



Oifig an Stiúrthóir Cúnta Náisiúnta,
Foireann Míchumais Náisiúnta,
An Chéad Urlár - Oifigí 13, 14, 15,
Àras Phlásóg na Rós, Coimpléasc Gnó na hOllscoile,
Páirc Náisiúnta Teicneolaíochta,
Caladh an Treoigh,
Luimneach.

Office of the Assistant National Director,
National Disability Team,
First Floor- Offices 13, 14, 15,
Roselawn House, University Business Complex,
National Technology Park,
Castletroy,
Limerick.

22nd May 2024

Deputy Neasa Hourigan,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: neasa.hourigan@oireachtas.ie

Dear Deputy Hourigan,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

PQ: 21047/24

To ask the Minister for Children; Equality; Disability; Integration and Youth whether there is a national and/or regional waiting list/register for those with an intellectual disability in need of residential placement; if so, the person or body responsible for the maintenance of the same; and if he will make a statement on the matter.

PQ: 21048/24

To ask the Minister for Children; Equality; Disability; Integration and Youth if he will provide, in tabular form, the number of adults on the waiting list for a residential placement; the number of new residential placements created, staffed and opened; the number of new placements filled by residents moved from a congregated setting; the number filled by residents moving from family homes in each of the years 2022 and 2023; and the number of new placements that are due to be fully funded and opened in 2024.

PQ: 21049/24

To ask the Minister for Children; Equality; Disability; Integration and Youth the number of persons in the State with an intellectual disability who are aged 40 years or over.

PQ: 21050/24

To ask the Minister for Children; Equality; Disability; Integration and Youth the number of person with an intellectual disability who are living in State-funded accommodation.



HSE Response

HSE Disability Services does not collect data on the number of people in the State who have an intellectual disability.

However, Census 2022 Profile 4 - Disability, Health and Carers reports that:

- the total number of people who experienced an intellectual disability to any extent was 109,288 people.
- that this represents 2% of the population or 10% of all people experiencing at least one long-lasting condition or difficulty to any extent.
- Looking at five year age groups, the number of people experiencing an intellectual disability increased up to the age of 14 and then declined quite rapidly for those aged 15 to 39 years.
- Incidence of an intellectual disability rose again among people in the age groups 40 to 59 years before declining for those aged 60 to 84 years.

Many people with a disability, live lives in the community and are supported by main stream health and social care services.

Specialist community based disability services are delivered to approximately 7% of those with a disability, (up to 80,000 people) for people with physical, sensory, intellectual disabilities or autism. These services focus on people with more complex needs, and complement the mainstream health and social care services provided to people with disabilities alongside the rest of the population.

The National Ability Supports System (NASS), is a national database that records information about disability-funded services that are received or required as a result of an intellectual disability, developmental delay, physical, sensory, neurological, learning, autism spectrum or speech/language disability.

NASS has been developed, and is managed, by the Health Research Board following extensive consultation with the Department of Health, the HSE, section 38 and section 39 disability service providers and is overseen under the governance of the Department of Children, Equality, Disability, Integration and Youth's National Database Committee.

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. For the future, this will provide a stronger basis for modelling service needs.

The latest published report for NASS is the 2022 annual report, which saw a record 73,927 service users of disability-funded services, recorded on NASS.

The NASS Report 2022, provides a Profile of people with an intellectual disability (ID) engaging with disability services.

- 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 gender 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.

The full 2022 NASS annual report is available at the following location:

<https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/publications/publication/overview-of-people-engaging-with-disability-services-in-ireland-2022-1/returnPage/1/>



Residential Services

Residential services make up the largest part of the Disability funding disbursed by the HSE – almost 60% of the total budget – and approximately 90 service providers provide residential services to 8,472 individuals throughout the country. The bulk of these are provided by the 50 highest funded agencies (comprising both Section 38 & Section 39 organisations) – some 6,356 places, or 75%. The HSE itself provides 1,069 or 13% of the places. While 1,029 places or 12% are provided by Private-for-Profit agencies.

The HSE developed a Residential Capacity Database to capture the number of residential placements / contract capacity per the service arrangement between the nine CHO areas and the service provider agencies.

Please see the table below which provides information on the number of residential places at the end of December each year up to the end of March 2024.

