

Joint Committee on Disability Matters, 24th June 2021

Opening Statement from the Ombudsman, Mr Peter Tyndall, on *“Wasted Lives: Time for a better future for younger people in nursing homes”*

Cathaoirleach and members of the Committee, thank you for the invitation to come here today to discuss my recently published report [*“Wasted Lives: Time for a better future for younger people in nursing homes”*](#).

Many Deputies and Senators here today will have had first-hand experience of the work of the Office of the Ombudsman but before I provide an overview of the findings of this investigation, I hope you don't mind indulging me a moment to set out how my office works and why I felt compelled to use my powers, as Ombudsman, to initiate a systemic investigation into the current situation for people under 65 living in nursing homes. Let me also say from the outset that this report is not a criticism of nursing homes. It is instead about the inappropriateness of nursing homes as accommodation for the people concerned.

Role of Ombudsman

As Ombudsman I consider complaints from users of our public services who believe they have suffered an injustice as a consequence of maladministration by a public service provider. In determining such complaints, I examine the decision from the perspectives of legality and compliance, as well as fairness and good administration. Earlier this month I published my 2020 Annual Report which set out that over 3,400 complaints were received by my office last year. Each one of these complaints was examined thoroughly in a fair, independent and impartial way. Each one of these complaints came from a person who had a story. Part of my work as Ombudsman is ensuring that the voices of people which might otherwise be ignored can be heard.

Some individuals, and their stories, are particularly moving and shine a light on issues of such significance to the system and how our public services work, that they need particular consideration.

It was four such complaints which came to my attention and were the catalyst for the *Wasted Lives* Report. The situation of these four individuals was very similar in many ways, and they all were able to articulate in their own words how inappropriate and unfair it was for them to have no option other than to remain in a nursing home. However, for each of these cases the system seemed to be constructed in a way that made it seem nearly impossible for their circumstances to change.

The Investigation into people under 65 living in Nursing Homes

With this in mind, in 2019 I commenced an own-initiative systemic investigation into people under 65 living in nursing homes. Through both individuals contacting my office and through outreach to various advocacy groups, we were able to visit 28 people under 65 living in nursing homes as part of this investigation. I wish I could have some of those individuals here with me today, to voice for themselves their powerful testimonies and to share their experiences. One of the people we met during the investigation said that he had wasted the best years of his life in an institution. Another, who had suffered his injuries in an assault, said the person convicted would one day leave prison - he had no prospect of leaving the nursing home. I hope I am able to do justice to their stories here with you today. You can hear some of their voices in a video produced by my office which is available on my website. ([Link to video](#))

The HSE told us that as of June 2020 there were 1,320 people under 65 being supported to live in nursing homes through the [Fair Deal Scheme](#). This figure may not be a comprehensive assessment of the number of people under 65 living in nursing homes, as it does not include those who self-fund or receive support from another sources. Therefore, I have suggested in my report that an audit should be undertaken by the HSE in order to establish accurate statistics. These may not vary greatly from the numbers identified but I think as a point of principle that all placements should be identified and documented.

My office also undertook a review of the relevant literature, legislation and any other material required to deepen our understanding of the issues involved. This 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 our commitments under the [UN Convention on the Rights of Persons with Disabilities \(UNCPRD\)](#).

Recommendations

Following my investigation, I have made a series of [findings and nineteen recommendations](#) which cover a range of themes including funding, informed consent, quality of life, access to services, navigating the system and policy and human rights. While I don't intend to go through each of these findings, I would like to highlight the following key recommendations today which I believe 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 in nursing homes unless it is their express wish to do so.

Firstly, in relation to informed consent, many of those we spoke with were, at the time of applying for the Fair Deal scheme, unaware of the longer term consequences of entering a nursing home or applying for the Fair Deal scheme. Some described a situation where they thought they were just entering for a short time before they returned home, others stated they were on heavy medication and felt they were not in a position to make decisions about their long term living arrangements. This highlights the importance of ensuring that safeguarding procedures are embedded throughout the application, decision-making and ongoing review processes for residents in long term residential care settings. I also look forward to the commencement of the relevant elements of the [Assisted Decision Making Capacity Act](#) which will provide a support framework that maximises a person's right to make their own decisions, with legally recognised supports for those that may need to be supported to make such decisions. It is likely that these issues also impact on some people over 65.

