



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.

Disability Federation of Ireland and Dublin City University

2018

Available to download from: <https://www.disability-federation.ie/>



## Authors

Dr Maria Pierce is an Independent Researcher and an Adjunct Faculty Member, Faculty of Health and Science, Dublin City University, Dublin.

Sophia Kilcullen, PhD candidate, School of Nursing and Human Sciences, Dublin City University.

Dr Mel Duffy is a Lecturer in the School of Nursing and Human Sciences, Dublin City University, Dublin.

## Acknowledgements

The authors would like to thank the Disability Federation of Ireland (DFI) for its foresight in commissioning this study and giving us an opportunity to undertake the research and to shed more light on the situation of younger people with disabilities in nursing homes. In particular, we would like to thank Joan O'Connor and Dr Joanne McCarthy. We would also like to thank members of the Research Advisory Group for their guidance, support and input during the course of the study:

Dr Emer Begley / Dr Bernadette Rock, Alzheimer Society of Ireland  
Harriet Doig, the Multiple Sclerosis Society of Ireland  
Claire Feeney, the Housing Agency  
Anthony Finnegan, Lakers Social and Recreational Club  
Caren Gallagher, Irish Council for Social Housing  
Dr Anne Good, Chair, DFI Disability Research Hub  
Gráinne McGettrick, Acquired Brain Injury Ireland  
Sinéad Morrissey, Nursing Homes Ireland  
Sarah Murphy, Health Information and Quality Authority  
Dr Meredith Raley, Disability Federation of Ireland

Special thanks to the Chair and Co-ordinator of the Local Placement Forum and other Health Service Executive (HSE) staff in this Community Healthcare Organisation (CHO) area who assisted us in gaining access to the Common Summary Assessment Report (CSAR) forms and supported the study. Without their support, this study would not have been possible.

We would also like to thank Dr Fiona Keogh from the National University of Ireland Galway and Dr Mary-Ann O'Donovan from Trinity College Dublin for their helpful comments and suggestions on an earlier draft of this report, as well as Marion Meany, and Dr Cathal Morgan in the HSE for their support to the research.

DFI would like to acknowledge the Bray Area Partnership Disability Network for initiating local research on this topic, 'Old Too Soon' which provided us with the impetus to conduct this study.

# 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.<sup>1</sup> 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.**

<sup>1</sup> <https://health.gov.ie/blog/press-release/ministers-harris-and-mcgrath-announce-opening-of-a-public-consultation-on-deprivation-of-liberty-safeguards/>

# Contents

The Authors .....	3
Acknowledgements .....	3
Foreword .....	4
Executive Summary .....	6
1. Introduction .....	10
1.1 Rationale for the study .....	11
1.2 Terminology .....	14
2. Background context .....	18
2.1 Irish policy context .....	18
2.2 Human rights context .....	22
2.3 Nursing home provision and financing in Ireland .....	25
2.4 Community-based services and supports .....	26
2.5 Rehabilitation services .....	27
2.6 Irish data on younger people with disabilities in nursing homes ...	28
2.7 Summary .....	31
3. Methodology .....	32
3.1 Negotiating access to the CSAR forms .....	32
3.2 Ethical approval .....	33
3.3 Accessing a sample of CSAR forms .....	34
3.4 Data analysis .....	35
4. Findings .....	36
4.1 Socio-demographic profile of NHSS applicants under 65 years of age	36
4.2 Source of referrals .....	39
4.3 Disability / health conditions and co-morbidity .....	41
4.4 Mental health status and cognitive impairment .....	42
4.5 Substance abuse .....	42
4.6 Dependency levels of NHSS applicants .....	43
4.7 Information on family carers .....	44
4.8 Community and home support service use .....	45
4.9 Medication use and polypharmacy .....	48
4.10 Communication .....	49
4.11 Risk assessment .....	49
4.12 Preference for care setting .....	50
4.13 Recommendations for Long Term Care Residential Setting .....	53
5. Discussion of findings .....	54
5.1 Socio-demographic information .....	55
5.2 Health conditions / disability and dependency .....	56
5.3 Source of referrals of younger people for NHSS .....	57
5.4 Factors contributing to referral of younger people for NHSS .....	58
5.5 Impact of residing in a nursing home .....	65
5.6 Younger people with disabilities moving out of nursing homes .....	66
5.7 Enhancing the lives of younger people in nursing homes .....	67
6. Conclusions .....	68
7. Recommendations .....	69
References .....	72
List of Tables .....	79
List of Figures .....	79
List of Boxes .....	80
Abbreviations .....	81

# Executive Summary

This study focuses on the placement of younger people with disabilities<sup>2</sup> in nursing homes. Nursing homes are generally considered as places for the care of older people and most people residing in nursing homes are older people. Nursing homes are not, however, restricted to older people, and close to 1,500 younger people with disabilities are currently residing in nursing homes in Ireland, in part because community supports are not sufficient.

The study is based on a review of Common Summary Assessment Report (CSAR) forms that accompany applications from younger people with disabilities for the Nursing Home Support Scheme. The review was undertaken to assess the level and sum of information that can be extracted from them with respect to the placement of younger people with disabilities in nursing homes. It also aimed to shed more light on the referral of younger people with disabilities to nursing homes.

Up until recently, the placement of younger people with disabilities in nursing homes received scant attention in Ireland. Several factors have served to increase awareness of this issue including the publication by the Working Group on Congregated Settings of its report, efforts by organisations advocating on behalf of people with disabilities to more forcefully highlight the issue, and the personal stories from the lived experiences of younger people with disabilities living in nursing homes being heard, often brought to public attention by the media.

The placement of younger people in nursing homes is taking place amid an evolving policy, legislative and human rights context. The central aim of current Government disability policy in Ireland is to support people with disabilities to live ordinary lives in ordinary places, and to reconfigure disability services and supports to achieve this. Ireland has now ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The equal right of people with disabilities to live independently and be in the community is enshrined in Article 19 of the UNCRPD, which also promotes the autonomy of people with disabilities who would otherwise be considered to be lacking capacity.

In Ireland, younger people with disabilities can make an application for the Nursing Home Support Scheme (NHSS) to access the state's statutory scheme of financial support for nursing home care. Latest figures from the HSE (June 2018) indicate that 1,313 people under the age of 65 years were accessing nursing home care via the NHSS scheme in public and private settings.<sup>3</sup> Evidence has shown that younger people with disabilities are most commonly placed in nursing homes from acute hospital settings. Issues that arise at time of hospital discharge such as urgent needs for beds and pressure on staff to discharge are likely contributing to their nursing home placement. The funding system, which is biased in favour of residential care, is another contributory factor. Community supports which could potentially support people with disabilities to live at home as an alternative to nursing home care are all too often insufficient or not tailored to meet their needs.

<sup>2</sup> In this report, younger people with disabilities are defined as people with a disability who are aged between 18 and 65 years of age.

<sup>3</sup> <https://www.rte.ie/news/health/2018/0808/983809-nursing-homes/>

Barriers to living independently in the community can be exacerbated by a lack of timely access to assessment and early intervention, and the therapy, rehabilitation or mental health services that people with disabilities may require.

It is in this context and the limited evidence available on the topic, that the Disability Federation of Ireland (DFI) commissioned this study. The study is based on a small sample of 48 CSAR forms accompanying applications from younger people with disabilities applying for the NHSS from one Local Placement Forum (LPF). Applicants in this sample ranged in age from 21 to 64 years, with a mean age of 53 years. One half were in the age group 56-65 years and most were over 45 years of age. It was not possible to report the proportion of the sample that were male and female, as the CSAR form does not record sex of the person assessed. While just over three-quarters of the sample were either single, widowed, separated or divorced, more than one-half were recorded as living with family at the time of application. Information on current housing situation from the CSAR forms was limited. The majority of applicants were referred from a hospital (acute, community or rehabilitation), with a much smaller number referred from the community.

In this sample, younger persons applying for the NHSS had a wide range of health conditions / disabilities as classified using the ICD-10. The six most common were diseases of the nervous system such as Multiple Sclerosis, followed by Acquired Brain Injury, people with severe and enduring mental health difficulties, people with stroke and cerebrovascular diseases, dementia and intellectual disability. Co-morbidity was common among the sample. A sizeable number of the sample were recorded as having cognitive impairment, and other mental health difficulties were also prevalent. Almost two-thirds had high to maximum dependency level (Barthel Index (BI) scores). Polypharmacy was very high.





The CSAR forms provided very little information on family caregivers, as the information was redacted from the vast majority of CSAR forms, to protect the confidentiality of applicants and their family members. Information on community supports availed of by the individuals in the sample was inconsistently recorded, but from information available less than 20% of applicants were availing of home help / support.

Although the majority of younger people applying for the NHSS had their care setting preference discussed with them, one-fifth of the sample did not. Where the person stated a clear preference to go home, quite often this preference did not seem to be an option. However, it is not clear from the reports why this was not a feasible option or what steps if any had been taken to explore discharge home. Of the 48 applications, 38% received a Multidisciplinary Team (MDT) recommendation for Long Term Residential Care Support (LTRCS), but no recommendation was recorded for the remaining 62% on the forms.

Detailed information can be gleaned from CSAR forms that can usefully inform the HSE about appropriate placement of younger people with disabilities in nursing homes. However, structure of the CSAR forms leads to an over-emphasis on the person's diagnosis and deficits, with little or no focus on the person's strengths or abilities and how the person might be supported to maintain these abilities.

A range of factors are contributing to the placement of younger people with disabilities into nursing homes. The predominant disabilities / health conditions among the 48 applicants are known to be those that place these people at a greater risk of admission to nursing homes. Many of the younger people in the sample have high and complex care needs; almost two-thirds of the sample in this study had a high or maximum level of dependency, with some needing 24-hour care and supervision or very high levels of daily care and support. There were high levels of co-morbidity amongst the sample as well as high levels of polypharmacy and excessive polypharmacy. Several of the younger applicants were recorded as being at high risk of either pressure ulcers, falls, malnutrition and risk of wandering. Seven younger people in the sample had severe and enduring mental health problems and many others had mental health problems which can sometimes be the decisive factor for placement in a nursing home. Substance abuse appeared to be a factor contributing to referrals in a small number of cases.



The findings from this study show that some younger people with disabilities were being placed in nursing homes as a result of a breakdown in family care arrangements, such as an ageing parent or the decline in the health of a family carer, rather than because of the disability itself. The availability of the NHSS since 2009 and the financial support provided by it may also be a contributing factor, since there is no equivalent scheme for the community care of younger people with disabilities. With community care remaining fragmented, underdeveloped and under-resourced, nursing home care may be the only option for some younger people with disabilities.

It is manifestly clear from this study that several of the applicants would have preferred to return home. Others expressed a preference for living in more supportive accommodation or moving to more independent living. However, it seems that the only other option available to people - who could not or did not want to for whatever reason return or remain living at home - was nursing home care. Nursing homes were also being used for temporary care for people awaiting a place in the National Rehabilitation Hospital.

This study suggests that expressing their care preferences does not always mean that younger people with disabilities will be effective in influencing the outcome of their care and that important changes are needed to ensure that younger people with disabilities will be supported not only to express their preferences, but to be involved in decision-making about where they live and about their care and to be supported as far as possible to achieve their desired outcomes. Much work needs to be done to prepare health and social care professionals for when the Assisted Decision-making (Capacity) Act 2015 is fully commenced.

Caring for younger people with disabilities and complex needs can be costly and this raises difficult questions about how much we as a society are willing to pay to support younger people with disabilities to live in the community if that is their expressed preference. But, since younger people with disabilities often have negative experiences of residing in nursing homes, this investment is critical to enabling younger people with disabilities to live ordinary lives in ordinary places. For those younger people with disabilities who do reside in nursing homes, efforts must be made to enhance their care within the nursing home environment and support these people to lead as full and as independent a life as possible.



# 1. Introduction

This study on the placement of younger people with disabilities in nursing homes was commissioned by the Disability Federation of Ireland (DFI). The study is based on a review of Common Summary Assessment Report (CSAR) forms that accompany applications from younger people with disabilities for the Nursing Home Support Scheme (NHSS). The review was undertaken to assess the level and sum of information that can be extracted from the CSAR forms with respect to the placement of younger people with disabilities in nursing homes. It also aimed to shed light on the referral of younger people with disabilities to nursing homes. This report presents the findings from the review. The rationale for the study is first provided in this introductory section, which also defines key terminology used in the report.

## 1.1 Rationale for the study

Under the Health (Nursing Homes) Act, 1990, a nursing home is defined as an institution for the care and maintenance of more than two dependent people. The tendency is to think of nursing homes as places for the care of older people and most people residing in nursing homes are older people. This is reinforced by the distinction enshrined in the Health Act, 2007, and made by the Health and Information Quality Authority (HIQA), between designated centres for children and adults with disabilities, on the one hand, and designated centres for older people, on the other; nursing homes fall within the latter group. Nursing homes are not, however, restricted to older people, and close to 1,500 younger people with disabilities are currently residing in nursing homes in Ireland, when we define younger people as those aged between 18 and 64 years. Latest figures from the HSE (June 2018) indicate that 1,313 people under the age of 65 years were accessing nursing home care via the NHSS scheme in public and private settings. <sup>4</sup>

The placement of younger people in nursing homes is not unique to Ireland. In Australia, for example, the Young People in Nursing Homes National Alliance estimated there were more than 6,000 younger people residing in what are termed residential aged care facilities in 2010, making up about 5% of residents. In the United States, the number of people under 65 in aged care facilities is reported to be increasing (Persson and Ostwald, 2009).

In Ireland, the placement of younger people with disabilities in nursing homes began to emerge as an issue of concern some years ago. In 2002, the Eastern Regional Health Authority (ERHA) estimated that 674 individuals with a congenital or acquired disability and aged between 18 and 65 years in the Eastern Region were waiting for appropriate accommodation. In its report the ERHA stated that:



**Nursing Homes are being used as a short-term solution to a long-term problem. As stated earlier, this accommodation, by its nature, is not appropriate for the young chronic disabled.**



<sup>4</sup> <https://www.rte.ie/news/health/2018/0808/983809-nursing-homes/>

More recently, the placement of younger people with disabilities living in nursing homes received renewed attention, when it was highlighted by the Working Group on Congregated Settings in its report, *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* (HSE, 2011). One of the principles agreed by the Working Group on Congregated Settings was that 'All people with disabilities can live with adequate support, in an ordinary home, in a range of typical neighbourhood settings' (HSE, 2011). Although people living with disabilities in nursing homes were outside its remit, the Working Group recommended that residential care settings including nursing homes, where younger people with disabilities may be inappropriately placed, should be reviewed by the HSE. It recommended that this review should identify actions needed to ensure that residents with disabilities can access the same levels of community-based support and inclusion that were proposed by the Working Group for residents of congregated settings. However, younger people with disabilities in nursing homes are not explicitly mentioned in the HSE's Transforming Lives Programme, a national collaborative effort dedicated to improving the delivery of health and social care services to people with disabilities (HSE, 2016).

Organisations advocating on behalf of people with disabilities have for some years been highlighting their concerns about this issue. For example, the Disability Federation of Ireland (DFI) first raised this issue in 2012.<sup>5</sup> It notes in its submission to the review of the Nursing Home Support Scheme (NHSS) that there are many younger people with disabilities resident in nursing homes including people with Down Syndrome at greater risk of experiencing early dementia, and people who acquire serious injuries that can make finding post-rehabilitative accommodation a challenge.

There is much anecdotal evidence and personal stories from the lived experience of younger people with disabilities residing in nursing homes. Attention has been drawn to the placement of younger people with disabilities in nursing homes by the media over the past few years with people with disabilities and their families raising awareness of this issue.<sup>6</sup>

<sup>5</sup>DFI (2012) Submission to the Review of the Nursing Home Support Scheme, Fair Deal. July 2012

<sup>6</sup><http://www.irishtimes.com/life-and-style/health-family/nothing-homely-about-being-young-in-a-care-home-1.1614724>, 3rd December, 2013

<http://www.irishtimes.com/news/health/patients-with-acquired-brain-injury-have-nowhere-to-go-1.669566>, 25th May, 2010

<http://www.herald.ie/news/young-victims-living-with-brain-injury-in-nursing-homes-due-to-funding-crisis-29386347.html>, 1st July, 2013.

<https://www.thesun.ie/news/2852866/man-32-who-suffers-from-spina-bifida-blasts-hse-for-moving-him-into-nursing-home-for-elderly-people/>

<https://www.rte.ie/news/health/2018/0808/983809-nursing-homes/>

A report commissioned by Bray Area Partnership, titled 'Old Too Soon', looked at the situation of 42 people with disabilities with an age range of 27 to 65 years who were living in nursing homes in the greater Bray area (Farrell, 2013), bringing the issue into the spotlight again. Generally, though, very little is known about the placement of younger people with disabilities in nursing homes and whether the placement is appropriate or not. This, according to research from Australia, may be due in part to the fact that younger people in nursing homes are difficult to access for research and typically there are only a few younger people in each nursing home (Winkler, Farnworth and Sloan, 2006; Winkler, Sloan and Callaway, 2007).

It is in this context that DFI commissioned this study on the situation of younger people with disabilities in nursing homes in Ireland. DFI sits on the HSE's National Consultative Forum (NCF) and it was agreed that the HSE would work in partnership with DFI to progress research in this area. A Research Advisory Group (RAG) was formed by DFI to oversee and support this research. The approach taken for this particular study was to undertake a review of CSAR forms to assess the level and sum of information that can be extracted from them on the placement of younger people with disabilities in nursing homes.



## 1.2 Terminology

**Younger people with disabilities** In this report they are defined as people with a disability aged 18 years or over, and under 65 years of age

**Disability** This is a broad concept for which there is no single definition and different definitions are used in different contexts. For example, in Ireland, the Disability Act 2005 sets out the following definition:

“disability”, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.’

The Equality Acts 2000-2015 (Employment Equality Acts and the Equal Status Acts), outlaw discrimination on nine grounds. Disability is one of these grounds. The Acts use the following definition of disability:

‘Disability means:

- (a) the total or partial absence of a person’s bodily or mental functions, including the absence of a part of a person’s body;
- (b) the presence in the body of organisms causing, or likely to cause, chronic disease or illness;
- (c) the malfunction, malformation or disfigurement of a part of a person’s body;
- (d) a condition or malfunction which results in a person learning differently from a person without the condition or malfunction; or
- (e) a condition, disease or illness which affects a person’s thought processes, perception of reality, emotions or judgement or which results in disturbed behaviour.’

For the purposes of this study, we use the definition of disability in the International Classification on Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO):

**an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)**

(WHO, 2001: 213).

