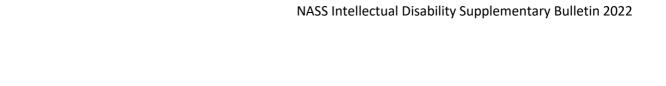


## HRB Supplementary Bulletin National Ability Supports System (NASS)

Overview of people with an intellectual disability engaging with disability services, 2022

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#### National Ability Supports System 2022

# Overview of people with an intellectual disability engaging with disability services, 2022

Nicola Caffrey, Sarah Fanagan, and Ena Lynn

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- The Health Service Executive, in particular the NASS personnel and National Disability Operations
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- Service providers
- The representative bodies for the providers of services to people with disabilities, specifically the National Federation of Voluntary Bodies, the Disability Federation of Ireland, and the Not for Profit Association, and
- The parents and families of people with a disability and their representative bodies, as well as all service users throughout Ireland.

#### **Overview**

This bulletin presents an overview of the information recorded for people with an intellectual disability (ID) reported as either a primary or additional disability on the National Ability Supports System (NASS) for 2022.

NASS is a national database that records information about Health Service Executive (HSE) disability-funded services<sup>1</sup> that are received or identified as required by a service provider as a result of an intellectual disability (ID); developmental delay; physical, sensory, neurological, learning, and speech and/or language disabilities; or autism.

There are some 18-year-olds who have moved to adult services while others remain in children's services until they finish secondary school. In this bulletin, 'children' includes service users aged 18 years and under who are engaging with children's disability services, and 'adults' refers to those engaging with adult disability services.

Overall, 26,628 people with an ID are included in this bulletin, as their records on NASS were confirmed as being up to date by their main service provider or were newly registered on NASS in 2022. Of these, 19,019 were adults and 7,609 were children.

#### Profile of people with an intellectual disability (ID) engaging with disability services, 2022

- A total of 25,187 people reported ID as their primary disability.
- The remaining 1,441 reported ID as an additional disability. Amongst those, the most common primary disability reported was autism (1,018; 71%).
- Where data on sex was provided (26,607; 99%), 15,764 (59%) were male.
- More than one-quarter (28%; 7,331) were under 18 years of age, while a similar number and proportion was reported in the age groups of 18 to 39 years (36%; 9,573), and 40 years and over (37%; 9,724).
- Of the adults not living in a residential setting (12,102), more than three-quarters (77%, 9,355) reported having a primary carer.

¹ 'HSE disability-funded' refers to the budget the HSE uses to fund services for people with disabilities. In 2022, the overall budget for disability services was €2.4 billion. See https://www.gov.ie/en/press-release/59a35-minister-anne-rabbitte-announces-disability-services-budget-for-2023/

<sup>&</sup>lt;sup>2</sup> A neurological disability can include epilepsy, spina bifida, Alzheimer's disease, multiple sclerosis, acquired brain injury, and Parkinson's disease. This term applies to impairments of the nervous system.

#### **Services**

Please note the limitations to this data as outlined in section 1.2. Information on residential services, respite (day and overnight) services, and supports for daily living is presented for the full cohort of people registered with NASS. Information on specialist supports for children is incomplete; therefore, these data are only presented for adults.

#### **Current service provision**

The following outlines 2022 data for current service provision.

- A total of 6,954 people were recorded as living in a residential setting.
  - o Of these, 6,877 were adults and 77 were children.
  - Most were living in a residential house in the community (2,819) or a community group home (2,656).
- A total of 1,935 people accessed a home support service.
  - Of these, 1,441 were adults and 494 were e children.
- Among adults only, 15,326 accessed either a day programme (14,105), or rehabilitative training (1,411).
- A total of 848 people accessed day respite.
  - o Of these, 569 were adults and 279 were children.
- Overall, 2,819 people accessed overnight respite.
  - o Of these, 2,356 were adults and 463 were children.
  - A total of 70,404 nights were accessed, with a median of 17 nights received by individuals annually.
- A total of 1,414 people received a community support service in 2022.
- Overall, 7,143 children were assessed and found to require the support of a multidisciplinary Children's Disability Network Team (CDNT).
- A total of 10,492 adults received at least one specialist support. The most commonly provided specialist supports were social work (4,596), speech and language therapy (3,756), and nursing (3,682).

#### New services required 2022-2027

The following outlines data regarding new services required for 2022-2027 as identified by service providers.

