



Oifig an Stiúirthóir 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.

2nd October 2024

Deputy Pauline Tully,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: pauline.tully@oireachtas.ie

Dear Deputy Tully,

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

PQ: 36215/24

To ask the Minister for Children; Equality; Disability; Integration and Youth the number of disabled people that were living in respite care as an emergency response to their needs in 2020, 2021, 2022, 2023 and to date in 2024, in tabular form.

PQ: 36216/24

To ask the Minister for Children; Equality; Disability; Integration and Youth the number of respite nights available to disabled people in 2020, 2021, 2022, 2023 and to date in 2024, in tabular form

HSE Response

The HSE and its funded Agencies provide respite care to children and adults with disabilities. Respite can occur in a variety of settings for various lengths of time, depending on the needs of the individual service user and their family or carer, and according to available resources. Respite is not always centre-based and can be provided in a number of ways, e.g. Centre based; In-Home; Home-to-Home; Family Support, etc. As a vital part of the continuum of services for families, respite potentially helps prevent out-of-home full-time residential placements, preserves the family unit, and supports family stability.

The provision of residential respite services has come under increasing pressure in the past number of years due to a number of impacting factors such as:

- an increase in the number of children and adults who are seeking access to respite as a reflection of general population increase;
- increasing levels of complexity across the sector due to better and improved health care;



- an increase in the age of people with a disability resulting in people presenting with “changing needs”;
- a significant number of respite beds have been utilised on longer-term basis due to the presenting complexity of the individual with a disability and also due to home circumstances, which prevents availability of the bed to other respite users;
- the regulation of service provision as set by HIQA, which requires Service Providers to comply with regulatory standards in order to meet regulation. Standards specify a requirement for personal and appropriate space which impacts on the capacity and Statement of Purpose for a Designated Centre. This has had a direct impact on capacity where respite beds are no longer allowed within a residential setting e.g. vacated by residents who go home at weekends or for holidays, can no longer be used for respite.
- Implementation of the national policy on congregated settings (Time to Move on from Congregated Settings Policy) is also affecting capacity.

Provision of respite for persons with disabilities

The table below provides information on the funding for respite services over the last 6 years:

Respite	2018	2019	2020	2021	2022	2023
Funding for Respite Service Provision as per National Service Plan across disability services	€53,595,000	€56,212,000	€70,677,000	€87,423, 000	€96,465,000	€105,703,000

Respite Overnights – Activity Levels 2018 – end of July 2024

The following table uses data taken from the Pre-Lim Reports for end of year 2018 – end of July 2024 reporting cycles, as issued by the HSE’s Business Information Unit. It provides information on the number of overnight respite in 2018, 2019, 2020, 2021, 2022, 2023 and to date in 2024.

	2018	2019	2020*	2021	2022	2023**	To end of July 2024
National	158,368	158,441	87,177	94,606	133,572	151,123	76,863

* In 2020, the delivery of Respite Services continued to operate during the pandemic, albeit at a reduced capacity; some centres remained open, while others were temporarily re-purposed as isolation facilities.

** we had a significant number of non-returns for Respite metrics, mainly due to the Industrial Action.

The level of activity shows that pre COVID-19, the number of Respite Overnights provided by the HSE and its partner Provider Agencies was running at around 158,000 Overnights each year. The delivery of services was significantly impacted by the onset of the pandemic in 2020. The number of respite overnights operated at just over 50% of the NSP target for 2020, due mainly to necessary precautions to maintain physical distancing and to adhere to infection prevention and control requirements.

As outlined above, there has been increased investment in Respite Service over the last number of years that includes additional allocation in successive National Service Plans to develop:

- In 2018, the Minister for Health announced an additional €10 million for the HSE, specifically to enhance respite care in the disability sector. In accordance with the National Service Plan for 2018, the HSE committed to providing:
 - An additional respite house in each of the nine CHO areas to support 450 individuals in a full year and 251 in 2018 (€5m).
 - Three additional respite houses in the greater Dublin areas (CHOs 7, 8 and 9) to support a further 225 individuals in a full year and 143 in 2018 (€3m).
 - Alternative models of respite to support 250 individuals with disability (€2m).



The funding provided for the equivalent of 12 new houses, 1 in each CHO, and 3 in the Greater Dublin area. This resulted in an additional 6,455 bed nights delivered to 763 people.

Alternative respite in the form of summer camps, evening and Saturday clubs were also put in place, benefiting hundreds of adults and children. Community-Based, alternative respite projects delivered 15,144 'in home' Respite Hours, to 400 users and 1,296 Saturday/Evening/Holiday Club 'sessions' to 1,500 people.