In this report, we do not use a definitive list of conditions that constitute a disability. This is because using such a list would mean that younger people with significant but less common conditions could be omitted. One such example is dementia, which has generally been perceived solely as a health problem. It is now increasingly being reframed as a disability (Gove et al., 2017; Cahill, 2018). However, when conditions such as dementia are not included as a condition that constitutes a disability, then younger people with the condition can be left out of critical discussions of younger people with disabilities, and this has significant implications for them. This can also happen when conditions like dementia are mistakenly regarded as being exclusively confined to older people.





### **Appropriate placement:**

According to the Report of Disability Policy Review, appropriate services are those which support the person 'to lead full and independent lives, to participate in work and society and to maximise their potential' (Keogh, 2011, p. 40). It considered this to be the most important objective for people with disabilities. The term appropriate placement in a nursing home, as used in this report, follows the definition proposed by the Department of Health and Children (2011), i.e. **a placement in a nursing home is considered to be appropriate where the nursing home can best support the person 'to lead a full and independent life, to participate in society and to maximise their potential'.**

### **Care assessment:**

The care assessment has a pivotal role to play in determining what supports are needed and ultimately provided to a younger person with disabilities and the setting in which care is provided. Different models can underpin the care assessment process. The Report of Disability Policy Review (Keogh, 2011) distinguishes between two care assessment models. In the first, the care needs assessment is underpinned by a rehabilitative / medical perspective and in the second by an independent living / person-centred perspective. These are two contrasting perspectives, the key features of which are reproduced in Table 1 below. Identifying which model or approach underpins the assessment of care needs of people with disabilities referred to the NHSS is critical as the model determines the approach that health professionals take when carrying out the assessment. This in turn impacts on the extent to which health professionals will be able to actively translate policy into practice and support people with disabilities to live ordinary lives in ordinary places.

Table 1: Contrasting the approaches of the rehabilitative / medical perspective and the independent / person-centred perspective

	<b>Rehabilitative / medical perspective</b>	<b>Independent living / person-centred perspective</b>
<b>The problem is:</b>	Impairment / skills deficiency	Dependent on professionals and others who take control of your life
<b>Located in:</b>	The person	The environment and services
<b>Solution is:</b>	Professional intervention	Removal of barriers, advocacy, control vested in the individual
<b>Person is:</b>	Patient / client	Person / citizen
<b>Who's in charge?</b>	Professional	Person
<b>Outcomes defined by:</b>	Level of functioning	Living independently and being in control of my life

Adapted from O'Brien and O'Brien (2000) as cited in Department of Health (2011)

It is beyond the scope of this study to ascertain the extent to which younger people with disabilities residing in nursing homes are supported to lead full lives. However, this study can explore the extent to which the care needs assessment accompanying the NHSS embodies a rehabilitative / medical perspective or an independent / person-centred perspective.

## 2. Background context

Before presenting the findings of the review, this section of the report begins by setting out the policy context in relation to younger people with disabilities in Ireland. It provides an overview of the human rights context, with particular reference to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its relevance to younger people with disabilities and their placement in nursing homes. It next outlines nursing home provision in Ireland and the Nursing Home Support Scheme (NHSS), the statutory scheme for financial support of residents in nursing homes. This is followed by a discussion of the current situation in relation to community-based, rehabilitation and acute hospital services. Data from a range of sources available in Ireland on the number of younger people with disabilities in nursing homes is then reviewed.

### 2.1 Irish policy context

The central aim of current government disability policy in Ireland is to support people with disabilities to live ordinary lives in ordinary places, and to reconfigure disability services and supports to achieve this. This is a key focus of the Transforming Lives Programme (HSE, 2016), which is dedicated to improving the delivery of health and social care services to people with disabilities. This programme arose out of the Value for Money and Policy Review of Disability Services in Ireland (2012), a report which, together with the allied Report of Disability Policy Review by the Expert Reference Group (Keogh, 2011), signalled new directions for disability policy and significant changes in how disability support services were to be delivered in Ireland. The vision of the HSE's Transforming Lives Programme is:

**To contribute to the realisation of a society where people with disabilities are supported;**  
**(a) to participate to their full potential in economic and social life, and**  
**(b) to have access to a range of quality personal social support and services that enhance their quality of life and well-being.**

The aim of supporting people with disabilities to live ordinary lives in ordinary places is reiterated in the National Disability Inclusion Strategy 2017-2021 (NDIS) (Department of Justice and Equality, 2017). This Strategy focuses on community living and independence, with the stated objective being to support people with disabilities to live an independent life in a home of their choosing in their community. The NDIS aims to promote an inclusive Irish society where people with disabilities can reach their full potential and participate in the everyday life and activities of their communities. Person-centred services that support individuals to live a fulfilled life of their choosing are central to this objective. The government has committed to work on introducing personalised budgets for people with disabilities and the Task Force established on foot of this commitment has recently published its report (Department of Health, 2018). The principles of self-determination and autonomy, enshrined in the Transforming Lives Programme (HSE, 2016), are also reflected in the NDIS. Under the theme of Equality and Choice, an objective of the NDIS is that people with disabilities make their own choices and decisions. Services are to be designed so that they provide support for empowering people to make decisions in their own lives (Department of Justice and Equality, 2017). The passing of the Assisted Decision-Making (Capacity) Act, 2015 provides a statutory framework to support decision-making by adults who have difficulty making decisions unassisted, and this is discussed briefly in Section 2.2 of this report.

Another goal of Irish disability policy is to develop public services that are universally designed and accessible to all citizens. Health and well-being is a key theme of Irish disability policy, with the aim being to support people with disabilities to achieve and maintain the best possible physical, mental and emotional well-being. There is a stated commitment that adults with disabilities will have timely access to assessment and early intervention, and the therapy, rehabilitation or mental health services they require (Department of Justice and Equality, 2017).

The National Housing Strategy for People with a Disability 2011-2016 is another key policy document signalling changes in how people with disabilities are to be supported. It sets out a number of strategic aims including 'equality of access for people with a disability to the full range of housing options' and 'to support people with a disability to live independently in their own houses and communities' (Dept. of the Environment, Community and Local Government, 2011).

There are several other key policy areas that are relevant to younger people with disabilities in nursing homes. These include the Neuro-Rehabilitation Strategy (Department of Health, 2011), focusing on the rehabilitation of those persons with a neurological presentation or with a significant physical disability. The Strategy clearly conveys the need for a continuum of services to support the timely transition from hospital to home, maximise recovery and support participation in community life. The Strategy is linked to the National Clinical Programme for Rehabilitation Medicine<sup>7</sup> and its implementation is currently being progressed. A major capital investment is also to be made in the National Rehabilitation Hospital (Department of Justice and Equality, 2017).

<sup>7</sup> <https://www.hse.ie/eng/about/who/cspd/ncps/rehabilitation-medicine/>

As some younger people in nursing homes will have younger onset dementia, intellectual disability and dementia and others will have mental health difficulties, the Irish National Dementia Strategy (Department of Health, 2014) and A Vision for Change, Ireland’s policy aimed at advancing mental health services (Government of Ireland, 2006), are both also relevant. Underpinned by the overarching principles of personhood and citizenship, the National Dementia Strategy is concerned with supporting people with dementia to remain in their own homes, but the Strategy offers no immediate improvements for people with young onset dementia (O’Shea et al., 2017). A Vision for Change, the Report of the Expert Group on Mental Health Policy, dating from 2006, describes a framework for providing accessible, community-based, specialist services for people with mental health problems. Irish national policy documents emphasise the rights of people with mental health disabilities to appropriate housing and accommodation (Government of Ireland, 2006).



Families are the most common source of help for many younger people with disabilities (Watson and Nolan, 2011). The National Carers’ Strategy sets the strategic direction for future policies, services and supports provided by Government Departments and agencies for carers. The four goals of the National Carers’ Strategy are to:

- Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for,
- Support carers to manage their physical, mental and emotional health and well-being
- Support carers to care with confidence through the provision of adequate information, training, services and supports,
- Empower carers to participate as fully as possible in economic and social life.



## 2.2 Human rights context

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), an international human rights instrument adopted by the United Nations in 2006, provides a useful frame for considering the human rights issues facing younger people with disabilities in nursing homes. It has only recently been ratified (March 2018) by the Irish government and entered into force internationally in May 2008. The Irish government chose not to ratify the Optional Protocol (OP), to the UNCRPD, at the same time as it ratified the Convention. The OP allows for individuals to bring complaints before the UN Committee on the Rights of Persons with Disabilities, under certain circumstances, alleging that their rights have been violated in relation to the provisions of the Convention. The OP provides a mechanism for enforcing an individual's rights, which could be availed of by a younger person with a disability living in a nursing home.

A principal role of the UNCRPD is to demonstrate how traditional rights are to be applied in respect of persons with disabilities, and as such can be read in conjunction with earlier core human rights instruments.<sup>8</sup> The purpose of the UNCRPD, outlined in Article 1, is 'to promote, protect and ensure the full and equal enjoyment of all human rights and freedoms by all persons with disabilities, and to promote respect for their inherent dignity'. In total, there are 50 articles in the UNCRPD and, to understand the full implications of UNCRPD rights and obligations, it is necessary to read these articles in relation to each other, rather than in isolation.

Article 19 is of particular relevance to the placement of younger people with disabilities in nursing homes (see Box 1). It explicitly states that all people with disabilities have the right to live and participate in the community. While this current report focuses on younger people with disabilities, this right equally applies to older people with disabilities in nursing homes. Article 19 requires states to develop a range of supports to facilitate people with disabilities to live in the community. Reliance on nursing homes as a model of care for younger people with disabilities because no other options are available means that Ireland may be failing to comply with Article 19 of the UNCRPD and therefore, placing people with disabilities in nursing homes against their will could constitute a violation of their human rights.



<sup>8</sup>. For example, the International Covenant on Civil and Political Rights (ICCPR), and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

## **Box 1: Article 19 of the UNCRPD – Living Independently and Being in the Community**

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a)** Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b)** Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c)** Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.



Another UNCRPD article of note is Article 12 on equal recognition before the law. This article is important because of its reference to people with disabilities as having legal capacity (decision-making ability) on an equal basis with others in all aspects of life. It includes a section on supported decision-making which respects the person's autonomy, will and preferences. Supported decision-making stands in stark contrast to a substitute decision-making model (Devi, Bickenback and Stucki, 2011). Within this latter model, a younger person with disabilities, for example, a person who has an acquired brain injury or younger onset dementia - who may have difficulties making decisions - may be considered to be lacking capacity, and because of this another individual is granted authority to make a decision on the person's behalf. While Article 12 has proved challenging to implement practically, it promotes the autonomy of people with disabilities who would otherwise be considered to be lacking capacity. This could include ensuring younger people with disabilities have access to independent advocacy for support with major decisions such as in relation to where people live and where they will be cared for.

In Ireland, the Assisted Decision-Making (Capacity) Act, 2015 is a key piece of legislation that forms part of Ireland's ratification of the UNCRPD. It provides a statutory framework to support decision-making by adults who have difficulty taking decisions unassisted. The Act though passed has not yet been fully commenced. When fully commenced, it will mainly be used by people with disabilities who have impairments that affect their ability to make decisions. This includes younger people with disabilities who are faced with making decisions about where they will live, about their care and possible placement in a nursing home. Any decision made under the Act in support of a person with disabilities and impaired ability to make decisions will be required to give effect to the person's will and preferences.

Other UNCRPD articles of relevance include;

- Article 9: Accessibility (ensuring accessible environments, transport, information and services),
- Article 25: Health (right to quality health services),
- Article 26: Habilitation and rehabilitation, which is concerned with maximising independence through comprehensive habilitation and rehabilitation services.

The PANEL principles are one way of breaking down what a human rights approach means in practice (SHRC, not dated; SHRC 2016) and these principles may be useful for the applicability of human rights to the placement of younger people with disabilities in nursing homes. PANEL stands for Participation, Accountability, Non-discrimination and Equality, Empowerment, and Legality (see Box 2).





<b>Box 2: PANEL Principles</b>	
<b>Participation</b>	People should be involved in decisions that affect their rights.
<b>Accountability</b>	There should be monitoring of how people’s rights are being affected, as well as remedies when things go wrong.
<b>Non-Discrimination and Equality</b>	All forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritized.
<b>Empowerment</b>	Everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.
<b>Legality</b>	Approaches should be grounded in the legal rights that are set out in domestic and international laws.

Source: SHRC (2016).

Guidance on using the PANEL principles has been developed in the form of the FAIR flowchart, which guides users on the use of a human rights approach. This consists of (1) Establishing the facts; (2) Analysing the rights at stake; (3) Identifying who is responsible for bringing about change; and (4) Reviewing an action taken. The Scottish Human Rights Commission has developed a guidance document on the FAIR flowchart (SHRC, not dated). Establishing the facts involves asking questions such as: What is the experience of the individual? Is the individual being heard and if not, do they require support to do so? What are the important facts to understand? Once the facts have been established, the next question is: What human rights are at stake? To identify who is responsible, first it is asked: What changes are necessary? Those who have responsibilities for helping to make the necessary changes are then identified. The final step is to record and review the actions that have been taken and to check whether the person affected has been involved. Case study examples have also been developed to illustrate how this approach can be applied in practice in the design and delivery of health and social care services (SHRC, 2016).

## 2.3 Nursing home provision and financing in Ireland

Nursing home care in Ireland is based on a mixed economy, with nursing home care provided by public, private and voluntary sectors. The Nursing Homes Support Scheme (NHSS), commonly referred to as the 'Fair Deal' scheme, was introduced in 2009 to provide financial support for people in need of nursing home care. It was introduced to make state support for nursing home care consistent and equitable across public, private and voluntary long-stay residential care settings. The scheme offers the only access to state financial support towards the cost of nursing home care, and as such is the only way that people gain access to publicly funded or subsidised long-stay residential care. The scheme is primarily for older people (i.e. people over 65 years of age) seeking access to long-stay residential care, in the public, voluntary or private sectors. However, younger people (under 65 years) seeking access to long stay residential care can also make an application to the NHSS.

Under the NHSS, applicants must have a care needs assessment carried out by a health professional. All applicants are required to complete an application form. The first step is an application for a Care Needs Assessment. An assessment of the person's needs is a legislative requirement under the NHSS Act 2009, the aim being to develop a national common assessment approach. This assessment is undertaken by the Multidisciplinary Team (MDT) and the report is compiled in the Common Summary Assessment Report (CSAR). The assessment is primarily for older persons but, as mentioned, the care needs of younger people applying for the NHSS are also assessed using the CSAR.

Once the CSAR form is completed by healthcare professionals, the application for the NHSS is submitted to the local Nursing Home Support Office (NHSO), of which there are 17 around the country. The CSAR must be approved by the 'Local Placement Forum' (LPF), which comprises medical and other healthcare professionals in each local NHSO area. Each LPF has a chairperson and holds meetings at regular intervals, e.g. weekly or fortnightly, at which CSAR forms are reviewed and a decision is made on the need for care. The NHSO is then informed of the LPF's decision as to whether long-term residential care is required or not (Department of Health, 2015).

The NHSS requires nursing homes residents to make a contribution towards the costs of their nursing home care, based on a financial assessment of their income and assets, including their family home. If the assessed contribution is less than the nursing home fee, the HSE pays the balance. The resident contributes up to 80 per cent of assessable income and up to 7.5 per cent per annum of the value of any assets above €36,000 for an individual or €72,000 for a couple. An optional element of the NHSS is the Nursing Home Loan, which allows residents to defer the asset-based contribution, which is then collected from the person's estate. The resident's principal residence is only included in the financial assessment for the first three years of a person's time in care, thus limiting the proportion of the value of their family home that must be contributed to their care. Wren et al. (2017) estimated that in 2015 there were 21,248 long-stay residents in nursing homes funded by the NHSS, of whom 1,010 were people under the age of 65 years.

## 2.4 Community-based services and supports

As an alternative to nursing home care, a range of supports are provided to people with disabilities under 65 years of age in the community. These are delivered across the country through a mix of HSE direct provision as well as through funded service providers from the voluntary and private sectors. In contrast to the NHSS, community-based services are not currently means-tested and recipients do not have to make a financial contribution towards the cost of these services. Community-based services include day places, personal assistant and home support hours, as well as multi-disciplinary teams and other community services and supports, aimed at meeting the personal care as well as the social care needs of persons with disabilities. The HSE's National Service Plan (NSP) for 2018 sets out the type and volume of health and personal social services to be provided by the HSE within the budget available. In its 2017 NSP, the HSE stated that it expected 2,357 adults with physical and / or sensory disabilities to receive 1.4 million Personal Assistance service hours in 2017 (HSE, 2016). These Personal Assistance hours are distributed across the nine Community Healthcare Organisations (CHOs). A case manager is assigned to each person who has been referred to the HSE as needing a care package and a needs assessment is carried out. Care is divided into essential care and social needs; essential needs get priority over social care needs.

While there is a broad policy commitment to the development of community-based care, the community supports currently available to people with disabilities to help them live independent lives in the community are underdeveloped and unplanned and often not sufficient to meet their needs (Doyle and Carew, 2017; Hourigan, Fanagan and Kelly, 2017). This is even more likely to be the case for those younger people with disabilities who have highly complex needs and require multidisciplinary support. Moreover, despite the stated intention of Irish disability policy in favour of community-based care, the funding system is biased in favour of residential care.

According to the HSE's National Service Plan (NSP) for 2018, 60% of the resources available for disability services are allocated to provide residential services to approximately 8,400 people with a disability (HSE, 2017). The Health Research Board (HRB) reports that there were almost 7,500 people with an intellectual disability on the HRB's National Intellectual Disability Database (NIDD) register and a further 329 people on its National Physical and Sensory Disability Database (NPSDD) register in full-time residential care in 2017 (Doyle and Carew, 2017; Hourigan, Fanagan and Kelly, 2017).<sup>9</sup> While the majority of adults with intellectual disability continue to live with their families, the demand on full-time residential care is ever increasing as a result of improved life expectancy among this group of people, especially for those with severe intellectual disability (Hourigan, Fanagan and Kelly, 2017).

<sup>9</sup> The NIDD and NPSDD are administrative databases for the purposes of service planning, with data provided mainly by disability service providers. The NIDD and the NPSDD have been merged into one database, the National Ability Supports System (NASS).

## 2.5 Rehabilitation services

Like community services, current rehabilitation services, both hospital and community based, are also underdeveloped in Ireland. Specialist rehabilitation services tend to be hospital-based and concentrated at a national level with community-based rehabilitation services fragmented and un-coordinated. Planning and further development of these services is hampered by a lack of data on how many people are actually in need of such services, and what are the needs of a range of people living with different complex conditions.

