

## Ombudsman Update on 'Wasted Lives'

Ombudsman's update following receipt of the HSE's ['Recommendations Implementation Progress Update'](#) (July 2024)

In 2021, my predecessor, Ombudsman Peter Tyndall, published "Wasted Lives: Time for a better future for younger people in nursing homes". The report followed an investigation which was prompted by a number of complaints from people under the age of 65 who were residing in nursing homes. These individuals had been moved to nursing homes because of the level of care that they required and an absence of appropriate alternatives. Their complaints reflected their personal experiences which highlighted issues such as being isolated from family and friends, a lack of any meaningful social engagement, living within the structure of a nursing home, residing with elderly patients of whom, many suffered from dementia. The complainants were clear that they desired the supports to live meaningful and independent lives where possible or to access a better quality of living, be that in their own homes or in more appropriate accommodation. Their complaints also reflected the sheer lack of hope to see a future beyond their current situation.

On foot of these complaints, the "Wasted Lives" investigation looked at the appropriateness of the placement of people under 65 in nursing homes. It focused on the changes that needed to be made to give these people the quality of life that every person is entitled to and deserves and which is in keeping with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The subsequent report identified some key factors that should be addressed to enable this to happen. The recommendations covered a range of themes including funding, informed consent, quality of life, access to services, navigating the system and policy and human rights. These recommendations have the ability to both improve the situation for many of those individuals under 65 currently in nursing homes, but also provide the opportunity to reduce the possibility of more people under 65 being placed long term in nursing homes unless it is their expressed wish to do so.

Following the publication of *Wasted Lives*, the HSE established an Integrated Governance Steering Group chaired by the Chief Operating Officer to oversee the implementation of the recommendations. In that same year the 2021 National Service Plan for the HSE committed to the transition of 18 adults with disabilities under the age of 65 years from nursing homes to an appropriate living arrangement in the community, 14 of which happened that year.

The Steering Group has recently provided my Office with its latest Recommendation Implementation Progress Update. The update tells us that since those initial transitions in 2021, a further 67 individuals under 65 have moved from nursing homes to more appropriate settings. It also shows that there are 51 individuals in active planning for potential discharge with 17 of those transitions due to take place in the short term. A further 20 of those individuals are ready to move from nursing homes to more appropriate settings in 2024 but by the end of August 2024 the annual funding was already spent or fully reserved and those moves cannot currently proceed.

In its update the HSE has also reported that feedback from disability teams shows concerns about managing expectations of individuals when funding cannot be guaranteed for their potential move. In the cases described above, considerable work has been undertaken by the individuals themselves and the HSE to put them in a position where a move to a more appropriate setting is possible and it cannot be the case that these moves are prevented by a lack of funds. It is vital that funding for these projects is provided and ring fenced to ensure that individuals already identified can move and that future plans and work are not delayed by fears that funding may not be available.

It is also important to note that that this is not a once-off body of work. Every year more and more individuals go into the system. The HSE's update reports that in 2024 there has been an average of 32 individuals under 65 entering a nursing home setting every month.

I acknowledge the ongoing work, both centrally in the HSE and at a local level, to implement the recommendations of this report and the structures that have been put in place to drive and monitor progress. I also acknowledge the considerable effort the HSE has put into providing a comprehensive update on the implementation process. My Office's interactions

with members of the Steering Group have found them to be engaged and enthusiastic about the issues and keen to facilitate as many individuals as possible to move to a more appropriate setting. It is difficult to quantify the positive impact on the 81 individuals that have already moved or on their family and friends, but we have seen a flavour of it, and it has meant huge improvements in terms of the quality of their daily lives. However, I am disappointed by the pace of the progress.

I am conscious that individuals, whether in nursing homes, other appropriate settings or leaving an acute hospital setting, require supports and rehabilitation to enable them to live the best life their condition allows. In that regard I welcome the plans from the HSE's National Neuro-Rehabilitation Programme to have a regional specialist in-patient service and a large Community Neuro-Rehabilitation Team in each of the new Regional Health Authorities. The development of Neuro-Rehabilitation services will help to improve outcomes for people by providing safe, high quality, person-centred Neuro-Rehabilitation at the lowest appropriate level of complexity.

For those who do enter into and remain in nursing homes, be that through their own will and preference or because it is the most clinically appropriate option for them, they must also be supported to ensure they receive the care and supports they need to live as active and independent lives as possible. For one person who spoke with us at the time of the report it was getting a TV put in their room, for another it was getting access to social care supports such as a motorised wheelchair or other aids to help them live more independently.

A key recommendation from Wasted Lives was the need for a case management approach and wrap around supports for people who wish to move out of nursing homes. My Office has met with Non-Governmental Organisations (NGOs) working in this area who support a case management approach. I note that the HSE has run a pilot project with a NGO in Community Health Organisation (CHO) 4 and that the outcomes have been very encouraging. The team, which is based in Cork, is working with 24 individuals under 65 in nursing homes to make improvements in the quality of their lives and to seek supports required for any of the individuals who are seeking assistance in making the transition from

the nursing home setting. NGO's can be agile and operate in a personal and local manner to help individuals assess, find and train for a move out of a nursing home setting. This is an approach that I strongly support and I would encourage the HSE centrally, as well as through individual CHOs, to work with capable NGOs to harness their specialist expertise and local knowledge.

In the main it is clear that progress has been slow for those affected and for their family and friends who often contact my Office. I am delighted that 81 people have been able to access the support they need to transition out of a nursing home but there are many more, over 1,200 in July 2024, who currently have not had that opportunity. While I recognise that for some of those, it may not be clinically possible to move, I know for others it is and it should not take years, important years that people cannot get back.

We all have a duty to recognise and respect the inherent dignity and worth of every individual, particularly those most vulnerable and with the most needs, and it is with this in mind that I would like to restate my call for adequate funding to be made available for people under 65 in nursing homes. A commitment to sustainable and annual funding is absolutely essential to enhance the quality of lives of those who will remain in nursing homes to allow them to live as actively and independently as possible, and to enable those who wish to move to a more appropriate setting, be that home or elsewhere, to do so as quickly as possible. While I accept the challenges to deliver on 'Wasted Lives', I do not accept that lack of funds should now become a barrier. I call on the Government to provide adequate funding to allow people to live to their full potential.

**Ger Deering**

**Ombudsman**

**18 September 2024**