



Oifig an Stiúrthóir Cúnta Náisiúnta,
Foireann Míchumais Náisiúnta,
An Chéad Urlár - Oifigí 13, 14, 15,
Áras 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.

14th May 2024

Deputy Duncan Smith,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: duncan.smith@oireachtas.ie

Dear Deputy Smith,

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: 20745/24

To ask the Minister for Children; Equality; Disability; Integration and Youth his plans to increase and expand respite services in Waterford and west Cork; 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 | 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 |

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.

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.

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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With regard to increasing respite services in West Cork and Waterford, under the NSP 2024, overall National funding for respite (new developments) of €15m in 2024 and €25m in a full year has been allocated for the provision of centre-based and alternative respite services.

The specific allocation for CHO 4 (which includes West Cork) and CHO 5 (which includes Waterford) will be determined in line with the relevant CHO area.



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

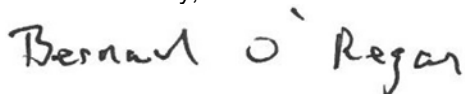
With regard to centre based respite, the Disability Capacity Review informs of up to €10 million in additional provision per year is required (20% additional quantum – 26,200 approx. additional overnights per year).

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