The public acute hospital sector in Ireland receives the largest allocation of public healthcare funding. However, the demand on acute hospital beds is high and is forecast to increase substantially by 2030 (Wren et al., 2017). Younger people with disabilities are most commonly placed in nursing homes from acute hospital settings. While younger people with disabilities may experience excellent care within the acute hospital system, issues seem to arise when it comes to discharge from the acute settings (Muldoon et al., 2017). With current community resources and limited rehabilitation services, the preference to be discharged home or to supported accommodation to live independently may not be an option for some younger people with disabilities who need full-time care and support. In the absence of appropriate community services, factors that are likely to be driving the transfer of these younger people with disabilities to nursing homes are the urgent needs for beds and the pressure on staff in acute hospitals to free up beds and discharge people from acute hospital beds.

In addition to having access to community-based services and personal assistance, enabling younger people with disabilities to live in the community requires access to appropriate and accessible housing. Inappropriate housing, an inaccessible environment and the lack of suitable home care services are factors contributing to younger people with disabilities leaving their homes and moving to a nursing home. As mentioned above, Article 19 of the UNCRPD sets out the rights of people with disabilities to community living and participation. Due to the significant lack of housing options and underdeveloped community services, this right has not yet become a reality for those younger people with disabilities whose preference it is to live in the community as opposed to being placed in a nursing home.

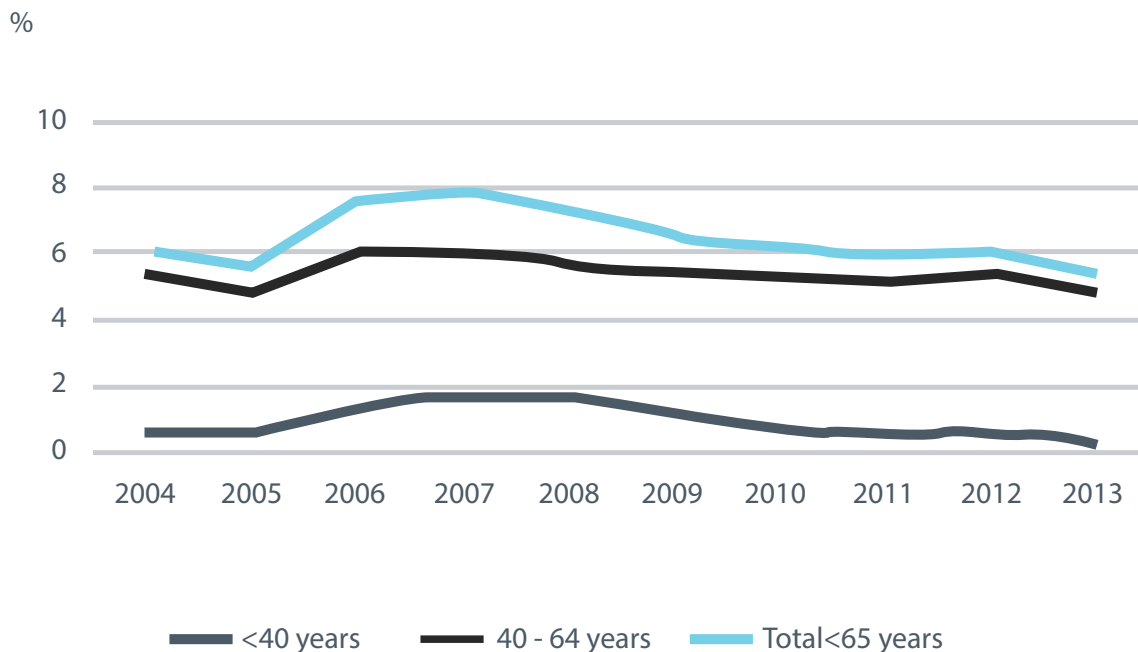
## 2.6 Irish data on younger people with disabilities in nursing homes

Data from a range of sources is available in Ireland providing information on the number of residents in nursing homes. In this section of the report, several data sources are reviewed for information on the number of younger people with disabilities in nursing homes.

The Census of Population reported that there were 20,802 people aged 65 years and over in nursing homes in Ireland in 2011 and that this figure increased to 22,762 in 2016 (CSO, 2012; CSO, 2017). However, data on the number of younger people aged under 65 years in nursing homes in Ireland is not available from the Census. Two surveys that provide information on the number or proportion of younger people with disabilities in nursing homes are the Department of Health Long Stay Activity Statistics (LSAS) and annual surveys of private and voluntary nursing homes published by Nursing Homes Ireland (NHI). Data collated by Wren et al. (2017) is another useful source as it brings together both survey and administrative data. Limited data is also available from the HRB's NIDD and NPSDD.

The most recent LSAS available from the Department of Health relate to 2013 (Department of Health, 2013). Data from this survey shows that 5.4% or 1,143 of the 21,175 long-stay beds in the participating long-stay residential care settings were occupied by people under the age of 65 and that a further 8% or 148 of the 1,851 of the limited stay beds (which include rehabilitation, convalescence, palliative care and respite) were occupied by younger people. The percentage of younger people in nursing homes varies by region with the highest proportion in Dublin North East at 9%. According to data from the LSAS (Department of Health 2013), while there was an upward trend in the proportion of younger people in nursing homes over the period 2004 to 2007, this was followed by a general downward trend from 7.8% in 2007 to 5.4% in 2013 (Figure 1).

**Figure 1: Proportion of younger people in nursing homes in Ireland 2004 to 2013**



Source: Department of Health (2013)

Nursing Homes Ireland has published data from annual surveys of private and voluntary nursing homes. Data on the percentage of residents under 65 years of age is available for the years 2007, 2009 and 2014, and is reported to be 4.8%, 4% and 3% respectively,<sup>10</sup> indicating that the proportion has fallen over the period 2007 to 2014, which is line with the downward trend observed in the Department of Health LSAS.

Wren et al. (2017) drew on a range of available administrative and survey data to produce estimates of the number of residents in long-stay and intermediate care settings (p. 64). They estimated that there were 30,106 beds in HIQA registered facilities in 2015, occupied by 28,992 residents (including short-stay residents), of whom 5.4% were estimated to be in the age group 18 to ≤ 64 years. The estimates presented in Table 2 are based on Wren et al. (2017). They show that in 2015 there was a relatively high proportion of younger people who were publicly financed long-stay residents under legacy schemes.<sup>11</sup> This would suggest that in 2015 there were 264 younger people who had been resident in nursing homes since at least 2009, the year the Nursing Home Support Scheme was introduced.

<sup>10</sup> Figures are based on a response rate of 35% in 2007, 34% in 2009/2010 and 35% in 2014 / 2015.

<sup>11</sup> Legacy schemes refer to schemes such as the Nursing Home Subvention, which the Nursing Home Support Scheme replaced. The Nursing Home Subvention closed on 27 October 2009. A person who was in receipt of the subvention on that date could choose to continue to receive it or move to the Nursing Home Support Scheme.

**Table 2: Younger residents in long-stay residential care settings 2015**

<b>Category</b>	<b>No. of residents</b>	<b>Number in age group 18 to ≤ 64 years</b>	<b>% in age group 18 to ≤ 64 years</b>
<b>NHSS-funded long-stay residents</b>	<b>21,248</b>	<b>1,010</b>	<b>4.8%</b>
<b>Publicly financed long-stay residents (under legacy schemes)</b>	<b>1,882</b>	<b>264</b>	<b>14.0%</b>
<b>Privately-financed long and short-stay residents (estimated)</b>	<b>2,634</b>	<b>126</b>	<b>4.8%</b>
<b>Short-stay residents excluding privately financed (estimated)</b>	<b>3,229</b>	<b>170</b>	<b>5.3%</b>
<b>Total estimated residents</b>	<b>28,992</b>	<b>1,569</b>	<b>5.4%</b>

**Source: Wren et al. (2017, Table 9.1, p. 222).**

Limited data on younger people with intellectual disabilities living in nursing homes is available from the National Intellectual Disability Database. Data from the National Physical and Sensory Disability Database is even more limited.

## 2.7 Summary

There is a strong policy commitment in Ireland to supporting people with disabilities of all ages to live ordinary lives in ordinary places and to reconfigure disability services and supports to achieve this. However, it is recognised that there are shortcomings in disability services and supports. Community supports which could potentially support people with disabilities to live at home as an alternative to nursing home care are all too often insufficient or not tailored to meet their needs. Barriers to living independently in the community can be exacerbated by a lack of timely access to assessment and early intervention, and the therapy, rehabilitation or mental health services that people with disabilities may require. At the same time, the shift away from traditional institutional models of care for people with disability continues, meaning that fewer residential care places are available and demands on community-based supports are increasing. Younger people are caught in the policy confluence of underdeveloped and underfunded community care services, longer life expectancy among people with disabilities, falling residential care places and greater reliance on family care. It is in this context that the younger people with disabilities and their placements in nursing homes need to be considered.

There are close to 1,500 younger people with disabilities residing in nursing homes in Ireland. Younger people with disabilities are most commonly placed in nursing homes from acute hospital settings and issues that arise at time of discharge such as urgent needs for beds and pressure on staff to discharge. In addition to this, the absence of appropriate community services is likely contributing to their nursing home placement, as is the funding system, which is biased in favour of residential care. However, little is known about younger people with disabilities who are placed in nursing homes, including who they are or to what extent they are involved or supported in making decisions about their care. This review will make a timely contribution by making available detailed information on a sample of younger people with disabilities who have made an application for financial support for nursing home care through the NHSS.



## 3. Methodology

The study involved a review of Common Summary Assessment Report (CSAR) forms to assess the level and sum of information that could be extracted from them on the placement of younger people with disabilities in nursing homes. The review of the CSAR forms involved the following:

- Reviewing and extracting the sum of relevant information from the CSAR forms
- Analysing the learning from the data in terms of addressing the research objectives to provide a profile and situation of people with disabilities, and to develop our understanding of the meaning of appropriateness / inappropriateness of placement
- Assessing the strengths / limitations of the anonymised CSAR forms in terms of addressing these objectives

To access the anonymised CSAR forms, two key steps were required. These were:

(1) negotiating access to the anonymised CSAR forms; and

(2) securing ethical approval to undertake the review. This report discusses these two steps, the challenges encountered and implications for completing the review.

### 3.1 Negotiating access to the CSAR forms

The completion of a Common Summary Assessment Report (CSAR) forms part of the application process for the Nursing Home Support Scheme (NHSS) (Section 2.2). The CSAR contains important information that could potentially provide valuable information that would contribute to a better understanding of the placement of younger people with disabilities in nursing homes. The data recorded on the CSAR form includes;

- age,
- county of residence,
- personal circumstances,
- information on self-determination,
- community / home support services,
- current diagnosis and medical conditions,
- mental health status,
- assessment of dependency levels (using the Barthel Index),
- communication, cognition and any other assessments,
- other significant, social and medical risk factors as well as information on whether or not health professional reports and / or specialist assessments have been completed,
- section recording the recommendation made by the multi-disciplinary team (MDT),
- section for the Local Placement Forum (LPF) to record its determination.

Although the HSE holds information centrally on the number of younger people approved for the NHSS, no other information on the placement of younger people with disabilities in nursing homes is held electronically. The CSAR forms that are completed as part of the application for NHSS are paper-based forms. They are not held centrally in one location, but held locally.

Since the CSAR forms are not held centrally, support was sought from HSE Senior Management for the study to ensure that the researchers would be facilitated locally to gain access to the CSAR forms and avoid delays in accessing the data. In January 2016, Senior Management responded, indicating support for the study and agreeing to issue a communication to the nine Heads of Social Care once ethical approvals were granted. This would be followed by a letter from the researchers to the Chairs of the Local Placement Fora, requesting their support for the study and access to relevant anonymised CSAR forms.

Three categories of CSAR forms were requested from the HSE for the purposes of undertaking the review, as follows:

- CSAR forms relating to all applications for the (NHSS) that were received and approved in 2015 in respect of applicants under 65 years of age at the time of application,
- CSAR forms relating to people under 65 years of age who applied for the NHSS in 2015 and for whom it was subsequently determined that the applicant did not require long term residential care services,
- CSAR forms relating to all people under 65 years of age who were in receipt of long term residential care services under the NHSS as at the 31<sup>st</sup> December 2015 and who applied for financial support under the scheme on or before 31<sup>st</sup> December 2014.

## **3.2 Ethical approval**

Securing ethical approvals was a straightforward process. This is a low risk study as it involves a review of anonymised data provided by the HSE to the researchers. An ethics application was submitted to the Dublin City University Research Ethics Committee (REC). In DCU, notification for ethical approval from the DCU REC is required where the research includes the analysis of data (e.g. CSAR) which have had all identifying information removed by the data holder and has been provided to the researcher in accordance with data protection legislation. Ethical approval was granted on 1st February 2016.

### 3.3 Accessing a sample of CSAR forms

Gaining access to the CSAR forms proved to be a time-consuming and protracted process, mainly because of resource issues, particularly staff availability in the HSE to retrieve and redact the forms. In addition, the study commenced during a time of restructuring of the HSE, whereby nine Community Healthcare Organisations were being established and Chief Officers and Heads of Social Care were being appointed to them who were faced with ongoing demands from other work. In this context, the HSE's National Consultative Forum (NCF) was asked to explore ways of addressing the resource issues. The NCF agreed that the study was important and that the redaction of the CSAR forms would be completed, but because of resource issues no timeframe was set.

In the meantime, several LPFs were approached to establish their interest in facilitating access to CSAR forms that had been submitted to their forum for people under 65 years of age. One LPF agreed to support the researchers. Approval was given by senior managers and the Chief Officer of the relevant CHO.

Anonymising the forms involved redaction of all personal details contained in the CSAR forms, i.e. applicant name (and preferred names), names of specified persons making an application on behalf of the applicant, names of principal carers or any family members, friends or neighbours providing support to the applicant, contact details of applicants, specified persons or carers, date of birth, PPS number, current and past home address, any hospital number or patient control numbers. While the home address of the applicant was redacted, the county in which the person lived and year of birth were not to be redacted. To assist the LPF co-ordinator in the redaction of the forms, the researchers prepared a CSAR template indicating the sensitive information that would need to be redacted in each form, accompanied by a set of brief, clear instructions. Due to time constraints, it was not possible for the LPF co-ordinator to retrieve and redact CSAR forms relating to all applicants under 65 years to this LPF for the NHSS. However, a sample of 48 CSAR forms selected at random were retrieved and redacted and were then made available to the researchers.

This LPF has served as a demonstration site for the retrieval and redaction of the CSAR forms and shows that it is feasible for LPFs to retrieve and redact CSAR forms for younger people with disabilities applying for the NHSS. A general estimate is that there would be between 30 and 50 CSAR forms completed for people aged under 65 years in each LPF area, and that it would take one person one half day to complete the retrieval and redaction of these forms. The experience from the demonstration site is that it would be feasible for 50 CSAR forms to be retrieved and redacted and that this would take one person one half day to complete.

## 3.4 Data analysis

Once the CSAR forms were received, each form was given a unique ID number and data from the form were entered into an excel workbook developed for the purposes of this study. Quantitative data on the forms was analysed with the aid of SPSS. There were a number of places on the CSAR forms where health professionals could write notes or comments, for example, the form asks for an outline of the outcome of discussions on preference for care setting and if no discussion has taken place the reasons for that. Qualitative data like this was transcribed verbatim and analysed using thematic analysis.

Anonymised CSAR forms for 48 younger people with disabilities applying for the NHSS to one Local Placement Forum (LPF) were included in the sample, which represents approximately one-half of all applications received from younger people by this LPF. This is a small sample and for this reason the statistical analysis is largely descriptive, with numbers rather than percentages being presented in most cases. Due to the sample size and because it is drawn from one LPF, results may not be generalised beyond the specific population from which the sample was drawn. Although the scope for making generalisations to the whole population of younger people with disabilities applying for the NHSS is limited, the findings are discussed in the context of findings from other studies, thus providing support for the findings. While the sample size is a limitation of this study, a strength is that it relies on HSE administrative data. It is a unique dataset, allowing for an audit that provides a profile of a specific group of NHSS applicants. Notwithstanding the study limitations, the findings represent the first profile, to the authors' knowledge, of younger people with disabilities applying for state-funded support for nursing home care. The data is useful in highlighting important considerations for policy implementation and service planning.

## 4. Findings

The findings, based on the analysis of 48 anonymised CSAR forms, provide a profile of one group of people, younger people with disabilities applying to one Local Placement Forum (LPF) for the Nursing Home Support Scheme, (NHSS).

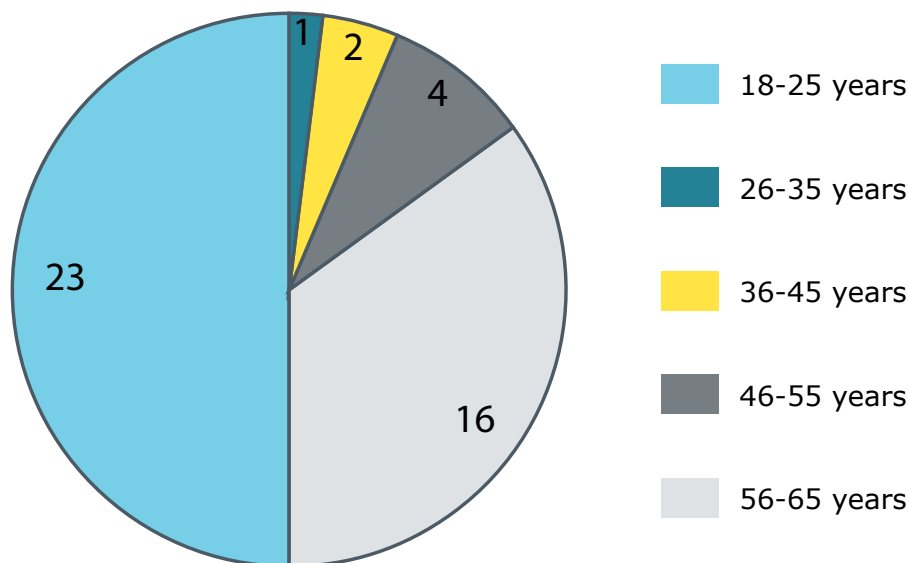
Quantitative and qualitative data recorded on the Common Summary Assessment Report (CSAR) form, as outlined in Section 3.1, was analysed.

### 4.1 Socio-demographic profile of NHSS applicants under 65 years of age

The available socio-demographic characteristics and living circumstances of this group of 48 younger people with disabilities applying for the NHSS in one LPF are as follows.

These applicants ranged in **age** from 21 to 64 years, with a mean age of 53 years. One half (23/46) were in the age group 56-65 years and more than 80% (39/46) were over 45 years of age.

