

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.

4th October 2024

Deputy Holly Cairns, Dail Eireann, Leinster House, Kildare Street, Dublin 2.

E-mail: holly.cairns@oireachtas.ie

Dear Deputy Cairns,

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: 38537/24

To ask the Minister for Children; Equality; Disability; Integration and Youth if he will release the necessary funding to continue to fund transitioning those under 65 years out of nursing homes and into appropriate accommodation; and if he will make a statement on the matter.

HSE Response

In 2019, the Ombudsman commenced a systemic investigation into people under 65, living in nursing homes (NHs), and in May 2021 "Wasted Lives: Time for a better future for younger people in nursing homes" was published.

The Ombudsman's research suggests that nursing homes in general are designed for frail older people in the latter stage of their life. They are therefore not equipped to provide the rehabilitation that a younger person living with a disability may require, nor do they provide a social model of care focused on enabling the people concerned to return to their communities. Such a model of care is essential to implement the Transforming Lives Programme and to meet the commitments under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The Ombudsman's report details a series of findings and nineteen recommendations covering a range of themes including funding, informed consent, quality of life, access to services, navigating the system and policy and human rights.

National and Regional U65 Structures and Supports

In response to the Ombudsman's report, the HSE is co-ordinating a programme of work at both the Health Regions (HRs)/CHO operational and at national levels, to progressively address the Wasted Lives Report review and implement the report's recommendations for which the HSE has accountability.



Nationally, the Implementation Steering Committee (ISC) oversees the programme of work. The membership represents, Acute Services, Older Persons services, Disability and Primary Care Services, along with Clinical Leads and representatives for people with lived experience. The ISC meets on a bi-monthly basis.

Additionally, there is an U65 Programme Office and the Implementation Project Team. The implementation programme has been divided into 5 work streams with 5 work stream leads.

The work streams are as follows:

- 1. Quality of life and model of service development
- 2. Funding and personal finances
- 3. Services access and navigation
- 4. Informed consent policy and human rights
- 5. NH U65 survey (previously SRF project)

At local Health Regions/CHOs, there is an identified U65 lead per CHO, who is responsible for progressing U65s transitions and working with individual disability case managers. The operational activity is supported by two U65 Trackers. Firstly the U65 Operational tracker which manages the U65 programme within each CHO and provides data on U65 operational activity for the National Office. Secondly, the U65 Finance Tracker, which manages and provides governance over the U65 budget within the CHO and Nationally.

Transitions to the Community

The CHO Areas have indicated that as of May 2024, a total of 81 individuals have transitioned to the community since the start of the programme. The majority moved to community residential placements including sheltered living, specialised and residential placements, with other individuals moving to their own home.

In addition, there are a further 51 individuals in active planning for potential discharge to the community in the short to medium term. These individuals are at different stages of the case management process as follows:

- Most individuals are at pre-approval stage i.e. their business case preparation is in progress
- Some are ready to move but are awaiting Home support staff availability
- Some individuals are in active transition planning including; working with potential service providers, sourcing suitable housing, planning adaptions to the home, recruitment of staff etc. and will be the next group to transition in the immediate to medium term

20 of these individuals are due to move by year end, providing there are no delays.

Based on NHSS data, there are 1,242 people under 65 years in Nursing Homes 56% are male (696) and 44% are female (546). (May 2024).

(Note: NHSS data is only Fair Deal funded individuals by age profile and hence does not cover privately funded residents).

Due to the work of the U65 Integrated Steering Committee, the Health Region/CHO disability teams and the U65 project team, there is a greater awareness across Acutes, Older Persons and Disability services of the need to prevent U65s being placed in NHs.

Data from the U65 Operational tracker shows that as of May 2024, 340 individuals will be continuing their NH placement. For the majority of those continuing a NH placement, the reason is due to their current personal will and preference. This is followed by those who are staying due to their assessment of needs requirements. Disability services recognise that the issue of will and preference is changeable and that there needs to be planned engagements with individuals to better understand their reasons why they may wish to stay.

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.

Any new funding secured is allocated to the CHOs to provide services to those with the greatest need.



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.

Based on the U65 Programme tracker data and transition trend information, the HSE made 2 submissions to government to continue to address unmet need and to support: 1) additional residents of Nursing Homes who are under 65 years of age to transition to the Community during 2025 and 2) to enhance the quality of daily life for those who need to continue their placement in a nursing home.

Yours Sincerely,

Bernard O'Regan

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Assistant National Director, National Disability Team

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