

HRB Supplementary Bulletin National Ability Supports System (NASS)

Overview of Autistic people engaging with disability services, 2022

Rachael Kelly, Claire Casey, & Ena Lynn

Published by:

Health Research Board, Dublin

An Bord Taighde Sláinte

© Health Research Board 2023

National Ability Supports System 2022 Overview of Autistic people engaging with disability services, 2022

Rachael Kelly, Claire Casey, & Ena Lynn

Acknowledgements

The authors wish to acknowledge the continuing commitment and co-operation of the following groups who are involved in the ongoing maintenance of the National Ability Supports System (NASS):

- The NASS Committee
- The National Health Information Systems Unit, Health Research Board, in particular Mary O'Gorman, Tiina Lynch, and Sarah Craig
- The Disability Services Unit of the Department of Health/ Department of Children, Equality, Disability, Integration and Youth
- The Health Service Executive, in particular the NASS personnel and National Disability Operations Team
- 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 who had autism recorded as either a primary or an additional disability, along with their primary 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 services¹ that are received or identified as required by a service provider as a result of an intellectual disability; developmental delay; physical, sensory, neurological,² 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.

Profile of Autistic people engaging with disability services, 2022

- Overall, 15,446 people had autism recorded as a disability.
 - o A total of 12,818 people had autism recorded as their primary disability.
 - The remaining 2,628 people had autism recorded as an additional disability to their recorded primary disability. Amongst those, the most common primary disability reported was intellectual disability (ID) (2,426; 92%).
- Where sex was known (15,234; 99%), 11,489 (75%) were male.
- Nearly four-in-five were under the age of 18 (12,217; 79%).
- Over one quarter (28%; 809) of Autistic adults were living in a residential setting. Over two-thirds (67%; 1,934) of Autistic adults lived with family, 4% (102) lived alone and 1% (34) lived with non-relatives.
- Amongst adults who do not reside in a residential setting (2,111), 77% reported having a primary carer (1,621).

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/

² 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 Autistic 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 for Autistic people registered on NASS.

- A total of 853 people were recorded as living in a residential setting.
 - o Of these, 54 were children and 799 are adults.
- A total of 401 people accessed a home support service.
 - o Of these, 223 were children and 178 were adults.
- Among adults only, 2,083 accessed either a day programme, or rehabilitative training.
- A total of 226 people accessed day respite.
 - o Of these, 171 were children and 55 were adults.
- Overall, 504 people accessed overnight respite.
 - o Of these, 187 were children and 317 were adults.
 - A total of 13,480 nights were accessed, with a median of 18 nights received by individuals annually.
- A total of 587 people had community support recorded as a service in 2022.
- Overall, 12,349 children were assessed and found to require the support of a multidisciplinary Children's Disability Network Team (CDNT).³
- A total of 1,251 adults received at least one specialist support. The most commonly provided specialist supports were psychiatry (522), social work (437) and speech and language therapy (404).

³ Information about children's disability services is available on the HSE website at https://www2.hse.ie/services/disability/childrens-services/overview/

New services required for 2022-2027

The following outlines data regarding new services required for 2022-2027, as identified by service providers for Autistic people registered on NASS.

- A total of 270 people require a residential service.
 - o Of these, 14 were children and 256 were adults.
- A total of 266 people require overnight respite.
 - o Of these, 89 were children and 177 were adults.
- Service providers identified 77 people as requiring a day respite service.
- Home support was required by 74 people.

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

- A total of 106 adults were identified as requiring either a day programme or rehabilitative training.
- A total of 326 adults required at least one specialist supports.
 - Overall, 560 specialist supports were identified as required. Speech and/or language is the most commonly required (106), followed by occupational therapy (90) and clinical psychology (65).

1 Background

This bulletin presents an overview of the information recorded for people who had autism recorded as either a primary or additional disability, along with their primary disability, on the National Ability Supports System (NASS) for 2022. This is a supplementary bulletin to be read in conjunction with 'Overview of people engaging with disability services, 2022' (https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/publications/).

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, 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, 15,446 people 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 the 15,446 people, 12,526 were children and 2,920 were adults.

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/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/or 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 Autistic people engaging with disability services

2.1 Number of Autistic people registered on NASS in 2022

A total of 15,446 people are included in this report.