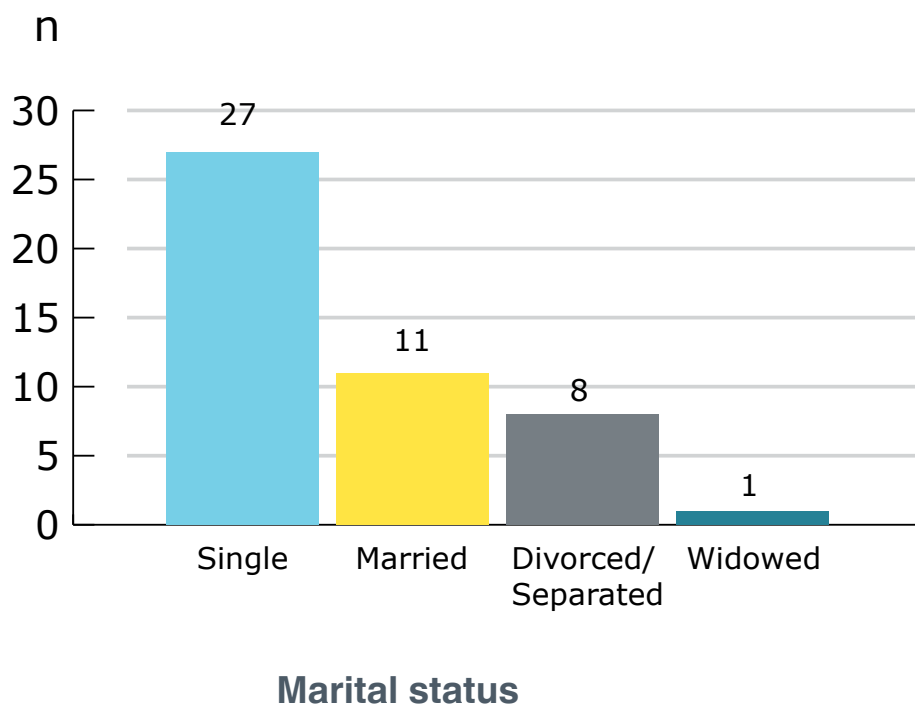
Fig. 2: Age profile of younger people with disabilities applying for NHSS, (n=46)



As the CSAR form does not record **sex** of the person assessed, we could not tell what proportions of the sample were male and female. Nor was it possible to determine the sex of the people on the CSAR forms in the majority of cases as personally identifying information (e.g. first name) was redacted to protect the confidentiality of applicants.

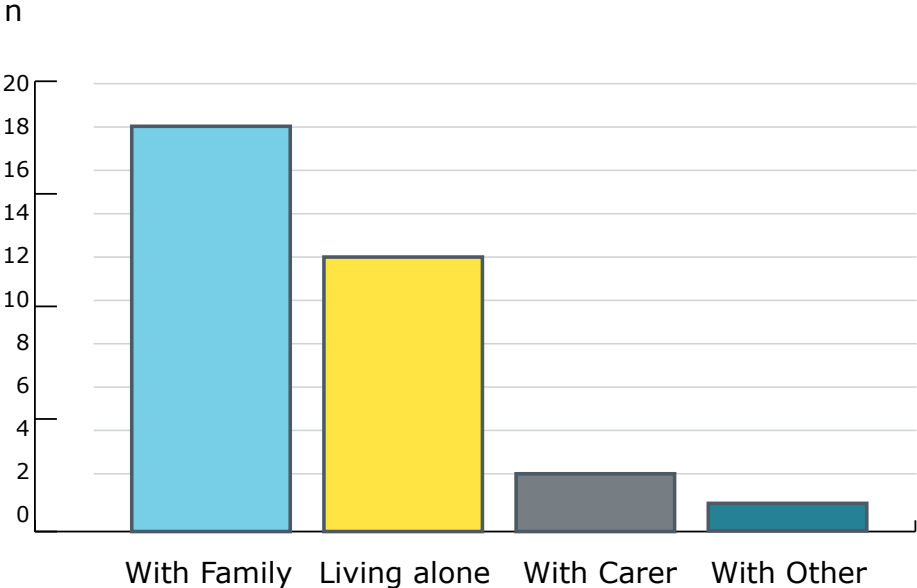
With respect to **marital status**, the majority (36/47) of the sample were either single, widowed, separated or divorced (Figure 3). This contrasts sharply with the findings of a much larger study of younger people with disabilities in nursing homes in Australia, which found that 48% were in partner relationships (Winkler et al., 2015).

**Fig 3: Marital status of younger people with disabilities applying for NHSS (n=47)**



More than a half (18/33) of those for whom information on living arrangements was available were recorded as living with family at the time of application (Figure 4), and more than one-third were living alone.

Fig 4: Living arrangements of younger people with disabilities applying for NHSS (n=33)



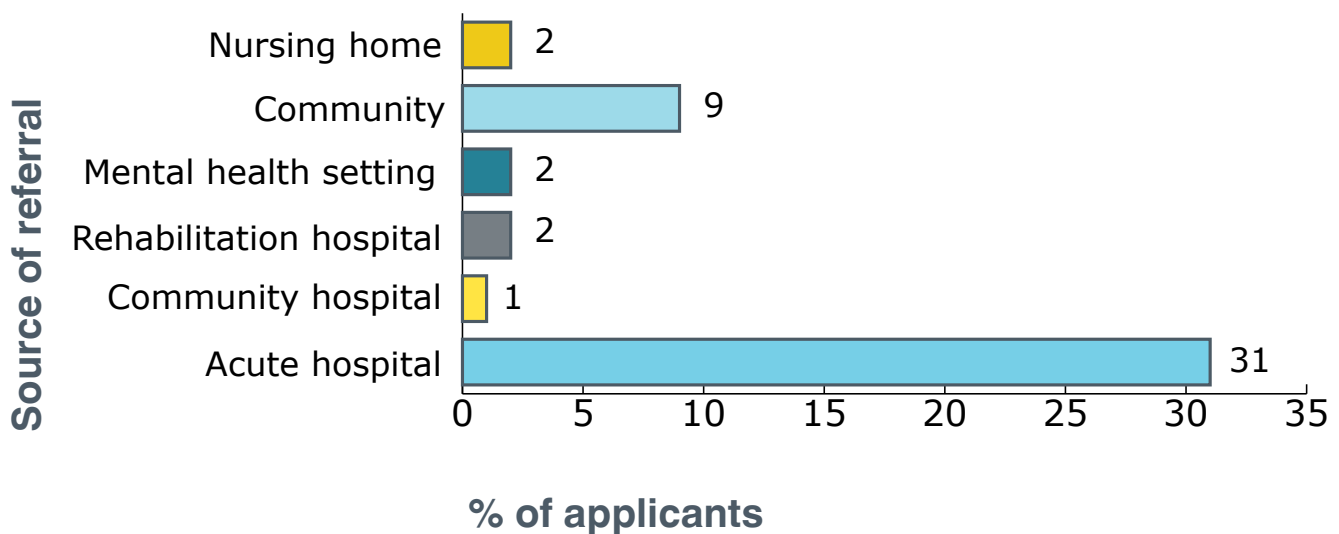
### Living arrangements

Information on **housing situation** from the CSAR forms was limited and available for only nine people (less than one-fifth) in the sample. Two people were recorded as having their own home, five persons were recorded as living in rented accommodation (three private rented and two local authority rented accommodation), one person was living in sheltered accommodation and one person was living in a high support hostel. Seven people were recorded as living in a two-storey building and one person was recorded as living in a one-storey bungalow.

## 4.2 Source of referrals

Information on **referral source** was available for 47 people. Most (34/47) of these applicants for the NHSS who were aged under 65 years were referred from a hospital, either an acute, community or rehabilitation hospital, whereas a much smaller proportion (9/47) were referred from the community (Figure 5).

**Fig 5: Source of Referral of NHSS applicants with disabilities under 65 years of age (n=47)**



For this group, the source of referral for the NHSS is shown in Table 3, which also shows the health professionals who completed the CSAR forms.

The majority (34/47) of applicants were referred from a hospital. The majority of CSAR forms relating to those referred from an acute setting were completed by a Medical Social Worker (MSW) or Social Worker with the remainder completed by a Consultant Psychiatrist. Of the referrals from a community hospital, the CSAR forms were typically completed by the Public Health Nurse (PHN) or by a MSW. The CSAR forms accompanying referrals from a rehabilitation hospital were completed by a MSW or a Social Worker.

Among this group, it was more unusual for younger people with a disability to be referred from a mental health setting or from the community for the NHSS. Two people were referred from a mental health setting, and the forms were completed by a Social Worker. Six people were referred from the community, with forms completed by a Public Health Nurse or an Assistant Director of Public Health Nursing (ADPHN).

Two people were referred from a nursing home and the forms were completed by a Social Worker or Community Mental Health Social Worker (CMHSW). This might suggest that some younger people under 65 years of age are admitted to a nursing home before the application for the NHSS is made. There were no referrals for NHSS consideration from GPs or a psychiatric hospital.



Table 3: Sources of referral of NHSS applicants under 65 years of age

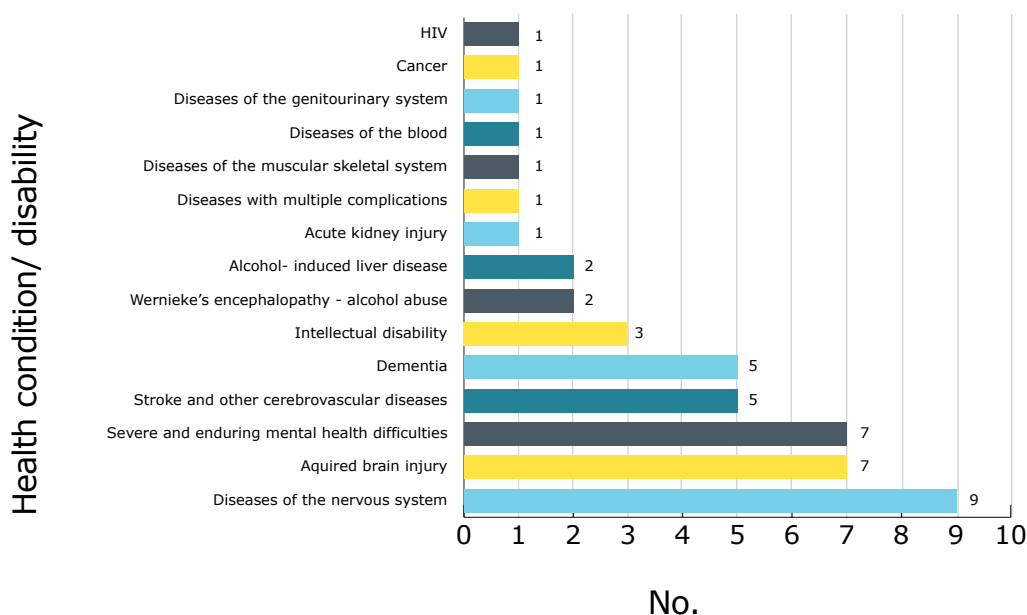
Referral Source (n = 47)	Referral of NHSS applicants
Completed by	Number of people
Acute hospital Social worker / MSW/ SMSW Consultant Psychiatrist	31 28 3
Community hospital MSW	1 1
Rehabilitation hospital MSW/Social worker	2 2
Mental health setting Social Worker	2 2
Community PHN / ADPHN	9 9
Nursing home Social Worker CMHSW	2 1 1

## 4.3 Disability / health conditions and co-morbidity

The main health conditions / disabilities of younger people applying for the NHSS were classified according to the WHO International Classification of Diseases (ICD-10). Figure 6 shows the range of health conditions / disabilities among this group of younger people applying for the NHSS classified using the ICD-10. The six most common were diseases of the nervous system such as multiple sclerosis, followed by acquired brain injury (ABI), people with severe and enduring mental health difficulties, people with stroke and cerebrovascular diseases, dementia and intellectual disability. However, if stroke and cerebrovascular diseases are classified as acquired brain injuries, then ABI becomes the most common health condition / disability of younger people applying for the NHSS. The term ABI includes both traumatic brain injuries (TBIs) and non-traumatic brain injuries. TBIs are those caused by assault, road traffic accidents, a trip or fall. Non-traumatic brain injuries are those caused by stroke, aneurysm, brain haemorrhage, viral infection (e.g. encephalitis, meningitis), tumour, seizures, anoxia or lack of oxygen to the brain (e.g. drowning). The five people with younger onset dementia were in their 50s or early 60s.

Five people have a dual diagnosis, which refers to the presentation of two or more conditions such as substance abuse or dependence and mental health problems. Most of those with a dual diagnosis in this sample were people with severe and enduring mental difficulties and an intellectual disability (4).

**Fig. 6: Main health conditions / disability of younger people applying for NHSS**



Co-morbidity was common among this sample, with almost half (23/48) of the sample having one or more comorbidity. The most common co-morbidities were depression, substance abuse, high blood pressure, kidney disease and epilepsy.

## 4.4 Mental health status and cognitive impairment

As mentioned earlier, five persons in the sample were recorded as having a diagnosis of dementia.

In addition to these five people, other people in the sample were recorded as having cognitive impairment. Cognitive assessment was carried out for 30 persons. Outcomes from cognitive assessment were recorded for 27 persons. Of these, 21 persons had cognitive impairment in accordance with the cut-off scores of the respective cognitive test. In some cases, cognitive impairment was documented elsewhere in the CSAR form, for example, under the section devoted to Mental Health Status. Under this section, 15 persons were recorded as having cognitive impairment, five of whom were also recorded as suffering from confusion and two documented as having poor insight.

There were seven people recorded as diagnosed with a severe and enduring mental health problem such as bipolar disorder or schizophrenia. One person was reported as having a hoarding disorder and had been prohibited from receiving in-home care because of this.

However, many of the younger people in this sample with a diagnosis other than a severe and enduring mental health problem, were recorded as having mental health problems. These included;

- Anxiety, depression or depressed mood: 12 people,
- Agitation: 2 people,
- Psychotic symptoms: 6 people.

## 4.5 Substance abuse

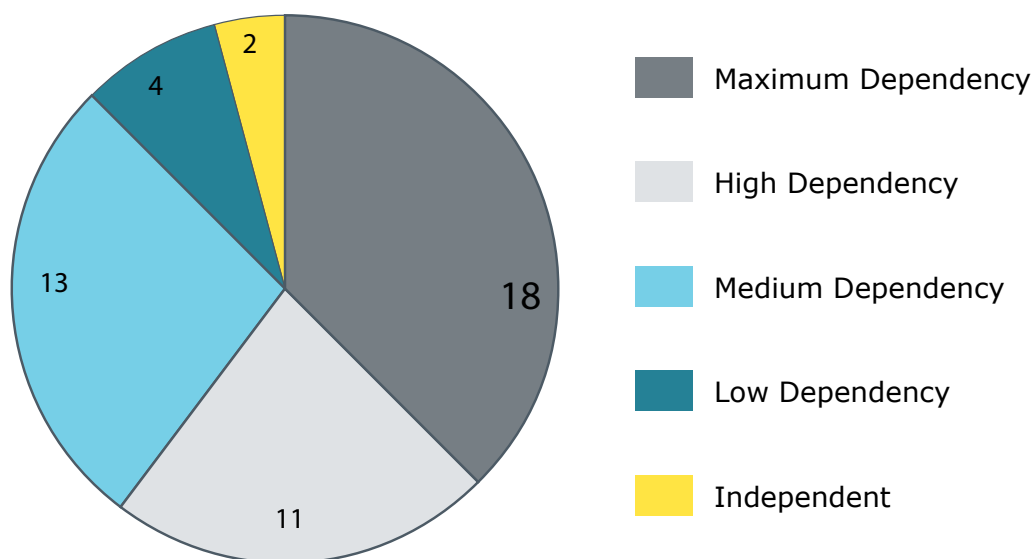
Eight of the 48 people had alcohol-related problems recorded in their notes. Two persons had a history of drug abuse and in both cases an overdose had led to an acquired brain injury.

## 4.6 Dependency levels of NHSS applicants

Regarding ability to perform activities of daily living, dependency level was recorded on the CSAR forms for all 48 people in the sample using the Barthel Index (BI). The BI is a simplex index based on the scoring of 10 items. Its main aim is to establish the degree to which a person is independent from needing any help, physical or verbal, with these items however minor and for whatever reason. A lower score on the BI indicates a higher level of dependency.

In this sample of younger people with disabilities, BI scores ranged from 0 to 20, with a mean score of 8.6 (SD = 6.22) and a mode<sup>12</sup> of 1. Almost two-thirds had high to maximum dependency level based on BI scores (Figure. 7) In general, the scores indicated the low level of ability in the sample to live independently without assistance at home, suggesting that level of dependency may be a factor contributing to application for a nursing home. However, six people in the sample were younger people recorded as having low dependency or being independent.

Fig. 7: Dependency levels of younger people applying for NHSS (n=48)



<sup>12</sup>. The score that appears most often.

## 4.7 Information on family carers

The CSAR forms provided very little information on family caregivers, as the information on the current or previous carer, level of carer support, carer assessment and support from others was redacted from the vast majority of CSAR forms, to protect the confidentiality of applicants and their family members, and so could not be analysed in any meaningful way.

However, in the section on current community and home support services, nine people were recorded as having family or private carer support.

Family and family carers were mentioned in the notes of several applications. These included notes referring to family carers and their inability to cope with caring for the person or being no longer able to provide the care needed due to the high levels of care required and progression of disease. Some family carers had their own health problems, or other caring responsibilities and some were older themselves. As one CSAR form notes:

**Mother provides the assistance for all the personal care needs, is 78 years old and suffers from COPD. She has had pneumonia and also cares for her 80-year old husband. Mother is no longer able to provide the care needed.**

Some families were reported as being very supportive but had been advised by staff that nursing home care was the best option. In one case, it was noted that the family were supportive and hoped that the admission to a nursing home would be a temporary admission and the person would eventually be able to return home, echoing findings from Moore and Ryan (2017). In another case the family had agreed to 'trial' home care, and it could be that an application for the NHSS was being made as a backup in case home care was unsuccessful. Some younger people with disabilities were reported to have limited or no family support or to have become isolated from their family.

## 4.8 Community and home support service use

CSAR forms include a section to record the person's current use of community and home support services. The community and home support services listed on the forms are;

- Home Care/Home Care Package (HCP),
- Day Care,
- Respite Care,
- Meals on Wheels,
- Laundry assistance,
- Aids and Appliances,
- Family / Private Carer,
- Therapy (e.g. physiotherapy, occupational therapy),
- Public Health Nurse (PHN) or Community Mental Health Nurse (CMHN),
- Visits to a Day Hospital.

