



Wasted Lives



Ombudsman

Time for a **better future**
for younger people in nursing homes

An investigation by the Ombudsman





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Foreword

In recent years, my Office has received a number of complaints from people under 65 who were living in nursing homes for older people, because they could not access the support which would enable them to live in their own homes in the community. It quickly became evident to us that these individuals were part of a much larger problem, with estimates placing the number of people in such circumstances as more than 1,300.



This report is not a criticism of nursing homes. It is instead about the inappropriateness of nursing homes as accommodation for the people concerned. The personal stories of the people we met were powerful and moving. I was particularly struck by the words of one of our interviewees. He said that he had wasted the best years of his life in an institution. Another who had suffered his injuries in an assault, said that the person who assaulted him would eventually be released from prison while he had no prospect of leaving the nursing home.

Once you start unpicking the issues, it is clear that the systems are not in place to support people with disabilities. There is no system to ensure that every person has a key worker to enable them to access services. There is no consistent process for establishing people's needs and preferences. As a consequence, there is no way of identifying overall requirements, and no planning to address them. The funding systems are balanced in favour of nursing home care. There is a statutory entitlement to funding under Fair Deal, but no statutory scheme to support people in the community. There is no proper co-ordination between services. At worst, this means that people can have access to a suitably adapted house, but can't access funding for the support they need to live in it.

Many people told us that they thought their stay in the nursing home was a temporary measure, but found themselves still there years later with no prospect of a move out.

The net result of all of this is lives wasted. People who could and should be living in our communities contributing to our society are left without hope or futures. By contrast, some individuals we met did succeed in leaving nursing homes, and the richness of their experiences, and the successful new lives they lived, were in stark contrast to the lives of those who remained.

Imagine the prospect of spending your life in institutional care without relationships, work, family, social life or friendships. Living with the monotonous routine of an institution where many of your fellow residents have dementia, and where all of them are older than you.

All of this has been exacerbated by COVID 19. The risks of congregated settings were well known before the pandemic, but the loss of life in nursing homes has been one of the most distressing features. I want to pay tribute to the staff of the nursing homes, and of our health services, for their outstanding work in addressing the huge challenges they faced. This report was inevitably delayed because of the pandemic. Tragically, several of our interviewees passed away while it was being drafted. The report is dedicated to their memory.

We have built on the complaints we received, and the personal testimony of those individuals who shared their experiences with us. We have also drawn on existing reports and research to develop a comprehensive picture. We met with NGOs and other agencies to help to seek a wider perspective. My thanks are due especially to the lead Investigator Ann-Marie O'Boyle and to Senior Investigator Tom Morgan for their work on the report. My thanks also to all of those individuals who spoke with us and their families and advocates, who together brought home to us the huge waste of lives that the current situation is causing.

As a country, we have not done well at addressing the problems of institutional care. It has often been the first resort when seeking to address the needs of disadvantaged groups, and once out of sight, people have been out of mind, and their needs have not been taken into account or addressed. There are still far too many people whose lives are being wasted through lack of a consistent and coherent strategy to meet their needs.



Supporting people to live full and active lives as engaged and valued members of their communities will not be cheap, but our response to the needs of people who are most disadvantaged in our society is how we will come to be judged. Historically, our priorities have lain elsewhere, and the rights and legitimate aspirations of people with disabilities have been the casualties. It is time now to develop an energetic, well-resourced and effective strategy to stop more people being inappropriately admitted to nursing homes, and to work with those already there so that they can move out at the earliest possible opportunity. The recommendations in this report are designed to bring that about.

Peter Tyndall
Ombudsman

May 2021

Introduction

Improved technology and medical care means people with disabilities are living longer. Furthermore, as will be highlighted throughout this report, there have been fundamental changes in the discourse on disability and a move from a medical model to a social model of disability. Both of these developments have had ramifications for the delivery of disability services. I refer to disability and disability service provision throughout this report as the reality is that most of the people under 65 living in nursing homes seem to have some level of disability, whether it be a life-long disability or an acquired disability. Section 2 of the Disability Act 2005 refers to disability as: “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”.

I have had long-term involvement in disability services. Prior to my role as Ombudsman, in Ireland, I was Ombudsman in Wales and before that, I worked in a variety of senior positions in housing and social care, most notably in developing housing and support services for people with intellectual disabilities. I strongly believe that the objective of our services should be to enable all people who need support to remain in or return to the community to be provided with that support, so that they can live, full, fulfilling and engaged lives. Acquired Brain Injury Ireland have used the theme “Don’t save me, then leave me” in their campaigns. I believe that this is a theme that is closely aligned with the findings and recommendations of this report.

I have received a small number of complaints from, or on behalf of, people under 65 who are living in nursing homes. These individuals were not happy in their placement and they felt that they were inappropriately placed. When my Office contacted the Health Service Executive, it was advised that statistics on this matter are held by the Health Service Executive Nursing Homes Support Scheme Office. The Health Service Executive reported that, as of 30 June 2020, there were 1,320 people under 65 years of age supported by the Nursing Homes Support Scheme. This an increase from the 1,293 they reported on 31 December 2018.



I will discuss these statistics later in this report. However, given the number of people affected and the potential for significant adverse affect, I decided under section 4 of the Ombudsman Act 1980 (as amended) to initiate a wide ranging investigation into all aspects of the role of the Health Service Executive and the Department of Health in making such placements. I had a number of questions surrounding the prevalence of such placements, given that they did not seem in line with the current vision of Disability Services. This is not a new issue. Numerous individual cases have also been highlighted in the media but yet this issue seems to persist.

The purpose of the investigation is to establish the facts relating to the placement of people under 65 in nursing homes and determine if these placements qualify under section 4.2. (b) of the Ombudsman Act 1980 (as amended) as having been -

- (i) taken without proper authority,
- (ii) taken on irrelevant grounds,
- (iii) the result of negligence or carelessness,
- (iv) based on erroneous or incomplete information,
- (v) improperly discriminatory,
- (vi) based on an undesirable administrative practice, or
- (vii) otherwise contrary to fair or sound administration.

This investigation was informed not only by the individual complaints made to me but also by the circumstances of others in a similar position who came to my attention.

I nominated an Investigator to lead the investigation. The Health Service Executive and the Department of Health each nominated staff to assist with my investigation. My Office conducted a review of relevant documentation and literature on this issue. My Office then carried out 28 visits with people directly affected by this issue. Some of these people had submitted formal complaints to my Office prior to the investigation, others contacted my Office after they were told about my

investigation by advocates, NGOs or they had heard about the investigation from other sources. We spoke to each and every person who contacted my Office.

The majority of this group were people under 65 who have resided, or are still residing, in a nursing home. We undertook semi-structured interviews that involved a discussion of their personal story of moving into a nursing home and their personal experiences having done so. It was made clear to these individuals that the purpose of the investigation was not to seek to resolve individual complaints but rather to highlight the circumstances of such residents generally. I wanted the voice of individuals affected by this situation to be at the core of the investigation and I believe that the personal accounts that you will see throughout this report are extremely powerful and really encapsulate the findings of this report.

I was conscious that visits to the individuals referred to above only represented a small percentage of this group. In order to ensure more representation, my Office took a number of further measures. A number of individual meetings took place with stakeholders and a workshop was held with a number of advocacy bodies and disability organisations. Overall, these meetings and the workshop led to the development of key themes that were largely in keeping with those identified in the stories of the individuals we met with.

I have no way of gauging the overall percentage of current residents who are deeply unhappy with their current placements and are actively seeking support to move into the community or who simply wish to be provided with additional levels of support and services to improve their daily lives. I cannot, therefore, suggest that the stories told here reflect the experiences and wishes of the generality of residents under 65. There is no source of official information at present which paints the bigger picture. Consequently, it is not possible either to say that they are not representative. This is why I have framed a recommendation about the need to gather detailed information on the circumstances of each of the individuals concerned, including the recording and analysis of their will and preference in relation to their placements. However, I would also like to emphasise that each of these stories involves an individual and is therefore important in its own right.

This investigation commenced two years ago and was unavoidably delayed due to the COVID 19 pandemic. The stories provided are, therefore, two years old. My



Office has kept in contact with the individuals who were kind enough to provide their stories. Some of the changes in circumstances in those two years serve to illustrate the impact and importance of each individual story. Conversely, the lack of change of circumstance for the majority of individuals also illustrates this point.

Sadly, in the past two years, four of the individuals that my Office met with have died. At least one of these deaths was as a result of the COVID 19 pandemic. All of these individuals had expressed a wish to live somewhere other than a nursing home but unfortunately, they did not have the opportunity to do so.

On a more positive note, in the past two years, three of the individuals have moved from a nursing home to alternative accommodation. They are now living independently with varying levels of support. One of these individuals has 24 hour care a day, one has 21 hours care a week and the other has a number of hours of a personal support service each week. They have also reported a dramatic improvement in their quality of life, even within the constraints of COVID 19 and the related lockdown. Their updated stories, and their varying needs, illustrates that it is possible, with appropriate support, for individuals to move from a nursing home to independent living. Their stories also demonstrate the tremendous qualitative impact that this can have on an individual and therefore highlights the importance of these individual accounts.

As stated above, I have no way of gauging the overall percentage of current residents who are deeply unhappy with their current placements. Obviously, there may be individuals under 65 who report being satisfied with their placement in a nursing home and I do not want to over generalise in this report. As Kanter (2012) states:

“we must bear in mind that people with disabilities are not a homogeneous group; they differ based on the type and severity of disability - not to mention age, nationality, race, gender and class“.

Again, it is difficult to definitively comment in the absence of official information on each of the individuals involved and that is why I feel this information needs to be gathered. However, I am of the view that the key issue here is that of will and preference, and this will be discussed in more detail in Chapter 2 on Informed

Consent. Furthermore, I acknowledge that there are some individuals under 65 who may be best placed in a nursing home, based on their needs. In response to my draft of this report, the HSE made this very point. It states that, for some people, and based on assessed need, nursing home interventions are appropriate, where the required clinical supports are available and best met. However, I do believe that it is likely that these are in the minority and that the majority should be supported to remain in or return to the community so that they can live, full, fulfilling and engaged lives. The HSE agrees that this must be the subject of a care and case management approach that facilitates structured reviews, and where the will and preference of the individual is given primacy. Even if there are individuals who are appropriately placed in nursing homes, I feel that it should not be a default option and this will be discussed throughout the report. The Department of Health has acknowledged that a nursing home may be an inappropriate setting for some of this group and is conscious of the fact that there are people with a disability in nursing home provision who wish to and should be supported to move back to their home of choice.

Related to the above, this investigation relates to people under 65. This does not mean some of the issues involved are not relevant to some people aged over 65. It is not my intention to make any over generalisations in relation to age and I support a life-course approach. However, the complaints to my Office in relation to this issue came from younger people and so this is the focus of this investigation. 65 has been chosen as an arbitrary age as it is the age that has been used in various other research, policies and strategies and it seems to be the overall age used within our health system when there is an age division in terms of provision of services. This does not mean that some of the recommendations in this report are not relevant to people aged over 65.

I would like to clarify from the start that this investigation is not about the individual care provided by nursing homes. I am aware that nursing homes generally provide a high level of care to both people under 65 and over 65 who are availing of their services. Rather, this investigation is in relation to the appropriateness of these placements for younger people. I am also conscious that the placement of people under 65 in nursing homes extends beyond the arena of health. Issues such as housing undoubtedly play a role in this discussion. However, at present, based



on the nature of the original complaints to my Office, I have focused on services provided by the Health Service Executive and Department of Health. That is not to say that discussions in relation to broader issues such as accommodation are not needed in the future.

It is also important to acknowledge the work that has been done by the Health Service Executive and Department of Health in this area. Overall, the recommendations of this report align with long-term objectives of the Health Service Executive and Department of Health. The Health Service Executive agrees that this report makes recommendations consistent with broad policy and strategy for these services and other recent reports such as Expert Panel Review of Nursing Home Report, HIQA report on the Need for Regulatory Reform etc. where there is a focus on the need for the Sláintecare requirement for “right place, right time”.

As is acknowledged in this report, the work that has been done on establishing a statutory home support scheme that enables people to live as independently as possible in their home is a very welcome and significant development in this area and it is a critical enabler in terms of underpinning broader home-based support packages.

A recent positive development has been the commitment in the current Programme for Government to “Reduce and provide a pathway to eliminate the practice of accommodating young people with serious disabilities in nursing homes”. As a consequence, the Health Service Executive has been able to establish a dedicated funding stream as part of its National Service Plan (NSP 2021) that will enable 18 people, with an investment of €3m, under the age of 65 years to transition to their own home with support. I understand from the Department of Health that this pilot programme will also involve a mapping exercise by the Health Service Executive to identify the number of young people aged under 65 inappropriately placed in nursing homes. This is timely and will serve to assist in the implementation of recommendation 6.1 in this report. The Department of Health has also stated that the pilot programme will also enable it to develop a robust business case in order to establish the approach and funding through the Estimates Process to continue to build on progress in relation to measures to improve the lives of this group in the short and longer term.

The National Service Plan 2021 also provides for implementation of the Neuro-Rehabilitation Strategy which will (i) utilise the Sláintecare 2020 care redesign fund in the development of neuro-rehabilitation teams commencing with CHO 7 and 8 and (ii) which is inclusive of the development of 10 specialist inpatient beds. All combined, this programme will provide additional options for people with complex care needs and develop models of support that can then be replicated across the State in line with Sláintecare.

The National Service Plan 2021 also includes provisions for an additional 40,000 Personal Assistant hours, with a total target of 1.74m hours to support people with a disability to live self-directed lives. The Government has also committed to publishing and implementing the Disability Capacity Review to meet growing demand for person-centred service over the next decade.

Many of these developments have emerged since the start of this investigation and, as stated, they are very welcome and positive steps. However, I feel that there is further progress to be made, and I feel that the implementation of the recommendations of this report through a collaborative process between my Office, the Health Service Executive and the Department of Health could play a key role in progressing this issue and making a meaningful change in the lives of individuals. The Health Service Executive has acknowledged that collaborative working and joint initiatives are an important means by which to effect change for the benefit of all citizens, including in the context of this investigation. It is open to this approach, which is very helpful.

In its response to my draft investigation report, the Health Service Executive strongly emphasised the point that it must operate within the budgets that it is allocated, that these are finite, and that within these budgets they must cater for a myriad of competing demands. I fully accept that the resources provided to the Health Service Executive are finite and it must operate within budgets. It would be a matter for the Department of Health and Government to deploy the necessary additional resources to facilitate the implementation of the recommendations in this report. I would hope that in the spirit of the United Nations Convention on the Rights of Persons with Disabilities, they will give favourable consideration to doing so.



Summary of Findings and Recommendations

Chapter One: State Funding and Personal Finances

1.1 Finding

This investigation has identified systemic issues, which are compounded by a fractured funding model, which does not address the issues highlighted in this report in a sufficiently targeted, coherent and progressive manner. The commitment in the Programme for Government to implement a statutory home support scheme will be necessary to address the current bias in favour of institutional settings.

1.1 Recommendations

- a. *A ring fenced annual budget should be allocated to each CHO Area in order to improve the quality of life of each of these individuals and to assist them in leaving nursing homes, if that is their preference, and to support and enable them to enter into more appropriate living arrangements.*
- b. *The new funding model should ensure that individuals in the community retain sufficient money to allow them to lead an ordinary life.*
- c. *The budget allocated to each CHO Area should be proportionate to the number of people under 65 in need of such support within the CHO's geographical area.*
- d. *The business plans for each CHO Area should set appropriate targets and progress should be reported to the HSE annually, particularly in relation to the reduction in numbers in nursing homes.*
- e. *A target date for the completion of this programme should be set and agreed with the Office of the Ombudsman.*



Chapter Two: Informed Consent

2.1 Finding

The personal experiences of a number of people who were interviewed during this investigation give rise to a concern as to whether they fully understood the long term consequences of entering the Fair Deal Scheme. This gives rise to the need for safeguards to be put in place to ensure that all individuals under 65 (and indeed all other applicants as well) who enter into the Fair Deal Scheme are giving fully informed consent in each and every case.

2.1 Recommendations

- a. The HSE, in conjunction with the Department of Health, should draw up strict procedural guidelines for staff involved in processing Fair Deal applications and CSAR forms with the aim of ensuring that fully informed consent is provided and documented in each and every case.*

Further guidance should also be provided for Local Placement Forums/ Integrated Decision Making Forums in view of their important oversight role.

- b. While the Assisted Decision Making Act is not fully commenced the principles enshrined in that legislation should be used to underpin the guidelines.*
- c. An audit system should be put in place to ensure that adherence to the guidelines is monitored and appropriate follow up action taken in light of any adverse audit findings.*

Chapter Three: Quality of Life

3.1 Finding

It is recognised that a full resolution of the systemic issues identified in this investigation will take time and the provision of additional resources. Notwithstanding this, it is clear that the lives of some individuals identified in this investigation and perhaps others in similar



situations, could be radically improved by the commitment of modest additional effort and resources.

3.1 Recommendation

This Investigation has identified a number of residents who have expressed a strong desire to move out of nursing homes and who could be quickly facilitated through the provision of relatively modest additional supports. These include Mark, Francis and Hannah. The example of Francis shows how the quality of life of individuals can be transformed through such minimal effort. The work on the national survey (see recommendation 6.1) should be used to identify other individuals in similar circumstances and appropriate follow up action in their cases should be agreed and implemented by the HSE as a matter of urgency.

3.2 Finding

In this Chapter I have highlighted HIQA's call for a more appropriate and progressive form of statutory regulation. HIQA has

contrasted the approach in Ireland to that of other jurisdictions. I am convinced that a move to a service model of registration would be a clear improvement in the regulatory regime in Ireland.

3.2 Recommendation

That the Department of Health review the current statutory provisions governing HIQA registration and bring forward legislative proposals to support a move towards a service model of registration.

Chapter Four: Access to Services

4.1 Finding

People living in nursing homes should have the same access to primary care services as people living in the community. However, the evidence provided by residents we met suggests that the availability of such services on the ground is at best patchy and at worst non-existent.



4.1 Recommendation

Each CHO Area should ensure that those people in their area who are identified by the national database (see recommendation number 6.1) are provided with the same level of access to primary care services as people living in the community.

4.2 Finding

Access to personal assistant support is inconsistent and inadequate.

4.2 Recommendation

The level of requirement should be established and a timescale put in place to deliver this in line with Sláintecare.

Chapter Five: Navigating the System

5.1 Finding

This group of people need support to enable them to understand and navigate the system, to have their wishes and preferences identified and acted upon and to have their voices heard.

5.1 Recommendations

- a. A case coordinator (key worker) should be appointed by the HSE for each individual included in the national database.*
- b. A comprehensive information package should be drafted by the HSE aimed specifically at these individuals. This should include relevant points of contact, an outline of rights and entitlements as well as a road map as to how to apply for and access any relevant support schemes and services such as relevant NGOs, the National Advocacy Service etc.*



5.2 Finding

The HSE has indicated that each CHO Area is encouraged to actively review each placement in nursing homes and that requests for additional supports and/or alternative placement options should be considered. The HSE says that, in this regard, the assessment process of individual needs should be supported by a suitable Case Management Model. The Department of Health has told my Office that it agreed that a care and case management approach should inform the approach to assessing the need for placement and that there should be provision for a review of such placements and consideration of requests for additional supports and/or alternative placement options.

5.2 Recommendation

A Case Management Model should be drawn up by the HSE and rolled out through each CHO Area within twelve months of the publication of this report.

Chapter Six: Chapter on Policy and Human Rights

6.1 Finding

The framing of policy in respect of people under 65 in nursing homes needs to be underpinned by a rigorous objective assessment their needs , both at an individual and an aggregated level. This is also necessary in setting targets, assessing progress against them and meeting policy objectives.

6.1 Recommendation

A full comprehensive national survey of persons under 65 in nursing homes should be undertaken by the HSE and completed within twelve months of the publication of this Report with all information collated on a centralised database. This database should be regularly updated.



6.2 Finding

While it is important to address the situation of persons under 65 currently in nursing homes it is equally important that appropriate measures be put in place in order to reduce the possibility, in so far as is practicable, of other people under 65 finding themselves in the same situation. It is acknowledged that, in a very small number of cases, a nursing home may be the most appropriate placement, provided that this is the will and preference of the individual.

6.2 Recommendations

- a. *An alert system should be put in place by the HSE throughout the health sector, but in particular in the acute hospital sector, to identify in future, at the earliest possible stage, individuals under 65 who, because of their circumstances, may end up in long term residence in a nursing home. The details should be notified to the national database (see 1 above) and an action plan should be put in place to avoid long term placement in a nursing home if that is the individual's preference.*

- b. A date should be set after which there will be no long term admissions to nursing homes by people under 65 unless it is their express wish to be so admitted and a plan developed to ensure that the necessary resources are made available to achieve this.*

6.3 Finding

This investigation has identified a specific systemic issue of concern which is adversely affecting a particular group of people. From a policy perspective and in terms of resolving this issue there needs to be a definitive policy framework put in place which acknowledges the issue and commits to its resolution within a reasonable timeframe. An example of an analogous policy document would be Time to Move On from Congregated Settings.

6.3 Recommendation

That the Department of Health, in consultation with the HSE, draw up and publish an overarching policy framework to remedy the situation of persons under 65 in nursing homes. This should be done by the end of 2021.



Chapter One: State Funding and Personal Finances

When my Office went out and met with individuals under 65 living in nursing homes, it is unsurprising that one of the issues that repeatedly came up was that of their finances. There is a longstanding link between disability and poverty. Banks et al (2018) confirm that the link between disability and poverty has been well documented, with evidence showing that people with disabilities are more likely to be in poverty and outside the labour force. This is evident both internationally and within Ireland. In her 2016 report to the United Nations, the Special Rapporteur of the Human Rights Council on the rights of persons with disabilities, Catalina Devandas-Aguilar stated; “There is a growing consensus that poverty affects persons with disabilities in a disproportionate manner, a correlation that is deeper than it first appears”. At a national level, the Disability Federation of Ireland (2017) reported, in their 2018 pre-budget submission, that the disposable income of people with disabilities fell by 7.4%, a drop of €1,047 between 2010 and 2015. This effectively means that people’s income was down by €20 a week. These issues seem to have continued and in their 2019 pre-budget submission for 2020, they stated that 24% of adults with a disability were living in consistent poverty, compared to 26% in 2016, 22% in 2015, and 11% in 2011.