- 12,526 were in children disability services, of whom 91% (11,416) had autism recorded as their primary disability. The remaining 9% (1,110) had autism recorded as an additional disability.
- 2,920 were adults, of whom 48% (1,402) had autism recorded as their primary disability. The remaining 52% (1,518) had autism 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 Autistic people availed of their service in CHO 4 (3,034, 20%) followed by CHO 3 (3,001, 19%).

Among children, CHO 3 had the highest number of registrations (2,808, 22%), followed by CHO 4 (2,754, 22%) and CHO 7 (1,956, 16%). Among adults, CHO 8 had the highest number of registrations (512, 18%), followed by CHO 9 (457, 16%) and CHO 2 (357, 12%).

Table 1 Number of Autistic people registered on NASS by CHO of Service, 2022

| | Children | | Adults | | Total population | |
|---|----------|-------|--------|-------|------------------|-------|
| | n | % | n | % | n | % |
| CHO 1 - Donegal, Sligo, Leitrim, Cavan, Monaghan | 826 | 6.6 | 240 | 8.2 | 1,066 | 6.9 |
| CHO 2 - Galway, Roscommon, Mayo | 1,001 | 8.0 | 357 | 12.2 | 1,358 | 8.8 |
| CHO 3 - Clare, Limerick, North Tipperary | 2,808 | 22.4 | 193 | 6.6 | 3,001 | 19.4 |
| CHO 4 - Kerry, Cork | 2,754 | 22.0 | 280 | 9.6 | 3,034 | 19.6 |
| CHO 5 - South Tipperary, Carlow, Kilkenny, Waterford, Wexford | 579 | 4.6 | 348 | 11.9 | 927 | 6.0 |
| CHO 6 - Wicklow, Dun Laoghaire, Dublin South East | 340 | 2.7 | 226 | 7.7 | 5,66 | 3.7 |
| CHO 7 – Kildare, West Wicklow, Dublin West, Dublin South City, Dublin South West | 1,956 | 15.6 | 307 | 10.5 | 2,263 | 14.7 |
| CHO 8 – Laois, Offaly, Longford, Westmeath, Louth, Meath | 1,446 | 11.5 | 512 | 17.5 | 1,958 | 12.7 |
| CHO 9 - Dublin North, Dublin North Central, Dublin North West | 816 | 6.5 | 457 | 15.7 | 1,273 | 8.2 |
| Total | 12,526 | 100.0 | 2,920 | 100.0 | 15,446 | 100.0 |

2.2 Demographic profile

Where sex was known (15,234; 99%), three-quarters of Autistic people were male (75%; 11,489). The percentage of males and females was very similar among children and adults. A breakdown of sex by cohort is shown in Figure 1.

Figure 1 Sex breakdown of children and adults registered on NASS who were Autistic, 2022

The median age of Autistic people registered on NASS was 12 years. Nearly half (49%) of Autistic people were aged between 5 and 12 years, while a quarter (25%) were aged between 13 and 17 years (Table 2).

Table 2 Age breakdown of Autistic people registered on NASS, 2022

| Age Group | n | % |
|-------------|--------|-------|
| 0-4 years | 767 | 5.0 |
| 5-12 years | 7,563 | 49.0 |
| 13-17 years | 3,887 | 25.2 |
| 18-24 years | 1,748 | 11.3 |
| 25-39 years | 948 | 6.1 |
| 40-59 years | 443 | 2.9 |
| 60-69 years | 69 | 0.4 |
| ≥70 years | 21 | 0.1 |
| Total | 15,446 | 100.0 |

^{*} Sex at birth was missing for 212 children.

The majority of Autistic people in each age group were male; however, the difference was smaller in the older age groups. Figure 2 below shows the sex breakdown in each age group.