- A total of 1,652 people require a residential service.
  - Of these, 1,620 were adults and 32 were children.
- Home support was required by 320 people.
- Service providers identified 171 people as requiring a day respite service.
  - o Of these, 95 were adults and 76 were children.
- A total of 1,149 people require overnight respite.
  - o Of these, 908 were adults and 241 were children.

#### New services required for 2022-207 (identified for adults only)

- A total of 293 adults require either a day programme (266) or rehabilitative training (27).
- A total of 1,774 adults required at least one specialist support.
  - Overall, 2,657 specialist supports were identified as required. Speech and language therapy is the most commonly required support (508), followed by occupational therapy (375).

#### 1 Background

This bulletin presents an overview of the information recorded by service providers for people with an intellectual disability (ID) reported as either a primary or additional disability on the National Ability Supports System (NASS) for 2022. This is a supplementary bulletin to be read in conjunction with the NASS 'Overview of people engaging with disability services, 2022'.

NASS is a national database that records information about Health Service Executive (HSE) disability-funded services that are received or required as a result of an intellectual disability (ID), developmental delay, physical, sensory, neurological, learning, speech and/or language disabilities or autism. Mental health as a type of disability is also recorded on NASS where an individual is in receipt of a HSE disability-funded service.

There are some 18-year-olds who have moved to adult services while others remain in children's services until they finish secondary school. In this bulletin, 'children' includes service users aged 18 years and under who are engaging with children's disability services, and 'adults' refers to those engaging with adult disability services.

Overall, 26,628 people with an ID are included in this bulletin, as their records on NASS were confirmed as being up to date by their main service provider or were newly registered on NASS in 2022. Of these, 19,019 were adults and 7,609 were children.

#### 1.1 Data Collection

Information on NASS is captured under four headings:

- Service user details
- Primary carer details
- Disability type and diagnosis, and
- Services

A primary disability should be recorded by the service provider for every person on NASS. There is also an option for reporting additional disability type(s). A primary disability refers to the disability which most restricts a person's ability to take part in daily life and/or the disability that gives rise to using or needing the most disability-funded services.

Within the Services section, NASS captures 77 service options across six service types:

- Residential setting
- Day services
- Day respite
- Overnight respite
- Supports for daily living (for example, home support, a personal assistant, or community support), and
- Specialist supports (for example, physiotherapy, speech and language therapy, or occupational therapy).

Service providers record information about current services funded through the HSE disability budget and services identified as being currently required or that will be required within the next 5 years.

#### 1.2 Limitations of data

It is important to note that the data returned for children by the newly established Children's Disability Network Teams (CDNTs) are less complete than the data provided by service providers for adults accessing HSE disability-funded services. Overall, a significant increase in the number of children registered on NASS was achieved in 2022. However, the data are largely incomplete for most of these children. Work is ongoing with our partners in the HSE to improve the completeness of these data.

### 2 Profile of people who have an intellectual disability (ID) engaging with disability services

#### 2.1 Number of people who have an ID registered on NASS in 2022

A total of 26,628 people are included in this report.

- Of the 19,019 adults, 96% (18,195) had ID recorded as their primary disability and the remaining 4% (824) had ID recorded as an additional disability.
- 7,609 were children, of these 92% (6,992) had ID recorded as their primary disability. The remaining 8% (617) had ID recorded as an additional disability.

The breakdown of registrations by Community Healthcare Organisation (CHO) area of service is listed in Table 1. The majority of people with an ID availed of their service in CHO 4 (4,570; 17%) followed by CHO 7 (3,648; 14%).

Among adults, CHO 4 had the highest number of registrations (2,858; 15%), followed by CHO 7 (2,595; 14%). Among children CHO 4 had the highest number of registrations (1,712; 23%), followed by CHO 2 (1,076; 14%) and CHO 7 (1,053; 14%).

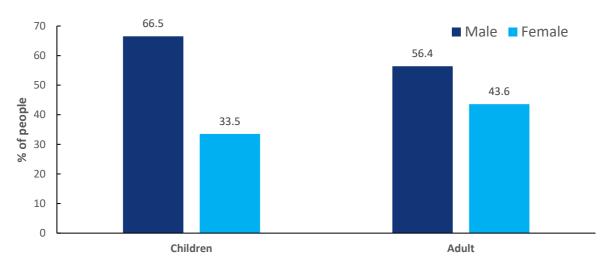
Table 1 Number of people with an intellectual disability (ID) registered on NASS by CHO of service, 2022