From meeting with individuals affected, I established that many individuals under 65 in nursing homes are dealing with financial issues on a daily basis. I am of the view that some of this is attributable to systemic issues. For example, I have noted that there is some disparity and discrepancy in how the placements of people under 65 in nursing homes are funded. I appreciate that my Office did not meet with everyone affected but I still feel that this highlights an overall issue of disparity. I believe that this links with overall issues in relation to a lack of policy and procedure for this group, which I will discuss further in Chapter 6.

The majority of individuals my Office met seem to fall under the Nursing Homes Support Scheme. This seems in line with the information from the Health Service Executive, who when originally asked for statistics in relation to the number of

people under 65 residing in nursing homes, quoted from statistics held by the HSE Nursing Homes Support Scheme Office. The HSE has advised my Office that it does not have data on nursing home residents under 65 who may self-fund or are funded from another source.

In short, The Nursing Homes Support Scheme, also known as “Fair Deal” is a scheme of financial support for people who need long-term nursing home care. The scheme is operated by the Health Service Executive (HSE). The statutory basis for the Nursing Homes Support Scheme is the Nursing Homes Support Scheme Act 2009, which was signed into law on 1 July 2009. Under this scheme, the applicant makes a contribution towards the cost of his/ her care in the nursing home (the level of which is determined in accordance with the criteria laid down in the Act of 2009) and the State pays the balance of the cost of the applicant’s care.

The Who Cares? Report

My predecessor, Emily O’Reilly completed an investigation called ‘Who Cares?’ in 2010 into the right to nursing home care in Ireland. Although that investigation was of a different nature to the current investigation, some of the points are relevant here. Her report stated that there was a lack of clarity regarding the type of patient whose needs were intended to be met under the Nursing Homes Support Scheme. It highlighted that within the HSE there was, at least for a period, a view that the Nursing Homes Support Scheme applied only to those over the age of 65 years and that it was not available to those under 65 years who needed long term residential care. The report suggested that perhaps because the Nursing Homes Support Scheme was developed within the Department by its Older Persons Services, there seemed to have been little anticipation of the fact that some people under 65 years old would also require long term residential care. Emily O’Reilly learned that at one point the HSE, acting apparently in consultation with the Department, decided to confine the benefits of the NHSS to those who fall within the age group served by its Older Persons Services and, accordingly, to exclude from the Scheme all persons under the age of 65 years. This decision was conveyed in an internal HSE memorandum on 16 April 2010.



Very shortly after this, the HSE issued a more nuanced memorandum which in effect said that, while the NHSS is open to people of all ages, younger people requiring long stay care are likely to have needs not capable of being met under the care packages agreed with those private nursing homes participating in the Scheme.

This suggests that although the Nursing Homes Support Scheme is available to people under 65, this was not originally the intention of the Scheme. The 2010 Ombudsman investigation stated that “There is a view within the Department and the HSE that many of those under 65 years who need long-term care are likely to be people with a disability or mental health needs and that such needs are not intended to be met under the NHSS Act”. It seems therefore that the Department of Health and the HSE were conscious that the Nursing Homes Support Scheme may not be the most appropriate scheme for this age cohort, although they are legally entitled to it.

The 2010 report noted that one recent complainant had argued that the NHSS financial assessment, as it operated at that point, failed to take account of the needs of families who must continue to run a household (including paying a mortgage) while also having to make a substantial contribution to the nursing home costs of a family member. This complainant observed that the NHSS was designed with older people in mind who would not have ongoing mortgage and other household costs and that, as operated at the time, it was unfair on families such as her own.

Although, as established in the 2010 Ombudsman report, people under 65 are entitled to access the Nursing Homes Support Scheme, given that it was not originally intended for younger people, the question arises as to whether the Nursing Homes Support Scheme, as it currently stands, is the best option for them.

Furthermore, the 2010 report highlighted that the range of services covered by the NHSS is quite narrow and excludes many elements which, on the face of it, are services which one would expect to be included as part of long term nursing home care.

In a letter to the HSE, dated 21 April 2010, the Department pointed out that the NHSS Act “only covers ‘long-term residential care’ which included nursing and personal care, basic aids and appliances, bed and board and laundry facilities”; the letter goes on to say, at least by very strong inference, that the NHSS Act does not extend to the provision of “therapies, behavioural programmes and communication devices”.

Financial Burden on Residents under 65

The NTPF agreement with nursing homes specifically excluded, and still excludes, some fundamental care elements such as all therapies, chiropody and social programmes. Access to services will be discussed in more detail in Chapter 4. However, the relevance here is the impact of this on the financial situation of applicants under the age of 65.

As highlighted above, individuals may be married with young dependents. Their partner may have had to give up their job to assist in caring for them or for altered childcare arrangements. The individuals themselves may be trying to re-enter the workforce in some shape or form. It is difficult having a lien on your house at this stage of your life. They will also be paying contributions under the Nursing Homes Support Scheme for a much longer period of time given that there is potential for their length of stay to be much longer, based on their age. The HSE has highlighted to my Office that the NHSS Act 2009 requires that a Financial Assessment be undertaken for all applicants who are deemed to require long term residential care. The format and detail of that assessment is laid out in the legislation and guidelines and the HSE must follow them. The Financial Assessment provides for issues such as dependents and other expenses being included. However, it is still limited in this regard and I would argue that it is more targeted towards older people. The Department of Health highlighted to my Office that, in recognition that younger applicants to the Scheme may have different financial, dependent, and social circumstances to older adults, there are a number of provisions in relation to the financial assessment that are applicable to longer residence in a nursing home, to the cost of maintaining or providing for a dependent, and in reducing financial and other burdens in relation to housing and property.



These include a three-year cap on principal private residence (PPR) contributions, allowable deductions for childcare, rent payments in relation to PPR in which spouses or dependents reside, further deferral on Ancillary State Support where a connected (dependent) person continues to reside in property). However, this is still not sensitive to the often very individual circumstances of applicants.

Given the nature of the current Nursing Homes Support Scheme agreement, residents may also have additional charges to pay on top of their contribution. Although the Competition and Consumer Protection Commission has launched guidelines for contracts of care in nursing homes, additional charges seem to be an issue that continues to impact on residents of all ages. People under 65 in nursing homes may also have other sundry expenses such as mobile phone and internet in order to maintain normal contact with friends and family for someone of their age. Whilst some individuals reported that toiletries etc. were provided by the nursing home, others had to buy their own. All this has the potential to leave them in a very difficult financial situation and often the onus can fall on families to subsidise costs or residents do without. I would like to highlight here that some of these issues may also be applicable to individuals over 65 but as previously explained, the scope of this particular investigation is limited to individuals under 65. However, this is not to minimise the experience of older people.

The Personal Experiences of Residents Under 65

Below are some examples of the information people under 65 provided to my Office in relation to financial struggles. Again, I appreciate this is not a large number of accounts but I believe that it highlights some of the issues that exist and it is also in keeping with other research in this area.



Mark is a 58 year old man who suffered a severe stroke in 2010. He has been resident in a nursing home since 2012. He has been asking to be discharged from the nursing home for the past few years as he is not happy living there. As a result of this, the HSE liaised with a local charity who put forward a house for him. He was waiting for a HSE support package to be approved to allow him to move into this house fulltime. He has applied for 26 hours personal assistance hours per week but feels he could manage with slightly less than this. Whilst waiting for this, he has been allocated 6 personal assistance hours a week to allow him to stay in his house once a week. Although Mark was not entirely sure, his advocate was of the understanding that his nursing home placement was funded through the Nursing Homes Support Scheme. He was therefore paying a contribution from his Disability Allowance towards this. He reported that this left him with approximately €43 per week. On top of this, he is paying €20 per week rent for the house as he stays there once a week. This would increase if he was staying there full time but he would not be paying a contribution towards the Nursing Homes Support Scheme. He also pays €8 per month to the pharmacy in prescription charges and he pays for his phone. He pays for transport when it is required and he pays for items for the house and has to get things like shampoo etc. for both house and nursing home so he has duplicated expenses. He also pays for his pendant alarm, as he needs this when he is in the house. He finds it very difficult to manage these expenses with the money available to him.



Francis is a 60 year old man who suffered a brain injury approximately 8 years ago. He has been in a nursing home since he was discharged from hospital. Francis had just finished building a new home for himself when he suffered his injury. His house has since been made completely wheelchair accessible. He is extremely unhappy in the nursing home and ideally would like to return home with a care package. Francis's placement in the nursing home is funded through the Nursing Homes Support Scheme. He pays his contribution. Because he still aspires to return to his home, he also pays his mortgage, house insurance and other bills such as electricity in order to maintain the house.



Charles is a 53 year old man with a progressive neurological condition. He has been in a nursing home for just under two years. Prior to this, he was living in council accommodation. Because he is unhappy in the nursing home, he continues to pay rent for his council accommodation, even though it is not wheelchair accessible. This is on top of what he pays from his Disability Allowance towards the Nursing Homes Support Scheme. He also pays an additional €20 per week to the nursing home for activities, although he says that he does not participate in the organised activities. His parents purchased a wheelchair accessible car as using a wheelchair accessible taxi for all Charles's appointments was very expensive. This was tax free but they are paying for fuel themselves. He says that he has very little disposable income and his parents assist him with expenses such as clothing and cigarettes. He informed my Office that in an ideal world, he would like to be able to save some money so he would feel some security. He said that given what has happened to him, he places great importance on being able to provide for himself and he would like to put some money aside for a rainy day.



Michelle is a 50 year old woman who suffered a brain haemorrhage and stroke 4 to 5 years ago. She was admitted to a nursing home 2 years ago. Her placement is funded through the Nursing Homes Support Scheme. She pays extra for some of the activities in the nursing home such as art and music. She has a medical card but pays monthly prescription charges. She said that she also has to pay for various medical items not covered by her medical card, such as "Sudocrem", and her toiletries. She attends a day centre twice a week and she has to pay €10 for her lunch there each day that she attends, so effectively she pays €20 extra each week on meals on top of her Fair Deal contribution. She said that she has no money left at the end of the month for things like clothes and makeup and her family have to supplement her finances.



Liam is a 52 year old with a rare progressive neurological condition. He is residing in a nursing home and his placement is funded through the Nursing Homes Support Scheme. Liam had been attending swimming outside the nursing home and he enjoyed this but he said that he had to pay for the swimming pool and for transport to and from the pool. He stopped going as he felt that he could not afford this. His activities are now very limited.



Rose is a 52 year old woman with a brain injury. She has suffered both a brain tumour and a stroke in the past. She lives in a brain injury unit in a nursing home. Her placement is funded through the Nursing Homes Support Scheme. When my Office visited Rose, she was visibly in a lot of pain and she said that she had hurt her lower back. Her advocate was present and suggested that she attend the Accident and Emergency Department. She said that she could not afford this. The nursing home had assessed her and told her that she would need to be accompanied by an escort if she left the nursing home, due to difficulties with her mobility. The nursing home charged €23 per hour for this escort. She said she would not go to hospital as she would be left on a trolley and if she was in A&E for hours, she would be charged by the hour for the escort. Rose



would also have to pay for transport to and from the hospital. Rose already pays an hourly charge for the escort on a regular basis as the escort brings her in her wheelchair to the local shop to buy toiletries etc. She also pays monthly prescription charges and she pays €50 when she requires chiropody. Rose says that she is left with very little money and her family have to buy her necessities like clothing.



Hannah is a 63 year old woman who has a spinal injury after a fall at home three years ago. She has been living in a nursing home for over a year. She has a medical card but she states that one of her creams prescribed to prevent bed sores is not covered by the medical card. It costs €700 and so she does not get it. She is charged €30 for chiropody every 4 to 6 weeks.



Daniel is a 47 year old man with a physical disability living in a nursing home. His placement is funded through the Nursing Homes Support Scheme and he makes the requisite contribution from his Disability Allowance. On top of what he is charged through the Nursing Homes Support Scheme, the nursing home also charges Daniel an additional €10 per day for therapies. Daniel does not understand what this charge is for. Further to this, if Daniel has to attend an appointment, he must pay to use the nursing home bus. If he wants someone from the nursing home to escort him, he has to pay an additional €30 an hour for this.



Leah is 49 years old. She has multiple complex diagnoses including physical disability, intellectual disability and cancer. She has been living in a nursing home for the past 19 months under the Nursing Homes Support Scheme. She is in receipt of Disability Allowance and pays her contribution from this, which leaves her with approximately €38 per week. Leah has various hospital appointments due to her various conditions. Her wheelchair is too big for wheelchair taxis and so she needs a minibus to get to hospital appointments. This costs €300 or €500 per trip, depending on where her appointment is. A charity provides some assistance towards this but this is limited and it is discretionary. Her mother advised my Office that her daughter's non-prescription medication costs over €100 per month. Leah was also paying extra charges in the nursing home such as laundry. Leah's mother advised my Office that she had to subsidise Leah but this was difficult as she was in receipt of an old age pension. She said that Leah was in a better position financially when she was previously in disability residential services. Leah is restricted to her room and occupies herself with arts and crafts. She buys and funds her arts and crafts supplies herself.



Inconsistent Funding Models

As illustrated above, the reality is that the Nursing Homes Support Scheme leaves many people under 65 in nursing homes in a difficult financial situation. The HSE advised my Office that it was not aware of any research or work done to establish the financial situation of those under 65 in nursing homes under the Nursing Homes Support Scheme once additional deductions such as activity charges, transport, escorts etc. have been deducted. It stated that the type of deductions that are allowable under the Financial Assessment are documented. Any other costs outside of those items that a resident may accrue cannot be included in the Financial Assessment and are therefore not included within Nursing Homes Support Scheme assessments.

Although the HSE's use of the Nursing Homes Support Scheme to provide statistics of individuals under 65 in nursing home suggests that this is the model of funding used for this cohort, this does not seem to be the case across the board. Although in the minority, my Office met one man under 65 who had been privately funding his placement for a period of time.

Other individuals met by my Office have their placements fully funded by the HSE. My Office met at least three individuals in this situation. When asked about this, the HSE advised my Office that NHSS only applies for registered nursing homes. Other centres may be registered for disability and therefore people residing there cannot avail of NHSS. However, the individuals in question were residents in registered nursing homes. In fact, one of these individuals was a resident in the same nursing home as someone else that met with my Office and who was funded through the Nursing Homes Support Scheme. Such disparity in funding is concerning. The HSE also referred to "top ups" as a possible explanation for this. Some persons with a disability under the age of 65 years who are resident in nursing homes under the Nursing Homes Support Scheme are in receipt of top up payments from Disability Services, as the weekly cost is in excess of the Fair Deal limit, due to the specialised nature of the care involved. However, this does not explain the disparity as these individuals are still paying a contribution through the NHSS.

The relative of one man told us that he was paying contributions under the Nursing Homes Support Scheme until his family highlighted that he was in the nursing home against his will and because there were no other available options. His contributions were then stopped. This does not seem to be the approach taken for the majority of individuals my Office met who did not wish to continue living in a nursing home and the HSE has advised my Office that if a client accepts funding under NHSS, their Financial Assessment dictates the contribution that they are required to make. There is no provision for any other charge to be calculated. Despite the personal account of this one individual, there does not seem to be any flexibility with payments in terms of individuals who are in a nursing home, which is not in keeping with their will and preference, once they have signed up for the Nursing Homes Support Scheme.

Some other examples of flexibility were mentioned, such as the Nursing Homes Support Scheme allowing some flexibility in terms of socialising. However, this was rare and those who mentioned it were not sure of the exact circumstances and one stated that she did not ask any questions, as she did not want to “rock the boat”.

This suggests inconsistent models of funding for this cohort and there are obvious implications for the use of differing models. This means that two individuals with the same needs and the same income can be in very different financial situations. Whilst someone under the Nursing Homes Support Scheme is paying a percentage contribution, someone who is self-financing their placement is paying the full contribution and someone whose placement is fully funded by the HSE, is paying no contribution. I cannot find any legislative or policy related explanation for why some individuals are funded under the Nursing Homes Support Scheme, which means they are paying a percentage of their Disability Allowance or other income, whereas others are fully funded by the HSE, which means they retain their full Disability Allowance or other income. This means that people under the Nursing Homes Support Scheme are at a monetary disadvantage compared to those who are fully funded by the HSE. Again, I am of the view that this issue may relate to the way that services for this group of people evolved and the lack of directly relevant policy. Such disparity without a clear process for determining how placements are funded means individuals are being treated differently.



Such inequities are also evident when further comparisons between individuals with similar needs and similar incomes are made. For example, a person under 65 with a disability living in a nursing home under the Nursing Homes Support Scheme and a person under 65 with a disability living in a HSE residential service for people with disabilities. Residents in the latter pay a Residential Support Services Maintenance and Accommodation Contribution (RSSMAC) otherwise known as a long stay contribution. In short, a long stay contribution is an affordable contribution towards a resident's basic living and accommodation costs in certain HSE, or HSE-funded, residential settings. These include nursing and non-nursing settings where accommodation is provided or where upkeep costs (for example, food and utility bills) are funded by or on behalf of the HSE. These contributions apply in residential accommodation in the mental health or disability sectors, and, to a lesser extent, convalescent homes, hospitals (while not receiving acute care) and nursing homes (including older people's units but excluding nursing home services supported under the Fair Deal Scheme). As with the Nursing Homes Support Scheme, an individual's income and essential outgoings are assessed in order to determine their contributions. Their level of need is also assessed. Individuals with high dependency who require 24 hour medical or nursing care fall into Category A and their contribution is larger than those with lower dependency. For someone who is fully reliant on Disability Allowance as their income, which many of this group are, a long stay contribution under Category A and a contribution under the Nursing Homes Support Scheme appear to be similar. However, inequities still exist.

National RSSMAC (Long-Stay Contributions) Waiver Guidelines were approved on 12 April 2019 (with effect from 29 March 2019) by the Minister for Health with the consent of the Minister for Public Expenditure and Reform. These guidelines are an updated and revised version of the previous (April 2018) guidelines. These guidelines are primarily intended for use by personnel of the HSE and relevant ("section 38") service providers when deciding the extent of any waiver to grant under section 67D of the Health Act 1970, i.e. any reduction or setting aside of a person's statutory obligation to pay a residential support services maintenance and accommodation contribution (RSSMAC) under section 67C, taking account of his/her financial circumstances.

This means that individuals who are paying a long stay contribution may apply for a waiver. Waivers may be granted to:

- A.** Avoid undue financial hardship on the part of the service user and/or on the part of the service user's dependant
- B.** Advance service user's identified (e.g. care plan) needs
- C.** Take account of separate contributions made by service users towards their maintenance and accommodation costs e.g. rent/kitty arrangements

Although the guidelines state "Most service users will not require any waiver in respect of financial hardship or identified needs and will pay the appropriate Standard RSSMAC rates, which are set at a level intended to provide every service user with reasonable retained income for personal use", this is still an option available to them. This is not available to people under 65 who are resident in nursing homes under the Nursing Homes Support Scheme. Such waivers are particularly relevant to this group as, given their age, they may have dependents and their care plan is essential in meeting their specific needs.

The HSE and Department of Health has advised my Office that the Residential Support Services Maintenance and Accommodation Contribution (RSSMACS) and the Nursing Homes Support Scheme are two very distinct schemes, particularly in relation to the financial contributions that are associated with each scheme. Similarly, the Department of Health stated that the NHSS and residential support services maintenance and accommodation contributions (RSSMACs) are discrete schemes with administration of each set out in guidelines, regulations and legislation, and the rules governing each are not interchangeable. However, I am of the view that the differences in these schemes suggests that individuals under 65 residents in a nursing home can potentially be at a financial disadvantage compared to those who are in residential services under a disability model of care. Again, I am of the view that this situation has arisen due to the way in which the provision of service for this group developed without a clear underlying policy and I believe it amounts to inequity, particularly for individuals who are explicitly expressing their preference to be provided a service through Disability Services, as opposed to a nursing home.



Ultimately, the majority of those under 65 in nursing homes are likely to have negligible disposable income and are thus living in extreme poverty, often depending on the generosity of others for basic items such as clothes, medicine and personal care items, with negligible access to a social or personal life outside the home.

Residential Care versus Home Care

Inequity does not just exist between those availing of residential care. One of the most glaring financial inequities faced by individuals under 65 with disabilities who require support is the provision of nursing home care on a statutory basis and the lack of a provision of home care on a statutory basis. The system is currently skewed towards residential care as opposed to home care, as is evident in the provisions of the Nursing Homes Support Scheme. Pierce et al (2018) state “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”. Fox (2013) states that there is a legislative skewing of support services towards groups as opposed to individuals and a lack of legislative provision for directing support funding towards individuals. A public consultation on home care in Ireland organised by the Institute of Public Health in Ireland (IPH, 2018) found that most of those responding agreed that home care needs to be placed on a statutory basis, with clear eligibility criteria and a guarantee of equality of access across regions.

In one of the complaints to my Office, the complainant requested that her Nursing Homes Support Scheme be used to fund home care but this is not currently possible. The Department of Health’s Sláintecare Implementation Strategy (2018) commits to the introduction of a statutory scheme for home support in 2021. The Department of Health has advised my Office that the development of the scheme has been significantly delayed by the diversion of resources in response to COVID-19. However, the Department remains committed to advancing this work as an immediate priority.

It is important to note that some individuals can access home care at present. Others have access to a personal assistant. This will be discussed further in Chapter 4. In the context of finances, given that these services are not on a statutory basis, they are usually fully funded and therefore these individuals may be in a better financial position to their contemporaries in nursing homes.

Geographical Disparities

As will be discussed in Chapter 5, for those under 65 who apply for home care and other community supports in order to avoid being admitted to a nursing home or in an attempt to be discharged, there are also further inequities in terms of finance and funding. Part of the issue seems to relate to geographical disparity. As will be discussed in Chapter 5, there is uneven access to services across different areas. Part of this relates to funding. This was an issue highlighted to us by a number of the hospitals that we met. The HSE Integrated Care Pathway for the Management of Spinal Cord Injury 2018 states, “Disability services are dependent on local services/budgets funding care packages, which can often be considerable. This local decision-making leads to significant variance in patient experience, as local managers struggle to absorb these often-time high cost packages while continuing to fund routine services”. Given that supports such as home care packages are funded at a local level, this means that accessing such services can often be impacted by how many other people in that area have disabilities and the extent of their individual needs. This means that two people with the same needs in different areas may be able to access different levels of funding. The HSE Integrated Care Pathway for the Management of Spinal Cord Injury 2018 states, “It is recommended that patients with complex needs require a centralised funding stream”. This would mean that applicants would not be disadvantaged by virtue of the fact that there were other applicants with similar high dependency needs in their geographical area.