- In 2021, nine additional centre-based respite services, providing some 10,400 additional respite nights along with a range of alternative respite projects including Saturday clubs, breakaway schemes, and summer schemes. The majority of these services are now in place.
- In 2022, three additional specialist centre-based services to provide 4,032 nights to 90 children, one to be Prader-Willi appropriate and the other two to provide high-support respite for children and young adults with complex support needs, in addition to seven further respite services which will provide 9,408 nights to 245 children and adults in a full year.
- In 2023, five additional respite services and one enhanced service from part time to full time opening to provide 7,872 additional nights to 278 people in a full year. Along with, the provision of 27 additional in-home respite packages to children and young adults in a full year and 265 day-only respite packages to 180 people in a full year.
- In 2024, in accordance with the NSP, the HSE committed to Increasing the occupancy of existing respite capacity, where feasible, and alternative respite provision, including in-home respite support hours and group-based targeted measures such as summer camps and evening provision.

The HSE is very much aware of the importance of respite service provision for the families of both children and adults with disabilities and the impact the absence of respite service provision can have on people's lives. Respite is a key priority area for the HSE for people with disabilities and their families and we have seen significant investment in respite services in the last few years. In this regard, the HSE continues to work with agencies to explore various ways of responding to this need in line with the budget available.

Respite care as an emergency response

With regard to data on the number of disabled people that were living in respite care as an emergency response, this specific information is not collated by the HSE. However, one of the suite of Key Performance Indicators that is collated provides information on the number of people with a disability in receipt of more than 30 overnights continuous respite (ID/Autism and Physical and Sensory Disability).

While we do not know the exact reasons why an individual's overnight respite stay has been extended, analysis of this data indicates the following figures:

- End of July 2024: **54** people are in receipt of more than 30 overnights continuous respite.
- End of 2023: **58** people were in receipt of more than 30 overnights continuous respite.
- End of 2022: **80** people were in receipt of more than 30 overnights continuous respite.
- End of 2021: **58** people were in receipt of more than 30 overnights continuous respite.
- End of 2020: **100** people were in receipt of more than 30 overnights continuous respite.

Future Planning

There is significant unmet need currently and the projected changes in the size and age profile of the disability population will add to unmet need over the coming decade.

The Disability Capacity Review Report shows that, overall, the disability population is expected to grow up to 2032, with a change in the overall age structure that will affect demand for disability services. The central projection forecasts that the number of adults with a disability would grow by around 10% to 2027 and by 17% in 2032 over the 2018 level.



Critically, the number of older adults is set to rise, driving up demand for full-time residential services when parents or natural support networks are no longer in a position to continue to care at home.

The fastest growth will be for young adults (up a third by 2032) and over 55s (up a quarter by 2032). The importance of early intervention and effective services for children and young people is important in this context to meet their needs now and to mitigate the requirement down the line of increasingly complex need coming through in young adults including earlier residential service, which is also seen in current DSMAT figures.

As the future course of birth rates is unknown, projecting the future size of child population is an uncertain exercise. The Disability Capacity Review considered the Central Statistics Office's analysis of population projection called M2F2 and indicated that:

- There will be a steady decline to 2032 in the number of under-6s and projects a 15% drop to 2032 relative to 2018
- A small increase of about 3% for those aged 6 -17 years in the mid-2020s, declining to around 91% of the 2018 level by 2032
- The school leavers age group of 18-19 year olds od projected to rise steadily by about 20% of 2018 levels to the late 2020s and then to decline to about 15% above the 2018 level. This reflects the baby boom of the first decade of the millennium.

This change in demographics, increased life expectancy and changing needs for those with both a physical and sensory disability, and an intellectual disability has led to a significant increase in the need for disability services across all settings. This includes day supports, residential and respite services, personal assistant and home support services

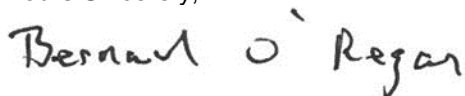
With regard to centre based respite, the Disability Capacity Review informs of up to €10 million in additional provision per year is required (20% additional quantum – 26,200 approx. additional overnights per year).

The just published *Action Plan for Disability Services 2024 – 2026*, prepared by the Department of Children, Equality, Disability, Integration and Youth, details the mix of overnight and alternative respite that will be provided in the short term, and will aim to maximise the impact and reach of these services.

It is proposed to increase the level of respite provision by around a third, through a mix of:

- Provision of alternative respite options including in-home respite, after-school and day respite programmes, host families, summer programmes;
- Using existing overnight residential capacity to the maximum extent;
- Providing additional overnight respite capacity where this is needed.

Yours Sincerely,



Bernard O'Regan
Assistant National Director
National Disability Team