Information on community supports availed of by the individuals in the sample was inconsistently recorded. From the information available, 21 persons (less than half of the sample) were recorded as receiving some form of community support. The information is summarised in Table 4.

Table 4: Community supports used by NHSS applicants

Type of Community Support	Community support use of applicants (n = 21)
Home Care / Home Care Package (HCP)	10
Day Care	4
Respite Care	3
Meals on Wheels	2
Laundry assistance	2
Aids and appliances	6
PHN / CMHN	12
Family support / Private Carer	9
Therapy or other discipline	7
Day hospital	2
Services refused	3

The most frequently used community-based service recorded was public health nursing or community health nursing, i.e. for a quarter of the sample. Nearly one in five were recorded as having family support / private carer. A similar proportion were recorded as having a home care package but the hours of home care were wide-ranging from as little as two hours per week to a maximum of 52 hours per week. Persons were next likely to have used 'therapy or other discipline' e.g. physiotherapy, occupational therapy. Six people were recorded as having received aids and appliances.

There were lower uses of Day Care (4/21), Respite (3/21) and few were recorded as attending a Day Hospital (2/21). Few availed of Meals on Wheels (2/21) or assistance with laundry (2/21).

In three cases, CSAR forms recorded information on refusals by people to avail of community supports. In other words, three people had refused community support services. One person had an acquired physical disability due to gangrene, aphasia and stroke and was recorded as having refused the opportunity to avail of respite. A second person had a neurological disability (multiple sclerosis) and comorbid anxiety and anhedonia and declined to see the Public Health Nurse and refused the opportunity to avail of a HCP. The third person had hepatic encephalopathy due to alcohol abuse and declined the offer of a Family Support Worker.

In a few applications, HCPs were being provided at the time of application, according to the notes. In one it was noted that although a Home Care Package of 21 hours per week had been approved, on further exploration the younger person had decided that nursing home care was a more appropriate option. Another noted that a person with dementia had a 'huge' package of home care but that the home care workers were finding it difficult to support the individual in the short hours available to them and there was limited family support. In a third case, the person had 52 hours of home care per week, but their needs had increased and it was noted that 24-hour care was now needed. In another case, despite the maximum home care package and a live-in carer, the family were finding it too difficult to cope with the care needs of the person:

**Has been living at home with a maximum home care package and private care from a live-in carer prior to admission. Family are finding it very difficult to cope even with increased community supports and therefore LTC [long-term care] is required.**



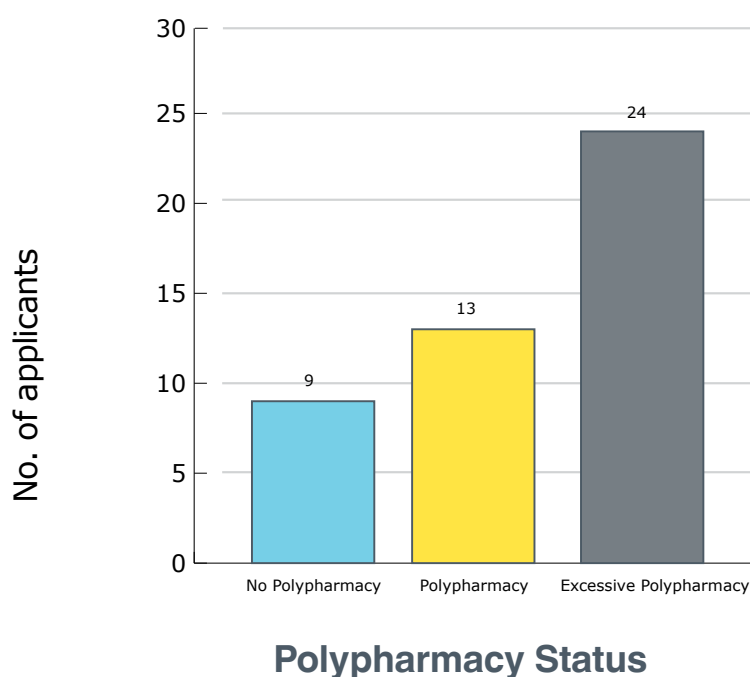
## 4.9 Medication use and polypharmacy

Medication use was recorded for 46 applicants. There was a notably high number of different medications prescribed to individuals in the sample. The number of medications recorded for persons ranged from 0 to 18. The mean number of medications was nine.

Because of the high numbers of medications prescribed to persons in the sample, it is useful to look at the sample in terms of polypharmacy. There are varying definitions of polypharmacy in the literature (Richardson et al., 2012), but it is most commonly defined as the concurrent use of five or more medications and excessive polypharmacy is defined as ten or more medications (Fulton and Riley Allen, 2005).

Using this definition, Figure 8 shows the polypharmacy status of the 46 applicants for NHSS under 65 years of age for whom medications were recorded. No polypharmacy was the status for nine out of 46 (less than 20%) applicants. Almost one-third (13/46) of applicants were categorised as having a polypharmacy status (5-9 medications) and over half (24/46) fell into the category of excessive polypharmacy status (10+ medications). Polypharmacy and excessive polypharmacy were therefore high among the applicants. The high number of medications prescribed may be necessary to properly manage certain conditions and accordingly could be an indication of the complexity of the conditions and medical needs of applicants. However, polypharmacy can also be an indication of over and inappropriate prescribing (Richardson et al., 2012), but it was beyond the scope of this study to examine this further.

**Fig 8: Polypharmacy status of NHSS applicants under 65 years (n=46)**



In general, in this sample, a much higher number of medications was recorded for younger persons referred from an acute hospital generally than for those referred from the community or the National Rehabilitation Hospital.

## 4.10 Communication

With regard to ability to communicate;

- 10 persons were recorded as having no problems with communication,
- 16 persons as being able to retain most information and indicate needs verbally,
- 7 persons had difficulty speaking but were able to retain information and indicate needs non-verbally,
- 8 persons were able to speak but could not indicate needs or retain information,
- 3 persons had no effective means of communication, and
- 3 had communication difficulties categorised as aphasia or dysphasia.

## 4.11 Risk assessment

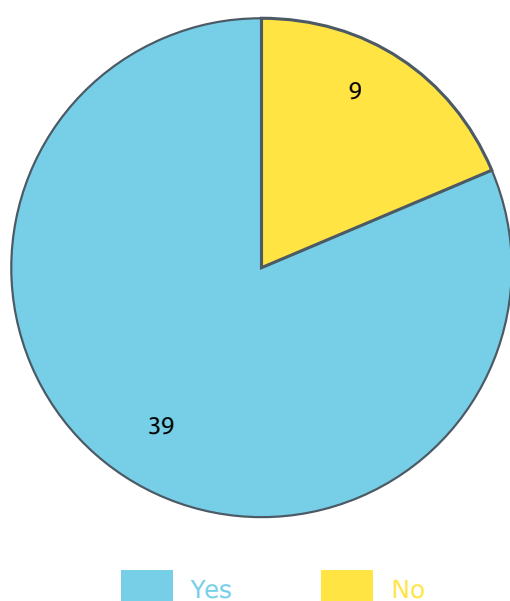
In addition to assessments of levels of dependency (BI), communication and cognition, there is also room to record pressure ulcer risk, falls risk, malnutrition risk and wandering risk. The findings from the 48 CSAR forms in relation to these risks are as follows;

- **Pressure Ulcer Risk:** The presence or absence of pressure ulcer risk was assessed for 33 persons. Of these, 12 were of low or no risk, 15 were of moderate risk and six were at high risk
- **Falls Risk:** 30 people were assessed for risk of falling; 14 were of low or no risk, 12 were of moderate risk, and 4 were high risk
- **Malnutrition Risk:** Risk of malnutrition was recorded for 26 persons. 18 were of low or no risk, 5 were at moderate risk, and 3 were at high risk of malnutrition
- **Wandering Risk:** Risk of wandering was recorded for 29 persons. Of these, 24 were of low or no risk of wandering and 5 were assessed as at risk of wandering. Three of these applicants had a diagnosis of dementia, one person had cognitive impairment due to radiation treatment for central nervous system lymphoma, and one person had Wernicke's Encephalopathy as a consequence of alcohol abuse

## 4.12 Preference for care setting

The CSAR records information on a person's preference to stay at home or to be admitted to residential long-term care. Among this group of younger people applying for the NHSS, the majority had their care setting preference discussed with them (Figure 9). However, of the sample, 9 out of 48 did not have their preference discussed with them.

Fig 9: Discussion of care setting preference (n=48)



For those who were asked their preference, it was reported that several had requested or had made the decision to be admitted to a nursing home. A reason for this preference was not always given. The reasons that were given for people stating a preference for admission to a nursing home included deteriorating health, increasing care needs, difficulties coping or managing at home and family caregiver burden and/or stress. Consistent with findings by Moore and Ryan (2016), some notes suggested that there were younger people with disabilities who were well aware of the difficulties their families experienced in attempting to care for them at home:

'Requested social work support to find a suitable nursing home'

'Condition is deteriorating and needs professional to provide care needs. Mother can no longer give the care needed. "This is my decision"'

'Has made the decision for LTC based on current care needs. A 21-hour HCP was offered to the individual and this was explored with them. However, they have made it clear they wish for LTC.'

'Has admitted that was not coping well at home and would like to be somewhere with contact supervision.'

'Yes. Is aware of high care needs and knows would not be able to manage at home'

'Yes. Has requested a LTC placement due to deteriorating condition.'

In some cases, the preference for care setting was not recorded, only the name of the preferred nursing home, or the preferred location of the nursing home, or a stated preference for a nursing home with people close to their own age.

'Has decided on [name of nursing home]'  
'Ideally in [name of area], with people close to own age.'  
'Yes. Wants to go to Nursing Home in [name of location].'

In several cases, it was recorded that preference had been discussed, and that the person was 'agreeable to', 'happy to consider', 'accepts' or is 'open to' placement in long term care, as indicated by the quotes below [bold added]. However, it is not stated whether the person would have preferred an option other than nursing home care:

'Has **agreed to** go to [name of nursing home]'  
'Yes. Long term care discussed / **Happy to avail** of same as care needs have increased. Places of preference are ...'  
'Yes. Is aware that is not able to manage at home. Has explained the process.'  
'Yes. Patient understands care needs have changed and stated that they cannot return home. Patient **open** to nursing home care. Would like placement in [name of nursing home].'  
'Is **happy to consider** nursing home care as care needs have increased and agrees for family's sake who are finding it difficult.'  
'Yes. Client is aware they are unable to care for themselves independently and has agreed to residential long-term care or supervised sheltered housing.'

In several cases, the person stated a clear preference to go home. Quite often this preference was followed by a 'but' which seems to indicate that this preference was not an option for these people. It is not clear from the reports why this was not a feasible option or why it was not possible or if any steps had been taken to explore discharge home:

'I (ADPHN) discussed preference with [name of person] ... wants to go home to own home.'  
'Consents to nursing home application. While prefers to be at home, knows this is not an option currently.'

'Would like to move from [name of acute hospital] and ultimately go home but is open to [name of facility] for rehab and is currently listed for the NRH'[bold added].

'Preference is to go to an apartment **but** agrees that a nursing home might be necessary' [bold added].

'Yes. I have discussed discharge options with family. Both individual and family would like to try home as their first option. However, if this is not possible they have agreed to nursing home. [name of person] has identified [name of nursing home] as his preferred choice.'

Two younger people with Acquired Brain Injury applying to the NHSS in this sample were awaiting a place in the NRH. Another person was referred to the NHSS by a Social Worker in the NRH - having already completed the NRH rehabilitation programme - as returning home was deemed not to be a viable option, even though the individual would prefer to return home. This latter situation potentially relates to the lack of suitable community-based supports for people with brain injury and their carers or families following discharge from rehabilitation in Ireland. On the other hand, this person was reported to have a history of multiple drug use, which was a factor in their acquiring a brain injury, and it could be that a return to the individual's previous environment and social networks was considered to constitute a risk for relapse (Walton et al., 2003).

In some cases, the individual's preference was discussed with them, but the comments indicated that there was difficulty assessing the person's preference due to cognitive impairment, lack of insight into their condition or communication difficulties:

'However, patient is very confused and dysphasic'

'Yes. Is aware of application for LTC. However, no insight into level of care required and poor carryover'

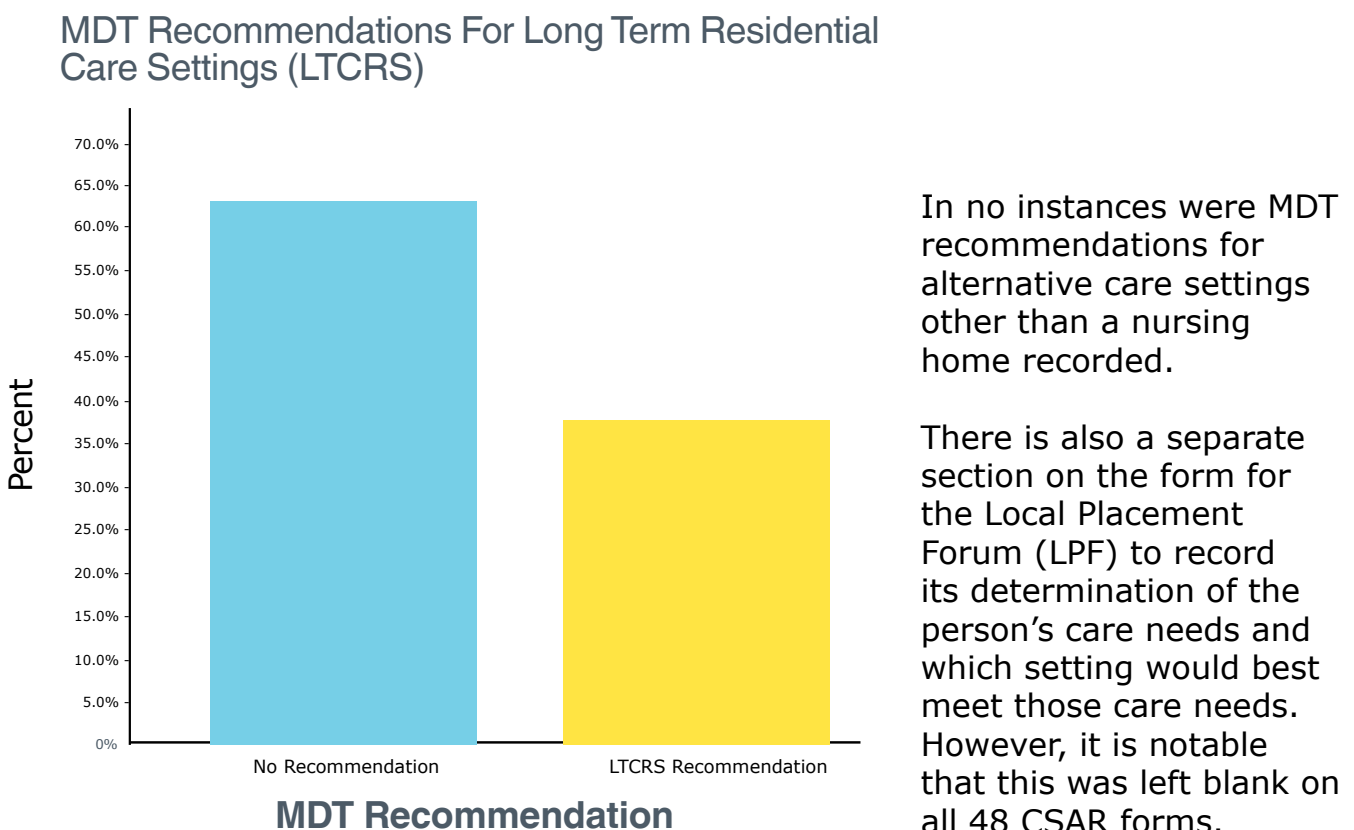
'Is unable to hold conversation or retain information'

'Has been discussed but person is cognitively impaired'

## 4.13 Recommendations for Long Term Care Residential Setting

In the section of the CSAR forms where the MDT makes its recommendation, only 18 people (37.5%) out of the 48 applications received a Multidisciplinary Team (MDT) recommendation for Long Term Residential Care Support (LTRCS). Surprisingly, for the remaining 30 people no recommendation was recorded on the CSAR forms regarding suitable residential support or otherwise (Figure 10).

**Figure 10: Number of individuals receiving MDT recommendation for LTRCS versus no recommendation for care setting**



Three of the younger people with disabilities in the sample had spent some time in the National Rehabilitation Hospital, and all three received a MDT recommendation for a nursing home placement. Of the 48 younger people in this sample, three had applied to the NHSS for temporary residence in a nursing home while they waited for a place in the NRH, which was their preferred option. They too all received a recommendation for a nursing home placement.

The extent to which a person's dependency level was a factor in MDT recommendations for care setting was reviewed. People with poorer ability to carry out activities of daily living – as reflected by lower scores on the Barthel Index – were more likely than those with greater levels of independence to receive an MDT recommendation for placement in a long-term residential care setting.

## 5. Discussion of findings

The findings presented in Section 4 relate to 48 younger people with disabilities who made an application for the NHSS and are based on an analysis of CSAR forms accompanying the application. The CSAR forms provide information on the socio-demographic profile of the younger people with disabilities. They also provide information on the health conditions / disabilities, co-morbidities and levels of dependency among these people. Comprehensive information on previous care arrangements and level of family support for the younger people with disabilities in this sample was not available. However, information regarding the source of referral for the NHSS, the community supports received, alongside the professional notes included in the CSAR forms, help to paint a broad picture of each person's situation at the time of application. Using referral source, it is possible from the information on the forms to shed some light on pathways to NHSS application, and, other information can be used to identify some of the factors contributing to the referrals. However, the CSAR does not include a housing needs assessment, and it is not clear if such an assessment is conducted as part of an application for the NHSS.

From the analysis of the 48 CSAR forms, the focus of the assessment is clearly on impairments and skills deficiency, consistent with a rehabilitative / medical perspective (as outlined in Table 1). The model that underpins the care assessment is significant as it sets up the approach that health professionals take when assessing the person's need for care and determining the most appropriate setting in which the care will be provided. In the current approach, the problem is seen to be located in the person as opposed to the environment. Furthermore, the care assessment is designed for one function only, that is, the assessment of persons for nursing home care. With a sole focus on nursing home care, alternatives are not considered, as evidenced by the notable absence of any recommendation for alternative care settings in the applications from younger people with disabilities in this sample.

