

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.

2nd May 2024

Deputy Matt Carthy, Dail Eireann, Leinster House, Kildare Street, Dublin 2. E-mail: <u>matt.carthy@oireachtas.ie</u>

Dear Deputy Carthy,

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: 14554/24

To ask the Minister for Children; Equality; Disability; Integration and Youth the adult and children overnight respite services currently operating in each county, in tabular form; and if he will make a statement on the matter.

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.

Increasing the provision of respite for persons with disabilities

Increased Investment

The table below provides information on the funding for respite services over the last 5 years:

Respite	2018	2019	2020	2021	2022
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

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 inhome respite packages to children and young adults in a full year and 265 day-only respite packages to 180 people in a full year.

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.

The following shows how the increased investment has impacted positively on the level of service delivered in successive years:

- 2020 87,177 overnights were accessed by people with a disability (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. The number of respite overnights operated at just over 50% of the NSP target for 2020; while the number of day only sessions operated at 62% of 2020 target. This was mainly due to necessary precautions to maintain physical distancing and to adhere to infection prevention and control requirements. Throughout the pandemic, staff and resources associated with closed or curtailed services were redeployed where possible to support residential provision and to provide for targeted in-home, community and tele-/online supports for service users and families based on prioritised needs.)
- 2021 94,606 overnights and 16,306 day only sessions were accessed by people with a disability (the number of respite overnights operated at 10.9% ahead of the target for the year of 85,336, which is reflective of the easing of restrictions during the second half of 2021.)
- 2022 131,057 overnights and 28,369 day only sessions were accessed by people with a disability (the number of respite overnights was 41.6% ahead of the target for the year of 92,555, and which is reflective of the gradual return to pre-pandemic levels of service. The number of day only sessions (28,369) was also significantly ahead of the target of 22,474 for 2022.)
- 2023–151,123 overnights (which is 16.8% ahead of NSP target of 129,396 and 13.1% ahead of SPLY) and 45,424 day only sessions (which is 85.8% ahead of NSP target of 24,444 and 58.9% ahead of SPLY) were accessed by people with a disability in 2023. The total number of people in receipt of Respite services in 2023 is 6,137, which is up on the NSP target of 5,758.

Information concerning children is not disaggregated separately.

There is no centrally maintained waiting list for respite 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.

The HSE Disability Services has introduced a system called the Disability Support Application Management Tool (DSMAT), which enables Community Healthcare Organisation (CHO) areas to record and manage requests for support and to ensure that the application process is equitable and transparent. The DSMAT provides a consistent listing process for each CHO Area by presenting a detailed profile of the individuals (Adults & Children) who require funded supports outside of the current service quantum.

It captures detailed information on home and family circumstances and a detailed presentation profile of the individuals, including specialised profiles of behavioural intensity, key diagnoses, and complex support needs due to the extent and intensity of intellectual and/or physical & sensory disability.

The DSMAT is not a chronological waiting list; 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.

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Respite Centres

With regard to the question asked, listing and numbers of Respite centres is not routinely compiled, however a review of centre-based respite capacity and provision in the CHO Areas was completed in 2023.

There is a maximum of 782 respite beds available (485 for Adults; 212 for Children; and 79 mixed) of which 642.5 respite beds are currently available.



It is important to note that there is reduced capacity in every CHO Area due to the following:

- a) Recruitment challenges;
- b) Complexity of some recipients leading to reduced capacity;
- c) Beds temporarily reduced due to redeployment of respite staff to adult residential services;
- d) Beds used for emergency residential for residents who are awaiting full time accommodation;
- e) Beds not always occupied due to complexity/compatibility of individuals;
- f) Risk of peer to peer behaviours may result in a reduction in capacity;
- g) HIQA Compliance issues e.g. Fire Doors;
- h) Ongoing negotiation with staff/Unions regarding rosters (sleep-over issues).

Yours Sincerely,

Bernard O'Regan

Bernard O'Regan Assistant National Director National Disability Team