 Diagnostic codes recorded for service users with ASD, NASS 2019

	n (%)
Mental and behavioural disorders (F00-F99)	154 (69.4)
Diseases of the nervous system (G00-G99)	15 (6.8)
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	15 (6.8)
Endocrine, nutritional and metabolic diseases (E00-E90)	~
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	~
Diseases of the eye and adnexa (H00-H59)	~
Diseases of the circulatory system (I00-I99)	~
Diseases of the musculoskeletal system and connective tissue (M00-M99)	~
Injury, poisoning and certain other consequences of external causes (S00-T98)	~
Diseases of the digestive system (K00-K93)	~
	197

Note that more than one diagnosis may be recorded for a person.
~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

Primary carer

For the purposes of NASS, a primary carer is someone such as a family member (e.g. parent or sibling), friend or neighbour, who has been identified as providing regular and sustained care and assistance (also referred to as 'informal carers').

Primary carers include those who are unpaid for this role and/or those who receive a pension or benefit for their caring role, but do not include paid or volunteer carers organised by formal services. This includes host families or foster families where the family is paid to care for the service user. The care is provided on an ongoing basis.

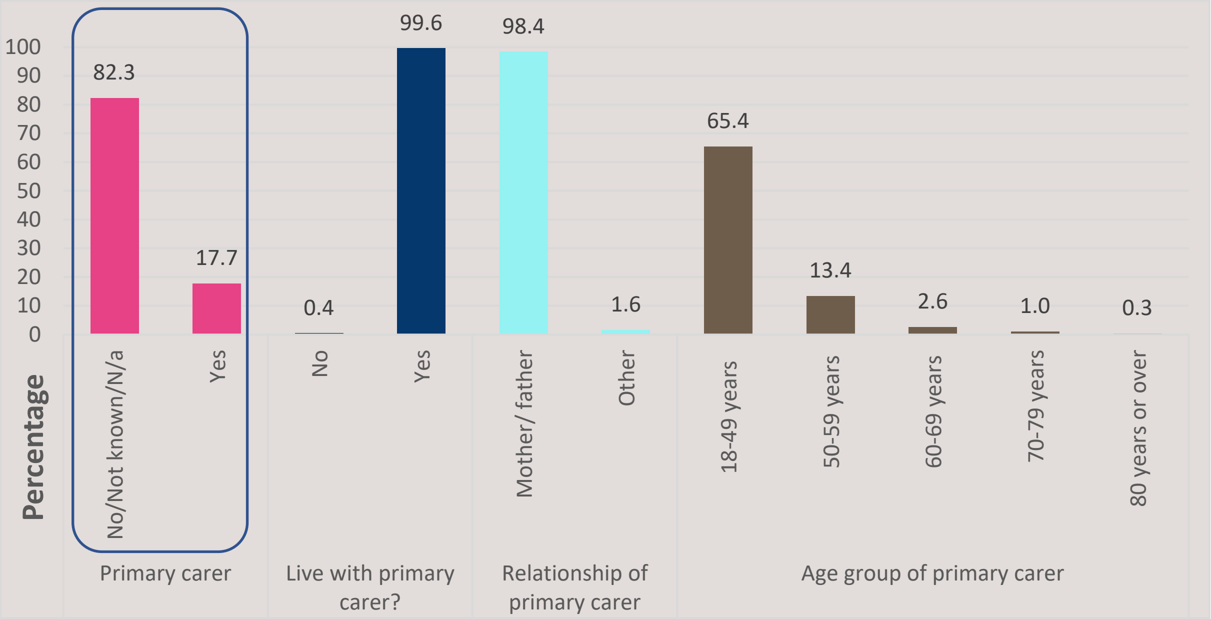
Of those registered on NASS with ASD as their primary disability type, 1,492 (82%) reported having a primary carer.

Almost all of those with a primary carer lived with them (1,486, >99%) and most (1,468, 98%) primary carers were parents (Figure 3).

Where the age group of the primary carer was known (n=1,234), the majority were aged between 18 and 49 years (976, 65%). There were 200 (13%) primary carers aged 50-59 years, 39 (3%) were 60-69 years, 15 (1%) were 70-79 years and <1% were 80 years of age and over. There were no reported primary carers under the age of 18.