Although the preference for care setting was discussed with some of the younger people with disabilities in this sample, it is clear in many cases that these people are not in charge of decisions about their lives, that health professionals were making decisions, and the referral of younger people with disabilities for placement in a nursing home is defined by their level of functioning. There is little or no evidence from the CSAR forms that there is any focus on supporting people to achieve the outcome of living independently and being in control of their life. Since our analysis was restricted to an analysis of the CSAR forms, it was beyond the scope of this study to examine the broader assessment process. However, this review of CSAR forms shows little evidence that the assessment process is underpinned by an independent living / person-centred perspective. The structure of the CSAR form does little to facilitate such an approach. The question that remains is how should an assessment of care be structured to facilitate people with disabilities to lead a full and independent life, to participate in society and to maximise their potential.

The findings from the analysis of the 48 CSAR forms are discussed in more detail below.

## 5.1 Socio-demographic information

The average age of these 48 people was 53 years, and although the majority are over 45 years of age, this study shows that there were two people in the sample as young as in their 20s making an application for the NHSS, both of whom had an Acquired Brain Injury (ABI). The age profile in this sample is similar to the findings of younger people living in aged care facilities in Australia (Winkler, Farnworth and Sloan, 2006). Age is commonly put forward as a key reason for why placement in a nursing home is inappropriate for younger people. Most residents of nursing homes are older people; in Ireland 70% of residents in nursing homes are aged 80 years and over (Department of Health, 2013). Nursing homes are generally designed for older people and while arguably they may have age-appropriate supports for people aged 65 years and older, they are not, it is claimed, typically set up or resourced to support younger residents (Winkler et al., 2015; Lannoo et al., 2008; McMillan and Laurie, 2004; Soulsby, 2008; Winkler, Farnworth and Sloan, 2006; Colantonio, Howse and Patel, 2010; Persson and Ostwald, 2009; Fries et al., 2005; Weingarden and Graham, 1992). In Australia, a Senate Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities found evidence that aged care facilities there were not set up or resourced to support younger people with disabilities (Senate Community Affairs References Committee, 2015).. The issues of the appropriateness of placement of younger people with disabilities in nursing homes is returned to later.

In this study, it was not possible to tell the sex of the younger people in the sample. However, it is likely that the sample is made up of a greater proportion of men, since according to the Long-Stay Activities Statistics 2013, the number of younger men in nursing homes is greater than the number of younger women. In 2013, 65.4% of the 21,175 residents in long-stay beds in nursing homes were women and 34.6% men, i.e. 13,848 and 7,327 respectively. Whereas 3.5% of women were younger (i.e. under 65 years of age), and 9% of men were younger, which equates to 484 younger women and 659 younger men residing in nursing homes in 2013.

The proportion of younger people who were single, widowed, separated or divorced was high in this sample at just over three-quarters and one-third were recorded as living alone. This has important implications for younger people with disabilities, as the most significant source of help for people with disabilities in Ireland is from family members living with the person, and it is family members who are most likely to provide help to people with disabilities on a daily basis (Watson and Nolan, 2011). Relationships with family members or an intimate partner are a central aspect of the social environment of people with disabilities, and not having these close relationships may not only diminish the social environment but also mean that there may not be a family member available to advocate for alternatives to nursing home care on behalf of the person. This finding also highlights the important role that financial supports, disability service providers, natural supports and advocacy services can play in supporting younger people with disabilities living alone and who want to return to or remain living independently in the community.



While all 48 people in the sample were under 65 years of age, a key finding is that younger people applying for the NHSS are a heterogeneous group of people, with different ages, marital status and living arrangements prior to admission. This is consistent with the findings of other studies of younger people with disabilities residing in nursing homes (Farrell, 2013; EHRA, 2002; Winkler, Farnworth and Sloan, 2006; Moylan, Dey, McAlpine, 1995; Cameron, Pirozzo, Tooth, 2001). The diversity of younger people with disabilities referred for the NHSS highlights the importance of an individualised supports model, as proposed by the Report of the Disability Policy Review (Keogh, 2011).

Information was not readily available about dependents or children of the NHSS applicants in this study. In a much larger study of younger people with disabilities in Australian nursing homes, 27% of younger residents were parents of school age children (Winkler et al., 2015).

## 5.2 Health conditions / disability and dependency

In this sample, the six most common health conditions / disabilities were diseases of the nervous system such as Multiple Sclerosis, Acquired Brain Injury, severe and enduring mental health difficulties, stroke and other cerebrovascular diseases and dementia. These results cannot be generalised to the whole population of younger people with disabilities applying for the NHSS. However, they give an indication of the range of health conditions/disabilities affecting younger people with disabilities applying for the NHSS. We do have information however about the prevalence of these six health conditions / disabilities in Ireland. There are approximately 9,000 people with Multiple Sclerosis in Ireland (Crowe and Doig, 2017) and it is estimated that some 11,000 people are admitted to an acute hospital with a traumatic brain injury each year (Muldoon et al., 2017). A further 10,000 people in Ireland experience a stroke annually, with 30,000 people in the community living with residual disability as a result of a stroke (Muldoon et al., 2017). It is estimated that there are over 4,000 younger people with dementia in Ireland (Pierce and Pierse, 2017), about 15% of whom are likely to be residing in a nursing home (Haase, 2005). The experiences of people with these conditions will be wide-ranging, from mild to severe disability, with some needing care in a long-stay residential care setting.

In addition to having information about their prevalence, it is also known that such health conditions / disabilities place people with disabilities at greater risk of admission to nursing home care (Van Rensbergen and Nawrot, 2010). Furthermore, the finding that younger people applying for the NHSS in this sample have a wide range of health conditions and disabilities, is similar to other Irish and international studies (Farrell, 2013; Winkler et al., 2007).

## 5.3 Source of referrals of younger people for NHSS

The study found that the majority of the referrals of younger people with disabilities for the NHSS in this sample were from an acute hospital, community hospital or rehabilitation hospital. With respect to the two people whose applications were referred from a nursing home, we can speculate that these two people had already been admitted to a nursing home and were applying retrospectively for financial support under the NHSS. One of these two people has previously been residing in a high support hostel before admission to hospital. Some authors, writing in a US context, have asserted that there is a trend towards transferring people with disabilities and mental health problems to nursing homes from institutional settings such as psychiatric hospitals without a full assessment of their needs or preferences (Grabowski et al., 2009; Birkett, 2001). However, based on the information available, there is little evidence from the sample in this study of “trans-institutionalisation”, i.e. the movement of people from previous institutional settings (e.g. congregated settings or psychiatric hospitals) into nursing homes (Birkett, 2001). The Progress Report on the Implementation of Time to Move On From Congregated Settings (HSE, 2016) reported that, of 74 people that transitioned out of a congregated setting in 2016, 10 transferred to nursing homes and a smaller number moved to specialist nursing home type units, but it is not specified whether or not these people were aged under 65 years.

The main pathways into nursing homes for younger people with disabilities in this sample are from hospital settings, and this would benefit from further investigation, especially the impact of the acute hospital bed crisis on the referral of younger people with disabilities for the NHSS and other factors that might be contributing to this referral. In the absence of adequate or appropriate community supports, it may be that referral for admission to a nursing home is considered by staff to be the safest decision. These issues can be explored further in the qualitative study that is currently being undertaken by DCU, as a second phase to this study.

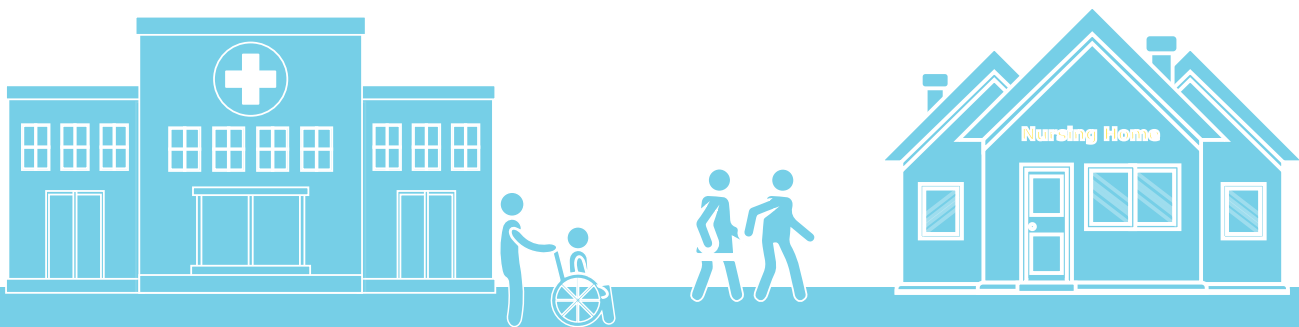


## 5.4 Factors contributing to referral of younger people for NHSS

The referral source gives some indication of the pathway to a referral for the NHSS. It is not clear how many of the 48 people in this study were actually admitted to nursing homes and it was not possible to establish this because of identification number differences. However, the analysis of the CSAR forms gives some indication of the factors that are likely to be contributing to the referral of these younger people for the NHSS.

The predominant disabilities / health conditions among the 48 applicants are known to be those that place people at a greater risk of admission to nursing homes (Van Rensbergen and Nawrot, 2013). In their study, Winkler, Farnworth and Sloan (2006) reported the prevalence among younger people in nursing homes of acquired brain injury to be 37%, multiple sclerosis to be 17%, intellectual disability to be 15%, and dementia to be 5%. There is evidence, for example, to show that people with younger onset dementia are at a higher risk of placement in nursing home care (Cepiou-Martin et al., 2016).

Many of the younger people in the sample have high and complex care needs; almost two-thirds of the sample in this study had a high or maximum level of dependency. Some of the people, including those with acquired brain injuries, neurodegenerative diseases such as Multiple Sclerosis, and dementia had severe and complex needs, in some cases needing 24-hour care and supervision or very high levels of daily care and support. This was likely affecting their ability to remain living at home or return home from hospital, as found in other studies (Moore and Ryan, 2017; Winkler et al., 2015). Farrell (2013) also identified younger people with an ABI with high nursing needs in a study for the Bray Area Partnership. This was a factor that was clearly leading staff to decide that nursing home care was the most appropriate care setting. In some cases, the younger people with disabilities, according to the notes recorded in their applications had made the decision themselves to make an application for the NHSS and be admitted to a nursing home.



## Co-morbidity

There were high levels of co-morbidity amongst the sample with almost half of the sample having one or more co-morbidity, which may have been a contributing factor to a referral for the NHSS. There were also high levels of polypharmacy and excessive polypharmacy among the applicants. Several of the younger applicants were recorded as being at high risk of either pressure ulcers, falls, malnutrition and risk of wandering.

## Mental health difficulties

There were seven younger people in the sample with severe and enduring mental health problems and many others with mental health problems. The 15% of people with a severe and enduring mental health disorder was close to the proportion of 19% reported as having a mental health problem in the study commissioned by the Bray Area Partnership (Farrell, 2013) of 42 people in nursing homes. Studies from the US show that having a mental health problem is one, and sometimes the decisive factor, contributing to placement in a nursing home (Black, Rabins and Germain, 1999). They also show that the number of people with mental health problems residing in nursing homes on any given day significantly exceeds the number residing in all other health care institutions combined (Fullerton et al., 2008). Newly admitted individuals with mental health problems in US nursing homes tend to be younger and more likely to become long-stay residents. In the sample of younger people with mental health problems in this study, there seems to be a mixture of younger people with mental health problems who accepted that nursing home care was the most appropriate care settings for them and those who would prefer to be at home. It is not clear from the CSAR forms what is driving these decisions.

## Substance abuse

Substance abuse appeared to be a factor contributing to referrals in a small number of cases including two people for whom an ABI resulted from a drug overdose. A US study of residents in nursing homes found that those with alcohol problems tended to be over-represented among younger residents; 41.7% of residents with alcohol problems were under 65 years of age, whereas only 9.8% of all residents in the nursing home were under the age of 65 years. The study also found that residents in nursing homes with alcohol problems were most likely to be men (Mjelde-Mossey, 2007).

## Family carers

While much of the information on family carers in the CSAR forms was redacted, there is much evidence in the literature showing that family members are the most common source of help and support to people with disabilities. For example, according to A Social Portrait of People with Disabilities in Ireland (Watson and Nolan, 2011), the most common source of help is from family members living with the person with a disability (42%) or family members living elsewhere (34%) in Ireland. Friends or neighbours are also an important source of help (19%). Family members are most likely to provide help on a daily basis. Help throughout the day is most likely to come from family who live with the person with a disability. However, even where family members are available and willing to provide care, the difficulties experienced by younger people with disabilities can impact on family carers and providing care to younger people with disabilities can pose challenges for them.

As the findings from this study suggest, some younger people with disabilities may be placed in nursing homes as a result of a breakdown in family care arrangements, such as an ageing parent or the decline in the health of a family carer, rather than because of the disability itself. This echoes the findings of the report of the Australian Senate Community Affairs Committee (2015) which summarised some of the reasons it found for why individuals and / or their families apply for placement in a nursing home or end up living there. It pointed out that many families care for younger individuals with a disability through courage and determination, with little external support, but that an unexpected crisis can lead to the care arrangement breaking down. This could be due to changes in the health of the carer, other caring or employment responsibilities, increase in the level of care required due to deterioration of the younger person's health, financial stress, and mental and physical exhaustion after a long period of caring with no respite.

There are examples of the breakdown of family care in this sample. It should also be noted that while a third of the participants in the current sample were recorded as living with family prior to the application, a quarter were living alone. Furthermore, there was a high proportion of younger people making applications who were single, widowed, separated or divorced, which may be another factor contributing to their referral for a place in a nursing home, particularly when family are relied on as the main provider of care, as is the case in Ireland.

## Inadequate community care

Another factor contributing to the referral of younger people with disabilities for nursing home care is - as Winkler, Farnworth and Sloan (2006) have pointed out - because health and community care systems often struggle to respond adequately to younger people with highly complex needs. For example, people with ABI often have nursing needs and a greater level of care needs than is generally available from community care services. One of the difficulties in this study is that the information on community supports availed of by the individuals in the sample was poorly and inconsistently recorded. Of the 21 people for whom information was recorded, nine were in receipt of home help / home care package with some receiving as little as two hours of home care per week and a small few with much larger packages of between 21 and 52 hours per week. Since 2015, the HSE has been providing Intensive Home Care Packages (IHCPs) for people with complex needs. To the end of December 2017, 32 younger people with disabilities and a further 15 people with younger onset dementia have availed of these packages of care nationally. The majority of younger people with disabilities in receipt of these packages were referred from an acute hospital or the National Rehabilitation Hospital. While there is much variation in the duration of these packages, more than 90% of IHCPs for younger people with disabilities have lasted for one year or more, demonstrating that if the necessary supports are put in place, it is feasible to care for people with complex needs at home, including younger people with disabilities (Keogh et al., forthcoming).

## Availability of NHSS

The availability of the NHSS since 2009 and the financial support provided by it is a factor contributing to the referral of younger people with disabilities to nursing homes. However, the number of younger people in nursing homes fell between 2009 and 2013, according to the most recently available Department of Health Long-Stay Activity Statistics (see Figure 1). Notwithstanding this, there is no scheme equivalent to the NHSS for the community care of younger people with disabilities, and with community care remaining fragmented, underdeveloped and under-resourced, nursing home care may be the only option for some younger people with disabilities. The Department of Health has been tasked with developing a statutory scheme for the financing and regulation of home care which will go some way to addressing this imbalance (IPH, 2018), and there are different models of funding that can be used.

## Lack of appropriate accommodation and rehabilitation supports

Another factor leading to the admission of younger people with disabilities to nursing homes is that more appropriate accommodation may not be available for them. It is manifestly clear from this study that several of the applicants would have preferred to return home. Others expressed a preference for living in more supportive accommodation or moving to more independent living, but it seems that the only other option available to people who could not or did not want to - for whatever reason - return or remain living at home was nursing home care. This is illustrated by the notes relating to a younger woman with an acquired brain injury:

**Mother is full-time carer ... The individual feels she is getting on in years and also is aware, she is now 40 years old and wants to move out of home to a residential, safe setting if possible, still under supervision of healthcare staff.**

Three younger people in this sample expressed a preference for the NRH in Dun Laoghaire, Co. Dublin, the only specialist rehabilitation hospital in Ireland, which is small and under-resourced. In these cases, an application to a nursing home was made for temporary care in a nursing home while awaiting a place in the NRH. A number of other hospitals including, the Royal Hospital Donnybrook, St. Mary's Hospital Dublin and Cherry Orchard Hospital Dublin, also provide a limited number of rehabilitation beds, but in general, there is poor availability of rehabilitation services in Ireland, which are underdeveloped and underfunded.

The need for dedicated regional neuro-rehabilitation teams together with specialist community supports has been emphasised, so that people can make a timely transition to care in their community. However, the lack of services means that only a minority with a brain injury receive rehabilitation. Most either enter a nursing home which may not be equipped to meet their needs or are cared for at home by families who may have little or no expertise, information or support. In considering the appropriateness of nursing home placement for individuals with ABI, consideration could be given to the professional consensus, the evidence from the rehabilitation literature (Cicerone et al., 2000) and published clinical guidelines (BRSM, 2003), which state the importance of early intervention to optimise rehabilitation gains as well as continued support to optimise independent living ability following discharge.

### Self-determination and care preferences

This study suggests that expressing their care preferences does not always mean that younger people with disabilities will be effective in influencing the outcome of their care. Self-determination has emerged as an important concept in health and social care and is a central concept in person-centred care. It is used to emphasise that people, including younger people with disabilities, should have the freedom and support to decide how and where they live and participate in the community. This study, therefore, highlights that important changes are needed to ensure that younger people with disabilities will be supported not only to express their preferences, but to be involved in decision-making about their care and supported as far as possible to achieve their desired outcomes.

When the Assisted Decision-Making (Capacity) Act, 2015 comes into full effect, there will be a requirement that, even where a person lacks capacity, decisions must take the person's will and preferences into account. If needed, persons who have capacity must be given support to help them make decisions. Younger people with disabilities are among those people with complex needs who present a great challenge to healthcare professionals who must act in accordance with the legislation. The 'Promoting Assisted Decision-Making within Acute Care Settings' (PADMACs) project aims to develop an educational tool to promote understanding of the Assisted Decision-Making (Capacity) Act, 2015 among healthcare professionals working in acute care settings. This project, which is currently underway, encourages their adoption of this understanding in their care planning with older people. The intention behind this project is to improve communication between healthcare professionals and their patients in relation to assisted decision-making and care planning (O'Donnell et al., 2018).

However, caring for younger people with disabilities and complex needs can be costly and this raises difficult questions about the level of cost that we as a society are willing to pay to support younger people with disabilities to live in the community if that is their expressed preference.

