



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.

23rd July 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: 32202/24

To ask the Minister for Children; Equality; Disability; Integration and Youth to provide details on the current number of individuals under 65 years residing in nursing homes; the total number of individuals who have been transitioned to their own home annually since 1 January 2020 to date; the average time the discharge process takes; and the measures in place to improve the quality of life and independence of people under 65 years who continue to reside in nursing homes; 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 adaptations 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.

Currently, there is not validated data on the average time the discharge process takes for either a move to a residential placement or to their own home. However, based on feedback from disability case managers, decongregation experience and the time an individual is placed on the U65 tracker, the estimated average time is 2 years, from initial assessment, working with service providers to final move. However, depending on personal circumstances, this time maybe less or more.

Number of U65 Residents in NHs

With regard to the question concerning the current number of on U65 numbers, based on NHSS data, Figure 1 on the next page shows the most recent profile of U65s residents in NHs as of May 2024.



Figure 1

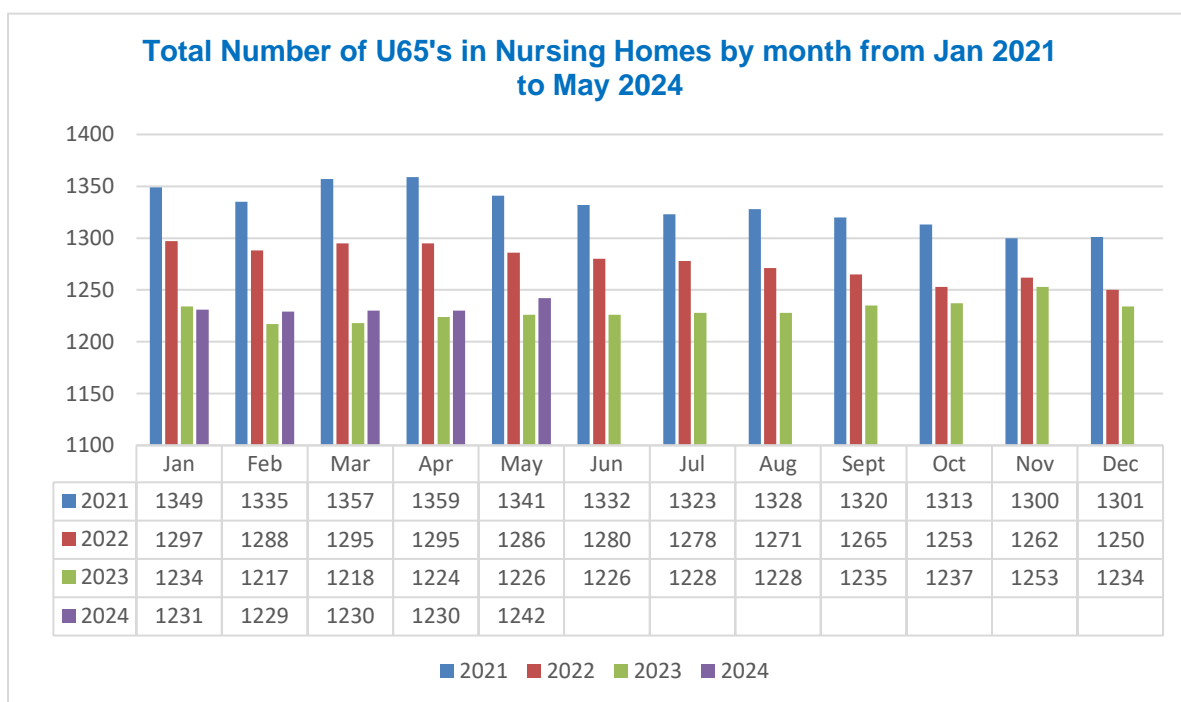


There are 1,242 people under 65 years in Nursing Homes 56% are male (696) and 44% are female (546).

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

For 2021, the average number of U65 individuals in NH per month was 1330. In 2022, this number drops to an average of 1277 and in 2023 this number drops even further to 1230. For 2024, year to date the average number is 1233.

The data shows that since 2019, the overall HSE system has managed to steadily reduce the numbers of individuals U65 in NHs. From 2021 to 2023 there has been a decrease of 100, for the average number of U65 individuals in NHs per month. However, the data does show that there is still a steady level of U65s in NHs this indicates the need for a continual system wide drive, to reduce admissions to NHs and increase discharges from NHs.



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.

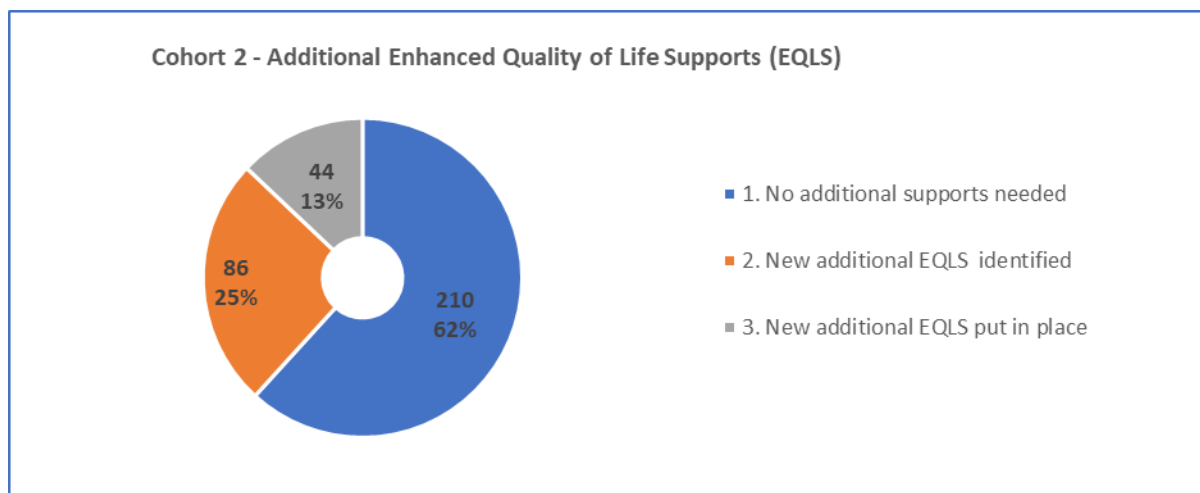
Data from the U65 Operational tracker shows that as of May 2024, 340 individuals will be continuing their NH placement. For the majority of those continuing a NH placement, the reason is due to their current personal will and preference. This is followed by those who are staying due to their assessment 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.



With regard to the question concerning the measures in place to improve the quality of life and independence of people under 65 years who continue to reside in nursing homes, the CHO teams are funding and enabling enhanced quality of life supports (EQLS) for individuals who through either will and preference and/or assessment of need will be continuing their placement in the Nursing Home. The aim of these supports is to improve the daily life of these younger people, while they are still in a NH or to help them prepare for a future transition.

These supports range from, Personal devices, Transport, Social care, Vocational, Therapeutic supports and PA hours etc.

The Pie Chart below provides an overview of the current EQLS status. The majority of individuals 62% require no additional supports, the remaining 25% have had new additional EQLS identified with 13% in place.



The U65 programme working in conjunction with CHO 4, have funded a 2 year specialised rehabilitation pilot. This programme is focused on individuals who have been in a nursing home long term and need bespoke supports to improved their daily lives and prepare them for potentially transition into the community. The U65 project team are currently in the process of applying for funding to enable other regions to benefit from similar programmes.

Yours Sincerely,

Bernard O'Regan
Assistant National Director
National Disability Team