Given the younger age profile of service users with ASD on NASS, most of those with a primary carer were under 18 years of age (1,209, 81%). A further 283 (19%) service users aged 18 to 59 years reported having a primary carer.

Figure 3 Primary carer, NASS 2019



Services

As outlined earlier, NASS collects information on the 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 services tables presented below represent whether a service was recorded for the individual as:

- Current: the number of people currently in receipt of that service.
- Enhanced: the number of people currently in receipt of that service but who require an enhancement to the service. This could be requiring additional hours/days, additional support within their current service or a different location for the service.
- Unmet need: the number of people who are not in receipt of that service but who require it within the next five years.

The services reported in the sections below are those that were reviewed/added in the data collection period. Efforts to increase the levels of recording of services data are ongoing in the current data collection period.

Service provision and future requirements (ASD)

The service use in 2019 and the service need for the next 5 years of those registered on NASS with ASD as their primary disability are displayed in the following tables and figures.

Residential services

114 (4%) of people whose primary disability is ASD were in receipt of residential services. 17 people (15%) receiving residential services reported requiring an enhancement to their existing residential service. Those reporting an unmet need for residential service on NASS was 2% (Table 7).

Table 7 Residential services of those with ASD as primary disability type; use, enhancement required and unmet need, NASS 2019

Residential service¥	Current	Enhancement required	Unmet need
	n (%)*	n (%)**	n (%)***
House in community (1-4 residents)	72 (3.9)	10 (13.9)	33 (1.9)
Community group home (5-9 residents)	23 (1.3)	5 (21.7)	0
Residential centre/on campus (10+ residents)	13 (0.7)	~)	0
Specialist facility - challenging behaviour	6 (0.3)	0	~
Specialist facility – neurological	0	0	~
Specialist facility - mental health co-morbidity	0	0	~
Home sharing - shared living family	0	0	~
Total	**114**	**17**	**41**

*% based on total with ASD as primary disability type (n=1,831)
** % based on number currently accessing the service
*** % based on the number not currently accessing the service

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.
¥ An individual may be in receipt of more than one residential service, services with no recorded current use or unmet need include: nursing home, specialist facilities for dementia and physical disabilities, hospice, psychiatric hospital and other hospital.

Day services

A total of 1,465 (80%) of those whose primary disability type is recorded as ASD were in receipt of one or more day services. Table 8 below refers to the number of services currently accessed and required.

A number of individuals may be in receipt of, or require, more than one day service hence the total is more than 1,465. As outlined in the main bulletin, gaps exist in the NASS data, especially in relation to special schools, therefore the data presented below is not exhaustive, rather is the information collected to date.

Table 8 Day services of those with ASD as primary disability type; use, enhancement required and unmet need, NASS 2019

Day service¥	Current Use	Enhancement required	Unmet need
	n (%)*	n (%)**	n (%)***
Activation and high support services	**279**	**52**	**21**
Day activation/activity	220 (12)	35 (15.9)	12 (0.7)
High support day service	59 (3.2)	17 (28.8)	9 (0.5)
Training, work and employment services	**83**	**10**	**10**
Rehabilitative training	68 (3.7)	9 (13.2)	~
Supported employment	10 (0.5)	0	7 (0.4)
Vocational training	~	~	~
Sheltered work-like work	~	0	0
Sheltered employment	~	0	0
All other day services (Schools/Third level education/Home tutor)	**1,120**	**223**	**67**
Total	**1,482**	**285**	**98**

*% based on total with ASD as primary disability type (n=1,831) however an individual may be in receipt of more than one day service.
** % based on number currently accessing the service
*** % based on the number not currently accessing the service
~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.
¥ An individual may be in receipt of more than one day service; services with no recorded current use or unmet need include: sheltered work - therapeutic, sheltered work - commercial and external work.

Respite services (day and overnight)

17 people (1%) with ASD registered on NASS were reported to have accessed day respite services, the most frequently reported of which was centre based respite (15, 1%). The most commonly required day respite services were centre based (9, 1%) and own home respite (<1%). Due to the low numbers with ASD accessing day respite, these services have not been shown in tabular format.

Table 9 presents the overnight respite use and need of the 103 people with ASD who accessed overnight respite in 2019 - representing 6% of NASS registrations whose primary disability type is ASD. 46 (50%) people in receipt of house in the community/centre based respite recorded their need for an enhancement to their service.