Year	December 2020	December 2021	December 2022	December 2023	End of March 2024
Residential Places	8,139	8,146	8,282	8,400	8,472

A number of new emergency residential places have been added to the residential base, which results in a capacity increase. However, it should also be noted that Residential Capacity will also reduce during the year as a result of the loss of places in congregated settings due to deaths, which cannot be re-utilised. This is in keeping with Government policy, which is to move away from institutionalised settings (i.e. Time to Move On from Congregate Settings) where the State is actively implementing a policy that will have a bed reduction impact. In addition, “in-year” capacity (bed) levels will also be impacted negatively as a result of regulatory requirements; that is, where an inspection outcome leads to capacity being reduced.

While data is not collated nationally regarding the number of people moving from family homes into a residential setting each year, the majority of people availing of Priority 1 Emergency Residential Placements would be moving from the family home, where their families are no longer able to maintain the level of support they have been providing, even when additional supports are being provided. This would largely be due to demographic challenges associated with the increase in age and life expectancy and the changing needs of people with a disability.

With regard to the number of person with an intellectual disability who are living in State-funded accommodation, based on the National Disability Database Reports, we can estimate that about 8% of our Residential Capacity is taken up by people with a physical or sensory disability and 92% by people with an Intellectual Disability or Autism.

Waiting List

There is no centrally maintained waiting list for residential services. The local HSE CHO areas would be aware of the need and requirements in their respective areas and would work with the local Service Providers with a view to responding to the level of presenting needs within the resources available.

Disability Support Application Management Tool (DSMAT)

HSE Disability Services has introduced a system called the Disability Support Application Management Tool (DSMAT), which provides a list and detailed profiles of people (Adults & Children) who need additional funded supports in each CHO.

DSMAT captures detailed information on home and family circumstances and a detailed presentation profile of the individuals. This enables Community Healthcare Organisation (CHO) areas to record and manage requests for support and to ensure that the application process is equitable and transparent.

It is important to note that in the absence of a statutory, legislative framework providing entitlement to services, the DSMAT is not a chronological waiting list. Rather, it is a support to the CHO area to feed into its decision making process around prioritisation of services, subject to budgetary constraints.



This means that services are allocated on the basis of greatest presenting need and associated risk factors.

Please see tables below- National Aggregation for 2019 to 2023.

The figures below represent a "point in time" analysis and may not include applications received in to the CHO but not yet processed onto the DSMAT tool.

Residential Services

Total Applicants New Residential Service	2019	2020	2021	2022	Mid. Yr. 2023	End of Q1 2024
	776	1033	1158	1205	1296	1,414

Applications for Non Residential Services

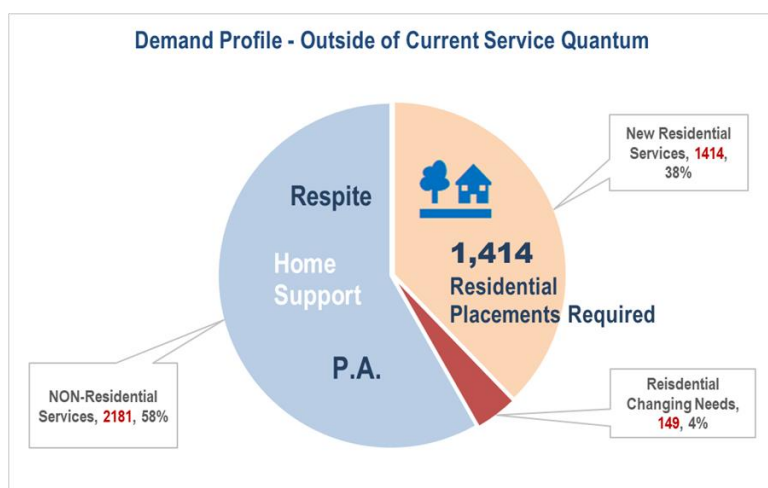
Total Applicants: Personal Assistance and Home Support Services and Day Respite Services	Mid. Yr. 2019	Mid. Yr. 2020	Mid. Yr. 2021	Mid. Yr. 2022	Mid. Yr. 2023	End of Q1 2024
	1117	1619	1903	2142	2492	2,181

The pie chart below, provides an overview of the demand for services – outside of current service quantum.

Just to note that 149 applications are linked to applications on behalf of existing persons in residential services in which there is significant changing need due to ageing, mental health, behavioural presentation etc., and there is a required need for additional funded supports on a recurring basis within the designated centres.

Such requirement for additional resource is also frequently an outcome of regulatory escalation by the HIQA Disability Inspectorate.