There is not just geographical disparity in relation to accessing funding, there also seems to be geographical disparity in relation to how funding is managed locally. One hospital advised my Office that it has access to a set amount of funding each week from their CHO area for home care packages whereas this did not seem to be the experience of other hospitals.



The HSE advised my Office that in general, home support services for persons under 65 years are funded through Disability Services. Home supports can also be provided through the generic home help service, which is operated through Older People's Services. The HSE states that, with respect to those with acquired neuro-disability who require home care packages to support a discharge home, funding is sought through individual CHO budgets. If funding is not approved, there is currently no process for escalating the request for funding and the person can remain in the acute hospital setting or alternatively, will be placed in long term care.

Home care packages are provided locally within a given CHO Area and each CHO has a budget for Disability Services on an annual basis and has to plan and deliver services within its allocation in accordance with the HSE National Service Plan. The HSE states that it wants to have multi-annual funding resources in place in line with the programme for Government and it is actively planning via the 2021 Estimates Process to target the nursing home area where under 65s are concerned.

The Department of Health's Value for Money and Policy Review of Disability Services in Ireland (2012) recommended the restructuring of disability services in Ireland through personalised supports and more effective systems of resource management. The report noted that disability services' infrastructure in Ireland has developed in an ad hoc way over many years and systems of allocation of resources and accountability have evolved differently in the former Health Board Regions.



1.1 Finding

This investigation has identified systemic issues which are compounded by a fractured funding model which does not address the issues highlighted in this report in a sufficiently targeted, coherent and progressive manner. The commitment in the Programme for Government to implement a statutory home support scheme will be necessary to address the current bias in favour of institutional settings.

Recommendations

- a. A ring fenced annual budget should be allocated to each CHO Area in order to improve the quality of life of each of these individuals and to assist them in leaving nursing homes, if that is their preference, and to support and enable them to enter into more appropriate living arrangements.*
- b. The new funding model should ensure that individuals in the community retain sufficient money to allow them to lead an ordinary life.*



- c. The budget allocated to each CHO Area should be proportionate to the number of people under 65 in need of such support within the CHO's geographical area.*
- d. The business plans for each CHO Area should set appropriate targets and progress should be reported to the HSE annually, particularly in relation to the reduction in numbers in nursing homes.*
- e. A target date for the completion of this programme should be set and agreed with the Office of the Ombudsman.*

Chapter Two: Informed Consent

In this Chapter I am considering the issue of informed consent. I am examining the matter in the light of research on the topic, the position of the HSE on the issue and the experiences of the people we spoke with during this investigation.

Research

Pierce et al (2018)'s research suggests 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. Their study was based on a review of Common Summary Assessment Report (CSAR) forms that accompany applications from younger people with disabilities for the Nursing Homes Support Scheme. It found that 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 indicated 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. 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. Farrell (2013)'s research on younger people with disabilities living in nursing homes in the Bray and Greystones areas of Co. Wicklow also found that only a minority of individuals were actively involved in the decision of being admitted to a nursing home.

These studies in relation to individuals under 65 living in nursing homes are in line with Duffy's (2019) broader study on the Nursing Homes Support Scheme and whether consent for long term care was demonstrated in section 4 of the Common Summary Assessment Report (CSAR). Her study also sought to identify if the information supplied on the CSAR document is of sufficient quantity and quality for the purpose of the supporting decisions made by the local placement forum. Eight percent or fourteen applicants in this study were people under 65 applying for the Nursing Homes Support Scheme.



This study found that in 53% of the CSARs reviewed as part of the study, including those of people over 65, there was either no demonstration of will and preference or it was unclear or not possible to obtain.

The HSE's Position and Issues Arising

My Office asked the HSE if it is satisfied that all people under 65 with capacity residing in nursing homes have given informed consent for their admission. We also asked, where applicable, whether section 4 of the CSAR form had been completed correctly and had this been audited or reviewed? The HSE responded stating:

“This is generally the case. The Local Placement Forum (LPF) is a HSE-led grouping consisting of clinicians and health staff whose primary role is to determine an applicant’s need for long-term residential care under the NHSS. The LPF reviews and comments (where appropriate) on each individual application/CSAR which is submitted to the Forum. All members of the LPF are entitled to question/express an opinion and/or seek additional information for any referral, where there is a question as to the requirement for long term care or indeed whether an alternative approach may be appropriate for an individual patient. The LPF reviews each application section by section to ensure that all parts are completed, including section 4 which comprehends consent. If the application is incomplete, same is returned to the applicant for completion and will not be considered until the completed form is returned to the LPF.

The HSE is not aware of any audit of the CSAR form at this point in relation to informed consent.

The HSE is awaiting enactment of the Assisted Decision Making legislation to support the whole area of consent.”

This is not in line with the findings of Duffy's (2019) study, which raises broader questions in relation to the functioning of the Local Placement Forums. When asked if there is governance of Local Placement Forums, the HSE advised that generally, the LPFs are governed by the CHO structure, with the Chief Officer having overall responsibility. I feel that an increase in structured governance could add to greater consistency, which would ensure that the issue of consent is looked at effectively for each application that comes before the Local Placement Forum.

Related to this is the signing of nursing home contracts. Sage (2017) issued a discussion document titled 'Contract of Care for Nursing Home Residents: Issues for Policy and Practice'. Sage stated (2017, 5) "... there appears to be a somewhat casual approach to the signing of contracts of care. Anecdotal evidence indicates that contracts are frequently signed by a relative on behalf of a nursing home resident, even when the resident clearly does not lack capacity. In other instances, contracts are signed by relatives without any proper assessment of the functional capacity of the resident to agree to the terms of the contract".

The Department of Health has since advised this Office that the HSE has indicated that consent matters will be further addressed through integration within the plan to move from Local Placement Forums (LPFs) to Integrated Decision Making Forums. A mapping exercise was carried out late in 2020 in relation to the functioning of the LPFS and the issue of consent was reviewed with the membership of the forums. Arising from that, the project team for the Assisted Decision Making Act in absence of full enactment of the 2015 Act have been asked to develop an operation guidance document based on the National Consent Policy to be used as a reference guide for forum members.

Integrated Decision Making Forums are to be stood up in each CHO area for the purpose of identifying a range of pathways of care across the different care groups including Mental Health and Disability Services. These forums will support the principle of a 'Home First' approach recognising the fact that service users want to be cared for within their own homes and communities. The Department of Health states that valid consent will be embedded in every decision making process of these forums.



The Personal Experiences of Some Residents

The above raises concern that at least some individuals may not have a meaningful say in the decision to be admitted into nursing home care. This is concerning for someone of any age. This is also an experience that seems to be mirrored in the experiences of many of the individuals that my Office met as outlined below.



Mark's advocate said that he had capacity. When my Office met with them, neither the man or his advocate were sure how his placement was funded, although the advocate thought it might have been under the Nursing Homes Support Scheme. Mark just knew that money was taken from his Disability Allowance each week. Mark said that he was not in a position to be involved when the original decision was made that he would move into a nursing home. However, amongst other things, his ability to communicate has improved and he has been articulating for some time that he does not want to live in the nursing home. He does not recall filling in a form for the Nursing Homes Support Scheme. He does not feel that he is involved or consulted in relation to current decisions made about his care.



Francis said that when he was ready for discharge from hospital, he was told that he could not stay at home due to his injuries and a nursing home was proposed. He said that he was not given any other options. His needs were much higher than they are now. He told my Office that when he was admitted to the nursing home 9 years ago, he thought it would be a short term arrangement. His sister told my Office that, at the time, they did not know if the nursing home would be long term as everything was so new to them. They were coming to terms with what had happened and were "thrown in at the deep end".



Charles was living at home prior to an admission to hospital. He was discharged from hospital to a nursing home. He has been living in a nursing home for approximately two years. His mother said that they were advised to find a nursing home for Charles, as he could not return to living at home. Various options were discussed but his parents said that they were shell shocked at what was happening and felt that he had no real option other than a nursing home. His mother feels that they were rushed into a decision and they felt pressurised. Charles says that he thought he was being admitted to the nursing home as a short term measure.



Michelle is a 50-year-old woman who was admitted to a nursing home 2 years ago after spending time in hospital and the NRH due to a brain haemorrhage and stroke 4 years ago. She said that the social worker in the hospital and her family were involved in discussions about discharge from hospital. When asked, she said that she did not feel included in them. She also said that no options were discussed other than a nursing home. She said that when she was first admitted to the nursing home, she did not think it would be long term and just thought that she would have a few weeks rest there. Although she did also say that she knew what the Nursing Homes Support Scheme was for when she filled out the form.



Alex is a 39-year-old man who was in an accident 6 years ago. This resulted in a brain injury, which affects him physically. He has been living in a nursing home for the past 5 years. He is not originally from Ireland and has no family living in Ireland. He said that his brain was only functioning at about 50% when his placement was organised in the nursing home. However, he does recall making certain stipulations in relation to location. He feels that there were no other options available to him other than a nursing home. He does not want to continue living in a nursing home.



Olivia is a 49-year-old woman with a progressive neurological condition. She was living at home with personal assistance support. She went in to a nursing home for what she thought was a short period of respite and her stay ended up lasting one and a half years. She signed the form for the Nursing Homes Support Scheme but she said that she thought this was for respite only and said that no one explained otherwise to her. She also said that she had been quite unwell and was on a lot of strong medication when she signed the form.



Adam is a 51-year-old man who acquired a brain injury after a fall at home 6 years ago. He was admitted to a nursing home from hospital. He said that he thought this was for a few weeks respite. Adam does not remember being offered any other options. At the time, he was having difficulty with mobility and memory, which have since improved. He spent almost five years in the nursing home before he went home, where he is now living independently with two hours support per day, six days a week. He said that he signed the form for the Nursing Homes Support Scheme but he did not realise what he was signing and the implications. He said when he subsequently told the HSE that he never signed for a permanent stay, they advised him that he was not in a position to remember this. He said that he then asked them why he was asked to sign a form if the HSE felt that he did not have the capacity at the time to do so. An application had been made by his family to make him a ward of court but this was unsuccessful.



When **Hannah** was medically ready to go home from hospital, she could not return home as her home was not wheelchair accessible. She said that the council provided her with a bungalow but further adaptations were needed. The nursing home was newly opened and Hannah was told that it was a unit for people under 65 with spinal injuries and brain injuries. However, it transpired that it is a nursing home for older persons. She said that she moved into this unit for what she thought would be a short period of time, while the council did

the necessary adaptations to her bungalow. The bungalow was finished some time ago but she is still in the nursing home over a year later as her application for a care package has not been approved.



Daniel was living at home independently with 25 hours personal assistance support a week. His medical condition deteriorated and he was admitted to hospital. It was felt that his needs had changed and he would need additional care that would require additional funding. He attended meetings but felt that nobody was listening to him. He said that he told them he wanted to go home. Additional funding was not available, so he was told that returning home was not an option. He said that he was not offered any real options other than a nursing home.



Thomas is a man with an alcohol related brain injury. He is 50 years old. He was admitted to hospital after a fall 4 years ago and he was discharged from hospital to a nursing home. Thomas does not really remember the details of his transfer to his current accommodation, which is a dementia unit in a community hospital. He does not know what assessments were done and what they concluded in relation to what he needed. He said that he was initially transferred to the main part of the hospital as a patient and was subsequently moved to the dementia unit. He said that the main part is a hospital for older people. He does not recall being offered any other options and he said that his family are from the area and would have wanted him close to them. He said that he knew at the time that he would need support but he thought his admission to a nursing home was a step towards going home as opposed to long term.



Andrew is a 49-year-old man with both a physical and intellectual disability. He has been living in a nursing home for almost 4 years. He was living at home with his father but his father was hospitalised. Andrew then began to have falls and was also hospitalised. He spent a year in hospital. His family said that there was no residential place available in the intellectual disability service that Andrew had been attending for years. The family felt that there were no other options at the time other than a nursing home and that this was the best of a bad situation. They thought his stay in the nursing home would be short term as they were informed he was top of the waiting list for a residential place in his day service. However, he has still not been offered a place.



Fiona is 36 years old. She has both a physical and intellectual disability and she has been resident in a nursing home for two years. She was living at home with her parents and was admitted to hospital for surgery. There were complications in her condition and her medical needs changed. She was transferred to a nursing home from hospital. Her advocate said that the HSE said that this would just be for 6 weeks whilst they organised a house in the community. However, funding has not been available for a care package to support Fiona in the community.

Consent and Admission into Nursing Home Care

Not all the individuals referred to above may have been deemed to have capacity at the point when they were admitted to a nursing home. However, many of them signed the form for the Nursing Homes Support Scheme, which suggests that they were deemed to have capacity and in one case, the fact that a ward of court application failed also suggests that the man in question had capacity.

Two main issues arise in these cases. The first is that it is questionable as to whether many of the individuals that my Office met provided informed consent in relation to their admission to a nursing home. For example, some described having signed consent under the impression that the nursing home stay would be temporary, even though the NHSS is in respect of permanent residency. The second is the fact that they remain in a nursing home despite this not being their will and preference.

Consent can be viewed as the healthcare formulation of autonomy and self-determination. It evolved from the Nuremburg Code and the Declaration of Helsinki. In the Irish context, in the *Re a Ward of Court (withholding medical treatment) (No.2) [1996]* case, the Supreme Court stated:

“The requirement of consent to medical treatment is an aspect of a person’s right to bodily integrity under Article 40.3 of the Constitution”.

However, consent extends beyond medical treatment. The HSE National Healthcare Charter (2012) highlights the importance of service user participation in making informed decisions about treatment and care and the importance of giving informed consent. The HSE National Consent Policy (2019, 20) states; “Consent is the giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed intervention. Consent must be obtained before starting treatment or investigation, or providing personal or social care for a service user or involving a service user in teaching and research (all defined as ‘interventions’ for the purpose of this policy). This requirement is consistent with fundamental ethical principles, with good practice in communication and decision-making and with national health and social care policy. The need for consent is also recognised in Irish and international law....



The need for consent, and the application of the general principles in this policy, extends to all interventions conducted by or on behalf of the HSE on service users in all locations.”

Furthermore, the HSE Code of Practice for Integrated Discharge Planning (2008) states that the assessment and discharge process must be person centred. The patient’s interests and wishes should be taken into account when considering future care options.

This suggests that consent applies to the decision to be admitted into nursing home care. The accounts outlined above and the research cited makes clear that some people were not included in this decision, which is of completely unacceptable. However, in this context, issues in relation to consent are not limited to those who were not explicitly involved in this decision and related conversations. The question also arises as to whether those who were involved, provided informed consent. The HSE National Consent Policy (2019, 23) states:

“For the consent to be valid, the service user must:

- have received sufficient information in a comprehensible manner about the nature, purpose, benefits and risks of an intervention/service or research project.;
- not be acting under duress; and
- have the capacity to make the particular decision.”

Again, I feel that the accounts outlined above suggest that valid informed consent is not always obtained.

Provision of Information

Farrell (2013) found in their research that not all individuals were involved in the decision to be admitted to a nursing home and there was also a lack of clarity in relation to the length of placement.

I am concerned about the number of individuals who told my Office that when they were admitted to the nursing home, they thought their admission was short term. I am of the view that prior to agreeing to admission to a nursing home, an individual should have all the relevant information available to them, including their anticipated length of stay. I appreciate that situations change and respite may change into a longer stay but based on the number of individuals who flagged this issue, I am not convinced that this accounts for all cases. I appreciate that these individuals, in most cases, signed a form for the Nursing Homes Support Scheme and there is information available explaining that this is for long term care. However, I would query whether all individuals in question had this information in a format they understood, when they signed this form. When asked whether all individuals had been advised of the length of stay that is envisaged for them and the services that will be available to them prior to their admission to a nursing home, the HSE advised my Office: “This is generally the case. CHO Areas, as part of transitional planning, will advise individuals and their families of the Care & Placement Plan, including available services and envisaged length of stay. However, it is often the case that the specific length of stay will not be known”. However, as highlighted above, again this does not always seem to be the reality on the ground. In my view, there should be comprehensive, properly documented evidence as to the precise extent and nature of the information provided to the individual prior to admission to a nursing home. This is all the more important because these are essentially life changing decisions.

Duress

I would like to clarify that I am not suggesting that the HSE or Department of Health are explicitly placing pressure on people to go into nursing home care. However, I believe that duress can be much more insidious and this may be where the risk lies in these cases. I would argue that individuals are under duress to choose one option if there are no other options made available to them. The Council of Europe Commissioner for Human Rights (2012) has highlighted that real choice may be curtailed if people with disabilities are not aware of alternative community based options or if no services exist to make that a real option.



A number of the individuals my Office spoke to said that they were offered no other options. The only options available to them were to remain in hospital or move to a nursing home. Remaining in hospital is not a real option as acute services need to have movement so that beds are freed up for other patients. Providing extended care is not the function of these hospitals and the fact that they are sometimes used for this is problematic and can cause systemic issues in relation to capacity and effectiveness. This has been highlighted to my Office by a number of the hospitals visited as part of this investigation. Patients are often conscious of this. Charles's father explained that it was the start of the flu season and the hospital had no beds. He said that Charles was one of the few people with potential to vacate a bed and so they felt pressurised. It is also important to note at this juncture that often individuals are being asked to make life changing decisions at a time when they are extremely vulnerable following the onset of serious illness or in the aftermath of an accident or other traumatic event. In the case of an acquired injury, they may be still coming to terms with their injury. Olivia described a situation where she went into a nursing home for respite as she was acutely medically unwell. She said that she was on a lot of a strong medication when she was asked to sign the form for the Nursing Homes Support Scheme and she did not fully understand what she was signing. I have also been advised that some individuals are asked to sign this form prior to moving to another facility for rehabilitation, which can be very dispiriting.

I would like to make clear again that I am not saying that these individuals should remain in hospital and I believe that I make that clear in this report. I also fully appreciate the pressures that hospitals and acute services are under. However, I believe it is important that consent is valid consent and does not involve duress, whether explicit or more subtle.

When asked, during the investigation, whether individuals have been given any choice in terms of being advised of alternative options prior to admission, the HSE told my Office: "In addressing the needs of adults with a disability the full range of community services available are tailored to meet the needs of the individual. The health service works with local authorities, the Department of Education and Skills and other public services as well as the voluntary sector in seeking to tailor the services to best fit the needs of the individual.

It is the policy of the HSE to provide support in the person's home, but where complex care is required, this option is explored. Therefore, an admission to a nursing home is often as a last resort for a person with a disability, where all other avenues of support have been exhausted". I am far from persuaded that any other avenues were explored in respect of some of the individuals we met. The fact that the HSE turns to nursing homes so often when complex support is required means that in effect, individuals often have no other choice.

The HSE provided me with further feedback on this issue when I asked for their observations on my draft investigation report. They pointed to the additional efforts planned under the National Service Plan 2021. The HSE also highlighted the limitations imposed on them in terms of service provision due to budgetary constraints and the fact that there is no rights based entitlement to services. They also made the point that competing demands have to be met on an on-going basis but the long term reforms as set out in Sláintecare will yield improvements in the provision of health services generally.

Capacity

Capacity refers to an individual's ability to make their own decisions. Not all individuals may have capacity to make a decision in relation to their placement in a nursing home. As outlined in some cases above, although this issue may endure, for others it may be a specific issue in the immediate period after an acquired injury. For others, it is not an issue. The Assisted Decision Making (Capacity) Act (2015) acknowledges that capacity may fluctuate. The legislation has seen a shift to the broad-minded functional test for capacity, that is an issue and time specific test and it is altogether different to the all or nothing test that exists for wardship. This functional approach allows for changes in a person's capacity over time. Capacity for decision-making is defined as the ability to understand, at the time the decision is being made, the nature and consequences of the decision in the context of the available choices. It also places a legal requirement on service providers to comprehensively enable a person to make a decision through the provision of a range of supports and information appropriate to their condition.



This legislation demonstrates a seismic cultural shift away from a paternalistic and ‘best interests’ approach to a rights-based approach of choice, control and consent. However, this legislation is not yet fully commenced. Therefore, if someone is deemed not to have capacity, the formal process for making a decision for them remains the ward of court system. However, both some of the cases above and the research cited highlight that at times decisions are being made for individuals outside any formal process. Some of the CSAR forms in studies such as that of Duffy (2019) suggest that an ad hoc approach is sometimes used in this regard. This can mean that individuals may not experience a comprehensive assessment of their capacity that is consistent and informed by uniform standards. This again is of concern.

The issue of whether someone consents to being admitted to a nursing home and, as will be discussed further below, whether they consent to their ongoing admission, is not straightforward. Some individuals explicitly articulate their wish to reside somewhere other than a nursing home. Others do not articulate this.

Fox (2013) states, “Even if it can be demonstrated that people have made an informed choice about living in grouped settings, the question remains as to whether this is, at least in part, influenced by the fact that there are few alternatives available to people, especially in the absence of a legal mechanism for PWID to access state support to live in their homes”.

The Council of Europe Commissioner for Human Rights (2012) has highlighted that “Once institutionalised, given the regimented lifestyle and absence of choice, it is difficult for a person to regain the ability to use personal skills for managing a life outside the institution, including voicing their will and intentions”. Although some individuals may articulate their wish to remain in a nursing home and not live within the community, it is possible that some of this may be related to the fact that they know no other way or as the then Senator John Dolan suggested when I met with him, people may not be able to choose what they have never had a chance to taste or experience.

It has also been highlighted that that the right to choose is not limitless – for example, human rights norms do not recognise an individual’s right to choose to be a slave, to be trafficked or to undergo torture, cruel, inhuman or degrading treatment.

It has been argued that it is unrealistic to expect those with severe impairments to live in the community and that only institutions could provide the necessary level of support. The European Union Agency for Fundamental Rights (2018) suggests that part of this hesitancy is linked to the lack of appropriate community-based services for people with complex needs. Some local practitioners who are committed to deinstitutionalisation for all argued that national-level policymakers, despite their insistence that deinstitutionalisation should be possible for all, do not allocate sufficient resources for developing relevant community-based services. The European Network of Independent Living (ENIL) (2017) state “Often the decision to live in an institution is not a matter of individual preferences, but a consequence of the lack of options to choose from. When people do not have a place to live, or the institution is the only place they can get support from, they are forced to ‘choose’ to live in an institution.... People may also ‘choose’ institutional settings because they are used to them – they have spent a significant part of their life in an institution and may find it difficult to imagine a different life. Sometimes, they may not have the confidence and the skills to make decisions for themselves, as they have never been allowed to do so. People’s vision and choices can also be limited by negative community attitudes and beliefs or by the lack of information about other options. It is impossible to claim that some disabled people choose to live in an institution, as if they were on a level playing field with others. Disabled people can have a genuine choice only in a truly inclusive and accessible community, with a range of adequate and quality support options, including from peers”. This ties in with the comments above in relation to informed consent and the role of choice in this. I would like to make clear here that I am not saying that younger people cannot consent to living in a nursing home nor am I denying their right to self-determination, which I strongly support. Rather, I am saying that this is a systemic issue and that a number of factors need to be considered in terms of consent.