Table 9 Overnight respite of those with ASD as primary disability type; use, enhancement required and unmet need, NASS 2019

Overnight respite	Current use n (%)*	Enhancement required n (%)**	Unmet need n (%)***
House in community/centre based	93 (5.1)	46 (49.5)	25 (1.4)
Home sharing-short breaks	5 (0.3)	~	6 (0.3)
Holiday (residential/centre-based/holiday)	~	~	7 (0.4)
Holiday (hotel/B&B/hostel)	~	0	7 (0.4)
Own home	~	~	~
Home sharing-contract family	0	0	~
Total	**104**	**51**	**50**

*% based on total with ASD as primary disability type (n=1,831) however an individual may be in receipt of more than one service; services with no recorded current use or unmet need include nursing home only.
** % based on number currently accessing the service
*** % based on the number not currently accessing the service
~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

Supports for daily living services

In 2019, 664 supports for daily living were accessed by 641 (35%) people with ASD as an individual may access more than one of these services. Community support[3] was the most frequently accessed support for daily living and was accessed by 30% of the total population with ASD (557 people), 5% of whom require an enhancement to their service (30 people). By contrast, home support[4] was accessed by 69 people (4%) with 38 (55%) of them requiring an enhancement to their existing service (Table 10).

Table 10 Supports for daily living of those with ASD as primary disability type; use, enhancement required and unmet need, NASS 2019

Supports for daily living¥	Current use n (%)*	Enhancement required n (%)**	Unmet need n (%)***
Community support	557 (30.4)	30 (5.4)	~
Home support	69 (3.8)	38 (55.1)	~
Transport services	14 (0.8)	~	~
Personal assistant	13 (0.7)	~	7 (0.4)
Participation in voluntary work	6 (0.3)	~	~
Peer support	~	~	15 (0.8)
Advocacy services	~	~	8 (0.4)
Guide dog/assistance dog	~	0	0
Total	**664**	**74**	**44**

*% based on total with ASD as primary disability type (n=1,831).
** % based on number currently accessing the service
*** % based on the number not currently accessing the service
~ 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 of the supports for daily living services listed in the table.

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[3] Community supports are programmes and supports specifically targeted towards the inclusion and active participation of service users in mainstream community programmes and activities.

[4] Home support services provide personal and/or essential domestic care to dependent people to support them to live at home. It includes home support, home care assistant service, and home help.

Specialist support services

The specialist supports listed below (Table 11; Figure 4) are based on the services received by 914 (50%) people with ASD. Speech and language therapy (423, 23%) and occupational therapy (393, 22%) were the most widely used supports and both recorded the greatest proportion of enhancement required (242, 57% and 231, 59%, respectively).