Demand Summary – Q1, 2024



Congregated Settings

Time to Move On from Congregated Settings is progressing and continues to demonstrate very positive results for service users who have transitioned to living in homes in community settings. The original 2012 report identified over 4,000 people living in 72 congregated settings. With the incremental progress made since 2012 to support people to



transition to homes in the community, there are now less than 1,600 people remaining in the tracked congregated settings identified in the original report.

A full audit of the current status of congregated settings is underway and an Annual Report will be prepared for 2023.

Please see the table below for the number of completed transitions since 2019.

The number of completed transitions since 2019 are as follows:	
Year	Transitions
2019	116
2020	118
2021	127
2022	38
2023	70

Emergency Residential Placements

In previous years, funding has been allocated in the National Service Plan to provide for additional new emergency residential placements, as follows:

- The HSE responded to 474 “emergency places/cases” between 2014 and 2016.
- NSP 2017 made provision for 185 new emergency residential placements
- Between 2018 and 2020, the HSE developed a total of 252 new emergency places across the 9 CHOs.
- In accordance with the NSP 2021, 91 new emergency residential places were developed; a further 25 planned residential places also opened in 2021; 4 adult transfers to Tusla also took place. A further 19 people aged under 65 living in nursing homes were supported to move to homes of their choosing in the community, during the year.
- In accordance with the NSP 2022, the HSE developed 103 new emergency residential places together with 11 Planned Residential places and 18 new intensive support packages and 19 new supported living packages. The CHO Areas indicated that 22 people transitioned from Nursing Homes to homes of their choosing in the community and 32 packages to support adults ageing out of Tusla services were put in place.
- In accordance with the NSP 2023, the HSE has been allocated funding to provide 43 additional residential places in response to current need. In addition, in line with the Winter Plan, 27 people received new residential places with 3 further receiving home care packages. A further 25 residential care packages were developed for young people ageing out of Tusla services in line with the Joint Protocol. At end of 2023, 160 Priority 1 (Emergency) Residential Places were developed. This is significantly in excess of the NSP target of 43 places based on funding allocation and reflects the increased demand for residential services throughout the country and the need to respond to changing/ unmet service user need (Including clinical/ safeguarding risks).
- In the National Service Plan 2024, the HSE will provide in the region of an additional 100 Priority 1 residential placements for immediate occupation.

Future Planning

The demand for full-time residential placements within designated centres is extremely high and is reflective of the absence of multi-year development funding that has not been in place since 2007/2008.

The Department of Health’s 2021 Disability Capacity Review has projected a need for a minimum of an additional 1,900 residential places by 2032 under a minimum projection and an extra 3,900 in order to return to levels of provision prior to the beginning of the 2008 recession.



Action Plan for Disability Services 2023-2026

The Action Plan for Disability Services 2024-2026, sets out a three year programme designed to tackle the deficits highlighted in the *Disability Capacity Review to 2032*, which identified the demand for specialist community-based disability services arising from demographic change, and considerable levels of unmet need.

Specifically, the Disability Capacity Review projected a need for a minimum of an additional 1,900 residential places by 2032 under a minimum projection and an extra 3,900 in order to return to levels of provision prior to the beginning of the 2008 recession. Moreover, the central projection of the Capacity Review suggests that adults with intellectual disabilities requiring specialist services will increase by a sixth between 2018 and 2032, with fastest growth for young adults (up a third by 2032) and over 55s (up a quarter). These projections include an average of approximately 90 new residential places that will be needed each year from 2020 to 2032 to accommodate changes in the size and age structure of the disability population.

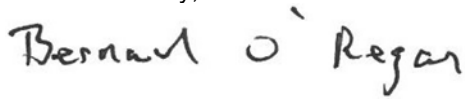
The Action Plan is designed to provide additional funding for developments that will help build capacity within services, so that the benefits of these funding increases will be felt directly by the service user. This will also help the HSE in dealing with some of the key cost-drivers in service delivery, such as high-cost emergency residential placements, giving greater flexibility and control when planning services.

The headline service improvements which are planned over the 2024-26 period are:

Residential

- Around 900 additional residential care places to tackle unmet needs and ensure supply keeps pace with demographic change;
- 500 new community-based residential care places to replace disability care in large institutional and campus-based settings, with a view to ending that form of provision by 2030;
- Continued expansion of respite services, including alternative residential options

Yours Sincerely,



Bernard O'Regan
Assistant National Director
National Disability Team