Ongoing Nursing Home Stay

A large percentage of the individuals that my Office met were clear and articulate in expressing the fact that they did not want to be living in a nursing home. Quite a number of them were proactively trying to change their current situation. This raises questions in relation to the idea of ‘deprivation of liberty’. This is a complex area. I am not saying that these individuals are necessarily ‘imprisoned’ but there are questions to be asked in relation to their ongoing consent to be living in a nursing home, or the lack thereof. This is further complicated by the fact that they cannot just discharge themselves, given their need for supports in alternative accommodation and the fact that these supports are not always available. A number of individuals compared their situation to being in jail. One man acquired his injury as a result of an assault. He said that he feels that the person who perpetrated this assault is spending less time in jail than him.

Article 40.4.1 of Bunreacht na hÉireann, the Constitution of Ireland, provides that ‘no citizen shall be deprived of his personal liberty save in accordance with law’. Article 3 of the United Nations’ Universal Declaration of Human Rights (1948) states that ‘everyone has the right to life, liberty and security of person’.

Article 14 of CRPD protects the right to liberty and security of persons with disabilities. In its Guidelines on Article 14 of the CRPD, the UN Committee on the Rights of Persons with Disabilities has ‘established that article 14 does not permit any exceptions whereby persons may be detained on the grounds of their actual or perceived impairment’. The right to liberty is linked to a number of other provisions in the CRPD.

Article 5(1) (e) ECHR allows for the detention of persons ‘of unsound mind’ where such detention is in accordance with the law. The European Court of Human Rights jurisprudence has focused on setting appropriate standards and safeguards to be applied in order to ensure that such a law is adequately precise and foreseeable. It is not sufficient simply to enshrine involuntary detention in statute: such legislation must comply with the principles set down by the ECHR.

The DOH (2019) Deprivation of Liberty Safeguard Proposals: Report on the Public Consultation highlights that “the terminology of article 5 of the ECHR should be considered in the context within which it was written. The ECHR was decreed by the General Assembly of the United Nations on 10 December 1948 in the aftermath of the Second World War. The aim of article 5 is that no one shall be deprived of their liberty arbitrarily”.

As highlighted in the ‘Roadmap to Ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)’, published by the Department of Justice and Equality in 2015, legislative clarity on the issue of the deprivation of liberty is required in order to ensure that Ireland meets its obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), (2006).

Various human rights treaties will be discussed in more detail in Chapter 6 on Human Rights. However, it is difficult to discuss the issue of consent without discussing scenarios where consent is not provided or is not ongoing.

In *MX v Health Service*, proceedings challenged the constitutionality of Section 57 of the Mental Health Act. Claims by a woman of unsound mind that consent procedures under mental health legislation were incompatible with the Constitution were dismissed because it was held the legislation could be constitutionally interpreted. The court also held that a mandatory court hearing was not required in every case arising under the said procedures, i.e. involuntary medication. The circumstances of the case were different to those being discussed here. However, it is relevant to note that the Court commented that the CRPD ‘can form a helpful reference point for the identification of “prevailing ideas and concepts” ’ and that ‘judicial notice is to be taken of the decisions of the European Court of Human Rights and the principles contained therein’.

On 5 December 2017 the Government approved the publication for public consultation purposes of preliminary draft Heads of Bill to form Part 13 of the Assisted Decision-Making (Capacity) (ADMC) Act, 2015. Neither the ADCM Act nor the Mental Health Act (MHA), 2001 provides procedural safeguards to ensure that people are not unlawfully deprived of their liberty in relevant facilities.



In developing the legislative proposals, the Department of Health was aiming to address this gap in the existing legislation. On 8 December 2017, the Department of Health launched a public consultation on this draft legislation. A report on the public consultation was published in 2019. This document includes some discussions that are pertinent to the issue of people under 65 in nursing homes who do not wish to reside there. For example, definitions in the proposed new Part of the ADMC Act, 2015 pertaining to the deprivation of liberty safeguards. As indicated in the Explanatory Notes, while the draft Heads do not provide a definition of the ‘deprivation of liberty’, this ‘is captured in the definition of “admission” and “admission decision”’.

‘Admission’ in relation to a ‘relevant facility’ means entry to, or residence in, a relevant facility where the relevant person will be under continuous supervision and control and will not be free to leave.

‘Admission decision’ means a relevant decision that a relevant person will live in a relevant facility where he or she will be under continuous supervision and control and will not be free to leave.

A number of respondents to the public consultation called for clarification of the meaning of the phrase ‘not be free to leave’ as well as for the definition of ‘continuous supervision and control’. This is a complex matter. Many of the people met by my Office would argue that they are not free to leave. However, this may often be because there are not supports in place to allow them to live in an alternative setting. Parker & Clements (2008, 516) state “The Strasbourg Court has emphasised that individuals may be deprived of their liberty notwithstanding (a) that they did not resist their institutional placement (particularly so where they lack sufficient capacity to give informed consent to the arrangement) and (b) that they are not ‘locked up’: that detention may exist even where there are no formal barriers. ...Whilst coercive institutionalisation may not always constitute a deprivation of liberty for the purposes of Article 5, Article 8 jurisprudence will be relevant to all restrictions placed on individual liberty: particularly to restrictions on social interaction, the ability to establish and develop relationships, educational and other personal opportunities as well as those that impair an individual’s ‘physical or psychological wellbeing’”.

Other individuals my Office met said that they are explicitly not allowed to leave their nursing home. This issue has also been highlighted further during the Covid

19 pandemic. Individuals have been told that they cannot leave the nursing home for even short periods of time as they may then pose a risk to other residents, particularly if they are sharing a room. This of course makes sense from a public health point of view. However, the ramifications of this must also be considered from the point of view of the right of individuals to self-determination and their right to make decisions about their own lives. This is a complex area, which I cannot explore in full here. My overall point is that the reality is that not all the individuals my Office have met with are truly free to leave their nursing home.

In *AC v HSE*, on 2 July 2018 the Court of Appeal found that Cork University Hospital acted unlawfully in 2016 by preventing an elderly woman with dementia from leaving, notwithstanding the hospital's concern that discharging her was not in her best interests. The ruling stems from the fact that, although the clinical consensus was that the woman did not have the capacity to make a decision to go home, there is currently no statutory or common law power which would enable the hospital to detain a patient in such circumstances. This case subsequently went to the Supreme Court. The central aim of the court was to explore the lawfulness of the procedures under which an individual could be kept in a hospital or nursing home and made a 'ward of court'. The Supreme Court held that under the doctrine of necessity a hospital had the right to lawfully detain a person briefly in circumstances where there was a concern that the patient would be put at risk if they were discharged, but that right is only temporary while further investigations are made. The Court set out the procedure to be followed in circumstances such as *AC's*. The Irish Human Rights and Equality Commission acted as *amicus curiae* in the case. Emily Logan, the then Chief Commissioner of the Irish Human Rights and Equality Commission stated:

"The outcome of this case has significant implications for the rights and protections afforded to people whose ability to make significant life decisions may be questioned, including their right to have their voices heard and to be afforded the dignity of being consulted on decisions which impact their lives."

This case asserts in Irish law, the rights of individuals to be involved in decisions about their own lives. I believe this should extend to their living arrangements and well beyond.



2.1 Finding

The personal experiences of a number of people who were interviewed during this investigation give rise to a concern as to whether they fully understood the long term consequences of moving to a nursing home and those of entering the Fair Deal Scheme. This gives rise to the need for safeguards to be put in place to ensure that all individuals under 65 (and indeed all other applicants as well) who move into nursing homes and/or enter into the Fair Deal Scheme are giving fully informed consent in each and every case.

2.1 Recommendations

- a. *The HSE, in conjunction with the Department of Health, should draw up strict procedural guidelines for staff involved in processing Fair Deal applications and CSAR forms with the aim of ensuring that fully informed consent is provided and documented in each and every case.*

Further guidance should also be provided for Local Placement Forums/Integrated Decision Making Forums in view of their important oversight role.

- b. While the Assisted Decision Making Act is not fully commenced the principles enshrined in that legislation should be used to underpin the guidelines.*
- c. An audit system should be put in place to ensure that adherence to the guidelines is monitored and appropriate follow up action taken in light of any adverse audit findings.*



Chapter Three: Quality of Life

At the core of any investigation I conduct, I pose two basic questions. Firstly, is there credible evidence to suggest that people have not been treated properly or fairly by the public service provider in question and, if this turns out to be the case, I need to consider the extent and nature of the adverse affect suffered by those people as a consequence.

It is difficult to discuss the adverse effects of someone under 65 being admitted into a nursing home without considering their “quality of life”. There are many discussions on the definition of quality of life but for the purpose of this investigation, I intend adopting quite a basic definition. The Oxford English Dictionary defines quality of life as “the level of health, comfort and happiness that a particular person or group has”. The World Health Organisation defines quality of life as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. The latter definition is important as it focuses on the individual’s own perception of their circumstances.

Having researched the issue of people under 65 in nursing homes, having spoken to individuals in this situation and having met with various advocacy bodies, I am of the view that much of the adverse effect of the placement of people under 65 in nursing homes is closely linked to a reduction in their quality of life. I will discuss some broader issues related to quality of life, such as finances and access to services in more detail in other chapters. However, my intention here is to focus on the day to day lives of the individuals in question.

I would like to reiterate again at this point that this investigation is not looking at the care provided by individual nursing homes or the overall concept of nursing homes as a model of care. I am by no means suggesting that residing in a nursing home universally equates to a poor quality of life. Various HIQA inspections of private nursing homes clearly show that this is not the case for the majority of residents. Rather, I am suggesting that the quality of life of a younger person can be impacted by the appropriateness of their placement in a nursing home.

My concerns in this regard are mirrored in various studies on this issue. Kane (2001) states; “More than a quarter of a century ago, Elaine Brody likened the one-size-fits-all nursing home to the Procrustean bed of the myth; victims were chopped or stretched to fit the bed (Brody 1973). This metaphor is still apt.”

The issue is whether a nursing home for older people appropriately meets the needs of those under the age of 65 or whether they are “stretched to fit the bed”. Wiener & Sullivan (1995) state that, in the past, the goals for long term care were to keep older people safe, clean and well fed. Advocates for younger people argue that these goals are far too limited.



The Personal Experiences of Residents Under 65

I will start this chapter by relaying the experiences of individuals that my Office met with and I will then put this in the context of broader discussion in this area. I believe some of these individuals' accounts of their daily lives are a clear reflection of some of the serious issues that arise in terms of quality of life. These are individuals who each have their own personality, their own history and their own hopes and dreams. Their disability or illness does not take from this. It does not define who they are. They have hopes, wishes and preferences like we all do. As President Mc Aleese so clearly articulated at the opening of the Independent Living Conference in Croke Park on the 5 June 2007: " So many lives are only half-lived through lack of opportunity, lack of choice, too many obstacles, too little help, too much of that lazy old thinking which used to say things like – you can't do that because you are a woman, you can't do that because you are in a wheelchair, you can't do that because you are blind, you can't because...What awful arrogance to dare impose restrictions on the life chances of another human being and what a waste of talents and skills it can lead to – for the individual, for his or her family and for all of us as a community".



Mark has repeatedly expressed his wish to move from the nursing home. Prior to his stroke, he was extremely active. He owned his own company and in the past he performed music on large world stages accompanying well known singers. He has done many parachute jumps and he has continued with these, even since his stroke. He still shaves his head every year in order to raise money for charity. He told us that there are no activities in the nursing home geared towards younger people. Although he attends a day centre, he expressed frustration with the repetition in his days. He said that he has no choice in relation to what time he eats meals or gets up and goes to bed. He can have visitors but they must ring the bell and he can leave the nursing home but he must inform staff where he is going. He informed my Office that when a recent election took place, he had not been told about the election and he was never informed that his voting card had arrived at the nursing home and he was not

facilitated to vote. Mark said that when he has made complaints about his situation in the past, he was told that staff could not understand him due to his speech impairment.



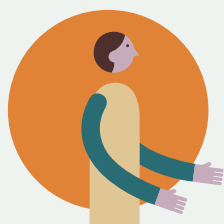
Francis said that when he was initially admitted to the nursing home 9 years ago, he was still coming to terms with his injuries. However, over time he has become increasingly frustrated and disheartened with his living arrangements. He said that there is only one other younger person living in the nursing home and they are not friendly. He said that he is very bored and there are no activities in the nursing home aimed towards younger people. He was extremely active in the community prior to his accident. He played sport and was involved in various committees. He was a good support for all his neighbours. His advocate told us that his mental health has suffered as a result of his current circumstances and she recounted one occasion where a family member went to visit him and found him sitting in a circle with a group of residents with them sleeping and him crying. After his morning shower, he spends most of his day in his room. Francis's advocate highlighted that many resources are put into keeping people like Francis alive when they are critically unwell and there is a fight to save their life. She said that it does not then make sense not putting resources in when they are in Francis's current situation and not helping them to live the life they have as best they can. She felt that the person at the heart of the issue is forgotten about.



Liam said that the nursing home is not currently wired for internet access and there were also some problems accessing television in the bedrooms. He said that he was an extremely active person prior to his diagnosis and his room was full of photos of him taken during various travels and activities. He also loved sports. Since being admitted to the nursing home, he started swimming again but this stopped as he did not feel he could afford it. Liam said that he would like to do further studying but he explained that dementia is part of



his condition and he does not know how fast it will progress and whether he would be able to complete any studying he started. He has previous third level qualifications. He said that there are activities such as bingo in the nursing home but he does not attend these. He said that there were no specific activities for younger people. During conversation, Liam commented that he has no fear of dying but he wants to live his best possible life and doesn't feel that he is doing so in nursing home. He said that currently, his room is his world.



Oliver is a 62 year old man. He suffered a serious spinal injury after a fall 9 years ago. He has been living in a nursing home since his discharge from hospital. He said that no one wants to live in a nursing home but he makes the most of it that he can. He has put a lot of effort into decorating his room in the nursing home. Oliver said that he can come and go from the nursing home as he wishes, once he tells staff and abides by certain regulations such as keeping his phone on him and not drinking alcohol when unaccompanied. He said that he does his own shopping, goes to the lake or wanders down town. He bought himself a wheelchair van and his carer or friends drive him places. He feels that he has freedom in this regard as he can leave the nursing home whenever he wants – once staff know where he is. He is on the resident's committee of the nursing home and tries to address any issues through this forum. The nursing home are currently giving consideration to getting a nursing home dog and he is enthusiastic about this. Oliver stated that he tries to make the best of his life. However, he still has bad days and has contemplated suicide at times. He would prefer to be living in a house in the community and he still constantly thinks of being able to walk again.



Alex told us that the nursing home has no activities aimed towards younger residents. He has 10 PA hours per week and attends a day centre twice a week. He said that aside from this, he spends a lot of his time on his iPad with his earphones in. He said that officially the nursing home has Wi-Fi. However, he

described it as a struggle and said that it tends to come and go. His friends visit him every two or three weeks. He informed my Office that within the nursing home, he mainly talks to staff, as opposed to other residents. He said that residents in the nursing home do die and a few people he was friendly with have died. His old room shared a wall with the oratory and he said that at one stage, there were three deaths in one week. Alex said that he would like to move out of the nursing home. He said that he is not interested in moving to somewhere similar with younger people. He said that just because people are the same age and have a disability does not mean they have anything in common and should be pushed together. He said he would like to be able to choose who he lives with – as most people do, such as housemates. He said that when he came into the nursing home, he did not think it would be for life. He said that if he thought it was for life, he would drive his chair off a bridge. He is not happy with his life as it currently is. He feels he is just vegetating. He said that he is trying to study a bit on line, as ideally he would like to work and have a meaningful life.



Mary is 66 years old and she has a physical disability. She was admitted to emergency respite due to domestic abuse and her deteriorating medical condition. She moved from respite to a nursing home and has been resident in a nursing home for a number of years. A member of Mary's family visit her every week but they do not have wheelchair accessible transport and so they cannot bring her out of the nursing home. She said that she misses doing simple things like doing a grocery shop once a week. She was attending a day centre but has largely stopped going as the long drive leaves her in discomfort.



Adam is a 51 year old man who acquired a brain injury after a fall at home 6 years ago. He was admitted to a nursing home from hospital and he spent almost 5 years there before returning home. Whilst in the nursing home Adam had 6 hours of rehabilitative assistant support per week and his RA brought him out of the nursing home. However, he said that apart from this, he did



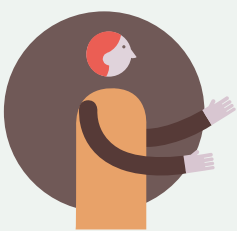
not leave the nursing home. He said that there were not many activities in the nursing home as many of the residents had dementia and were not able to engage in them. Neither Adam nor his advocate felt that Adam received rehabilitative support from the nursing home. Adam now lives at home with 2 hours support six days per week, which is funded by the HSE. He is much more active now. He likes walking and he attends mass regularly. He said that his friends have started visiting him again. He also hopes to start swimming again. His advocate said that he has noticed a big change in Adam and he has become more sociable and is taking more pride in his appearance. Adam is starting to take charge of his own affairs and he described himself as being much happier.



Hannah *has been living in a nursing home for over a year. She has a council house, which she visits once a week. Aside from this, she rarely leaves the nursing home. She eats her meals by herself in her room as she finds it difficult to be in the communal dining room with some of the older residents. She described herself as having no social outlets. She said that there are not many activities in the nursing home as the residents there are too old to even engage in activities like bingo. She said that they had flower arranging the previous week but this involved watching someone flower arranging as opposed to participating. She tries to go out to get her hair cut. She is very careful about her appearance and told us that the hairdresser in the nursing home gives everyone the same haircut. Hannah said that the other residents treat her like a member of staff. She also said that she has a good relationship with staff, which is the only thing that keeps her sane. She said that her days are extremely long. She said that if she talks to another resident, they often do not remember the conversation the next day. She said that living in the nursing home gets her down. Hannah has no PA support although she said that she would like some in order to get out of the nursing home more. Her advocate said that they are impossible to get in their area.*



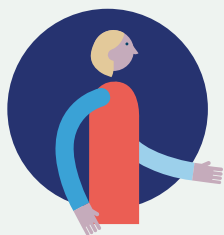
Daniel retained 4 hours personal assistance support a week when he entered the nursing home. He also continued to attend his disability day service two or three times a week. He travels there himself using public transport. This was only facilitated after he told the nursing home himself that he had a powerchair at home and he insisted that he should have access to this. He also arranged for his computers to be brought in from home and this helps keep him occupied. He said that the activities in the nursing home are geared towards the general population. However, he does engage in a number of these activities. Daniel has a long term girlfriend but she does not visit him in the nursing home as she finds it difficult. Even if she did, there is not really anywhere private for them to sit. Daniel shares a bedroom with two other men and even when my Office met him, it was difficult to find a private space to talk in the nursing home. Daniel has relative freedom in terms of coming and going from the nursing home. Daniel is quite torn in relation to living in the nursing home. On one hand, he wants to return home. However, he said when he was living at home he was very isolated when carers were not there.



Max is a 40 year old man who acquired a brain injury in an accident 9 years ago. He spent two periods of time living in a nursing home. He was there for over a year and a half on his second stay when he was 33 years old. His family stated that whilst he was in the nursing home, he spent all day in his room. His family tried to bring him out when they could but they felt that he had no lease of life and it was like he was in prison. His family felt that the nursing home did not work on his independence and curtailed him a lot. They did not feel that the nursing home had enough experience with brain injuries. Max did not want to be labelled as disabled and did not leave his room as he did not want to see older people. He would not eat in the dining room as he didn't want to watch older people eating. His family said that he didn't want people to visit him in nursing home and see where he was. His family felt that there were no activities for Max in the nursing home. There was no Wi-Fi cover in one home and poor coverage in another. Eventually with the intervention of an advocate, Max was transferred to an acquired brain injury rehabilitation unit and he was discharged back to the community from there, where he is still



living with supports. Since moving into the community, his independence has improved and he is doing his own shopping and cooking his own meals. His family felt that he is much happier than when he was in nursing home and that his happiness continues to grow. They felt that he is consistently improving and that this confirms his rehabilitation potential. They also felt that he is much more positive. For example, he is now walking everyday whereas in the nursing home he didn't want to.



Thomas said that although the staff in the nursing home are excellent, he feels very constricted. He is living in a dementia unit for older persons, which is a locked unit. He said that he spends most of his time sitting in a room by himself watching television. He said that this is a lonely existence although there are lots of people around. He said that if staff have time they will chat to him but they don't generally have time. He said that he finds himself going to bed in the afternoon to pass time, which is not like him. He said that generally he spends his time in the nursing home sleeping or watching television. He said that there are no activities in the nursing home. He said the residents in the dementia unit would not be able to take advantage of them. He said that conversation in the unit is nil. He said that he finds it heart rending to have a conversation with someone and shortly after they have no recollection of the conversation. He said that residents often talk about family members who are long deceased. He said that due to their dementia, a number of residents scream during the night. He appreciates that they cannot help this but he said it is very distressing and distracting. He said that it also means staff are passing by his room at night calling to various residents. He said that it is difficult hearing people in pain. He attends a day centre twice a week and he enjoys socialising with other young people. He also attends a social farming programme once a week and he enjoys this. He said that he does not like having people visit him in the unit as he doesn't want to invade the privacy of other residents by letting people who may be local see them as they now are. He said that this adds to his isolation. He said that staff in the nursing home see that it is not an appropriate placement for him but their hands are tied. He described it as depressing. He said that he is outgoing and active and yet he is sitting around. He said that he is starting to

get angry with his situation. He said that he tries to view the nursing home as “a stepping stone back to reality”. However, he feels like his current situation is very “jail like”. Although staff are very good, they are not trained for his specific needs. Thomas felt that there is damage being done to him by being in nursing home – e.g. the fact that he is starting to spend more time in bed. Thomas felt that he has potential to do much more with his life. Thomas said that he feels that he is in a position where he does not feel he has authority to say no to anything. He said that he feels like he has to go where he is told and that he is like a “puppy on a lead”. He said that he finds that as he continues to lack in independence, his motivation continues to decline.