## Assessment of needs

All of the above information shows that the sample in this study were younger people with highly complex needs. However, one of the shortcomings of the CSAR forms is that there is an over-emphasis on impairments, diseases, deficits, social problems and risks. There is little or no room in the CSAR form for attention to be paid to the strengths, abilities and capabilities of younger people with disabilities. The form does not facilitate health professionals to explore what it would take to support these persons physically, psychologically, socially, emotionally and practically to return or remain living at home or move to other accommodation more appropriate than nursing home accommodation if that is their expressed wish. This is exemplified by the use of the Barthel Index, which focuses exclusively on physical dependency without any reference to a person's capabilities and no means of assessing a person's psychosocial needs.

The Department of Health and Children (Keogh, 2011, p.126) pointed out that:

'The Assessment of Need under the Disability Act 2005 does not correspond to a 'needs assessment' as understood in the wider, international disability sector. Needs assessment generally refers to a highly structured process to gather information on a person's current abilities, resources, goals and needs.'

The same could be said of the use of the CSAR to assess the needs of people applying for the NHSS, since, as far as we can ascertain, information on the current abilities, resources, goals and needs of a younger person with disabilities is not gathered in this process. The Department of Health (Keogh, 2011, p.126) goes on to describe needs assessments as understood in the wider disability sector:

**Most needs assessments in other jurisdictions are used to identify what is needed to maximise a person's independence so that they can participate as fully as possible in their community. Thus, all relevant needs are included in context, which may include recreational, social and personal development needs, training and education needs, vocational and employment needs and where appropriate the needs of family and carers.**

(Keogh, 2011: 126)

The Bray Area Partnership report (Farrell, 2013) concludes that while the placements may have been appropriate for a number of younger people with disabilities, based on their nursing needs, for many the nursing home was probably not an appropriate environment, but the only one available at the time of admission. With regard to younger people with ABI, Farrell (2013) suggested that the needs of younger people with disabilities could be met in more appropriate settings possibly geared to more slow-stream rehabilitation, which would facilitate them to gain independence, autonomy and self-determination, and support them to maintain and build relationships and friendships, and to explore community links. We echo this conclusion.



## Alternative models of care

From this study, it would also seem that while some younger people with disabilities are asked about their preferences for care settings, transforming their preferences into a reality is often beyond their reach. It appears from the analysis of the CSAR forms that some younger people with disabilities were referred for nursing home care because of a lack of alternative options. At least some of these younger individuals with disabilities could possibly be appropriately diverted from referrals or admission to nursing home care if suitable alternative options and supports were available. Alternative models of care for younger people with disabilities exist in other countries and these offer examples of good practice. One example is the Brain Injury Rehabilitation Trust (BIRT) in the UK, which provides a range of purpose built residential services, providing high quality and individually tailored person-centred care and support throughout England.<sup>13</sup>

This also requires a greater focus on the prevention of younger people going into nursing homes in the first instance. As recommended by the Bray Area Partnership Report, revising funding arrangements for younger people admitted to or at risk of admission to nursing homes so that funding follows the person and not the place would support this (Farrell, 2013).

In some other countries such as Australia, efforts are being made to prevent admissions of younger people with disabilities to nursing homes. The Young People in Residential Aged Care Programme, a five-year programme introduced in 2006 to assist younger people with disability living in or at risk of entering residential aged care throughout Australia, offers an example of such efforts. The three key objectives of the [Younger People with Disability in Residential Aged Care \(YPIRAC\) initiative](#)<sup>14</sup> were to:

1. divert future admissions of younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation;
2. move younger people with disability currently in residential aged care into appropriate supported disability accommodation, where supported disability accommodation can be made available and only if the client chooses to move; and
3. enhance the delivery of specialist disability services to those younger people with disability who choose to remain in residential aged care, and if residential aged care remains the only available suitable supported accommodation option.

One reason to support an initiative aimed at diverting younger people with disabilities away from nursing home care or enhancing care in nursing homes is the negative impact that nursing home care can often have on this group of people as shown in the literature. Before looking at the issue of supporting younger people in nursing homes to move to more appropriate accommodation and the issue of enhancing the experience of living in a nursing home, the next section (5.5) presents the findings on the impact of residing in a nursing home from the review of the literature.

<sup>13</sup><https://www.thedtgroup.org/>

<sup>14</sup><https://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/younger-people-with-disability-in-residential-aged-care-initiative>

## 5.5 Impact of residing in a nursing home

Younger people with disabilities often have negative experiences of residing in nursing homes. There are several reasons for this. Persson and Ostwald (2009) found that opportunities for agency and everyday decision-making are reduced and they have limited opportunities for exercising independence. The authors found that people could not cook for themselves, or 'just do their own thing', or engage freely in many of the usual activities and interests. Barriers facing younger people included their own health conditions and mobility, as well as the nursing home setting and routine, space, interests of others, and staff availability.

Opportunities for leisure activities is also an issue for younger people in some nursing homes. As mentioned earlier, in general, nursing homes are not designed or resourced to facilitate the active involvement of younger people with high care needs in everyday activities or to support their continued participation in the life of their community (Winkler et al., 2015). Many nursing homes do not have leisure facilities that are appropriate for younger people (Stringer, 1999; Cameron, Pirozzo and Tooth, 2001). Even when a range of activities are available, these are generally activities that are commonly available in a typical nursing home setting and designed for older people (Parke, 1997; McMillan et al., 2004; O'Reilly & Pryor, 2002).

Social isolation from peers is common (McMillan and Laurie, 2004; Stringer, 1999; O'Reilly and Pryor, 2002), as shown in a US study, which found that younger people spent most of their time alone (Persson and Ostwald, 2009). An Australian study found that 53% received a visit from a friend less often than once per year and 45% almost never participated in community-based leisure activities (Winkler, Sloan and Callaway, 2007). Social isolation has also been identified as an issue for younger people with disabilities in Irish nursing homes. Many of the younger people in nursing homes participating in the study commissioned by Bray Area Partnership (Farrell, 2013) reported spending much of their time in their bedrooms. Few participated in nursing home activities, although it was noted that some were unable to participate due to the extent of their disability. Many rarely left the nursing home campus, whether they were physically able to or not. The study also found that although most had some visits on a regular basis, predominantly from family members, few had regular contact with friends and unfortunately many had lost contact with immediate family for a variety of reasons.

Where younger people with disabilities experience social isolation in a nursing home this is likely to lead to harmful outcomes especially for those with pre-existing mental health problems. Nursing homes are often not resourced to provide psychological therapies or other rehabilitative services, and occupational health and safety requirements restrict the types of leisure activities otherwise able individuals might engage in (Senate Community Affairs Reference Committee, 2015).

The nursing home setting for people with mental health problems is not recommended by mental health advocates and researchers for several reasons, not least of which is the evidenced effect of environment on mental health. People in nursing homes with severe and enduring mental health conditions, e.g. schizophrenia, have been shown to have greater cognitive and functional deficits, as well as more behavioural problems, when compared with community-dwelling persons with the same condition (Bartels, Mueser and Miles, 1997). There is a widespread dearth of staff training in managing behaviours that challenge and other mental health care related issues (ERHA, 2002) that need to be addressed to best meet the needs of those for whom a nursing home is deemed the best current housing option.

Nursing homes by their definition are registered as designated centres for older people and, while a small number do have rehabilitative supports in place which may assist younger people, the majority rely on support from the HSE / other community services. An Australian study found that for many nursing home residents, therapeutic or other health and social-related services (occupational therapy, professional social care services, key worker roles, speech and language therapy, psychological services, community facilitator), other than GP or hospital appointments and physiotherapy, were either not available at all, or only available in a limited manner, and privately paid for by the person or the nursing home in some cases (Winkler, Sloan and Calloway, 2007).

In some countries it has been reported that younger people with specialist care and rehabilitation needs may lose their eligibility to receive services upon moving from disability support to nursing home care (e.g. rehabilitation support following brain injury) (Cameron, Pirozzo and Tooth, 2001). This was highlighted as a concern by the Disability Federation of Ireland in their submission to a review of the NHSS in 2012. This is an issue that could be explored further in the qualitative interviews with younger people with disabilities, as part of the second phase of this study.

## 5.6 Younger people with disabilities moving out of nursing homes

Given the experiences of and poor outcomes for younger people with disabilities in nursing homes, it is not surprising that some younger people prefer not to be there and wish to move out of the nursing home. Winkler, Sloan and Calloway (2007) found that 65% of young people in residential aged care in Australia wanted to explore alternative places to live. However, once younger people move into a nursing home they are unlikely to move out. There are several reasons for younger people remaining in nursing homes despite their preference to move. Some people simply have nowhere else to go. Others can be reluctant to move to other accommodation, which has been attributed to the fact that when younger people are placed in nursing homes their social supports and connections to their local community tend to diminish over time (Winkler, Sloan and Calloway, 2007; Winkler, Farnworth, Sloan and Brown, 2006).

Winkler, Farnworth and Sloan (2006) found that some younger people had expressed a clear preference to leave to nursing home managers and others, but no discharge date had been planned for these persons. The presence of people with alcohol problems in nursing homes is a relatively underexplored area (Mjelde-Mossey, 2007), but nursing homes are sometimes used as a temporary care setting where persons with alcohol problems can be treated for their other health problems (Adams and Cox, 1995).

The research by the Bray Area Partnership (Farrell, 2013) reported on a cohort of 10+ younger people with Korsakoff's syndrome in nursing homes who expressed a clear preference to move. Some had made good recovery since being admitted to a nursing home and were unhappy with their placement. While moving was a clear possibility, there was no review mechanism in place to trigger their transfer out of the nursing home. The Bray Area Partnership report (Farrell, 2013) thus recommended that a central review mechanism be put in place which would trigger actions to review the cases of individual younger people within nursing homes who have expressed a wish to transfer out of the nursing home or who may be suitable for transfer to a lesser care facility due to positive progress in their conditions. The report of the Bray Area Partnership recommended the development of a centralised register to identify cases and regularly review younger people in nursing homes (Farrell, 2013). The need for person centred care plans and personal development plans has been highlighted by the Disability Federation of Ireland in their submission to the review of the Nursing Homes Support Scheme, A Fair Deal, as well as by Bray Area Partnership.

The Bray Area Partnership also recommended that younger people with disabilities who express a preference to move out of a nursing home should be supported to apply for inclusion on the Local Authority Housing List and access other accommodation supports in the community (Farrell, 2013).

## 5.7 Enhancing the lives of younger people in nursing homes

As mentioned earlier, age is commonly put forward as a key reason for why placement in a nursing home is inappropriate for younger people. The main point of the argument is that nursing homes are generally designed for older people and are not set up or resourced to support younger residents. One approach taken to enhancing the lives of younger people with disabilities residing in nursing homes is to establish separate nursing homes or wings within nursing homes to accommodate younger people with disabilities. The literature offers some examples of innovative models of care for younger people in nursing homes. These include Mt. St. Vincent's Nursing Home in Tasmania, which has built a separate wing for younger people who can come and go as they please with an electronic key (Senate Community Affairs Reference Committee, 2015). In some nursing homes in Ireland residents are free to come and go as they please and have access to keycodes or their own entrance into self-contained units. The report of the Senate Community Affairs Reference Committee (2015) provides some other innovative examples in Australia, and also proposes a list of recommendations to improve the lives of those still living in nursing homes.

Another approach to enhance the lives of younger people with disabilities living in nursing homes is to apply a Universal Design approach. There is no single agreed definition of Universal Design in Ireland, the Centre for Excellence in Universal Design at the National Disability Authority, drawing on the definition coined by Mace (1998), defines Universal Design as 'the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people, regardless of age, size, ability or disability.' Universal Design is an inclusive philosophy that conveys the idea that all spaces, including nursing homes, should be inherently accessible for all users, irrespective of age or disability. Rather than focusing on users with specific disabilities or certain ages, Universal Design creates solutions that will work for everyone. The driving force behind the Universal Design philosophy is human capability, not age or disability. By adopting a Universal Design approach, nursing homes would not only improve the lives of younger people with disabilities, but also the lives of older people residing in them.

## 6. Conclusions

The analysis of a sample of 48 CSAR forms accompanying applications for the Nursing Homes Support Scheme (NHSS) in one Local Placement Forum, LPF area has offered valuable insights into the referral of and pathways into nursing homes for this group of people. Quite a substantial amount of information can be gleaned from an analysis of these forms including where the referral was made, socio-demographic information, health conditions and disability, co-morbidity, mental health status and cognitive impairment, dependency, medication use and levels of polypharmacy, risks, some information on family carers and use of community-based supports. However, there are glaring omissions. Surprisingly, the sex of the applicants is not recorded on the forms and there is an overemphasis on impairments, deficits, dependency, health care needs and risk with little or no record of a person's abilities or capabilities or of their psychosocial needs or what it would take for persons to be cared for in the community if that is their expressed preference. In addition, not all of the information is consistently recorded, which makes analysis difficult and time consuming. Discussions around preference for care setting were poorly recorded in many instances and no discussions had taken place in about one-fifth of cases.

This study is based on a small sample and is restricted to one LPF and the results cannot be generalised beyond the specific population from which the sample was drawn. With a large sample size drawn from LFPs across the country, however, it would be possible to generalise to the whole population of younger people with disabilities applying for the NHSS. The study is also limited in that the CSAR forms form only part of the application for the NHSS. However, there is little or no evidence from the CSAR forms reviewed in this study that younger people with disabilities are being given an opportunity to explore their skills and strengths or that their goals and aspirations are being discussed with them in any meaningful way.

Determining whether or not placement in a nursing home is appropriate or not for younger people with disabilities is not straightforward. In this study, following the Report of Disability Policy Review (Department of Health, 2011) a placement in a nursing home is considered appropriate if the placement can best support the person 'to lead a full and independent life, to participate in society and to maximise their potential.' Thus, in this study we were exploring through the analysis of CSAR forms the extent to which the assessment of needs was leading to an appropriate placement of younger people with disabilities in nursing homes.

Since the CSAR forms and the information that they provide embody a rehabilitative / medical perspective, it can be concluded that younger people with disabilities are being referred for an application for the NHSS without an assessment of all needs including recreational, social and personal development needs and the needs of family and carers where appropriate. It is likely that because younger people with disabilities are being assessed for placement in a nursing homes using a model underpinned by a rehabilitative / medical perspective, this may well be leading to the placement of these people in nursing homes that are inappropriate, that is, living in a care environment where they are not being supported to live full and independent lives.

A second phase of this study has commenced and is exploring the experiences of younger people with disabilities with regard to their transfer to nursing homes as well as the experiences of staff involved in making and reviewing the referrals. This second phase will shed further light on the appropriate placement of younger people with disabilities in nursing homes.

# 7. Recommendations

## Policy

For some time now, Ireland has been undergoing a paradigm shift from the traditional model of institutional care for people with disabilities to one focused on enabling people with disabilities to live independent lives in the community. There are many initiatives underway aimed at enabling people with disabilities to live ordinary lives in ordinary places. This is encouraging. Importantly, the work being undertaken has much relevance for younger people with disabilities who are being referred for the NHSS for a place in a nursing home and those already residing in nursing homes.

1. The placement of younger people with disabilities should be taken into consideration in work aimed at progressing and implementing government policy, such as Personalised Budgets, a Statutory Homecare Scheme, the Neuro-Rehabilitation Strategy, policies relating to de-congregation, the Personal Assistant, and Home Supports Service.
2. The Department of Health together with other relevant governmental departments should consider the possibility of developing and funding an initiative to prevent admissions of younger people with disabilities to nursing homes, in particular, looking at the specific needs of younger people with Acquired Brain Injury, Multiple Sclerosis, and dementia. The Australian government has developed an example of good practice, The Young People in Residential Aged Care Programme, a five-year programme to assist younger people with disability living in or at risk of entering residential aged care, as discussed on page 49.
3. The Government should support efforts to reduce the number of younger people placed in nursing homes, including through the development of alternative models of care, such as the provision of a range of purpose built residential services, providing high quality and individually tailored person-centred care and support; and revision of the funding arrangements so that funding follows the person and not the place.
4. A Universal Design approach should be adopted for the design and development of all accommodation, including dwellings in the community and nursing homes, in which younger people with disabilities live. Work to move towards this could be supported by the Centre for Excellence in Universal Design at the National Disability Authority.

## Practice

5. Younger people with disabilities are a diverse group of people, which demands that a personalised approach is taken to the assessment and care of younger individuals with disabilities.
6. It should be a pre-requisite of any needs assessment for the NHSS that the person is centrally involved, either speaking for themselves or with the support of an advocate and / or family member(s) as appropriate. Every effort should be made by all health care and social work staff involved in assessing and planning care for younger people with disabilities to discuss their preference for care setting with them. This is in line with the Assisted Decision Making (Capacity) Act 2015.
7. There is an urgent need to move towards a person-centred approach to assessment and care planning, whereby younger people with disabilities are given every opportunity to explore their skills and strengths and have an opportunity to contribute in a meaningful way to decisions about their goals and aspirations and where they wish to live.
8. Where the person has stated a clear preference for care in the community, there should be a commitment by all staff involved in this person's care to exhaust all possibilities before nursing home care is considered and efforts should be made to transform this preference into a reality. If home is the preferred option, but not feasible, this should be clearly reported on the CSAR form together with what steps had been taken to explore discharge home.
9. Where a younger person with disabilities residing in a nursing home has expressed a preference to move out of the nursing home, a clear process should be in place to trigger a review of their case.

## Research

10. An analysis needs to be undertaken of a larger sample of CSAR forms accompanying applications for the NHSS from a range of Local Placement Fora across the country to more precisely reflect the population of younger people with disabilities referred for the NHSS. This will require the support of the HSE and dedicated funding to complete the collection and analysis of data. The experience from the demonstration site is that it is feasible for LPFs to retrieve and redact at least 50 CSAR forms and that it would take one person one half day to complete.
11. Since the majority of applications were referred from an acute hospital, it would be useful for an analysis of Hospital In-Patient Enquiry data to be undertaken to provide information nationally on discharges of younger people with disabilities to nursing homes from an acute hospital setting. This could take place concurrently as part of a study analysing a greater sample of CSAR forms.
12. For the government to make decisions about the most appropriate place to care for younger people with disabilities, the costs of alternative models of care vis-à-vis nursing home care is needed.