	Children		Adults		Total population	
	n	%	n	%	n	%
CHO 1 - Donegal, Sligo, Leitrim, Cavan, Monaghan	643	8.5	1,482	7.8	2,125	8.0
CHO 2 - Galway, Roscommon, Mayo	1,076	14.1	2,111	11.1	3,187	12.0
CHO 3 - Clare, Limerick, North Tipperary	247	3.2	1,709	9.0	1,956	7.3
CHO 4 - Kerry, Cork	1,712	22.5	2,858	15.0	4,570	17.2
CHO 5 - South Tipperary, Carlow, Kilkenny, Waterford, Wexford	574	7.5	2,337	12.3	2,911	10.9
CHO 6 - Wicklow, Dun Laoghaire, Dublin South East	505	6.6	1,161	6.1	1,666	6.3
CHO 7 – Kildare, West Wicklow, Dublin West, Dublin South City, Dublin South West	1,053	13.8	2,595	13.6	3,648	13.7
CHO 8 – Laois, Offaly, Longford, Westmeath, Louth, Meath	871	11.4	2,369	12.5	3,240	12.2
CHO 9 - Dublin North, Dublin North Central, Dublin North West	928	12.2	2,397	12.6	3,325	12.5
Total	7,609	100.0	19,019	100.0	26,628	100.0

#### 2.2 Demographic profile

Where sex was known (26,607; 99%), almost three-fifths of those with an ID were male (59%; 15,764). The differences in the proportions of males and females were greater for children than adults. A breakdown of sex by cohort is shown in Figure 1.

Figure 1 Sex breakdown of children and adults with an intellectual disability (ID) registered on NASS, 2022



<sup>\*</sup> Sex at birth was missing for 21 children.

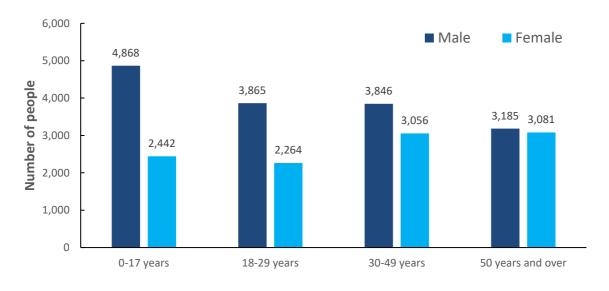
More than one-quarter (28%; 7,331) of people with an ID registered on NASS were under 18 years of age, while a similar number and proportion was reported in the age groups of 18 to 39 years (36%; 9,573) and 40 years and over (37%; 9,724) (Table 2).

Table 2 Age breakdown of people with an intellectual disability (ID) registered on NASS, 2022

Age group	n	%
0-4 years	438	1.6
5-12 years	3,722	14.0
13-17 years	3,171	11.9
18-24 years	3,921	14.7
25-39 years	5,652	21.2
40-59 years	6,757	25.4
60-69 years	2,155	8.1
≥ 70 years	812	3.0
Total	26,628	100.0

A larger proportion of people with an ID were male in each age group; however, the differences were smaller in the older age groups. Figure 2 below shows the sex breakdown for each age group.

Figure 2 Number of people with an intellectual disability (ID) registered on NASS by age and sex, 2022



Age groups

<sup>\*</sup> Sex at birth was missing for 21 children.

#### 2.3 Additional sociodemographic data for adults

Information on ethnicity, living arrangements, employment, and primary carer was limited for children due to differing methods of data collection. As a result, the following section focuses on **adults only.** 

- Where information was known (16,217; 93%), just under half of adults with ID were in a training/day programme (46%; 7,385), while a third (33%; 5,315) were unable to work due to disability. Less than one in 10 (7%; 1,187) were in paid employment and unemployed (7%; 1,175), with smaller proportions retired (3%; 425), students (2%; 322) or reported as other (2%; 403).
- Where information was known (13,631; 72%), most adults with an ID self-identified as Irish (93%; 12,732).
- Where information was known (18,731; 98%), over half of adults with ID (57%; 10,604) were living with family members, more than a third were living in a residential setting (37%; 6,916), 925 (5%) were living alone, and 286 (2%) lived with non-relatives.
- Among adults with an ID who did not live in a residential setting (12,102), over three-quarters (9,355; 77%) reported having a primary carer. Nearly all of whom (94%; 8,829) live with their primary carer.
  - o Four-fifths (85%; 7,988) of primary carers were parents.
  - Age was recorded for three-quarters (75%; 7,033) of primary carers; of whom, 58% (4,105) were aged between 18 and 59 years and 42% (2,928) were aged 60 years and over.