Emma is a 45 year old woman. Following an illness, she developed a spinal injury 13 years ago. She spent time in an acute hospital and the National Rehabilitation Hospital, before being discharged to a nursing home. Emma told my Office that she was “devastated” the first day that she went in to the nursing home. She spoke about how difficult it was sitting in the dining room surrounded by people, who would or could not talk. She said when she was there a while longer, she found herself feeding another resident as all the staff were busy. Sometimes she felt more like a staff member than a resident and the staff are the only people in the nursing home that she really talked to. Emma said that initially she became too complacent and was allowing the nursing home to help her with too much. She is since more proactive in terms of dressing herself, doing exercise etc. Emma has returned to the job she had prior to her spinal injury and she goes to work from the nursing home three days a week. The HSE fund her transport to and from work. Emma enjoys work. When she first returned, she felt that she didn’t fit in as everyone was discussing their lives outside work and she had nothing to discuss. She said she felt “inadequate” and like an “imposter”. However, she said she is more comfortable now. She loves work as it means she gets out of the nursing home. In the nursing home, she tries to keep herself busy by doing things like her laundry. She has very supportive friends and she goes out with them. She is also currently in a relationship. She spoke about the embarrassment of telling people she lives in a nursing home, particularly when starting a new relationship. Emma



said that she can come and go from the nursing home as she wants but still has to let them know her plans. Emma highlighted that the nursing home is in quite an isolated location. She said that she can't even go out by herself to get a newspaper or a pint of milk. She said that she also can't access public transport from the nursing home. She said that this isolation can impact on her mental health. Emma said that there are no activities in the nursing home geared towards younger people. She said that when she first moved in to the nursing home, she wanted to belong as she thought it would have to be her home and she attended some of the activities for older people. However, she does not attend them anymore. She said that almost all the rest of the residents of the nursing home are older than her or, if younger, they have complex brain injuries. She said that there is another resident of a similar age but they have other issues and they do not have anything in common. She said that living in the nursing home as a younger person can be isolating. She also spoke about the noise in the nursing home, such as from other residents at night and sharing a dining room with older people. She said that she feels bad but sometimes this is all very difficult to face.



Leah's mother spends most of her time in the nursing home with Leah due to her complex needs. Leah does not leave her bedroom at all. She eats all her meals in her room. Some of the doorways in the nursing home are too narrow for her wheelchair and so there are whole areas that she can't access even if she was using her wheelchair. She is also currently having problems with her wheelchair. She is unable to attend any activities in the nursing home. She has 3 PA hours support a week but they are limited in what they can do as she cannot leave her room. Her mother would like to bring her home but their home is not accessible.

I would like to highlight at this juncture that my Office met all of these individuals prior to the COVID 19 pandemic. As has been widely covered in the media, the experience of all individuals living in a nursing home has been strongly impacted by the pandemic. This has particularly been the case in terms of quality of life. This is not the appropriate place to discuss the impact of the pandemic on nursing home residents. This is being addressed in various other forums. However, my Office has maintained contact with a large number of these individuals. In terms of quality of life, they have reported that their isolation has further increased and many of them have been confined to their rooms for lengthy periods of time. Those who did have access to day services or spent time outside the nursing home have been unable to avail of this. Many individuals have reported feeling isolated, depressed and frustrated. I feel that it is important to note how the pandemic has highlighted and possibly magnified some of my concerns in relation to the quality of life of these individuals.

Literature and research in this area has outlined a number of ways in which nursing homes may not meet the needs of younger persons and may therefore lead to adverse effect in this regard and a reduction in quality of life. These findings are in keeping with the experiences outlined above.

Focus of Care

Hay & Chaudbury (2013) state that previous literature on younger residents in long term care facilities suggests that this group's distinctive needs are not taken into consideration, as the care services and activity programs are typically planned and designed for the older and more impaired population. O'Reilly and Pryor (2002) query whether aged care is in contradiction to rehabilitative care and the Report of the Senate Standing Committee on Community Affairs, Australia (2015) also identified similar concerns in relation to the inappropriateness of residential aged care for younger persons. The Committee received evidence that younger residents may have inadequate access to rehabilitation.



Acquired Brain Injury Ireland (2017) suggest that nursing homes in Ireland are largely designed for older people and are not equipped to support a rehabilitation programme for a younger person with an ABI or as somewhere for them to live long term. Similarly, Farrell (2013) states that the nursing home setting, strongly influenced by the medical and care models, is designed to provide nursing care for frail elderly people at the later stages of life, and not designed for younger people with disabilities, with an independence-enhancing perspective or focus on slow-stream rehabilitation, with a view to moving on. This issue will be discussed further in Chapter 4. However, I think it is also important to note this issue when discussing quality of life. One of the original complaints to my Office came from a 50 year old woman with a diagnosis of a progressive neurological condition. For 36 months prior to her complaint to this Office, she had been requesting discharge from a nursing home. She felt that this setting was inappropriate at every level for her and was having a highly negative impact on her health and general mental wellbeing. She wanted to live independently in the community and she also wanted to work. She was told that funding was not available to finance the supports she would require to live independently in the community. This complaint is closed at present as she agreed to transfer to a nursing home with rehabilitative facilities. Her plan was to avail of these and then apply for independent living. Prior to this, she had been receiving no rehabilitative services and no input to assist her in progressing towards her goal of living independently and working. She is aware that it is open to her to come back to my Office in the future.

Staff training

There is a range of international research on this topic, which I feel is nonetheless applicable to the Irish situation. In the research of Cameron et al (2001), the majority of care facilities questioned indicated that they had inadequate numbers of staff to meet the care needs of people under 65 with ABI and that staff training was not adequate. They found that few facilities reported problems in providing physical care to clients with ABI, however the social, cognitive and rehabilitation aspects of care were often unmet in facilities where staffing levels, training and funding resources were reported as being inadequate.

The most frequently reported difficulties in providing care were related to challenging behaviour, emotions/ moods of resident, communicating with resident and providing supervision. The majority of respondents reported that the client group of interest had different needs to other residents and experienced difficulties living in an aged care setting. I would think that this must not only be difficult for younger residents but also for staff.

Hay & Chaudbury (2013) similarly refer to inadequacy of staff training for meeting the particular needs of younger residents and Winkler et al (2016) spoke about the cognitive and communication impairments experienced by people with severe ABI and how staff in more appropriate services had more time to encourage interactions with participants as well as the skills to facilitate both verbal and non-verbal communication for the person with disability to make everyday choices.

This relates to the above discussion in relation to the focus of care and is reflected in a number of conversations my Office had with younger people with acquired brain injuries and their families. They mentioned that they did not feel that staff had the necessary skills to assist them with improving their skills and that they were not pushed to progress themselves.

This issue extends beyond acquired brain injury and is equally applicable to intellectual disability, physical disability and various medical conditions. When my Office held a workshop for advocacy bodies, as part of this investigation, someone suggested that staff, family members and individuals with rare conditions themselves may not be aware of the specific care or treatment they require or should/could be able to access. Often people with rare conditions receive the same care/treatment that people with more common conditions receive. In terms of intellectual disability, the very fact that there is a specific BSc Nursing (Intellectual Disability) programme highlights the specialist nursing needs of these individuals. This can also be said of the variety of other specific needs they may have, as opposed to the more standard residents of nursing homes. Some of these may be related to their disability or as highlighted elsewhere in this chapter, often they are needs that are specific to anyone of their age.



When asked about this the HSE advised: “the suitability of staff for their roles forms part of recruitment and employment processes specific to each provider and must comply with regulations set out in the Health Act 2007. In Private Nursing Homes, staff education and training is the responsibility of the employer, so not all Nursing Homes would be proficient in the delivery of care for a younger cohort and be able to respond to specific needs such as neurological conditions. However, placements that are governed by a Service Arrangement would require the service to undertake training needs analysis to ensure that the needs of the person can be appropriately met”. However, although some nursing homes may have specialist units, the majority do not and younger residents are by far in the minority. Almost all the individuals that my Office met with advised that they were the only young person in the nursing home or that there were only one or two others. Obviously then, and perhaps understandably, when recruiting staff, the main focus of the nursing home will be to source staff who are skilled in the care of older people. This again has potential impact on the quality of life of younger residents.

Related to this is the ‘Statement of Purpose’ of the nursing home. The Statement of Purpose is required in order to register or renew the registration of a designated centre. The regulations under the Health Act 2007 (as amended) require providers to compile a written Statement of Purpose for designated centres and to submit it as part of the registration process. It provides as follows:

- Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013
- Health Act 2007 (Registration of Designated Centres for Older People) Regulations 2015

A registered provider must, at all times, operate strictly in accordance with the Statement of Purpose. The Statement of Purpose describes the purpose and function of a designated centre. HIQA (2018) states that the statement of purpose should:

- clearly describe care and support needs that the service intends to meet
- set out the range of services and supporting facilities to be provided at the designated centre in order to meet the residents care and support needs

- clearly define the admission criteria to the designated centre
- describe the management and staffing arrangements in place to meet the residents' care and support needs
- ensure that people who use the service, prospective residents and other key stakeholders understand:
 - the range of services being provided and how these are delivered to meet the residents' requirements.

Amongst other things, the provider is required to set out the specific care needs that the designated centre is intended to meet. The provider should indicate the age range of the residents for whom it is intended that accommodation be provided.

As this is not an investigation into private nursing homes, my Office did not request statements of purpose from individual nursing homes. However, it is our understanding that there seems to be no onus in a statement of purpose to demonstrate exactly how the nursing home can provide an appropriate service to this specific age group.

Regulation

Regulation of designated centres plays an important role in monitoring the quality of life of residents. In Ireland, HIQA has responsibility for the regulation of designated centres. HIQA has National Standards for Residential Care Settings for Older People in Ireland (2016). It also has National Standards for Residential Services for Children and Adults with Disabilities (2013). People under 65 with disabilities living in nursing homes fall under the former standards, despite the reference in the title to 'older people'. There are many similarities between these sets of standards. However, there are also some subtle differences. This includes simple things like mention of employment & education in the National Standards for Residential Services for Children and Adults with Disabilities as opposed to the National Standards for Residential Care Settings for Older People in Ireland. HIQA itself has identified that the current system of regulation can be problematic, as compared to other jurisdictions.



In its document exploring the regulation of health and social care services, HIQA (2017) stated:

“The examples of how other regulators define services shows that the majority follow a model of registering and or certifying the service provider as opposed to the physical location at which the service is provided. This approach offers a number of advantages:

1. It provides clarity to service users, providers and regulators.
2. Separate regulations can be tailored to the service model.
3. Service providers can be more flexible and innovative. For example, they could accommodate service users with different support needs in the same setting.
4. Administration would be reduced, both for the service provider and the regulator.”

It would seem that if younger people are in nursing homes, that this would be a more appropriate model of regulation. HIQA has flagged (2017) that in order to move from an establishment to a service model of registration, a number of steps would need to be taken. Firstly, the sections dealing with registration in the Health Act 2007 would need to be revised. In addition, the sections dealing with enforcement would also require review as the focus of an enforcement action would be on the service provider and not the designated centre. Secondly, the Department of Health and or the Government would need to consider what service and or activities it wishes to regulate, that is to say, as ‘regulated activities’.

In 2019, HIQA stated “... In the years ahead, we will also be increasing our focus on the provision of age-appropriate community-based activities for younger residents who have found themselves living in a nursing home due to the lack of more appropriate care placements for them. “ However, the focus is still very much on the standards as they currently stand.

HIQA has advocated for a move to a service model of registration and I would support this, with the hope that it would lead to a more person centred, human rights based approach to regulation and one which would better meet the needs of this younger group. It should also provide more scope for the regulation of appropriateness of placement.

The Department of Health states that it is currently reviewing the regulatory framework with the aim of enhancing the oversight and regulation of nursing homes at both primary and secondary legislation level. In January 2021, the Government approved the inclusion of a Health (Amendment) Bill 2021 on its spring legislative agenda. It is anticipated that a consultation process will be undertaken before the summer on a number of proposals before seeking Government approval to draft a General Scheme on a Bill. A scoping exercise for a wider root and branch review of the legislation will be undertaken later this year with a view to commencing the review in 2022.

Autonomy

Autonomy is an important element of quality of life. Winkler et al (2016) outline that evidence in the developmental disability field demonstrates that enhancing personal control in everyday life through choice making is associated with improved quality of life, greater independence and a sense of personal dignity.

In Winkler et al (2007)'s sample study, many people in the sample had very limited opportunity to make everyday choices such as the time they go to bed or the content of their meal and the majority had lost several valued life roles such as friend, caregiver, worker and home maintainer. Similarly, Hay & Chaudbury (2013) discuss an over structured environment with lack of individual freedom over various issues, such as the desire to sleep in, stay out late, take a shower, or manage their money independently. Many of the individuals under 65 residing in nursing homes who were visited by my Office did have choices in relation to things like bed times. However, this was not universal and some who required assistance getting in and an out of bed described having their bed times set by the nursing home. This was dictated by the routine of the nursing home, which as discussed in Chapter 6, can be viewed as a form of institutionalisation.



People recounted that meal times were generally at set times although some individuals had the option of eating in their room as opposed to the dining room if they so wished. Farrell (2013) highlighted in her study that many residents shared a bedroom with people they didn't choose and again, this arose in the meetings that my Office held with individuals. One woman spoke at length about her frustrations in this regard. As a grown woman, she had to share a set of drawers with someone she did not know. Farrell (2013) also states that while a few residents in her sample study had a fridge or kettle in their bedroom, none had the facility to make a simple meal, look after their clothes or do other household chores. In essence, they could not exercise ordinary independence, regardless of whether they were able or interested in doing so. One of the individuals my Office met with spoke about the joy she has had from the nursing home arranging for her to have her own washing machine to do her own washing. However, this was unusual and some individuals spoke about not being able to prepare a meal or do food shopping. Winkler et al (2016) stated, "Participants were strong in their opinion regarding the lack of choice and taste in the food provided previously in RAC. For some, this was a key reason for wanting to move out. Both participants and families reported increased choice and control related to meals in SSA, when compared with RAC. After moving out of RAC, many participants found much joy in being able to choose what they would eat, and plan meals with the other residents".

Some individuals could come and go from the nursing homes as they wished. However, they had to advise staff where they were going and they had to be contactable by phone. Others were risk assessed and had to be accompanied by a member of staff. Others described having to pay for an escort if they were leaving the nursing home. Farrell (2013) found in her study that while some of the independent residents could 'come and go as they pleased', no one had a key or access to the door code.

Living in any form of communal living can mean a reduction in personal space. This is something that was flagged by a number of individuals that my Office met with. One woman spoke at length about how difficult she found sharing a room in the nursing home. One element of this was her lack of choice in relation to who she shared with. One man pointed out that generally, people get to pick their own housemates but this right often seems to be negated for people with disabilities.

Individuals often equated a lack of personal space with a lack of privacy.

Overall, both the research reviewed and my Office's visits to people under 65 in nursing homes suggest that they have a significantly reduced level of autonomy in their lives to individuals living in the community. This applies not just to decisions such as where to live and whether to work, but also to even more day to day decisions, such as what time to eat and what to eat. The subject of risk is also relevant here. Nursing homes obviously have to be concerned about risk and by their very nature must be risk averse. However, the question arises as to how this is balanced with the autonomy of individuals. This is something that has become more relevant in the recent pandemic.

Social programmes/recreational activities

The 'Who Cares' investigation carried out by my predecessor, Emily O'Reilly suggested that in practice, the range of services covered by the NHSS is quite narrow and excludes many elements which, on the face of it, are services which one would expect to be included as part of long term nursing home care. She highlighted that the NTPF agreement with the nursing homes specifically excludes some fundamental care elements such as social programmes. This investigation brings this a step forward and identifies that even when social programmes are provided, they often do not meet the needs of this specific group of people.

Weingarden & Graham (1992) say that "Although some similarities may exist in nursing care needs, psychosocial needs differ greatly. Most nursing homes do not have the recreational programs that will meet the needs of both groups". Hay & Chaudbury (2013) found that planned activities were generally seen as being more targeted toward the older, cognitively impaired adult population, and not toward the younger residents. O'Reilly and Pryor (2002) suggest that nursing homes have a lack of age appropriate activities for younger people with acquired brain injuries. In Winkler et al (2007)'s sample study, many younger people did not participate in activities organised by the residential age care facility. In an Irish context, Farrell (2013) states that there is huge dependence on the nursing home facility to provide stimulation 24/7, in what is an institutional setting designed for elderly, frail people and activities are usually geared towards older people.



HIQA completed a recent inspection of one of the nursing homes where one of the individuals my Office met lives. HIQA commented “Activity provision for younger residents and for residents with high dependency needs were limited and required review.... Activities provided in the centre were not age appropriate to these younger residents”. This was the experience of many of the individuals that my Office met with. Few of them participated in organised activities within the nursing, although as mentioned in Chapter 1, they were still paying for them.

Some individuals my Office met with discussed access to technology such as the internet. They described how they use technology such as computers and music to ease their boredom. Some individuals mentioned difficulty accessing the internet. HIQA in a recent inspection report on a nursing home commented “There was limited access to Wi-Fi in bedrooms and the provider confirmed that residents regularly sat on the corridor to use the Internet. One younger resident who largely depended on the Internet to meet their recreational needs, was using the Internet on the corridor as the signal in their bedroom was poor”. In this report, HIQA included activities not being age appropriate as a factor in how quality of life of residents was adversely impacted.

The HSE advised my Office that Designated Centres (both Public & Private/Voluntary) are required to have appropriate choices of activities in place (within reason) to address the expressed wishes of the individual service user. In relation to under 65’s in nursing homes, the HSE said that it would generally adopt a “Person Centred Planning” approach for each individual. This would normally ensure that service users have engaged time in purposeful, meaningful activities that are age appropriate. However, this is not reflected in the experiences of the individuals who my Office met. The discussion above is in relation to programmes provided within the nursing homes. Day services and meaningful activities will be discussed further in Chapter 4. These are also extremely important in terms of quality of life.

Access to Peers

O’Reilly and Pryor (2002) suggest that younger people with acquired brain injury who reside in nursing homes have fewer opportunities for interaction with people of

a similar age. Winkler et al (2007) state that many people in their study sample were effectively excluded from participation in community life. Many participants never participated in community-based activities such as shopping, recreation or leisure. Similarly, The Report of the Senate Standing Committee on Community Affairs, Australia (2015) refers to difficulties in participating in education, employment and social and recreational activities. Occupational deprivation occurred when an individual was excluded from the everyday activities of life including social isolation. They discussed a lack of involvement in basic tasks and inappropriate activities and poor community engagement.

This is reflected in the accounts provided by those individuals that my Office met with. Many spoke about rarely leaving the nursing home and a number of individuals spoke about the difficulties they felt about living with an older age cohort. Some spoke about guilt in articulating this but spoke about some of the practicalities of living with people with conditions such as dementia.

Hay & Chaudbury (2013) and Cameron (2001) both refer to these concerns about living with residents who are frail, terminally ill or dying or as Dwyer et al (2019) refer to it, a terminal environment. A number of people that my Office met with spoke about people dying around them and how it can be difficult to experience this on a daily basis. I can only assume that this issue has become even greater for many during the COVID 19 pandemic. Cameron (2001) refers to the psychological and social implications of repetitive grief and loss. This is something that is particularly relevant at this time.

Hay & Chaudbury (2013) and Cameron (2001) also refer to unmet needs in terms of intimacy, companionship and sexual needs. Quite a number of individuals that my Office met with described being lonely. One man said that he would like to have a relationship. Two individuals who mentioned being in relationships spoke about the related difficulties of living in a nursing home. One woman spoke about the challenges of telling people where she lived during the early stages of dating. Another spoke about how his partner did not like visiting the nursing home and the challenges of finding private space to talk when she did. This man shared a bedroom with other residents and communal visiting spaces were generally quite busy.



In terms of access to peers, not only can living in a nursing home make it difficult to interact with people of one's own age on a daily basis but Farrell's study (2013) highlights that upon admission, individuals often lose contact with immediate family and friends, for a variety of reasons. Winkler, Farnworth & Sloan (2006) found that 44% of those in their sample study received a visit from a friend less often than once per year. One individual my Office met with spoke about not liking people coming to visit him in the nursing home. Another spoke about sometimes struggling to talk to people of their own age outside their own nursing home as their day to day life was so different to everyone else's lives. A few individuals commented that they felt pushed towards the one or two younger people in the nursing home because of their age but they felt they had nothing in common with these individuals.

Conclusion

The impact that residing in a nursing home has on the quality of life of younger residents is quite clear in the personal accounts given to my Office. It is particularly clear in the accounts from those who have since accessed alternative accommodation and are able to compare and contrast their quality of life. McCarron et al (2018) on behalf of the Health Research Board systematically evaluated the evidence on quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with an intellectual disability. They found "There was a substantial level of agreement between quantitative meta-analytic (i.e. standardised mean differences for all movers) and other results, supported by the qualitative findings, that a move to the community was associated with improved quality of life versus the quality of life for those living in an institution".

I believe that autonomy is at the front and centre of this. The issue of 'fear' came up when my Office met with individuals and their advocacy groups. They spoke about the fear of losing what they had, the fear of asking for anything and the fear of being labelled as a trouble maker. When my Office visited one individual, she had told the nursing home that my staff member was from another organisation. She did not want them to know that she was speaking to the Ombudsman. She was not

the only individual in this position. However, this woman was scared to even ask for a chair for her visitor to sit on, in case she brought attention to herself. This level of powerlessness and anxiety is not compatible with a good quality of life.

In the HSE Transforming Lives Programme, which will be discussed further in Chapter 6, at the heart of the reform is an intention to support persons with a disability to live a life of their own choosing in the community, and to make services genuinely person-centred. This approach is grounded in a move from organisation-led services to community and individualised supports, which are focussed on the achievement of meaningful personal outcomes. The evidence above is not in keeping with this ambition.

The reviewable agencies which are the subject of this investigation are the HSE and the Department of Health and, as such, any recommendations set out in this report will be addressed to those bodies. They, in turn, have little or no statutory role in controlling many aspects of the day to day operation of private nursing homes.