# References

- Adams, W.L., and Cox, N.S. (1995). Epidemiology of problem drinking among elderly people. *International Journal of the Addictions*, 30(13-14), 1693-1716.
- Bartels, S. J., Mueser, K. T. and Miles, K. M. (1997). A comparative study of elderly patients with schizophrenia and bipolar disorder in nursing homes and the community. *Schizophrenia Research*, 27(2), 181-190.
- Bigby, C., Webber, R., Bowers, B. and McKenzie-Green, B. (2008). A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. *Journal of Intellectual Disability Research*, 52(5), 404-414.
- Birkett, D.P. (2001). *Psychiatry in the Nursing Home*, 2<sup>nd</sup> Edition. US: Routledge.
- Black, B. S., Rabins, P. V. and German, P. S. (1999). Predictors of nursing home placement among elderly public housing residents. *The Gerontologist*, 39(5), 559-568.
- British Society of Rehabilitation Medicine (2003). *Rehabilitation Following Acquired Brain Injury*.
- Cahill, S. (2018) *Dementia and Human Rights*, Bristol: Policy Press.
- Cameron, G., Pirozzo, S., and Tooth, L. (2001). Long-term care of people below age 65 with severe acquired brain injury: appropriateness of aged care facilities. *Australian and New Zealand Journal of Public Health*, 25(3), 261-264.
- Cicerone, K.D., Dahlberg, C., Kahmar, K., Langenbahn, D. and Malec, J.F. (2000). Evidence based cognitive rehabilitation: recommendations for clinical practice. *Archives of Physical Medicine and Rehabilitation*, 81, 1596-1615.
- Cepiou-Martin, M., Tam-Tham, H., Patten, S., Maxwell, C. and Hogan, D. (2016) Predictors of long-term care placement in person with dementia: A systematic review and meta-analysis, *International Journal of Geriatric Psychiatry*, 31, 1151-1171.
- Colantonio, A., Howse, D. and Patel, J. (2010). Young adults with traumatic brain injury in long-term care homes: a population-based study. *Brain Impairment*, 11(01), 31-36.
- Crowe, S. and Doig, H. (2017) *My MS My Needs: Comprehensive Survey of the Needs of People with MS*, Dublin: MS Ireland.

CSO (2006) National Disability Survey 2006. Dublin and Cork: Central Statistics Office.

CSO (2012) Census of Population 2011

CSO (2017) Census of Population 2016

Department of Environment, Community and Local Government (2011) National Housing Strategy for People with Disability 2011-2016. Dublin: DECLG.

Department of Environment, Community and Local Government (2012) National Housing Strategy for People with Disability 2011-2016 National Implementation Framework (2012). Dublin: DECLG.

Department of Health (2011) National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015, Dublin: Department of Health.

Department of Health (2012) National Carers' Strategy: Recognised, Supported, Empowered Dublin: Department of Health.

Department of Health (2012) Value for Money and Policy Review of Disability Services in Ireland. Dublin: Department of Health

Department of Health (2013) Long Stay Activity Statistics 2013, Dublin: Department of Health.

Department of Health (2014) Irish National Dementia Strategy, Dublin: Department of Health.

Department of Health (2015) Review of the Nursing Home Support Scheme, A Fair Deal, Dublin: Department of Health.

Department of Health (2018) Towards Personalised Budgets for People with a Disability in Ireland Report of the Task Force on Personalised Budgets, Dublin: Department of Health.

Department of Justice and Equality (2017) National Disability Inclusion Strategy 2017-2022, Dublin: Department of Justice and Equality.

Devi, N., Bickenbach, J. and Stucki, G. (2011) Moving towards supported or substitute decision-making? Article 12 of the Convention on the Rights of Persons with Disabilities, ALTER European Journal of Disability Research, 5, 249-264. doi:10.1016/j.alter.2011.07.002.

Disability Act 2005.

Doig, E., Fleming, J., Kuipers, P. and Cornwell, P. L. (2010). Comparison of rehabilitation outcomes in day hospital and home settings for people with acquired brain injury—a systematic review. *Disability and Rehabilitation*, 32(25), 2061-2077.

Doyle, A. and Carew, A-M. (2017) Annual Report of the National Physical and Sensory Disability Database Committee 2017: Main Findings, HRB Statistics Series 36, Dublin: HRB.

Eastern Regional Health Authority (2002) Survey of Services available to Young Chronically Ill and Physically Disabled People aged between 18 and 65. HSE.

Farrell, M. for Bray Area Partnership Disability Cluster Group (2013) Old Too Soon: Younger People with Disabilities Living in Nursing Homes in the Bray and Greystones areas of Co. Wicklow, Bray Area Partnership and Citizens Information Board.

Fries, B. E., Wodchis, W. P., Blaum, C., Buttar, A., Drabek, J. and Morris, J. N. (2005). A national study showed that diagnoses varied by age group in nursing home residents under age 65. *Journal of Clinical Epidemiology*, 58(2), 198-205.

Fullerton C.A., McGuire, T.G., Feng, Z., Mor, V. and Grabowski, D.C. (2008) Trends in Mental Health Admissions to Nursing Homes: 1999–2005, Working Paper, Boston: MA Harvard Medical School.

Fulton, M.M. and Riley Allen, E. (2005) Polypharmacy in the elderly: A literature review. *Journal of the American Academy of Nurse Practitioners* 17, 123–132.

Fyffe, C., Bigby, C. and McCubbery, J. (2006) Exploration of the Population of People with Disabilities who are Ageing, their Changing Needs and the Capacity of the Disability and Aged Care Sectors to Support Them to Age Positively: Final Report. Adelaide: National Disability Administrators Group.

Fyffe, C., McCubbery, J. and Honey, K. (2003). Young People with ABI Less than 65 Years Requiring Nursing Home Level of Care. Melbourne: Grimwood Pty Ltd.

Gove, D.M., Andrews, J., Capstick, A., Geoghegan, C., Georges, J., Libert, S., McGettrick, G., Rochford-Brennan, H., Rohra, H., Vehmas, S. and Williamson, T. (2017) Dementia as a Disability? Implications for Ethics, Policy and Practice: A Discussion Paper, Luxembourg, Alzheimer Europe.

Government of Ireland (2006) A Vision for Change: Report of the Expert Group on Mental Health Policy, Dublin: Stationary Office.

Grabowski, D. C., Aschbrenner, K. A., Feng, Z. and Mor, V. (2009) Mental illness in nursing homes: Variations across states. *Health Affairs*, 28(3), 689-700.

Haase, T. (2005) *Early Onset Dementia: The Needs of Younger People with Dementia in Ireland*, Dublin: The Alzheimer Society of Ireland.

Health (Nursing Homes) Act, 1990

Hourigan, S., Fanagan, S. and Kelly, C. (2017) *Annual Report of the National Intellectual Disability Database Committee 2017: Main Findings*, HRB Statistics Series 37, Dublin: HRB.

HSE (2007) *Report of the HSE Working Group on Residential Treatment and Rehabilitation (Substance Users)*.

HSE (2011) *Time to Move on from Congregated Settings: A Strategy for Community Inclusion*, HSE: Report of the Working Group on Congregated Settings.

HSE (2016) *Transforming Lives: Progress Report 2016*, HSE. Available at: <https://www.hse.ie/eng/services/publications/transforming-lives-progress-report-2016.pdf>.

HSE (2016) *HSE National Service Plan 2017*, Dublin: HSE.

HSE Working Group on Congregated Settings (2016) *Progress Report on the Implementation of Time to Move On From Congregated Settings: A Strategy for Community Inclusion Annual Report 2016*, Dublin: HSE.

HSE (2017) *HSE National Service Plan 2018*, Dublin: HSE.

Hendricks, A. (2007) UN Convention on the Rights of Persons with Disabilities. *European Journal of Health Law*, 14, 273.

Institute of Public Health in Ireland (2018) *Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation*, Dublin and Belfast: IPH.

Keogh, F. on behalf of the Expert Reference Group on Disability Policy (2010) *Report of Disability Policy Review*, Dublin: Department of Health and Children.

Lannoo, E., Larmuseau, D., Van Hoorde, W. and Eyssen, M. (2008) Prevalence of young adults with acquired brain injury (ABI) in nursing homes in Belgium: aged care facilities are not the best option. *Brain Injury*, 22(Suppl 1), 1-127.

McMillan, T.M. and Laurie, M. (2004) Young adults with acquired brain injury in nursing homes in Glasgow. *Clinical Rehabilitation*, 18(2), 132-138.

Mace, R.L. (1988) *Universal Design: Housing for the lifespan of all people*. Available at <http://www.ca-ilg.org/sites/main/files/file-attachments/101-153-1-pb.pdf>.

Mjelde-Mossey, L. A. (2007) Alcoholism Treatment in a Nursing Home: Meeting the Needs of a Special Population. *Alcoholism Treatment Quarterly*, 25(3), 87-98.

Moore, K. and Ryan, A. (2017) *The Lived Experience of Nursing Home Residents in the Context of the Nursing Home as their 'Home'*, Dublin: Nursing Homes Ireland and University of Ulster.

Moylan, M., Dey, P. and McAlpine, E. (1995) *A National Research Project examining the Placement of Younger People with a Disability in Nursing Homes for the Aged: Data Supplement*. Sydney: NSW Department of Community Services.

Muenchberger, H., Sunderland, N., Kendall, E. and Quinn, H. (2011) A long way to Tipperary? Young people with complex health conditions living in residential aged care: a metaphorical map for understanding the call for change. *Disability and rehabilitation*, 33(13-14), 1190-1202.

Muldoon, O., Walsh, S., Curtin, M. and Kinsella, E. (2017) *Getting My Life Reset – Living with an Acquired Brain Injury: The Irish Experience*, Dublin: Acquired Brain Injury Ireland.

O'Brien, C.L. and O'Brien J. (2000) *The Origins of Person-centred Planning: A Community of Practice Perspective*. Available at: <https://files.eric.ed.gov/fulltext/ED456599.pdf>.

O'Donnell, D., Ní Shé, É., Davies, C. et al. (2018) Promoting assisted decision-making in acute care settings for care planning purposes: Study protocol [version 1; referees: 2 approved]. *HRB Open Research*, 1:2 (doi:10.12688/hrbopenres.12797.1)

O'Reilly, K. and Pryor, J. (2002) Young people with brain injury in nursing homes: not the best option! *Australian Health Review*, 25(3), 46-51.

O'Shea, E., Cahill, S., Pierce, M., Hennelly, N. and Carney, P. (2017) 'Introduction' in O'Shea, E., Cahill, S. and Pierce, M. (eds.) *Developing and Implementing Dementia policy in Ireland*, Galway: Centre for Economic and Social Research on Dementia, National University of Ireland Galway.

Parke B. (1997) The young adult as a nursing home client ... the challenge of Karl's legacy. *Canadian Nursing Home*, 8(1): 27-28.

Persson, D. I. and Ostwald, S. K. (2009) Younger residents in nursing homes. *Journal of Gerontological Nursing*, 35(10), 22-31.

Pierce, M. and Pierse, T. (2017) 'Prevalence of dementia in Ireland' in O'Shea, E., Cahill, S. and Pierce, M. (eds.) *Developing and Implementing Dementia Policy in Ireland*, Galway: Center for Economic and Social Research in Dementia, National University of Ireland Galway.

Richardson, K., Moore, P., Peklar, J., Galvin, R., Bennett, K. and Kenny, R-A. on behalf of TILDA team (2012) *Polypharmacy in Adults over 50 in Ireland: Opportunities for Cost Saving and Improved Healthcare*, Dublin: TILDA.

SHRC (not dated) *A Human Rights Based Approach: An Introduction*, Edinburgh: Scottish Human Rights Commission. Last accessed: 15.08.2018. Available at: [http://www.scottishhumanrights.com/media/1409/shrc\\_hrba\\_leaflet.pdf](http://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf)

SHRC (2016) *Human Rights in Health and Social Care: Case Studies*, Edinburgh: Scottish Human Rights Commission. Last accessed: 15.08.2018. Available at: [http://www.scottishhumanrights.com/media/1408/shrc\\_case\\_studies\\_report.pdf](http://www.scottishhumanrights.com/media/1408/shrc_case_studies_report.pdf)

Senate Community Affairs References Committee (2015) *Report on the Adequacy of Existing Residential Care Arrangements Available for Young People with Severe Physical, Mental or Intellectual Disabilities in Australia*. Parliament of Australia.

Soulsby, G. (2008) Returning to the community – issues in placing people with complex care needs following brain injury in their own homes. *Brain Injury*, 22, 129-217.

Stringer, K. (1999). *Study into the accommodation needs for young people requiring nursing home level of care*. Melbourne City Mission, Victoria, Australia.

*Survey on Income and Living Conditions (SILC) 2014*. Central Statistics Office.

United Nations (2006) *Convention on the Rights of Persons with Disabilities*

Van Rensbergen, G. and Nawrot, T. (2010) Medical Conditions of Nursing Home Admissions, *BMC Geriatrics*, 19(46).

Walton, M. A., Blow, F. C., Bingham, C. R. and Chermack, S. T. (2003) Individual and Social / environmental predictors of alcohol and drug use 2 years following substance abuse treatment. *Addictive Behaviors*, 28(4), 627-642.

Watson, D. and Nolan, B. (2011) A Social Portrait of People with Disabilities in Ireland, Dublin: Department of Social Protection and Economic and Social Research Institute. [http://www.socialinclusion.ie/publications/documents/2011-09-21\\_SocPortraitPWDReportforWebsite\\_000.pdf](http://www.socialinclusion.ie/publications/documents/2011-09-21_SocPortraitPWDReportforWebsite_000.pdf).

Weyerer, S., Schaufele, M. and Hendlmeier, I. (2006) Alcohol abuse and dependence among residents in nursing homes: Representative results from the City of Mannheim. *Zeitschrift fur Gerontopsychologie und Psychiatrie* 19(4), 229.

Weingarden, S.I. and Graham, P. (1992). Young spinal cord injured patients in nursing homes: Rehospitalization issues and outcomes. *Spinal Cord*, 30(12), 828-833.

WHO (2001) International Classification of Functioning, Disability and Health, 54th World Health Assembly, 22 May 2001, Accessed at: [http://apps.who.int/gb/archive/pdf\\_files/WHA54/ea54r21.pdf?ua=1](http://apps.who.int/gb/archive/pdf_files/WHA54/ea54r21.pdf?ua=1)

WHO (2015) Ensuring a Human Rights-based Approach for people living with dementia, Geneva, World Health Organization.

Winkler, D., Farnworth, L. and Sloan, S. (2006). People under 60 living in aged care facilities in Victoria. *Australia Health Review*, 30(1), 100-108.

Winkler, D., Reynolds, A., Klein, L. and McLeod, J. (2015) Housing for young people in nursing homes: A report from a Social Finance Think Tank. Melbourne, Australia: Summer Foundation Limited.

Winkler, D., Sloan, S. and Callaway, L. (2007) Younger People in Residential Aged Care: Support Needs, Preferences and Future Directions. Melbourne, VIC: Summer Foundation Limited.

Wren, M-A., Keegan, C., Walsh, B., Bergin, A., Eighan, J., Brick, A, Connolly, S. Watson, D and Banks, J. (2017) Projections of Demand for Healthcare in Ireland, 2015-2030: First Report from the Hippocrates Model, Dublin: ERSI.

## List of Tables

- Table 1 Contrasting the approaches of the rehabilitative/medical perspective and the independent/person-centred perspective
- Table 2 Younger residents in long-stay residential care settings
- Table 3 Sources of referral of NHSS applicants under 65 years of age
- Table 4 Community supports used by NHSS applicants

## List of Figures

- Figure 1 Proportion of younger people in nursing homes in Ireland 2004 to 2013
- Figure 2 Age profile of younger people with disabilities applying for NHSS
- Figure 3 Marital status of younger people with disabilities applying for NHSS
- Figure 4 Living arrangements of younger people with disabilities applying for NHSS
- Figure 5 Source of referral of NHSS applicants with disabilities under 65 years of age
- Figure 6 Main health conditions/disability of younger people applying for NHSS
- Figure 7 Dependency levels of younger people applying for NHSS
- Figure 8 Polypharmacy status of NHSS applicants under 65 years
- Figure 9 Preference to stay at home
- Figure 10 Number of individuals receiving MDT recommendation for LTRCS versus no recommendation for care setting



# List of Boxes

Box 1 Article 19 of the UNCRPD – Living Independently and Being in the Community

Box 2 PANEL Principles

# Abbreviations

ABI	Acquired Brain Injury
ADPHN	Assistant Director of Public Health Nursing
BI	Barthel Index
BIRT	Brain Injury Rehabilitation Trust
CHO	Community Healthcare Organisations
CMHN	Community Mental Health Nurse
CMHSW	Community Mental Health Social Worker
COPD	Chronic Obstructive Pulmonary Disorder
CSAR	Common Summary Assessment Report
DCU	Dublin City University
DFI	Disability Federation of Ireland
ERHA	Eastern Regional Health Authority
HCP	Home Care Package
HIQA	Health Information and Quality Authority
HRB	Health Research Board
HSE	Health Service Executive
ICD-10	International Classification on Functioning, Disability and Health
IHCP	Intensive Home Care Package
IPH	Institute of Public Health in Ireland
LPF	Local Placement Forum
LSAS	Long Stay Activity Statistics
LTC	Long Term Care
LTRCS	Long Term Residential Care Support
MDT	Multidisciplinary Team
MS	Multiple Sclerosis
MSW	Medical Social Worker
NCF	National Consultative Forum
NDIS	National Disability Inclusion Strategy 2017-2021
NHI	Nursing Homes Ireland
NHSO	Nursing Home Support Office
NHSS	Nursing Home Support Scheme
NRH	National Rehabilitation Hospital
NSP	National Service Plan
PADMACS	Promoting Assisted Decision-Making within Acute Care Settings project
PHN	Public Health Nurse
RAG	Research Advisory Group
REC	Research Ethics Committee
SHRC	Scottish Human Rights Commission
SMSW	Senior Medical Social Worker
SPSS	Statistical Package for the Social Sciences
TBI	Traumatic Brain Injury
TILDA	The Irish Longitudinal Study on Ageing
UK	United Kingdom
UNCRPD	United Nations Convention of the Rights of Persons with Disabilities
WHO	World Health Organization

**DFI is about making Ireland fairer for people with disabilities.**

**We work to create an Ireland that everyone can access. Where everyone is equally valued.**

**We do this by strengthening the voice of people with disabilities and strengthening the work of the disability sector.**

**There are over 120 member organisations of DFI. We also work with a growing number of other organisations that have a significant interest in people with disabilities.**

**DFI provides:**

- **Information**
- **Training and Support**
- **Networking**
- **Advocacy and Representation**
- **Research, Policy Development and Implementation**
- **Organisation and Management Development**

**Disability is a societal issue and DFI works with Government, and across all the social and economic strands and interests of society.**



Disability Federation of Ireland, Fumbally Court, Fumbally Lane, Dublin 8  
Tel: 01-4547978, Fax: 01-4547981  
Email: [info@disability-federation.ie](mailto:info@disability-federation.ie) Web: [www.disability-federation.ie](http://www.disability-federation.ie)  
Follow us on Facebook and Twitter.

Disability Federation of Ireland is a company limited by guarantee not having share capital, registered in Dublin. Registered No 140948, CHY No 6177