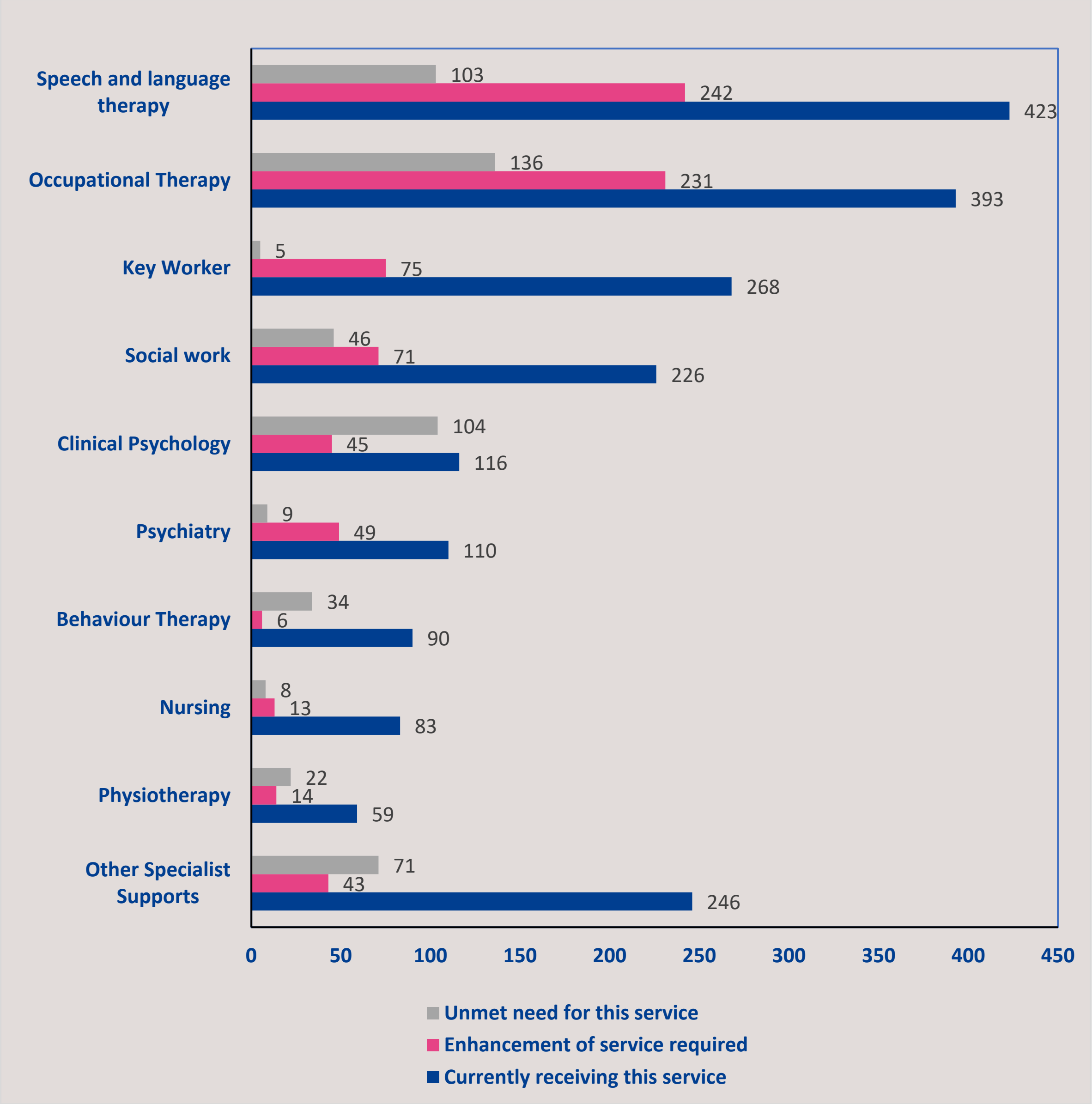
The greatest unmet need was recorded for occupational therapy (136, 10%), clinical psychology (104, 6%) and speech and language therapy (103, 7%).

Table 11 Specialist supports of those with ASD as primary disability type; use, enhancement required and unmet need, NASS 2019

Specialist support services	Current use	Enhancement required	Unmet need
	n (%)*	n (%)**	n (%)***
Speech and language therapy	423 (23.1)	242 (57.2)	103 (7.3)
Occupational therapy	393 (21.5)	231 (58.8)	136 (9.5)
Key worker	268 (14.6)	75 (28)	5 (0.3)
Social work	226 (12.3)	71 (31.4)	46 (2.9)
Clinical psychology	116 (6.3)	45 (38.8)	104 (6.1)
Psychiatry	110 (6)	49 (44.5)	9 (0.5)
Behaviour therapy	90 (4.9)	6 (6.7)	34 (2)
Nursing	83 (4.5)	13 (15.7)	8 (0.5)
Special Needs Assistant	76 (4.2)	12 (15.8)	24 (1.4)
Physiotherapy	59 (3.2)	14 (23.7)	22 (1.2)
Resource teacher	58 (3.2)	9 (15.5)	11 (0.6)
Case manager	49 (2.7)	~	0
Educational psychology	40 (2.2)	16 (40)	12 (0.7)
Complementary therapy	~	~	~
Creative therapy	~	~	~
Dietetics	~	~	~
Chiropody	~	~	~
Dentistry/orthodontics	~	0	~
Assistive technology/client technical	~	~	~
Counselling psychology	~	0	~
Neurorehabilitation	~	0	0
Animal assisted therapy	~	0	~
Play therapy	0	0	~
Neuro psychology	0	0	~
Total	**2,014**	**789**	**538**

*% based on total with ASD as primary disability type (n=1,831)
** % based on number currently accessing the service
*** % based on the number not currently accessing the service
~ 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 of the services listed in the table, services with no recorded current use or unmet need include Aural rehabilitation, Aural communication- IT/AT and alternative formats, Vision rehabilitation, Vision communication, Palliative Care and Orthotics/prosthetics