It is evident that many of the quality of life issues raised by residents during this investigation arise from their daily experiences of currently living in nursing homes. This arises from their placement in settings which are not designed for the purpose of supporting and enhancing the lives of people of their age and particular needs. As I have not joined the nursing homes in the investigation, I cannot make formal recommendations here. Nonetheless, following the launch of this report, my Office will engage actively with Nursing Homes Ireland and individual nursing homes to press for major improvements in the day to day lived experience of residents under 65 in nursing homes, as long as they remain there.



3.1 Finding

It is recognised that a full resolution of the systemic issues identified in this investigation will take time and the provision of additional resources. Notwithstanding this, it is clear that the lives of some individuals identified in this investigation and perhaps others in similar situations, could be radically improved by the commitment of modest additional effort and resources.

3.1 Recommendation

This Investigation has identified a number of residents who have expressed a strong desire to move out of nursing homes and who could be quickly facilitated through the provision of relatively modest additional supports. These include Mark, Francis and Hannah. The example of Francis shows how the quality of life of individuals can be transformed through such minimal effort.

The work on the national survey (see recommendation 6.1) should be used to identify other individuals in similar circumstances and appropriate follow up action in their cases should be agreed and implemented by the HSE as a matter of urgency.

3.2 Finding

In this Chapter I have highlighted HIQA's call for a more appropriate and progressive form of statutory regulation. HIQA has contrasted the approach in Ireland to that of other jurisdictions. I am convinced that a move to a service model of registration would be a clear improvement in the regulatory regime in Ireland.

3.2 Recommendation

That the Department of Health review the current statutory provisions governing HIQA registration and bring forward legislative proposals to support a move towards a human rights based, service model of registration.



Chapter Four: Access to Services

When my Office met with a number of younger individuals who were resident in nursing homes and other interested parties including advocacy providers, the issue of access to services was repeatedly raised. This arose in two main contexts. The first of these was that individuals, especially younger people, had difficulties accessing services when resident in a nursing home. Secondly, respondents repeatedly reported difficulties in accessing support services in the community. In many instances, this had played a role in the admission of younger people to nursing homes.

It is difficult to address issues about access to services without addressing the issue of eligibility for services. Linked to access and eligibility is how these are assessed. These will also be discussed further in Chapter 5. I would like to highlight again that much of the content below may also be applicable to older people but for the purposes of this particular investigation, I am focusing on younger individuals in nursing homes. This does not in any way minimise the experience or impact on older residents and I would hope that some of my recommendations in chapters such as these would also be considered in the context of the wider nursing home population.

The Personal Experiences of Some Residents Under 65

I will start by outlining some of the personal experiences of residents under 65, as told to my Office. These are helpful in informing any discussion on this matter. Most of these relate to the experiences of those who were resident in nursing homes at the time of meeting.



The physiotherapist from the local HSE Disability Team visits **Francis** but he would prefer if this was more frequent. He has an exercise machine, which was funded by charity, and he uses this as much as he can. His advocate said that at times he has been told to stop as he has been doing so much. He also practices a little bit of walking with a high walker. He has requested a motorised wheelchair twice but has heard nothing back from the HSE. Francis currently gets out of the nursing home approximately every second weekend when he goes home to his house. He is accompanied by a carer. This is funded by fundraising in his community. This charitable funding does not cover the cost of a carer for all visits home during the year and the rest has to be funded privately.



Charles can access respite through a support organisation for his particular condition. He receives physiotherapy from the HSE for half an hour once a week. He has recently been offered an extra half hour a week physiotherapy from the aforementioned support organisation. He was given a motorised exercise bike by someone he knows and he gets the nursing home to put him on this. Charles said that he is seen by an occupational therapist from time to time but he is not sure what service they are connected to. Charles attends a day centre three times a week. His father drives him there.



Michelle attends a day centre twice a week. She said that she receives some physiotherapy from the nursing home but she has no physiotherapy input from the HSE. She has previously complained about a lack of structure to the physiotherapy provided by the nursing home and this has improved a bit. She would still like more physiotherapy input. She applied for personal assistance hours to try get out of the nursing home more often but her application was refused and the HSE advised that they were only funding personal hours as opposed to social hours. Her applications for home support were also refused.



Luke is a 52-year-old man with a brain injury. He has been living in a nursing home for approximately two years. His family have been told that he will not engage with physiotherapy. His family feel that not enough effort is made to encourage him to do so and that the physiotherapy provided may not be suitable. Similarly, his family do not feel he is encouraged enough in terms of rehabilitative tasks. He attends a social group in a brain injury service once a week. This was organised by his family and another family member brings him there by taxi and collects him. His family pays for the taxi. His family also organised a volunteer from a charity to visit him. Luke's family say that the HSE are no longer involved in his care. He did have a case coordinator in the past. His family would like him to have a job and some more purpose in his daily life.



Conor is a 42-year-old man with a brain injury. He has been living in a nursing home for 4 years. Conor currently has a rehabilitation assistant from ABI 3 hours per week and this is funded by the HSE. ABI has also offered respite for Conor in a house they have but the HSE has refused to fund the support he would require whilst there. Conor's advocate said that aside from the 3 hours R/A support a week, Conor has no other HSE input or rehabilitative support. His advocate felt that his potential is not being fulfilled in the nursing home.



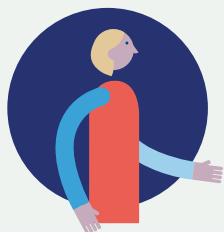
Siobhán is a 49-year-old woman. She was left with a disability after suffering multiple strokes five years ago. She was discharged from hospital into a nursing home. Her family say that she is not currently linked in with any other services. She is on the waiting list for ABI services. Siobhán is trying to work on her own mobility in the nursing home and her family feel this has helped but they would very much like for her to be able to access physiotherapy.



Hannah has a council house, which she visits once a week. Aside from this, she rarely leaves the nursing home. She does not attend a day centre and has no P/A support. She is waiting for her application for funding for a home care package to be approved so that she can return home.



Daniel was living at home independently with 25 hours personal assistance support a week. His medical condition deteriorated and he was admitted to hospital. It was felt that his needs had changed and he would need additional care that would require additional funding. This funding was not available and so he was told that returning home was not an option. He said he was offered no other real options other than a nursing home. He retained 4 hours personal assistance support a week. He also continued to attend his disability day service two or three times a week. He travels there himself using public transport. He feels that initially he was discouraged from attending his day service but he persevered and is now back in attendance. This is an important social outlet for him. He receives 1 group physio session a week in the nursing home. He said he is not in receipt of any services such as O/T and physio from the HSE.



Thomas said that generally he spends his time in the nursing home sleeping or watching television. He attends a day centre twice a week and he enjoys socialising with other young people. The day centre provides transport. He also attends a social farming programme once a week and he enjoys this. There were some queries in relation to the funding of the social farming programme and whether Thomas should be making a contribution to this but these have now been resolved. Staff bring him out from the nursing home at times but this is sporadic. He has no PA hours. He does not know which service he falls under. He receives some O/T support but this is from the community hospital attached to his unit.



Emma has returned to the job she had prior to her spinal injury and she goes to work from the nursing home three days a week. The HSE fund her transport to and from work. Emma enjoys work. Emma had applied to the HSE for home care support. She originally made a submission, which included overnights, but the HSE wrote back to her saying they would not cover nights and asking her to resubmit. The IWA assessed her and did a costing and submitted it to the HSE. She is awaiting a response. She does not currently have P/A support. Emma receives physiotherapy twice a week from the nursing home. She thinks this may be paid for as part of her package but she is not sure. She said that she used to have a HSE caseworker in but they haven't been in touch and she doesn't know if they are still on the scene. She said that access to primary care whilst in a nursing home seems to be a grey area. She said that she previously applied to primary care for services but was told that she would need to have an assigned address.



Leah's family said that her wheelchair is currently broken. They stated that they had not been able to access primary care as Leah was in a nursing home and this has made arranging for her wheelchair to be repaired much more difficult. Her family said that the HSE advised them that the nursing home should provide Leah with what she needs. This has also caused difficulties with accessing a special air mattress that Leah needs. Her family eventually paid for a private occupational therapy report and on receipt of this, a disability service has arranged a seating assessment. Leah has 3 hours P/A support a week but they are limited in what they can do as Leah is confined to her room. Her family said that she was not in receipt of supports such as physiotherapy or social work as the nursing home did not provide these.



Andrew was attending a day centre regularly prior to his admission to a nursing home but this stopped in the period prior to his admission to this nursing home. He had been accessing physiotherapy, occupational therapy and orthotics through this day service. Physiotherapy is available in the nursing home at an extra charge, if requested. Andrew has no access to speech and language therapy and his family said that his speech has disimproved. Andrew's family have advocated strongly for his attendance at his day centre. He has been linked in with this service for some time. This included a complaint to my Office. Prior to the pandemic, it was agreed that Andrew would start attending again and the day centre would provide transport. Andrew is not in receipt of P/A hours. Andrew's family would prefer if he was provided with accommodation by his disability service but they have been told there is no place available, despite also being told, at the time of admission to the nursing home, that Andrew was a priority for a placement.



Jack is a 44-year-old man. He acquired a brain injury 3 years ago after being assaulted. He has been living in a nursing home for over a year. He does not leave the nursing home during the day and does not attend a day centre. He said that he spends a lot of his day sleeping. He also fixes computers and laptops that staff bring in to him. The nursing home have set up a room with all his tools for him to work from. He orders parts from all over the world and repairs computers. Jack said that he would like to have a formal job. The nursing home put in an application to an acquired brain injury training course for Jack. They were told that Jack was not eligible for this. They were told that the rehabilitation window had passed but also that Jack was not eligible as he is in a nursing home and service is for people in the community. His advocate wrote to the Disability Manager about this and also queried the possibility of a PA for Jack. She was told that Jack was not entitled to these, as he is resident in a nursing home. Jack is not in receipt of physiotherapy or occupational therapy from the HSE. The occupational therapist and physiotherapist in the nursing home do their best to work with him but this can be difficult, due to his brain injury. Jack is on the waiting list for specialised accommodation for individuals with brain injuries but there are no vacancies.

Access to Services Whilst Resident in a Nursing Home

Access to Primary Care and related services

A number of individuals that my Office met with spoke about difficulties accessing services including physiotherapy, occupational therapy and speech and language therapy. In fact, as discussed in Chapter 3, one of the first complaints I received from someone under 65 in a nursing home was from a woman in such a position. She had a progressive neurological condition. Ultimately, she wanted to live independently with supports and work. At the time of her complaint, she was not in receipt of any services such as physiotherapy and occupational therapy, which would help her work towards this goal. She was advised that many of the primary care services such as physiotherapy and occupational therapy were unavailable to her without additional cost. A number of other individuals gave a similar account of their experience and this was something also raised by advocacy bodies during the workshop I held as part of this investigation. Farrell (2013) also found in her study that “For many of the 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”.

As discussed in Chapter 1, the NTPF agreement with nursing homes specifically excluded and still excludes some fundamental care elements such as all therapies, chiropody and social programmes. In a submission to this Office, Nursing Homes Ireland stated “Access to GMS services presents as a severe challenge not just for younger residents but also older residents in nursing home care. People in nursing home care are being discriminated against by the HSE due to insufficient capacity and resourcing for the provision of GMS services. The HSE itself has admitted it prioritises providing such specialist care to people residing at home over people within nursing home care”.



HIQA (2019) stated “Common issues raised by registered providers during these regional meetings — and during inspections and regulatory meetings between the Chief Inspector and providers — included difficulties in accessing community allied healthcare professionals for residents, difficulties accessing support from the HSE safeguarding teams and access to medical card services”. It has raised the issue at national level with the HSE and engaged with the Department of Health, stating that nursing home residents should not be in any way disadvantaged by virtue of living in a nursing home and services that they could have availed of free of charge in the community should equally be available to them on moving to live in a nursing home. Nursing Homes Ireland stated that timely and continued access to allied health professionals such as OT, speech and language therapists is essential to meet the care needs of younger people requiring nursing home care. Yet private and voluntary nursing homes have very restricted and limited access to these services from the HSE.

The HSE has advised my Office that “Individuals under the age of 65 living in nursing homes are entitled to access the full range of Primary Care Services. Referrals can be made within the local CHO Area and are accordingly assessed under specific criteria similar to all referrals. These are then considered and prioritised in line with risk and available resources, which it should be noted, are finite”. However, the Department of Health has pointed out to my Office that the likely intention of this statement is to confirm that those aged under 65 living in nursing homes have equivalent access to primary care services as individuals living at home. It highlights that there is no statutory obligation on the HSE to provide primary care services nor is there any individual “entitlement” to such services.

On a broader front, there is acceptance from the Department of Health that legislative underpinnings of eligibility should be revisited, and this issue has been identified for further consideration as part of the Sláintecare programme.

It seems that perhaps finite resources may be the reason provided by the HSE as to why younger (and older) people in nursing homes may have difficulty accessing primary care services. However, a number of individuals told my Office that they were told they were not eligible for these services, which is a different matter.

Furthermore, it seems to be the experience of both HIQA and Nursing Homes Ireland that nursing home residents are being disadvantaged in this regard. This is of great concern to me. Cowman et al (2010, 5) state “There needs to be an increased societal awareness that stroke patients who live in nursing homes are community residents whose home address happens to be a nursing home. They thus should feature as community residents in any planning or service developments”.

HIQA (2019) has stated that some providers, in recognition of the regulatory requirement to ensure a resident’s healthcare needs are addressed, have secured the services of allied healthcare professionals on a fee-per-session basis which is then passed on to the resident and his or her family. Residents and families are then faced with the choice of paying for the service privately if they can afford it or seeing their health and quality of life deteriorate further. This is reflected in some of the accounts above, where individuals have stated that services such as physiotherapy are available to them, at a charge. It is obvious from the accounts provided by individuals that they are able to access such services from their nursing home, at a charge. It is also evident that some residents seem to be able to access such services without charge. As Nursing Homes Ireland correctly point out, in the absence of State support services, private and voluntary nursing homes are doing their best to provide this group with services. However, the difference between individual experiences of accessing such services when resident in a nursing home is extremely concerning and one that needs to be addressed as a matter of urgency.

Related to the above, some individuals have advised me that they must use the GP attached to the nursing home as opposed to their own GP, with whom they may have had a long term professional relationship. The HSE advised my Office that, in most cases individual residents in nursing homes can retain their own GP or move to a GP in the area where the nursing home is located. However, this will vary from area to area and nursing home to nursing home and depend on the proximity of the GP to the nursing home. Again, this leads to a disparity in access to GP services, and impacts on the autonomy of the individual, which is of concern to me. Some individuals may opt to move GP but I would suggest that this should be their choice.



Some individuals also referred to difficulties with accessing equipment and this again, was raised by a number of advocacy bodies in the workshop I organised for the purposes of this investigation. The HSE advised my Office that people in nursing homes have the same entitlement to equipment as those in the community. They will be prioritised in accordance with their need and urgency, from a professional perspective. The HSE advised that it is expected that nursing homes will provide for the person's general needs in relation to any equipment but where there is a need for specialised items this will be provided through the general prioritisation process for Aids and Appliances. Again, I feel that this leaves some scope for ambiguity between the responsibility of the nursing home versus the responsibility of the HSE. One hospital told my Office that it funded equipment in order to facilitate someone moving from the hospital to a nursing home, which seems to indicate an inefficient system. As outlined above, when my Office met with Leah, her wheelchair was broken. Her family said that they had not been able to access primary care as Leah was in a nursing home and this has made arranging for her wheelchair to be repaired much more difficult. They said that the HSE told them that the nursing home should provide Leah with what she needs. This has also caused difficulty with accessing a special air mattress that Leah needs. Her family eventually paid for a private occupational therapy report and on receipt of this, a disability service has arranged a seating assessment. Leah is already confined to her room and problems with her wheelchair restrict her access even further. Delays in accessing equipment or equipment repairs can have a significant impact on an individual's quality of life.

Rehabilitative Services

As discussed in Chapter 3, O'Reilly and Pryor (2002) query whether aged care is in contradiction to rehabilitative care and the Report of the Senate Standing Committee on Community Affairs, Australia (2015) identified similar concerns in relation to the inappropriateness of residential aged care for younger persons. The Committee received evidence that younger residents may have inadequate access to rehabilitation.

In an Irish context, Acquired Brain Injury Ireland (2017) suggest that nursing homes in Ireland are largely designed for older people and are not suitable to support a rehabilitation programme for a younger person with an ABI to live long term.

Part of this may be related to the above discussion in relation to allied health professionals such as physiotherapists and occupational therapists. However, the conversation in relation to rehabilitation in nursing homes extends beyond this. For example, residents with acquired brain injury or particular medical conditions may require a very specialised approach to rehabilitation. Nursing Homes Ireland advised my Office that “It should be recognised nursing homes specialise in providing rehabilitative care. Nursing homes provide step-down care for people being discharged from hospital and following an intensive period of person-focussed, specialised care – which can be provided over periods of weeks, months or years – many young people are discharged home or to supported living”. However, the reality is this does not seem to be the experience of all the individuals that met with my Office nor does it seem to be the experience of the various advocacy bodies that I have spoken with. Although some individuals may be in specialised units, this is often not the case. Again, I do not consider this a poor reflection on nursing homes but rather a systemic issue in terms of appropriateness of placement.

Adam is a telling example of this. Neither Adam nor his advocate felt that Adam received rehabilitative support from the nursing home where he lived. Adam now lives at home with 2 hours support six days per week, which is funded by the HSE. He is much more active now. He likes walking and he attends mass regularly. He said that his friends have started visiting him again. He also hopes to start swimming again. His advocate said that he has noticed a big change in Adam and he has become more social and is taking more pride in his appearance. Adam is starting to take charge of his own affairs and he described himself as being much happier.

A few individuals with a brain injury who met with my Office reported that a HSE funded Rehabilitative Assistant (R.A) was available to them for a few hours a week but this was not a service that was available to everyone and again, this disparity is of concern to me.



It is obvious that Acquired Brain Injury Ireland, who often provide these R.As are an excellent service but funding is limited and individuals such as Siobhán end up on waiting lists. Again, this leads to disparity in service provision and can have a significant impact on the quality of life of individual residents.

The implementation plan for the National Neurorehabilitation Strategy outlines a ten-step plan to develop neuro rehabilitation services at hospital and community level nationwide. The overarching aim of the Strategy is to develop neuro-rehabilitation services that improve patient outcomes by providing safe, high quality, person-centred neuro rehabilitation at the lowest appropriate level of complexity. This must be integrated across the care pathway, and provided as close to home as possible or in specialist centres where necessary. However, I remain concerned about those individuals who are currently in nursing homes and who would benefit from rehabilitative services. Pierce et al (2018) state that the professional consensus, the evidence from the rehabilitation literature and published clinical guidelines, highlight the importance of early intervention to optimise rehabilitation gains as well as continued support to optimise independent living ability following discharge.

Personal Assistance

I will discuss the Personal Assistance Service (PAS) in further detail below in the context of community supports. However, I think it is important to note the disparity younger individuals in nursing homes experience in accessing a personal assistant. As illustrated in the accounts above, whilst many individuals cannot access a personal assistant, others have a personal assistant for a few hours a week. One individual had 3 hours PA support a day but this seems to have been a very rare exception, as opposed to standard. If a younger person must be resident in a nursing home for older people, and as outlined, I do not believe that they should be, then a personal assistant can provide them with some level of independence. Again, I will discuss the PAS in more detail below. However, it is also important to note this issue here as I have been told that there are certain geographical areas where individuals in nursing homes are never eligible for PA support. This produces even further inequity. I will also address this issue of geographical inequity in more detail below.

Meaningful Activities

I have touched on this in Chapter 3 in discussing activities in nursing homes. However, this extends beyond activities provided within nursing homes. As previously stated, in the HSE Transforming Lives Programme, at the heart of the reform is the intention to support persons with a disability to live a life of their own choosing in the community, and to make services genuinely person-centred. In 2012, the HSE published ‘New Directions: Review of HSE Day Services and Implementation Plan 2012-2016’. This outlined the proposed new approach to adult day services. It envisaged that all the supports available in communities will be mobilised so that people have the widest possible choices and options about how they live their lives and how they spend their time. It places a premium on making sure that being part of one’s local community is a real option.

The Council of Europe Commissioner for Human Rights (2012) states that time and again it has been demonstrated that people who were deemed too “disabled” to benefit from community inclusion thrive in an environment where they are valued, where they partake in the everyday life of their surrounding community, where their autonomy is nurtured and they are given choices. Ratzka (2013) explains this further. He states “When people around you expect very little of you, it is difficult to acquire and maintain a healthy self-confidence. Most likely you play it safe and avoid risks and challenges for fear of failing. Without the experience of success and failures, we will not realize our potential, will not grow as persons. Thus, we will confirm society’s prejudice that disabled people are incompetent and helpless”.

Linked to the above is the concept of ‘social role valorisation’ (SRV). SRV was formulated in 1983 by Wolf Wolfensberger. Genio, a European organisation based in Ireland working with philanthropy and government at national and EU levels, explains that SRV “is a dynamic set of ideas useful for making positive change in the lives of people disadvantaged because of their status in society. SRV is utilized mainly in services to children and adults with impairments as well as elders, but it can be helpful to uplift the social situation of any person or group”. Genio explain that a basic tenet of role-valorising efforts is the notion that the good things any society has to offer are more easily accessible to people who have valued social roles.



Conversely, people who have devalued social roles, or very few or marginally valued ones, have a much harder time obtaining the good things of life available to those with valued social status. Therefore, valued social roles and the positive status that typically attends them are a key to obtaining the benefits inherent in any given culture. This highlights the importance of people with disabilities having valued roles in the community.

As evidenced above, some individuals regularly access a day centre attached to a disability service. A number of individuals said that they enjoy this and they appreciate the opportunity to meet with other young people. Some individuals do not recall ever being offered this as an option and they spend the majority of their time in the nursing home. Others have been offered the opportunity to attend a day centre and have declined this offer as it is not something that interests them. It seems that in the majority of cases, when this offer is declined, there are no other options available. This was also the experience of Farrell (2013) who stated “Many people were reported to spend much of their time in their bedrooms, or rarely participate in nursing home activities; 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. Many expressed interest in having day service options off site; while some went out several times a week to a local day place, others have been refused by agencies or they have refused the placement on offer. Two people in the study had volunteer roles or small jobs in the local area, and were reported to enjoy these. While eight residents had a day place to go out to during the day, this was not considered an option for others due to complex support needs. Others refused what was on offer, or wanted a place but did not meet the criteria. (This was often referred to in the literature as ‘doubledipping’, where different streams of services were involved - for example, not being able to access a particular type of day or clinical service from a private nursing home setting”. This does not suggest a uniform individualized approach.