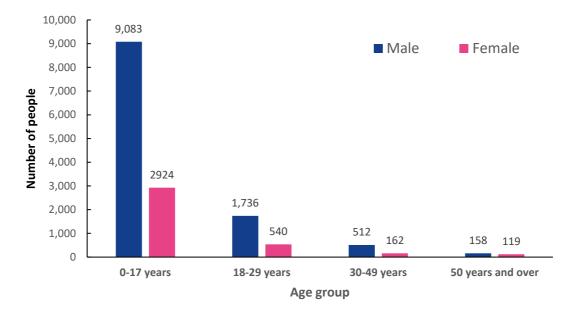


Figure 2 Number of Autistic people on NASS by age and sex, 2022

2.3 Additional sociodemographic data for adults only

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 (2,707; 93% of adults), just under half of adults reported being in a training/day programme (47%; 1,268), while a further 30% (818) reported being unable to work due to disability. One in 10 were unemployed (265; 10%), 228 (8%) were students, 82 (3%) were in paid employment, 35 (1%) reported 'other occupational status', while 10 (0.4%) were retired.
- Where information was known (2,092; 72% of adults), most adults self-identified as Irish (1,967; 94%).
- Where information was known (2,879; 99% of adults), 67% (1,934) of adults were living with family members, 28% (809) were living in a residential setting, 4% (102) were living alone, while 1% (34) lived with non-relatives.
- Among those who did not live in a residential setting (2,111), over three quarters (77%; 1,621) reported having a primary carer, with almost all living with their primary carer (98%; 1,593).
 - Most primary carers were parents (96%; 1,552).
 - Age was recorded for 83% (1,340) of primary carers; 20% (270) of whom were aged 60 years and over.

^{*} Sex at birth was missing for 212 children.

2.4 Reported disabilities

Of the 12,818 people who had autism recorded as a primary disability, 15% (1,849) had at least one additional disability. The most common additional disability recorded was intellectual disability (1,018;8%), followed by speech and/or language (310; 2%).

Table 3 Additional disabilities among people who had autism recorded as a primary disability, NASS 2022

| Additional disabilities | Children | | Adults | | Total population | |
|--|----------|------|--------|------|------------------|-------|
| | n | % | n | % | n | % |
| Total population | 11,416 | 100 | 1,402 | 100 | 12,818 | 100.0 |
| Intellectual | 521 | 4.6 | 497 | 35.4 | 1,018 | 7.9 |
| Speech and/or language | 255 | 2.2 | 55 | 3.9 | 310 | 2.4 |
| Mental health | 45 | 0.4 | 132 | 9.4 | 177 | 1.4 |
| Specific learning difficulty (other than intellectual) | 111 | 1.0 | 45 | 3.2 | 156 | 1.2 |
| Physical | 115 | 1.0 | 31 | 2.2 | 146 | 1.1 |
| Developmental delay (under 10 years only) | 111 | 1.0 | 0 | 0.0 | 111 | 0.9% |
| Neurological | 48 | 0.4 | 44 | 3.1 | 92 | 0.7% |
| Visual | 17 | 0.1 | 18 | 1.3 | 35 | 0.3% |
| Hearing loss and/or deafness | 13 | 0.1 | 15 | 1.1 | 28 | 0.2% |
| DeafBlind (dual sensory) | ~ | ~ | 0 | 0.0 | ~ | ~ |
| Not verified* | 10 | 0.1 | 5 | 0.4 | 15 | 0.1% |
| No additional disability recorded | 10,296 | 90.2 | 673 | 48.0 | 10,969 | 85.6 |

^{*} 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.

[~] In order to protect against the risk of indirect identification of individuals, values less than 5 have been suppressed.

Of the 2,628 people who had autism recorded as an additional disability the most common primary disability recorded was intellectual disability (2,426, 92%).

Table 4 Primary disabilities among people who had autism recorded as an additional disability, NASS 2022

| Primary disability | Children | | Adults | | Total population | |
|--|----------|------|--------|------|------------------|-------|
| | n | % | n | % | n | % |
| Total population | 1,110 | 100 | 1,518 | 100 | 2,628 | 100.0 |
| Intellectual | 967 | 87.1 | 1,459 | 96.1 | 2,426 | 92.3 |
| Developmental delay (under 10 years only) | 54 | 4.9 | 0 | 0.0 | 54 | 2.1 |
| Physical | 45 | 4.1 | 7 | 0.5 | 52 | 2.0 |
| Visual | 11 | 1.0 | 16 | 1.1 | 27 | 1.0 |
| Neurological | 12 | 1.1 | 11 | 0.7 | 23 | 0.9 |
| Mental health* | ~ | ~ | 12 | 0.8 | ~ | ~ |
| Hearing loss and/or deafness | 6 | 0.5 | 7 | 0.5 | 13 | 0.5 |
| Specific learning difficulty (other than intellectual) | ~ | ~ | ~ | ~ | 8 | 0.3 |
| Speech and/or language | ~ | ~ | ~ | ~ | 7 | 0.3 |
| DeafBlind (dual sensory) | 0 | 0.0 | ~ | ~ | ~ | ~ |
| Not verified** | ~ | ~ | 0 | 0.0 | ~ | ~ |

^{*}All those with a primary disability of mental health had a secondary disability type eligible for HSE disability-funded services.

