

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.

13th September 2024

Deputy Michael Lowry Dail Eireann, Leinster House, Kildare Street, Dublin 2.

E-mail: michael.lowry@oireachtas.ie

Dear Deputy Lowry,

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: 35661/24

To ask the Minister for Children; Equality; Disability; Integration and Youth if he will provide increased funding to expand capacity and support alternative models of respite care for children and adults with disabilities, in light of the significant unmet need identified by an organisation (details supplied) in a pre-Budget 2025 submission; if he will consider this matter when finalising his Budget plans; and if he will make a statement on the matter.

Details Supplied: Avista

PQ: 35686/24

To ask the Minister for Children; Equality; Disability; Integration and Youth to consider measures to address the cost of living to attract and retain staff in residential and day supports, as proposed by an organisation (details supplied) in its pre-Budget 2025 submission, to ensure appropriate staffing levels and service delivery; will the Minister take this matter into consideration when finalising his Budget 2025 plans; and if he will make a statement on the matter.

Details Supplied: Avista.

PQ: 35682/24

To ask the Minister for Health to ensure adequate funding to respond to the changing needs of people supported by an organisation (details supplied); whether he will take this matter into consideration when finalising his Budget 2025 plans; and if he will make a statement on the matter.

Details Supplied: Avista, recognising the financial implications of providing a robust, person-centred, quality-based service, as recommended by Avista in the 2025 pre-budget submission.



HSE Response

The HSE takes note of Avista's Pre Budget 2025 submission concerning disability service provision including respite services and acknowledges that there is a high level of unmet need, that there is a need to expand capacity, is aware of the changing needs of people with disabilities and the increasing challenges for Service Providers to ensure that high quality person centred services are provided to services users.

The majority of disability service provision in Ireland is by voluntary agencies, which are funded under Section 38 and Section 39 of the Health Act 2004. The HSE funds a range of organisations to ensure the best level of service possible is provided to people with a disability, and their families, within the available resources. The majority of specialised disability provision (approx. 80%) is delivered through non-statutory sector service providers.

Under Section 38 of the Health Act, 2004 the HSE may enter into an arrangement with a service provider for the provision of health and personal social service on its behalf.

Under Section 39, the HSE provides financial assistance to organisations by means of a grant. Section 39 legally underpins the provision of services similar or ancillary to a service that the HSE may provide. These grants can range from very large amounts in their millions, to much lower amounts of just a few thousand euros.

The HSE acknowledges the role and contribution of non-statutory agencies in the development and provision of health and personal social services and is committed to the development of effective working relationships as enacted by the Health Act 2004. All of these organisations are governed by voluntary Boards of Directors and are subject to the wide range of applicable legislation, regulation, including Company law, HIQA, Health and Safety, Charity and Housing regulations, among other.

Estimates Process and Multi Annual Investment

Each year the HSE participates in the Estimates Process with the Department of Children, Equality, Disability, Integration and Youth and makes a submission for additional monies to meet the health and social care needs of the population it services.

The Disability Service makes submissions for additional funding for all services including Day, Residential, Respite, Home Support/PA hours, Multi-Disciplinary Posts and Neuro Rehab monies as a key element of its submission. Any new funding secured is allocated to the CHOs to provide services to those with the greatest need (priority basis).

The HSE makes every effort to secure multi-annual investment for services via the Estimates process and is very conscious of the need to deliver disability policy on a more sustainable footing given the significant levels of need for increased and more effective services and supports to enable people with a disability to live independent lives in their own community.

Cost of Living

While the issue of cost of living is a matter for the Government to address, the HSE acknowledges that recruitment remains a challenge across all areas in the health sector, including the HSE, S38 organisations (like Avista which has the same pay and conditions as HSE) and also our S39 funded Service Providers.

This is compounded by the limitations of the employment market and other matters such as housing and rising costs in all areas.

The HSE and disability providers continue to focus on staff retention and recruitment. There is an acknowledged national and international shortage of health and social care professionals with the necessary qualifications and experience. Seven of the disciplines working in disability services have been included on the Department of Enterprise, Trade and Employment's Critical Skills Occupations List.

However the HSE and its agency partners are continuously working to recruit staff for all disability services.

Respite Services

The HSE and its funded Agencies provide respite care to children and adults with disabilities. 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.

As mentioned also in Avista's 2025 pre-budget submission, the provision of residential respite services for all Service Providers, 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.

Increased Investment

The table below provides information on the funding for respite services over the last 7 years:

Respite	2018	2019	2020	2021	2022	2023	2024
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	€125,120,344

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.
- 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.

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
- To date in 2024 (end Q2), 76,863 overnights have been accessed by people with a disability. The number of day only sessions (29,077) is 43.9% ahead of the NSP target and significantly ahead (31.4%) of service delivery for the same period last year. In addition, at end of July 2024, 79 new in-home respite packages have been put in place.

Future Planning and the changing profile of the disability population

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.

The Disability Capacity Review to 2032-A Review of Disability Social Care Demand and Capacity Requirements up to 2032, suggests that how future requirements for respite will alter given demographic change will depend on the scale of residential care provided, and how that impacts on the number of people with disabilities living with family carers.

Data for 2017 shows only one in four family carers of over 5s with ID had received any respite, and only one in three family carers of adults. Latent unmet need could be considerably higher than what is recorded.

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 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.

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It is important to note that these are approximate figures as it is not possible to give exact figures.

Yours Sincerely,

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Bernard O'Regan

Assistant National Director National Disability Team