My Office met one or two individuals where there was some innovation shown in this regard. One man had been linked in with a social farming programme, another nursing home had researched local men’s sheds as a possibility for a younger resident. These indicated more tailored approaches that were based on the needs of the individual and assimilated them into the community.

However, as stated, access to such activities seems to be in the minority and there seems to be a lack of innovation in this regard. Again, the disparity in options available to different individuals is concerning. I will discuss individualized care plans further in Chapter 5 but as Farrell (2013) suggests, individual personal planning is important in ensuring individuals have a meaningful day and as full a life as possible.

The HSE informed my Office that “Some nursing home residents under 65 years of age avail of Day Service opportunities in various settings of their choice and this is resourced by the local HSE Disability Services. In some CHO Areas, there are specific posts of Day Opportunities Coordinators, who endeavour to provide day services to individuals in the local community, which are appropriate to meet their assessed needs and personal choice. In other CHO Areas, this role is carried out by Case Managers, Disability Managers or Key Workers, while in others, there are Occupational Guidance Officers who link with service users requiring a Day Service placement. In general, people under 65 in nursing homes can be, and are, assessed to evaluate their potential to participate in therapeutic and/or recreational day activities and can be linked with an appropriate provider locally, where a suitable service can be accessed. However, it should be noted that currently in Ireland there is not an entitlement to social care services, but rather services are made available from within existing resources”. Again, I would like to express my concern about the lack of uniform approach in this regard and the potential for individuals not having equality of opportunity and access.

Related to this, I would like to highlight that for those attending a day service, there again seems to be great disparity in relation to how transport is organised. Some day services provided transport, other individuals were funding their own transport, if using private transport. One man told us that he was able to use public transport. Some nursing homes seemed to provide transport, either free of charge or at a cost. The HSE told my Office that “The provision of transport services is not part of core services within disability services and does not form part of the funding allocated from the Department of Health for Day Service provision. As a general rule public transport should be used in all circumstances where it is an option.



This is in keeping with the principle of mainstreaming with a clear focus on ensuring persons with a disability have access to the normal range of services and participate in community life as far as possible. It must be noted that in general, all persons with a disability are eligible to apply for a travel pass/companion travel pass and some people choose to use personal hours funded by the HSE to travel to various locations using public or private transport with their carer. Notwithstanding the above, requests for additional funding for transport may be provided on an individualised basis. This would be assessed on a case by case basis and where appropriate and as allowed within funding/budgets, additional supports may be approved. However, there is no uniform policy in this regard across the country”. I support the concept of mainstreaming but it seems that based on their need, or the location of their nursing home, many younger people residing in nursing homes do not have the option of using public transport. The lack of a uniform approach in relation to alternatives is of concern and again creates inequity, not least from a monetary perspective.

Further to this, in employment, people with disabilities have the same employment rights as other employees. Equality legislation: The Employment Equality Acts 1998-2015 outlaw discrimination on the grounds of disability in employment, including training and recruitment. The Disability Act 2005 places an obligation on public bodies to consider and respond to the needs of people with disabilities. Under Part 5 of the Act, 3% of jobs in public service bodies (local authorities, civil service, the Health Service Executive and so on) are reserved for people with disabilities. The Comprehensive Employment Strategy for People with Disabilities 2015-2024 sets a whole-of-government agenda for increasing access to employment for people with disabilities. However, the National Disability Authority (NDA) states that people with disabilities are only half as likely to be in employment as others of working age.

Of the individuals my Office met, only one was in formal employment. She was facilitated by the HSE to attend work 3 days a week from her nursing home. She spoke about the positive impact this had. One or two other individuals mentioned being in employment linked in to their disability service day centre. A small number of individuals were trying independently to improve their computer skills. This was challenging at times, due to problems with internet access.

One man, with the assistance and support of his nursing home was running a small computer repair business from the nursing home. He said that he had applied for a training course but had been told that he was not eligible. Others expressed their desire to work but said that they did not have the opportunity. They felt that this would improve their lives and make their days more meaningful. One woman spoke about how she could input into the economy and how it would be of benefit for her to work from an economic perspective. The NDA states that people with greater levels of impairment are less likely to be at work and this may be the reason provided for why the rate of employment and training for younger people in nursing homes is so low. However, the accounts above demonstrate that there is a willingness to work and people have various skills that are not being tapped. I believe that the lack of access to such opportunities may again relate somewhat to the lack of proper individualised planning. However, I do appreciate that there are also broader societal issues at play.

Advocacy

Many of the individuals that I met with had access to an independent advocate and found this service extremely helpful. However, my Office met with at least one man who was not aware of the National Advocacy Service. The HSE advised my Office that all residents of public facilities for older people are informed of their right to a SAGE advocate and given information regarding safeguarding and protecting vulnerable adults. Nursing homes are regulated under the Health Act 2007, which requires them to provide details of access to advocacy services to all residents and potential residents, and details of advocacy services are also routinely displayed on notice boards throughout services.

The HSE stated that Disability Services would also routinely advise people under 65 years with a disability resident in a nursing home of their right to independent advocacy and also of the Office of the Confidential Recipient, which is a national service that receives concerns/complaints related to vulnerable adults in HSE or HSE-funded care services. However, I am not convinced that this system is robust enough to ensure that all individuals under 65 living in a nursing home are aware of their right to an independent advocate. Information is key in this regard.



Article 12 of the UNCRPD deals with equal recognition before the law. Pierce et al (2018) suggest that 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. Some individuals may be able to self-advocate and this may be their preferred option. However, this is not for everyone and some may benefit from access to independent advocacy, particularly given how complex the system is, as will be discussed in Chapter 5. The National Advocacy Service's 2019 Annual Report states that as their work has become more complex and is provided to more people, they have a need for an increase in resources. This is most acute in locations where there are waiting lists for access to their service, but it is also needed across the country to ensure as many people as possible have access to advocacy. The number of people on the waiting list to access NAS services rose from 98 (in January 2019) to 130 (at the end of December 2019). It is important that this service has appropriate funding and resources.

Safeguarding

I do not propose discussing the issue of safeguarding in great detail, as there are on-going developments and imminent changes in this area. As recently as February 2021, the Minister for Health welcomed publication of two reports to inform health sector adult safeguarding policy. However, I do think it is important to note that, as things currently stand, within HSE and HSE funded social care (including older persons residential/ nursing care) facilities, the Safeguarding Vulnerable Persons at Risk of Abuse, Policy and Procedures (2014) would apply. However, the situation is less definitive when it comes to private nursing homes. Guidance has been developed by the National Safeguarding Office for Safeguarding and Protection Teams in relation to responding to concerns of abuse that may arise in private nursing homes. The Chief Officer/ Head of Service for Social Care have operational governance within each of the nine Community Health Care Organisations. The HSE advised my Office that I should seek clarity from the operational governance line for clarity on the position within each of the Community Health Care Organisations. This in itself would suggest the lack of a standard approach.

The HSE Safeguarding Vulnerable Persons at Risk of Abuse, Policy and Procedures (2014) was devised for Community Referrals and HSE/ HSE funded social care services. This HSE policy has recently been reviewed and implementation planning on a revised policy is currently being undertaken. The Department of Health is also developing a health-wide sector policy on adult safeguarding which will encompass private sector provision of service. The Law Reform Commission has an issues paper currently out for consultation on adult safeguarding and future potential legislation in the adult safeguarding field which could address the gap of coverage within the private sector and the HSE has previously made submissions to both the Law Reform Commission and the Joint Oireachtas Health Committee on this matter.

Access to other Services

It is impossible to cover all services that a younger person in a nursing home may seek to access. However, one case that struck me was that of Conor. Conor is a 42 year old man with a brain injury who is living in a nursing home. ABI offered respite for Conor in a house they have but the HSE refused to fund the support he would require whilst there. If Conor was resident in an alternative residential setting for people with brain injuries, such as one run by ABI, then this is something that he could more readily access. We all appreciate a holiday and a break from our everyday life. I cannot see why this would be any different for someone whose current 'home' happens to be a nursing home.

The HSE advised my Office that there is no prohibition on the provision of holiday respite services to individuals under 65 with a disability residing in nursing homes, as long as the capacity exists within the CHO Area to make it available, as in many cases there will be high medical needs or a requirement for nursing care. In this context, referrals for respite services would be considered and prioritised in line with risk and available resources. I believe, that in reality this means that individuals under 65 with a disability residing in nursing homes would have much more limited access to such services than those in alternative settings.

Overall, I am concerned that younger people who are resident in nursing homes may not have the same opportunities or access to services than they would have if they



were living in an alternative setting. I am of the view that this raises concerns in relation to discriminatory practice. Under section 4 (2) (b) 9v) of the Ombudsman Act 1980, improperly discriminatory actions amount to maladministration.

Access to Services as part of the Broader Issue of Admission of Younger People to Nursing Homes

As I stated at the beginning of this chapter, the issue of access to services repeatedly arises in two main contexts. The first of these is difficulty in accessing services when resident in a nursing home. The second is the difficulties experienced by people with disabilities within the community in accessing services. This seems to play a significant role in the admission of younger people to nursing homes. I will address the latter point below.

I would first like to make two points. The first of these is to clarify that this particular investigation relates to the HSE and the Department of Health. However, it is impossible to refer to access to services as a key factor in leading to younger people being admitted to nursing homes without acknowledging that access to housing plays a key role in this. Access to suitable and accessible housing is essential. In an Irish context, Pierce et al (2018) state “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”.

However, the issue of housing does not come within the scope of this investigation. It is, however, interesting to note that a number of individuals that my Office met with had access to suitable and accessible housing but could not avail of it due to a lack of supports. This will be referred to in Chapter 5.

It is also important to note again that, although this investigation is focused on the experiences of those under the age of 65, some of the issues in relation to access to services are also applicable to those who are over 65.

‘Your Voice Your Choice’ was organised by the NDA as a consultation where individuals with disabilities could have their say on issues that matter most to them. The ideal was expressed as: ‘Living independently, with a house close to the job’. The majority of individuals that my Office met with expressed a preference to be living in an alternative setting to a nursing home. Many of these individuals expressed a strong desire to live in their own home. Benjamin Franklin stated “A house is not a home unless it contains food and fire for the mind as well as the body” or as the old Irish proverb states ‘Níl Aon Tinteán Mar Do Thinteán Féin’. Although named nursing ‘homes’, many individuals my Office spoke to do not consider this their true home. Although they may be receiving the nursing care they need and receiving excellent care from the nursing home, they still aspire to be living somewhere that they truly consider home. In speaking with various individuals, advocacy groups and from reviewing relevant literature, it seems that difficulty accessing a number of services can play a role in placing obstacles in reaching this goal. I will discuss these below.

Home Support

What is home support?

The Department of Health completed a public consultation on home care services in 2017 and the Institute of Public Health in Ireland provided an overview of the findings in 2018. The DOH consultation paper points out that the meaning of home care can differ significantly between countries, and as such, there is no standardised definition.

In correspondence with this Office, the HSE stated that the home support service provides domestic and/or personal care inputs at regular intervals on a weekly basis. Temporary relief is offered to the carer by providing a trained reliable care attendant to look after the needs of the person with the disability. Home supports can be an alternative to residential care, where support to individuals in daily living can avoid the need for full time residential services.



Smith et al (2019) explain that from 2006 to 2018, two parallel schemes existed in Ireland: the Home Care Package (HCP) scheme and the Home Help scheme. These were merged into the Home Support Scheme in 2018.

Difficulty accessing home support

Donnelly et al (2016) completed research on meeting older people's preference for care and how these are met in practice. This investigation is in relation to a younger group but from speaking with younger people in nursing homes, their advocates and various hospitals, I think that some of the findings of this study may also be reflected in the experience of this younger group.

The findings of Donnelly et al's study (2013) echo previous Irish research studies, which show the preferences of older people are to remain living at home for as long as possible, receiving care when it is needed in this setting.

The survey shows that nearly 30% (n=144) of social work cases in acute hospitals in June 2015 were medically ready for discharge but were awaiting supports to be put in place. Delays in discharge (48% of cases) were most likely to be due to inability to access home supports rather than long term care. For older people in hospital and at home, accessing timely home care in the community was found to be more difficult than accessing long term residential care.

Pierce et al (2018) discuss this in the context of younger people with disabilities. They state that, 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. They suggest that 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.

I have referred to this in Chapter 1, where I have discussed the fact that the provision of nursing home care is on a statutory basis and there is a lack of a provision of home care on a statutory basis. This in itself accounts for some of the disparity in accessing the two services.

In 2019, the Joint Committee on Health published a report on the provision of home care services. The Committee noted the increasing number of unmet hours for home care services despite additional funding. It stated that the current structure for providing home care is struggling to adapt and is unlikely to be able to efficiently provide for future demand increases. The Committee made a number of recommendations including the enactment of legislation underpinning the provision of home care and that home care services should be regulated by HIQA or another independent body. The Committee also noted the importance of a unified, consistent and transparent assessment tool to be operated by all CHOs. It also suggested that the HSE record and publish details of the number of people on waiting lists for home care, that such lists are updated and published on a regular and continuous basis and that such lists are included in key metric data with the objective of delivering month on month improvements. These are all recommendations that I would fully support and it is obvious that developments in this regard have started. A substantial increase in the provision of home support is a key recommendation of both the Sláintecare report and the Health Service Capacity Review. The Department of Health's Sláintecare Implementation Strategy (2018) commits to the introduction of a statutory scheme for home support in 2021 [sub-action 6.3.1], However, the Department of Health has advised me that the development of the scheme has been significantly delayed by the diversion of resources in response to COVID-19.

Around 87% of the 2020 HSE allocation to Disability Services was spent on Residential, Day Services and Respite. 5% was spent on PA and Home Support.



Younger people as a distinct group

I would suggest that the need for home support for younger people needs to be made available other than on an exceptional basis. For example, the HSE Home Support Service for Older People Information Booklet & Application Form 2018 states “The service is for people aged over 65 who need help to continue living at home. Sometimes exceptions are made for those younger than 65 who may need support”. Similarly, the IPH Overview of the DOH public consultation on home care stated “While the home care service in Ireland is mainly used by older people, it is also available, in a limited way, to some people with disabilities and other identified care needs”. The IPH (2018) also highlights that while home care services can be required by people of all ages due to, for instance, care needs associated with a chronic condition or disability, or following a stay in hospital, older people represent a large proportion of service users; this is reflected in the allocation of resources for home care service-provision. This younger group will continue to experience difficulties in accessing these services if access to the service is framed in such terms.

I have found that much of the conversation on home care seems to focus on the older population. Obviously, this service is equally important to that group but I think it is important to ensure that the conversation is broader than this and explicitly includes younger people. I have asked the Department of Health whether all groups will be treated uniformly in any statutory scheme for home support or whether there are any separate measures envisaged for those under 65. The Department advised me that discussions are on-going within the Department to determine the optimal approach to the development of the statutory scheme within the broader context of the Sláintecare reform of Ireland’s health and social care system. This includes the eligibility for such a scheme. I am not necessarily advocating for a separate approach but rather I am highlighting the need for this group to be formally and clearly acknowledged as potential service users. The objective of our social care services should be to enable all people who need support to remain in or return to the community to have access to it, so that they can live, full, fulfilling and engaged lives.

Grotti et al (2019) in a report for the Department of Employment Affairs and Social Protection state “there is large variation in receipt of professional home care among those needing help. Indeed, almost 42 per cent of older adults in need of help are in receipt of professional home care while the figure is less than half of that (20 per cent) among those in households containing people with disability and other working-age households (19 per cent)”. Di Gennaro Reed et al (2014) conclude from their research that the barriers to independent living are unique to the respective populations. The top barriers for individuals with disabilities differ to those of senior citizens. Grotti et al (2019) state that their analysis showed that access to care services for people of working age with an illness or infirmity lags behind access to such services for older adults.

On a positive note, the HSE has been able to establish a dedicated funding stream as part of its National Service Plan (NSP 2021) that will enable 18 people, with an investment of €3m, under the age of 65yrs to transition to their own home with support.

I very much welcome this as a valuable first step as it acknowledges the needs of this particular group. It is important that this is rapidly expanded and broadened in scope.

Level of Need

It has been suggested that the younger people in nursing homes often have a high level of need and that it can be difficult to cater for this in the community.

Di Gennaro Reed et al (2014) suggest that level of functioning may influence the degree to which an individual lives independently. In the area of intellectual disability, Stancliffe et al (2011) also highlight that individuals with more severe conditions and support needs experience less choice regarding living arrangements. McMillan & Laurie’s research (2004) suggests that young adults with acquired brain injury in nursing homes were more likely to have a severe disability. In their submission to the SAGE Forum on Long-Term Care, ABI Ireland (2016) highlighted that many of these individuals are those that are considered to be “bed blockers” in the acute hospital system.



Pierce et al (2018) state that their study in an Irish context shows that “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”.

This is consistent with the complaints to my Office and the individuals in nursing homes that my Office met as part of this investigation. Many of these individuals had very high levels of needs. In a number of complaints, this had been provided by the HSE as a reason for difficulty in accessing services other than a nursing home.

The HSE funded an Intensive Home Care Packages (IHCP) initiative in 2014. In the context of older people with complex needs, Keogh et al (2018)’s evaluation of the HSE Intensive Home Care Packages Initiative found that it is possible to support older people with complex needs at home in Ireland given sufficient provision of home care and other services. In terms of younger people with disabilities, Pierce et al (2018) highlight that to the end of December 2017, 32 younger people with disabilities and a further 15 people with younger onset dementia had availed of these packages of care nationally. They state that while there is much variation in the duration of these packages, more than 90% of IHCPs for younger people with disabilities had lasted for one year or more, demonstrating that if the necessary supports are put in place, it is entirely possible to care for people with complex needs at home, including younger people with disabilities.

The International Disability Alliance (2015) has suggested that eligibility and provision criteria should not restrict access to support services to live independently and be included in the community. For example, support systems, including personal assistance services, must not exclude persons with disabilities on account of the type of disability. Also support must not be limited on account of the “degree” of disability or the “multiplicity of disability”. I think this is an important point to note. Although there may be resourcing issues in terms of funding home care for people with higher levels of needs, it is also important to ensure that they are not discriminated against, based on their level of need or their particular disability.

Geographical inequity

Di Gennaro Reed et al (2014) suggest that geographical area may influence the degree to which an individual lives independently. This seems to be reflected in the Irish experience.

Smith et al (2019) state “in addition to the lack of national resource allocation formulas, some of the differences in supply identified in this report may be a consequence of the historical regional health board structure of the Irish health and social care system. In this context, local autonomy for some aspects of service planning has resulted in a divergence in the development of non-acute care supply in the past, with some of this divergence remaining and underpinning the large inequalities in supply across Ireland”. They state “The data show that there is an unequal distribution of non-acute services across the country. The finding that the distribution of supply is unequal even after controlling for healthcare need factors is consistent with anecdotal evidence of inequity in access to non-acute care cited in many policy documents, and it underlines the importance of moving towards population-based resource allocations if equity is to be improved”.

The Committee on the Future of Healthcare - Sláintecare Report (2017) acknowledges that people with disabilities experience geographic differences in access to certain services.

ABI (2017) highlight how some of these issues related to funding and has suggested that funding and provision of intensive home care packages should be on a national level. This was also something suggested to my Office by the NRH and will be referred to again in Chapter 5.

This issue of geographical inequity is something that arose in complaints to my Office and in the accounts from people under 65 in nursing homes and their advocates. As well as differences in funding, access to services to facilitate options such as independent living may be less available in more rural areas. Again, this inequity in access to services concerns me.



Personal Assistance Service

A Personal Assistance Service (PAS) is another service that assists in allowing individuals with disabilities to live independently and may therefore play a role in preventing admission to a nursing home.

The ILMI define personal assistance services (PAS). They state:

“The Personal Assistance Service (PAS) is a tool that allows disabled people to live independently. The PAS provides us with the freedom and flexibility needed to live our lives as we chose as it enables us to do all the tasks that we cannot do for ourselves”.

The two fundamental elements of this service are the ‘leader’ and the ‘personal assistant’. The ILMI states that:

“A Leader is a disabled person who employs directly or indirectly (through a service provider) Personal Assistants. A Leader takes full responsibility for the instructions given to the Personal Assistant, for the actions and consequences that follow from these, for training and day-to-day management of the service. The Leader is in charge”.

They also outline the role of the Personal Assistant:

“A Personal Assistant, when on duty, only takes instructions from the Leader. A Personal Assistant does not report on the Leader’s activities to service provider, nor does a Personal Assistant write in any ledger or notebook information about the Leader to be viewed by others, unless instructed by the Leader to do so.

Personal Assistants do not work in day centres or nursing homes or in any similar establishment where they are responsible only to management of the said establishment. Personal Assistants’ tasks are customized to the individual needs of the Leader and may include personal care, household help, assistance in the college or at the workplace, driving, interpretation etc. The major difference between a Personal Assistant and a carer is that in case of Personal Assistance the service is designed and managed by the service user directly”.

James Cawley of ILMI has previously stated “A PA does not ‘look after’ or ‘care for’ us disabled people. We delegate these tasks to our PAs and in doing so take back control of our lives”.

The DFI (2014) outlines the history of PAS in Ireland. In the early 1990s a small group of people with significant physical and sensory disabilities pioneered the PAS in Ireland, using EU and FÁS funds to finance a ‘pilot’ scheme, called INCARE. The pilot scheme involved training and peer support arrangements, including the establishment of the first Centre for Independent Living, (CIL). After the pilot funding ended in 1993 and the CIL incurred a growing deficit, disabled people protested outside the Dáil demanding public commitment to the initiative. When the Eastern Health Board took over in 1994, funding was based on the cost of the supports for each INCARE participant, which in turn was based on the person’s own assessment of their needs supplemented by advice from their CIL. The Irish Wheelchair Association (IWA) was contracted to run the service rather than continuing with the CIL. Those people who had set up and benefited from the pilot initiative were thus safeguarded in this transition but the government did not at this time articulate a policy position on the new service.

Outside Dublin, independent CILs were established using FÁS funding under the Community Employment (CE) scheme and later health funding was received to pay for PAs. Negotiations late in the decade to transfer responsibility from FÁS to the health authorities broke down, and FÁS’s role in relation to the delivery of the PA service tended to diminish as restrictions on the CE scheme tightened. Nonetheless, a number of CILs still rely on CE training to provide PAs, supplementing HSE-funded support.