Secondly, I would like to highlight the impact the current fragmented funding model has on the ability of individuals to access appropriate services in the community to support people with care needs to live at home or in a more appropriate community setting. Currently there is a statutory scheme which provides financial assistance for those who wish to be placed in a nursing home, and no similar entitlement for the broad range of supports a person requires to remain living at home. Instead access to such services is often on based on what is called a “postcode lottery” determined by a local CHOs budgetary position at a point in time, rather than a national, equitable, transparent system of allocating and accessing services.

This provides an unintended bias towards residential care in the system, which also affects people over 65, and often leaves people with no option other than to move into a nursing home. Within this context I welcome the Programme for Government commitment to introduce a statutory home support scheme and I look forward to a day when this bias is reversed and people are supported as a first point of principle to remain living at home independently or with appropriate support.

Furthermore, as part of this investigation it became apparent that once a person was placed in a nursing home, they often found it challenging to access primary care or social care supports such as physiotherapists, aids and appliances or personal assistance hours. In the cases that we investigated it was apparent that the quality of life for these individuals could be improved significantly by ensuring they get access to relatively modest additional supports.

With at least 1,300 people under 65 currently residing in nursing homes it is essential, in my opinion, that we urgently look at this group of people and determine what can be done to improve their situation. Therefore, I am delighted that the HSE has accepted my recommendation to undertake within 12 months a national survey to identify other individuals in similar circumstances, to ascertain their will and preference and to develop a national database to ensure appropriate follow up for all such cases.

In my guide to good public administration called [‘Six Rules for Getting it Right’](#), rule number two is *‘be customer oriented’* and rule number three is *‘be open and accountable’*. These rules are particularly important when dealing with vulnerable members of our society who should

be supported to navigate the system. Therefore, a further recommendation of this report is that the HSE should provide a case coordinator, or key worker, for each individual in the national database and develop a comprehensive information package setting out their rights and entitlements and the relevant points of contact. This will provide for person-centred, individualised, integrated support or in the words of [Sláintecare](#) – “the right care, in the right place, at the right time”

Moving forward we should try to reduce the risk, in as much as possible, of other people under 65 finding themselves in the same situation. Therefore, I have recommended that a date should be set after which there will be no long term admissions to nursing homes by people under 65, unless it is their express wish to be so admitted, and that a plan is developed with appropriate funding to ensure that the necessary resources are made available to achieve this.

As with so much other work, the completion of this investigation was delayed by COVID. However, during the course of the investigation, I wrote to party leaders, to highlight the issue of people under 65 living in nursing homes so that this might be taken into account in preparing the Programme for Government. I was delighted that the [2020 Programme for Government: Our Shared Future](#) took this issue on board and has stated that it will “*Reduce and provide a pathway to eliminate the practice of accommodating young people with serious disabilities in nursing homes*”. The HSE have also advised me that they have established a dedicated funding stream of €3 million as part of the National Service Plan 2021 that will enable 18 people under the age of 65yrs to transition to their own home with support. This, I believe, is an important step forward and will provide the opportunity to significantly improve the quality of life for these individuals.

Throughout this period my office also liaised with officials in the Department of Health and the HSE, advocacy bodies and other key stakeholders as part of this process. I wish to thank all those who participated in this work for their contribution to the *Wasted Lives* report. I also appreciate the ongoing commitment of the HSE to continuing to engage with the Office of the Ombudsman on the implementation of the recommendations emanating from this report which have potential to make such a significant improvement to the quality of life for both

those individuals directly interviewed as part of this process, and more broadly to individuals who find themselves in similar situations now or in the future.

Conclusion

In conclusion, however, I would like to focus our minds back to the 28 individuals who spoke to me and my office during this period. I would like to acknowledge that since this investigation was initiated four of the people we interviewed have sadly passed away. I want to give my sincere condolences to their families and loved ones.

A society should be judged by the way it treats its most vulnerable citizens. During this investigation I was humbled and moved by stories I heard and I would like to leave you with some of their words - **Charles** who described himself as being on the “*scrapheap*”; **Francis** who feels “*forgotten about*”; **Oliver** who “*contemplates suicide at times*”, and **Liam** who describes “*his room as his world*”. These are real people with real lives, who deserve a system that works to support them to live independent and full lives.

As you may be aware I am due to retire in the coming months, I look forward to these changes in my own personal circumstances. However, it is my sincere hope that after I leave, this report will be a catalyst for change in the personal circumstances of all of the individuals we spoke about today and that as a society we will no longer see people under 65 inappropriately placed in nursing homes, and indeed, those people over 65 who want to remain in their communities.



Peter Tyndall
Ombudsman