Figure 4 Specialist supports by those with a primary disability of ASD; use, enhancement required, unmet need, NASS 2019



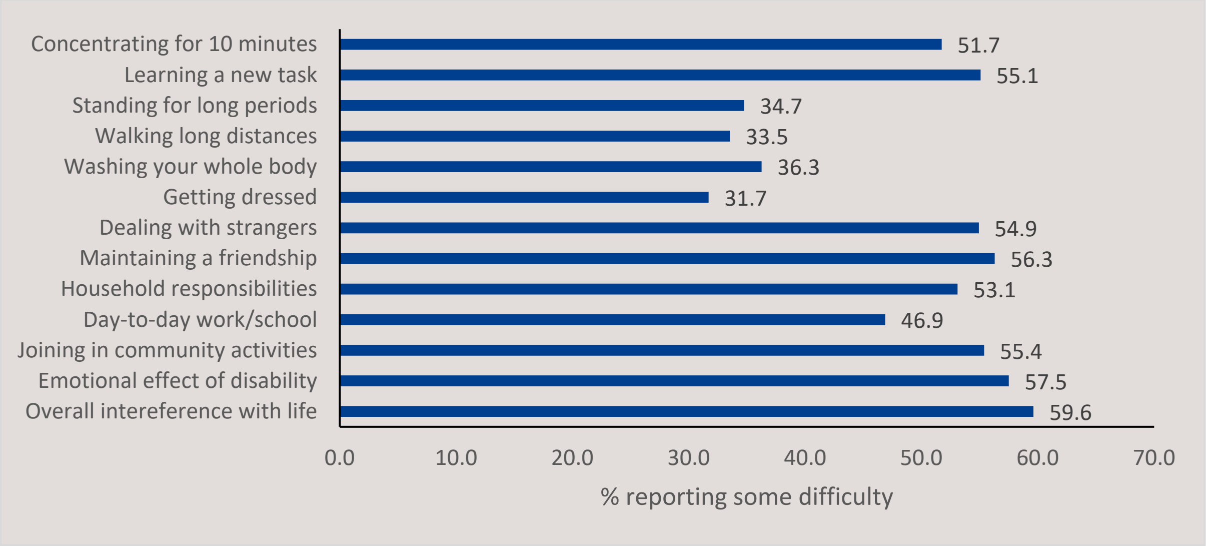
World Health Organization Disability Assessment Schedule V.2 (WHODAS 2.0)

The WHODAS 2.0 captures information on the extent of difficulty an individual had 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 presented are based on those who completed WHODAS (659 people out of 728 eligible). In 608 (93%) cases the answers were provided by proxy and the remainder were provided by the service user.

341 people (60%) reported that their disability had an overall interference with their life (Figure 5). The areas where people reported the most difficulty were the emotional effects of their disability (379, 58%) and maintaining a friendship (371, 56%); while 55% reported some difficulty with learning a new task (363), dealing with strangers (362) and/or joining in with community activities (365).

Figure 5 WHODAS 2.0 - World Health Organisation Disability Assessment Schedule, NASS 2019



Section 4: Summary

This bulletin is a supplementary bulletin to be read in conjunction with the main NASS bulletin. It represents 1,831 people registered on NASS in 2019 who reported ASD as their primary disability. A further 1,439 people reported ASD as an additional disability.

This is the first time that data are available for those with a disability type of ASD who are in receipt of disability-funded services. It represents the culmination of efforts to merge the two HRB-managed disability databases, the NIDD and NPSDD, into a single comprehensive system that takes a more holistic view of the disability-funded services that people use and require in their everyday lives.

As outlined in the main bulletin, the data are incomplete, but it is envisaged that the number of registrations on NASS will continue to grow so that there will be fuller picture of service use and need for people with ASD.

As with the main bulletin, this supplementary bulletin sets out the day, residential and respite service data recorded on NASS for those with ASD as well as data on specialist supports and supports for daily living.

Although gaps exist in the data overall, this cohort of the NASS population provides a snapshot of service provision and need for 2019. Efforts to increase the levels of return will be undertaken by the HRB in the next NASS period.

A further supplementary report has been developed for those with physical/sensory disabilities.

Additional breakdowns of NASS 2019 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

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