#### 2.4 Reported disabilities

Of the 25,187 service users with ID as a primary disability, 40% (10,196) had at least one additional disability. The most common additional disability was a physical disability, and this was present in 17% (4,198) of people with ID as their primary disability. A physical disability was the most common additional disability for adults (1,066; 15%), while the most common additional disability for children was a speech and/or language disability (1,254; 18%).

Table 3 Additional disabilities among people reporting intellectual disability (ID) as a primary disability, NASS 2022

Additional disabilities	Children		Adults		Total population	
	n	%	n	%	n	%
Total population	6,992	100	18,195	100	25,187	100
Physical	1,066	25.4	3,132	74.6	4,198	16.7
Speech and/or language	1,254	32.9	2,562	67.1	3,816	15.2
Autism	967	39.9	1,459	60.1	2,426	9.6
Visual	313	20.8	1,194	79.2	1,507	6.0
Hearing loss and/or deafness	289	25.1	862	74.9	1,151	4.6
Mental health	12	1.4	823	98.6	835	3.3
Neurological	113	16.7	562	83.3	675	2.7
Specific learning difficulty (other than intellectual)	24	20.7	92	79.3	116	0.5
DeafBlind-dual sensory	7	17.9	32	82.1	39	0.2
Developmental delay (under 10 years only)	37	100	0	0.0	37	0.1
Not verified*	~	~	37	94.9	~	~

<sup>\*</sup>Not verified - where the type of disability has not been verified for an individual by an appropriate healthcare professional.

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

<sup>~</sup> In order to protect against the risk of indirect identification of individuals, values of less than 5, or where individuals may be identified, have been suppressed.

Of the 1,441 people with an ID as an additional disability the most common primary disability reported was autism (1,018; 71%). Autism was the most common primary disability for both children (521; 84%) and adults (497; 60%).

Table 4 Primary disabilities among people reporting intellectual disability (ID) as an additional disability, NASS 2022

Primary disability	Children		Adults		Total population	
	n	%	n	%	n	%
Total population	617	100	824	100.0	1,441	100
Autism	521	51.2	497	48.8	1,018	70.6
Physical	37	21.8	133	78.2	170	11.8
Neurological	21	21.6	76	78.4	97	6.7
Visual	14	25.9	40	74.1	54	3.7
Mental health*	0	0.0	53	100	53	3.7
Hearing loss and/or deafness	8	38.1	13	61.9	21	1.5
Developmental delay (under 10 years only)	9	100	0	0.0	9	0.6
Specific learning difficulty (other than intellectual)	~	~	~	~	7	0.5
Speech and/or language	6	100	0	0.0	6	0.4
DeafBlind-dual sensory	0	0.0	5	100	5	0.3
Not verified**	0	0.0	~	~	~	~

<sup>\*</sup>All those with a primary disability of mental health had a secondary disability type eligible for HSE disability-funded services.

<sup>\*\*</sup>Not verified - where the type of disability has not been verified for an individual by an appropriate healthcare professional.

<sup>~</sup> In order to protect against the risk of indirect identification of individuals, values less than 5, or where individuals may be identified, have been suppressed.

#### 3 Services

The following section outlines the current service use of people with an intellectual disability (ID) registered on NASS as well as the new services they require either currently or within the next 5 years, as reported by service providers.

NASS collects information on the HSE disability-funded services people with disabilities use and/or will require in the next 5 years in the following categories:

- Residential and home support services
- Day services
- Day and overnight respite, and
- Support services (including personal assistant (PA), multidisciplinary and specialised disability supports).

The information presented in this section represents whether a service was recorded as:

- Current services: The number of places accessed in the reporting year.
- Enhancement required to current services: The number of places accessed which
  require an enhancement in the next 12 months; for example, additional hours/days
  or additional support.
- **New services required:** The number of new places required for those not in receipt of that service but who require it now or will require it within the next 5 years.

This section reports on children and adults with an ID engaging with disability services. Information on residential services, respite (day and overnight) services, and supports for daily living is presented for the full cohort of people with an ID. Information on specialist supports for children is incomplete; therefore, these data are only presented for adults.

Individuals may access one or more services within our broad categories of services outlined e.g. a person can access both centre based day respite and day respite in their own home over the calendar year.

#### 3.1 Current service provision

The following outlines 2022 data for current service provision.

