

# The situation of younger people with disabilities living in nursing homes in Ireland - phase 1

## Plain English Summary

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This report was prepared by Dr Maria Pierce, Sophia Kilcullen, and Dr Mel Duffy. The report has been peer-reviewed prior to publication. The views expressed in this report are those of the authors and do not necessarily represent those of the Disability Federation of Ireland.

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# Foreword

This research is very timely given Ireland's recent ratification of the UN Convention on the Rights of Persons with Disabilities, the imminent full commencement of the Assisted Decision Making (Capacity) Act, 2015 together with proposed legislation dealing with Deprivation of Liberty. Although the sample in the study is small, it offers valuable insights into the referral of, and pathways into nursing homes for younger people with disabilities.

Whilst law and policy are centred on the enabling of people with disabilities to live the lives of their choosing in the community, the report notes that the supports to enable them to do so 'are underdeveloped, unplanned and often not sufficient to meet their needs'. Instead of taking a human rights based, social model approach, which would look to the person's will and preference, there is an overemphasis on the medical model in the assessment form. There is little focus on a person's abilities, capabilities or on options for care in the community. Indeed a person's preference for care seems to have been poorly recorded or not recorded at all.

The research makes it clear that younger people with disabilities do not often have a meaningful say in decisions that profoundly affect and impact their lives, rather their referral to nursing homes is defined by their level of functioning. The vast majority of these people, who enter nursing homes remain there without assistance to achieve an outcome of living independently and without really being in control of their own lives.

The report concludes with some very good and practical recommendations for both government and practice. These include adopting a personalised approach to the assessment and care of younger people with disabilities, and a commitment to exhaust all possibilities with the person centrally involved, assisted where necessary, before nursing home care is considered. We hope that government and the Department of Health will take the time to review the findings and recommendations of the report, and to take the necessary action to address the inappropriate placement of younger people with disabilities in nursing homes.

**Gary Lee,  
Chairperson, Disability Federation of Ireland.**

# Introduction

This study looks at the younger people with disabilities who have been placed in nursing homes. Younger people in this study means anyone over 18 and under 65 years old. The study looks at the characteristics of younger people who have applied for a place in a nursing home. This includes:

- Age
- Where they were living before arriving at the nursing home
- Marital status
- How they were referred to a nursing home
- Information on their type of disability
- Information on the supports they received before arriving at the nursing home
- Information on whether they wanted to live in a nursing home

In the past, the issue of younger people with disabilities in nursing homes did not get much attention. Recently, several events have brought more attention to this issue. In 2011 the Working Group on Congregated Settings published its report. Advocacy organisations worked to bring attention to the issue. The media also began bringing attention to the personal stories of younger people in nursing homes. For all of these reasons, this important issue has become much better known. This summary presents the findings of the report in a more accessible format.

# Findings

To collect data, the study looked at the information in 48 Common Summary Assessment Report, CSAR, forms. These CSAR forms were filled out for every younger person who applied for a place in a nursing home through the Nursing Home Support Scheme, NHSS. All 48 forms are from one area of Ireland. This is a small sample, but the goal is to learn more about why younger people are placed in nursing homes and what the care assessment can tell us. The findings are summarised below:

## Age

The ages of the 48 people ranged from 21 to 64 years old. Half of the group was over 56 years old.

## Living Situation before Nursing Home

Most of the 48 people were either single, widowed, separated or divorced. 11 people were married. Of those whom we have data for, over half were living with family when they applied to enter a nursing home. One third were living alone.

There is little information on the family care that the group received before they entered the nursing home. Several CSAR forms include notes about family carers. These include notes that family carers may be unable to continue providing care. Other notes mention supportive families who have been told a nursing home is the best option.

Information on community supports received by the group is inconsistent. Community support includes home care, respite care, and visits from a Public Health Nurse. From the information given, less than half of the group received community supports.

## Where they were referred from

47 forms recorded who referred the person to the NHSS. Most were referred from a hospital, usually an acute hospital. A much smaller number were living in the community when they were referred.



## Disability

The 48 people had a range of disabilities. The six most common disabilities were:

- Diseases of the nervous system such as multiple sclerosis
- Acquired brain injury
- Severe and enduring mental health difficulties
- Stroke and cerebrovascular diseases
- Dementia
- Intellectual disability

Five people in the group had a dual diagnosis, meaning they had two or more disabilities. Almost half of the group had a co-morbidity, meaning that in addition to their disability, they had other health conditions. A significant number of the group were listed as having a cognitive impairment. A significant number were also recorded as having mental health difficulties. This includes people who applied for a nursing home placement for reasons other than mental health difficulties.

Dependency levels were determined for each of the 48 people. This means that their ability to perform daily activities independently was determined. Two-thirds of the group had high dependency levels. This suggests that high dependency levels may be a factor in entering a nursing home as a young person. However, the group also contained six people who had low dependency levels.

## Personal Preferences

In the group of 48, 39 were asked about their preferred care setting. Of this group, several had requested placement in a nursing home. A reason for this request was not always given. Reasons that were given included:

- Deteriorating health
- Increasing care needs
- Difficulties managing at home
- Burdens on family caregivers

In several cases, the form said that the person had agreed to enter a nursing home. It did not say if they would have preferred to live somewhere else, if that was an option. In several other cases, the person had a clear desire to go home. Often, this was followed by an understanding that going home was not an option. The forms do not explain why going home was not an option in these cases.

# Conclusions

These findings come from a small sample. They do, however, show some reasons for why younger people are placed in nursing homes. When people are placed in nursing homes, the focus seems to be on their disabilities and health. This means there is less focus on the preferences or abilities of the person. There is also little focus on helping the person live an independent life with community supports. It is true that many of the people in this sample agreed to move to a nursing home. It is also clear that many of them felt they had no other choice.

Another factor may be the existence of the NHSS. The NHSS guarantees people who need care a place in a nursing home and provides financial support to those who need it. The government is reviewing home care, but currently there is no similar programme to guarantee people support in the community or in their own homes. This means that some younger people may find themselves with no other option.

Finally, for many people, there may be no other suitable place to live. People in the sample said they would like to go home, or to other places where they could be supported. For whatever reason, in many cases, this was not an option.



# Recommendations

Based on these findings, it is clear that there is a need to take the wishes of the person into account in any assessment. When a person is being assessed for the NHSS, their preference for where to live should be discussed. The person should be provided with support to make their wishes known if needed. People who are being assessed should be given a chance to contribute to decisions that are made about them. The government should adopt a personalised approach to assessment. The government should also commit to exploring all possibilities with the person being assessed, before considering nursing home care.

Many government policies around disability are currently being implemented. This process should take into consideration the living situations that younger people with disabilities are placed in. The Department of Health, with other departments, should consider setting up an initiative. This would be an initiative to prevent younger people with disabilities from being placed in nursing homes.

The government should support efforts to reduce the number of younger people placed in nursing homes. This could be done in a number of ways. These include developing other models of care and providing at-home services. All accommodation should be developed with the principles of Universal Design in mind. More research is needed about the situation of younger people with disabilities living in nursing homes across the country.





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