^{**}Not verified - where the type of disability has not been verified for an individual by an appropriate healthcare professional.

[~] 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 service use and services needed now or within the next 5 years, as reported by service providers, for Autistic people registered on NASS are displayed in the following section.

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.

Information on residential services, respite (day and overnight) services, and supports for daily living will be presented for the full cohort of Autistic people registered on NASS. 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 data of current service provision for Autistic people registered on NASS.

3.1.1 Residential and home support services

- A total of 853 people were recorded as living in a residential setting.
 - o Of these, 54 were children and 799 are adults.
 - A house in the community was the most common residential setting (501), followed by a community group home (207), a residential centre (100) and a specialist facility for challenging behaviour (48).
 - Sixteen percent (140) of current residential places accessed require an enhancement.
- A total of 401 people accessed a home support service.
 - Of these, 223 were children and 178 were adults.
 - Nearly three-in-ten (29%; 115) of current home support services require an enhancement.

3.1.2 Day Service (Adults only)

- 2,083 Autistic adults accessed either a day programme, or rehabilitative training.
- A day programme was most commonly accessed (1,715; 82%). An enhancement was required to 368 (21%) day programmes.
- Rehabilitative training was received by 406 adults, with an enhancement needed to 40 (10%) of those places.

3.1.3 Day Respite

- A total of 226 people were reported to be accessing 240 day respite services.
 - Of these, 171 were children and 55 were adults.
 - Of the day respite services provided, 148 were centre-based respite places,
 48 received day respite in their own home and 44 were home sharing places.
 - One-fifth (20%; 45) of people receiving day respite require an enhancement to their current service.

3.1.4 Overnight Respite

- In total, 504 people accessed overnight respite places.
 - Of these, 187 were children and 317 were adults.
 - Overnight respite in a house in the community or a dedicated respite centre was the most commonly accessed type of overnight respite (451), followed by holiday respite in a hotel/B&B (26).
 - A total of 13,480 nights were accessed, with a median of 18 nights received by individuals annually.
 - Nearly one-half (247; 49%) of people receiving overnight respite required an enhancement to their service.

3.1.5 Support services

- A total of 587 people accessed community support, of whom 267 were children and 320 were adults. Over one in ten (12%; 72) community supports require an enhancement.
- In 2022, 161 people used a transport service, of whom 67 were children and 94 were adults.
- In total, 12,349 children were assessed and found to require the support of a multidisciplinary Children's Disability Network Team (CDNT).
- A total of 1,251 adults received at least one specialist support. Overall, 3,797 specialist supports were accessed.
 - The most commonly provided specialist supports were psychiatry (522), social work (437), and speech and language therapy (404).
 - Nearly two in five people required an enhancement to at least one of their specialist supports (36%; 447).

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 need it now 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 for Autistic adults registered on NASS.

3.2.1 Residential and home support requirements

- A total of 270 people were identified by service providers as requiring a residential service.
 - o Of these, 14 are children and 256 are adults.
 - Over nine-in-ten (93%; 252) of residential services required are for a place in a house in the community with four of fewer residents.
- A home support service is required by 74 people, of whom, 31 are children and 43 are adults.

3.2.2 Day service requirements (adults only)

- A total of 106 adults require a day service, including either:
 - A day programme (80), or rehabilitative training (26).

3.2.3 Day respite requirements

- A total of 77 people require a day respite service.
 - Of these, 50 were children and 27 were adults.
 - The most commonly required day respite service is centre based respite (59), followed by day respite in their own home (22).

3.2.4 Overnight respite

- A total of 266 people require overnight respite.
 - o Of these, 89 were children and 177 were adults.
 - Overnight respite in a house in the community or in a dedicated respite centre is the most commonly required (206), followed by holiday respite in a hotel or B&B (28), and holiday respite in a residential centre or summer camp (23).

3.2.5 Support service requirements (identified for adults only)

- A total of 326 adults required at least one specialist supports.
 - Overall, 560 specialist supports were identified as required. Speech and language is the most commonly required (106), followed by occupational therapy (90), and clinical psychology (65).

4 Publications and analysis

This bulletin provides an overview of data recorded on NASS about Autistic people registered on NASS. This bulletin should be read in conjunction with our main bulletin 'Overview of people engaging with disability services, 2022'. Additional supplementary bulletins presenting information on people with an intellectual disability, and physical or sensory disabilities, and by CHO area are available on the 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.