#### 3.1.1 Residential and home support services

- A total of 6,954 (26%) people with an ID were recorded as living in a residential setting.
  - Of these, 6,877 were adults and 77 were children.
  - A house in the community was the most common residential setting (2,819), followed by community group home (2,656).
  - Just over one-fifth (21%; 1,505) of current residential places require an enhancement; of which, 537 relate to places in community group homes, and 502 to places in houses in the community.
- A total of 1,935 people accessed a home support service.
  - o Of these, 1,441 were adults and 494 were children.
  - More than one-quarter (28%; 533) of those currently accessing home support require an enhancement to their service.

#### 3.1.2 Day Service (Adults only)

- 15,326 adults with an ID accessed either a day programme, or rehabilitative training.
- A day programme was most commonly accessed (14,105; 82%). An enhancement was required to 3,134 (22%) day programmes.
- Rehabilitative training was received by 1,411 adults, with an enhancement needed to 232 (16%) of those places.

#### 3.1.3 Day Respite

- A total of 848 people were reported to be accessing 1,733 day respite services:
  - o Of these, 569 were adults were 279 were children.
  - Of the day respite services provided, 638 were centre-based respite places, 181 were home sharing places and 66 were day respite in the person's own home.
  - More than one-in-ten (14%; 234) day respite services were reported as requiring an enhancement.

#### 3.1.4 Overnight Respite

- In total, 2,819 people accessed overnight respite places.
  - o Of these, 2,356 were adults were 463 were children.
  - Respite in a house in the community or a dedicated respite centre (2,492) was the most commonly accessed type of overnight respite, followed by home sharing (174).
  - More than two-fifths (41%; 1,211) overnight respite services required an enhancement.
  - A total of 70,404 nights were accessed, with a median of 17 nights received by individuals annually.

#### 3.1.5 Support services

- A total of 1,414 people accessed community support, of whom 1,266 were adults and 148 were children. Of those accessing community support, 233 (16%) require an enhancement to their service.
- In 2022, 1,001 people used a transport service, of whom 876 were adults and 125 were children. Almost one-fifth (18%; 185) of those using transport services require an enhancement to their current service.
- In total, 7,143 children were assessed and found to require the support of a multidisciplinary Children's Disability Network Team (CDNT).
- A total of 10,492 adults received at least one specialist support. Overall, 33,306 specialist supports were accessed.
  - The most commonly provided specialist supports were social work (4,596),
     speech and language therapy (3,756) and nursing (3,682).
  - Nearly one in two people required an enhancement to at least one of their specialist supports (46%; 5,036).

#### 3.2 Services required 2022-2027

As outlined in Section 1, NASS collects information on the HSE disability-funded services that people with disabilities currently use and/or will require in the next 5 years. New services required are the number of new places that service providers have identified as being required by people who are not yet in receipt of a particular type of service but who currently need it or will need it within the next 5 years.

The following outlines data regarding new services required for 2022-2027 as identified by service providers.

#### 3.2.1 Residential and home support requirements

- A total of 1,652 people with an ID were identified by service providers as requiring a residential service.
  - o Of these, 1,620 were adults and 32 were children.
  - 1,510 new places are required in a house in the community with four of fewer residents.
- A home support service is required by 320 people; of these, 279 were adults and 41 were children.

#### 3.2.2 Day service requirements

- A total of 293 adults with an ID require a day service, including either:
  - A day programme (266), or rehabilitative training (27).

#### 3.2.3 Day respite requirements

- A total of 171 people require a day respite service.
  - o Of these, 95 were adults and 76 were children.
  - The most commonly required day respite service is centre based respite (124), followed by day respite in the person's own home (48).

#### 3.2.4 Overnight respite

- A total of 1,149 people require overnight respite.
  - o Of these, 908 were adults and 241 were children.
  - Overnight respite in a house in the community or a dedicated respite centre is the most commonly required (840), followed by holiday respite in a hotel, B&B or hostel (171) and holiday respite in a residential centre or summer camp (168).

#### 3.2.5 Support service requirements (identified for adults only)

- Service providers reported that community support is required by 226 adults, transport services are required by 162 adults, advocacy services are required by 105 adults, and PAs are required by 97 adults.
- A total of 1,774 adults required at least one specialist support.
  - Overall, 2,657 specialist supports were identified as required. Speech and language therapy is the most commonly required support (508), followed by occupational therapy (375) and clinical psychology (281).

#### 4 Publications and analysis

This bulletin provides an overview of data recorded on NASS about people with an ID. This bulletin should be read in conjunction with the main NASS bulletin 'Overview of people engaging with disability services, 2022'. Additional supplementary bulletins presenting information on people with physical or sensory disabilities, autistic people and by CHO area are available on the Health Research Board (HRB) website <a href="https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/publications/">https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/publications/</a>.

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