During the mid-2000s, the National Disability Strategy prioritised the expansion of personal care hours. However, the HSE at this time did not specifically identify the PA service, referring instead to ‘PA / Home Support’ service (i.e. including provider managed care service). The DFI (2014) highlight that, although a considerable funding increase was reported from 2006 to 2008 (inclusive), there is no evidence available of any government evaluation of what was achieved from this investment.



DFI (2014) states:

“In summary, the research found that the original model of the PA service established by the pioneers has been undermined”

In August 2012, the Government of Ireland, without warning, announced that it was going to cancel the personal assistance budget for the rest of that year, which led to protests and the decision was eventually reversed. Furthermore, DFI (2014) suggest that over time, the focus on leadership faded and there did not appear to be ‘buy-in’ to the idea that the key performance indicator for a PA service should relate to the achievement of independent living. They state “Discussions with service providers and other stakeholders suggest that the HSE, especially since 2008, has made it more difficult for an applicant to demonstrate support needs that reflect their full life agenda. The emphasis is on care rather than on enabling the disabled person to take charge of their life”. This is reflected in the experiences of individuals that spoke with my Office and some complaints received by my Office. Individuals have been informed that applications for personal assistants can only be made for personal care as opposed to for social reasons. Similarly, the account provided by the DFI (2014) in relation to accessing the PAS seems to be reflected in these accounts. At least one individual living in the community spoke about their PAS hours being cut after they were admitted to hospital and a number of advocacy bodies spoke about the ongoing fear that people have about having their PAS hours reduced. The number of hours allocated also seems to be an issue in terms of accessing a meaningful service. Nic Aogáin et al (2019) reported that “84 percent of those in receipt of a PA service received less than three hours a day and 42 percent of these people were in receipt of between one and five hours a week. This is only an average of 42 minutes a day, despite there being 1,440 minutes in a day and disability being a 24- hour affair”.

The HSE informed my Office that it acknowledges the valuable role of PA Services in supporting the person with a disability to realise the entitlements set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). PA Services are funded through Disability Budget Allocation. The HSE advised that, at present each CHO Area has a process to manage applications and referrals for PA Services.

In general, services are accessed through an application process or through referrals from public health nurses or other community based staff, although an individual may also contact the CHO Area personally. The local CHO Area would have an application form and decision making process in place and while they may not have a formal right of appeal system, appeals may be reviewed on an individual basis.

The HSE states that individuals' needs are evaluated against the criteria for prioritisation for the particular services and then decisions are made in relation to the allocation of resources. Resource allocation is determined by the needs of the individual, compliance with prioritisation criteria, and the level of resources available. The HSE stated that, as with every service there is not a limitless resource available for the provision of home support services and while the resources available are substantial they are finite. In this context, services are discretionary and the number of hours granted is determined by other support services already provided to the person/family. Although I appreciate that the HSE must act within resources, unfortunately, I feel that this leaves scope for a very minimal service that does not meet the original intended focus of PAS.

Sweden is the only European country which legally confers a right to personal assistance, although there is some legislation in this area in many countries, such as Denmark, France, Germany, Latvia, Norway, Serbia, Slovakia, Spain and the UK.

Nic Aogáin et al (2019) suggest that in the absence of a legal right to personal assistance in Ireland, those in need of this support often find the application process problematic, as there is no standardised procedure and those in receipt of this support do not have any security regarding the continuation or extent of their service due to lack of legislative protection. This is evident in the system described above by the HSE where the process can seem to vary between different CHO areas. The issue of eligibility will be explored further in Chapter 5. However, it is also important to note in the context of accessing services.

On 19 November 2019, a motion was put before the Dáil, which called on the Dáil to legislate for the right to access a personal assistance service for disabled people. The Government did not oppose the motion meaning it was passed with cross-party and unanimous support.



When asked whether consideration had been given to enacting legislation in relation to personal assistance services, the Department of Health advised my Office that “Work is continuing on the final legislative reforms needed for the highest possible level of compliance with the UNCRPD requirements”. I consider this to be vague and non-committal.

Personalised Budgets

Personalised budgets are connected but not exclusive to PAS. Egan (2010) states that the concept of direct payment schemes first emerged in the 1970s. He states that these were developed by disabled people and their organisations as a response to traditional dependency creating services run and controlled by non-disabled professionals. He explains that they “provide disabled individuals with funding to pay for the support they need to live independently in the community. This may include purchasing technical aids and equipment and, or more commonly, the employment of personal assistants to do the things they are unable to do for themselves due to the effects of their impairment”. These payment schemes give service users choice and control over their services.

Keogh & Quinn (2018) state that a move towards individualised supports for people with disabilities in Ireland is gathering momentum. The Task Force on Personalised Budgets was established in 2016 by the Government with the aim to make recommendations on a personalised budgets model which would give people with disabilities more control in accessing health-funded personal social service. However, Keogh & Quinn (2018) state that “Though Ireland has made a commitment to the advancement of service provision for persons with disabilities and the disability sector has advanced somewhat, individualised funding has not become a reality, except for the limited numbers using the Direct Payments model facilitated by ÁT”.

The Task Force published a report in 2018 recommending the trial of three demonstration models for the implementation of personalised budgets in Ireland before a national roll out. The DOH has advised my Office that the Personalised Budgets test pilot project has begun.

There are to be 180 participants, split into two phases of 90 each. Phase one participants have been selected, and the phase 2 participants will be selected from the expression of interest phase, which closed on September 7th. There are 10 participants currently receiving a direct payment, there are others in the process of 'unbundling' their payments from the provider, and others are in the process of on-boarding their payments.

Phase one is for direct payments only, while phase two will also include co-managed payments and brokerage payments.

Outside the pilot project, the HSE advised my Office that over the last number of years and in line with disability policy, bespoke individualised arrangements have been established for a number of individuals and in that regard the HSE currently funds a number of organisations (Áiseanna Tacaíochta and Possibilities Plus) whose core ethos is the development of individualised services.

In the context of the Task Force Report, it was agreed that a personalised budget is an amount of funding that a person with a disability may be considered for by the HSE. If a person qualifies for a Personalised Budget they can make their own arrangements to meet their support needs, instead of having their needs met directly for them by the HSE and HSE funded service providers. People with disabilities currently in receipt of HSE funded services can apply for a personalised budget if they so choose or they can choose to continue with their traditional services from the HSE or a HSE funded service provider.

I think this pilot project is a positive development. However, I realise there are complexities involved and the management of their own support service may be daunting for some service users. This is not the forum for detailed discussion on this but I think that the acknowledgement of the importance of choice and control is an important step forward.



Rehabilitation

Again, this is an area where there have been positive policy developments but these have been slow and may not yet be evident to those currently in need of services under this model of care.

The World Health Organisation defines rehabilitation as “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment”.

Rehabilitation is often associated with those who have an acquired injury. However, it may also be pertinent to those with other forms of disability. I have discussed above the difficulties these individuals may experience accessing such services whilst resident in a nursing home. There can also be difficulties accessing such services if living in the community,

Back in 2001, the Health Strategy, Equality and Fairness stated that “an action plan for rehabilitation services will be prepared”. This plan has been slow to come to fruition. In 2011, the Department of Health and the HSE published a Neuro rehabilitation Strategy. This set out a policy framework for developing neuro-rehabilitation services in Ireland in the period 2011-2015. It recognised that services in this area were underdeveloped. The National Clinical Programme for Rehabilitation Medicine was established in 2011 and a clinical lead was appointed. In 2018, the clinical programme published the Model of Care for the Provision of Specialist Rehabilitation Services in Ireland in 2018. An implementation framework for the strategy was finally published in 2019. This was 8 years after the strategy was initially developed.

O’Driscoll et al (2017) discuss the impact of this delay. They state “Currently, in the absence of established clinical pathways across existing acute and rehabilitation services, patient pathway is convoluted. For patients with the most complex and severest injuries access to complex specialist rehabilitation services is compromised and outcomes such as discharge to community is poor”. This explains some of the difficulties in accessing these services and the possible role this could play in younger people being admitted to nursing homes. Burke et al (2020) suggest that despite the publication of the implementation framework, challenges still exist.

They state that these include “the absence of services across the ‘pathway’, the under-resourcing of specialist rehabilitation services, the impact on the lives of people with brain injury of poor or no access to services, and the lack of good data on this population”.

My Office met a number of younger people with acquired brain injuries who are living in nursing homes. We also met a man who had transitioned from a nursing home back to his own home. This was a good example of how access to these services can make a difference.

The National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland from Theory to Action Implementation Framework 2019-2021 states “At an individual level, the impact of not receiving appropriate and timely services and supports can include deterioration in function and the associated physical and psychological sequelae. At a system level, it can lead to increased hospital admissions, with consequential delayed discharges and with many of the early advances negated by the absence of downstream services”.

I believe that at a systems level, this can also lead to inappropriate placements, which is of concern. I am hopeful that the implementation framework will bring positive change in the future. However, I remain concerned about those who have previously been impacted by poorly developed services and gaps in services, particularly where this may have played a role in their admission to a nursing home. It is important that we do not forget those affected by focusing on possible future positive developments. Furthermore, it is important not to forget these individuals because they are not currently ‘blocking’ acute hospital beds.

Ventilation

As outlined above, many younger people who are resident in nursing homes are those with high levels of dependency. Individuals who require ventilation would generally qualify as having a high level of dependency. Domiciliary ventilation is where ventilation is provided at home. In Ireland, domiciliary ventilation is available for children but it has not really been implemented for adults, unless paid for privately.



When asked about whether there was any plan for a National Domiciliary Ventilation Programme, the HSE advised my Office that the multidisciplinary team in the National Rehabilitation Hospital (NRH) have supported the development of a pathway with all of the necessary competencies and the provision of training. However there is the issue of funding home care packages and this is unlikely to change without a centralised budget. It stated that a National Domiciliary Ventilation Programme with access to resourcing would be welcomed greatly by the rehabilitation community.

Further to this the HSE advised that, in neurology, there was evidence that in some rare cases families independently fundraised to support family members that required full ventilation at home, but even with fundraised monies there were concerns from the medical community over the availability of 24/7 adequately trained staff to manage patients safely in the home. There is the need to have governance and oversight of a programme with a standardised approach.

The National Motor Neuron Service operated from Beaumont Hospital is one example of an outreach service where they provide Non Invasive Ventilation in patients' homes. The HSE advised that this has proven hugely successful (financially and from a holistic patient centred perspective) and has allowed patients stay supported in their home environments. This is a well-recognised service and during the COVID pandemic the service received additional funding to provide a more sustainable service with adequate staffing into the future and they hope to grow the service more in the coming years.

The HSE advised that at present these patients remain in the acute hospital setting for extended periods of time – often spending years in ICU or HDU beds. This was reviewed as part of the critical care programme in 2018, which gave a snapshot of data of those patients who were considered to be delayed in ICU because of the lack of funding for placement who could be considered appropriate for domiciliary ventilation. In essence, there is a plan with the foundations to implement this service, but there is the requirement for a dedicated funding package.

Again, the above suggests a lack of a uniform approach and an inequity in access to a service, which can impact on an individual's living arrangements.

Primary Care and Related Services

As outlined above, it seems that residents in nursing homes can experience difficulties in accessing primary care services. However, this problem is not confined to this group. I have also come across situations where people with disabilities in the community have experienced difficulties accessing such services. This can make living in the community much more difficult and can even lead to instability in an individual's living arrangements. My Office received a complaint from an individual who had moved from a congregated setting to independent living in the community. Various services were put in place when this individual transitioned. However, within the next few years, this individual found that a number of services provided through Primary Care, such as occupational therapy, physiotherapy support, care coordinator, social worker and incontinence advisor were stopped. The HSE advised my Office that this was mainly due to significant staffing issues in these departments at the time in question.

Time to Move on from Congregated Settings – A Strategy for Community Inclusion states “The Working Group is proposing a new model of support in the community. The model envisages that people living in congregated settings will move to dispersed forms of housing in ordinary communities, provided mainly by housing authorities. They will have the same entitlement to mainstream community health and social services as any other citizen, such as GP services, home help and public health nursing services, and access to primary care teams. They will also have access to specialised services and hospital services based on an individual assessment. People will get the supports they need to help them to live independently and to be part of their local community”.

It acknowledges that “The proposed model will test also the capacity of Primary Care Teams to respond effectively to community needs and it will demand an acceleration of the roll out of Primary Care Teams”.

I fully appreciate that the HSE must function within certain budgetary constraints. However, it is of deep concern to me that someone with a disability living in the community could be deprived of such essential services, particularly when they had moved to the community with the understanding that such services would be



available to them. This leaves individuals, such as in this case, in a very difficult position and may make it less feasible for them to continue living in the community.

Another extremely important service that individuals have reported difficulty in accessing is that of case management. However, this will be addressed in Chapter 5.

Pendant Alarms

Again, it is impossible to cover access to all services within the context of this report. However, I believe that the issue of pendant alarms highlights how the access to a service that people may not even think of, can have a broader impact.

A pendant alarm is a light-weight and discreet personal alarm trigger which can be worn on the wrist, around the neck with a wide and comfortable strap, or on clothing. When pressed, an alarm is raised.

The Seniors Alert Scheme provides grant support for the supply of alarm equipment to enable older people of limited means to continue to live securely in their homes. The scheme is run by Pobal, a not-for-profit organisation that manages programmes on behalf of the Irish Government and the EU. The grant assistance is made available through community, voluntary and not-for-profit organisations that are registered with Pobal.

To be eligible for the Seniors Alert Scheme, a person must be aged 65 or over and have limited means or resources. This means that younger people, including those with disabilities do not have access to a service such as this and if they require a personal alarm, they must fund it themselves.

Overall, difficulty in accessing a variety of services can greatly diminish the quality of life of those living in a nursing home and it can also play a role in the admission of younger people to nursing homes. I am particularly concerned about the lack of a uniform approach to applications for such services and determining eligibility. This will be discussed further in Chapter 5.



4.1 Finding

People living in nursing homes should have the same access to primary care services as people living in the community. However, the evidence provided by residents we met suggests that the availability of such services on the ground is at best patchy and at worst non-existent.

4.1 Recommendation

Each CHO Area should ensure that those people in their area who are identified by the national database (see recommendation number 6.1) are provided with the same level of access to primary care services as people living in the community.



4.2 Finding

Access to personal assistant support is inconsistent and inadequate.

4.2 Recommendation

The level of requirement should be established and a timescale put in place to deliver this in line with Sláintecare.

Chapter Five: Navigating the System

In my 'Six Rules for Getting it Right - The Ombudsman's Guide to Good Public Administration', rule number two is 'be customer oriented' and rule number three is 'be open and accountable'. Both of these rules are very applicable to this section.

A service is customer oriented when people can access services easily, including those with a disability or special needs. Furthermore, customers should be informed what they can expect and what the service provider expects of them. Customers should be dealt with helpfully, promptly and sensitively, bearing in mind their particular individual circumstances. Services should respond to customers' needs flexibly including, where appropriate, coordinating a response with other service providers.

A service that is open and accountable is open and clear about policies and procedures, and ensuring that information and any advice provided is clear, accurate and complete. It also explains the criteria for decision making and gives reasons for decisions.

All public services should be easy to navigate but this is particularly the case when it is a service that individuals may need to use at a time when they may be particularly vulnerable, for example, after a serious accident or illness. From speaking with individuals who have tried to access some of the services referred to in this report and from speaking to various advocacy groups, it seems that, at times, disability services can be difficult to navigate. This issue is very much connected to Chapter 4 in relation to access to services as some of the difficulties in accessing services seem to involve difficulties in navigating the system. These include accessing appropriate information on services, establishing entitlement and eligibility to services, knowing how to apply for services and understanding how services are allocated.

I will start by outlining some of the individual accounts provided to my Office. These highlight some of the difficulties these individuals have experienced in navigating the system. I will then discuss in more details some of the specific issues that seem to arise.



The Personal Experiences of Some Residents Under 65



Mark wishes to move from the nursing home. When he initially expressed his dissatisfaction with his living arrangements, a multidisciplinary meeting was held and the HSE agreed to look at community engagement. The HSE asked a local charity if they had any accommodation available as they had a number of houses for people with disability in the area. The charity put forward a house, which would be solely for Mark. The HSE then approved 6 P.A. hours a week to allow him to stay in the house once a week. It was his understanding that this was a trial and that the plan was that eventually he would live there full time. He thought that a business case was being submitted at that stage. He said that there has been no progress in the past 2 to 3 years and he has now discovered that his business case was only submitted a few months ago, as opposed to a few years ago as he thought. He has also now been advised that his business case has been looked at and there is no funding available for his increased hours. He has now been told that he may lose his house, as it is unoccupied for 6 days a week. There has also been discussion between different sections of the HSE as to who was responsible for his rent and this has led to arrears. His advocate stated that there seems to be a lack of clarity in relation to who in the HSE was responsible for Mark's care and she feels that no one person has taken control of his case and he does not seem to have a case coordinator or key worker. She said that this makes it more difficult when trying to progress his case as they don't know who they should be writing to. Mark does not feel that he is involved or consulted in relation to current decisions made about his care. He said that his only input is through the National Advocacy Service and often he receives information second hand or third hand through the National Advocacy Service.



Francis is anxious to return to his home, which is fully wheelchair accessible. The HSE has stated that Francis would need a full time carer to go home. The National Advocacy Service requested that his needs be reassessed. The HSE was planning a re-referral to the NRH at the time and said that this would involve reassessment, however, he was not eligible for the NRH as he had been there twice previously. There seems to be no other plan to have his needs formally reassessed. An application for home support has been made and refused. Francis has been informed that home support provided through disability services does not cover care at night, which it is felt he would need. Individualised funding and a personalised budget is now being discussed but his advocate is unsure whether this is under Disability Services or Older Persons Services. Francis has a case coordinator through acquired brain injury services in the HSE but his advocate and family feel that the case coordinator does not advocate enough on his behalf.



Charles is unhappy in his current placement. He does not think he has a case coordinator in the HSE. Charles and his family said that once he was admitted to the nursing home, HSE involvement largely ceased and there has been no on-going discussion in relation to his care. Charles described himself as being on the “scrapheap”. Neither Charles or his parents were aware of the National Advocacy Service. His mother was doing the best she could to advocate on his behalf by phoning various people in the HSE. She has also approached local politicians for assistance.



Michelle has a house but it is not wheelchair accessible. She applied for a grant to adapt it but she was informed that she would have to be living in the house to apply for the grant. Her advocate described this as a “chicken and egg situation”. She has applied for home support but this has been declined and her advocate states that she has to constantly chase the matter and send emails every few weeks to try to highlight her case. Michelle’s advocate said that only personal care hours are being granted and these are going to people currently in their homes or when family members can no longer provide care. She said that Michelle is considered safe as she is in a nursing home.



Alex wants to live independently. He said that he had a HSE social care worker or social worker who was based locally. He saw her around twice a year and seems to have found this useful. He says that she left her post and he was allocated a new person based further afield and he doesn’t think he has met them. His advocate assisted him with an application for local authority housing. He said that his social care worker was supposed to do this but as stated, he has very little, if no, contact. He said that he does not know where he is on the housing list. He said his advocate is of help to him but he feels that he has no one to “nag” the HSE about his case and he feels that he misses out in this regard. He did not know if an application had been ever made to the HSE for home support. He seemed to have difficulties differentiating between PA support and other home support. He said that he is not currently linked in with the HSE in relation to his future care.



Olivia is a 49-year-old woman with a progressive neurological condition. She was living at home with personal assistance support. She entered a nursing home for what she thought was a short period of respite and her stay ended up lasting one and a half years. She has since moved back into her apartment. She said that when she signed the Nursing Homes Support Scheme form, she thought it was just for respite and she spent her period of admission trying to get home. While she was in the nursing home, her apartment was kept for her and remained empty for the time she was in the nursing home.



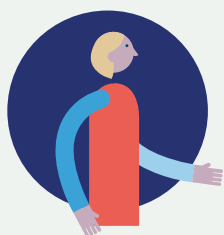
While **Adam** was in the nursing home he said that he submitted medical reports from doctors to the nursing home and that these reports supported that he did not need to be in a nursing home. However, he was only able to return home when the safeguarding officer from the HSE became involved. He had been referred to the safeguarding team due to a number of concerns, which did not relate to the care provided by the nursing home. The safeguarding officer organised a second opinion/reassessment of Adam's needs and abilities. The safeguarding officer also worked with ABI Ireland to prove that Adam had capacity to make his own decisions



When **Hannah** was medically ready to go home from hospital, she could not return home as her home was not wheelchair accessible. She told us that the Council provided her with a bungalow but further adaptation needed to be made. The nursing home was newly opened and Hannah was told that it was a unit for people under 65 with spinal injuries and brain injuries. However, she said that this turned out not to be the case. She said that she moved into this unit for what she thought would be a short period of time, while the Council did the necessary adaptations to her bungalow. The bungalow was finished some time ago but she is still in the nursing over a year later as her application for a care package has not been approved. The HSE is currently fully funding her placement in the nursing home, which involves a very sizeable top up payment.



They also pay for Hannah to go home in a taxi once a week. Meanwhile, her Council house is unoccupied. This is full of equipment such as bed, hoist etc. that has been funded by the HSE. A business case went to the primary care team but Hannah has been told that it is outside the remit of community care nurses to provide the level of care she requires. Her case is now gone to disability services under the social care division. Hannah has a case coordinator in the HSE but she feels that she is not advocating on her behalf and she finds this frustrating.



Although **Thomas** says that the staff in the nursing home are excellent, he feels very constricted. He is living in a dementia unit for older persons, which is a locked unit. He said that he addressed the inappropriateness of his placement with the nursing home. He said that he had meetings with staff and they agreed that it was not an appropriate placement. Himself and his advocate wrote to the Disability Manager twice. They had difficulty getting a response. When they did receive a response, they were advised that Thomas didn't meet the criteria for Physical and Sensory Disability Services. Neither Thomas nor his advocate are sure what service Thomas is currently under and what service he is linked in with. Because he is in a community hospital, they think that it may be older persons' services but this does not make sense, as he is 65. He receives O/T support but this is from the community hospital. Because they don't know what service he is under, it is difficult to know who to speak to about moving from the nursing home.



Initially, **Emma** resigned herself to living in the nursing home but 6 years ago, with the encouragement of her friends, she became more proactive in trying to move out of the nursing home. At the time, Emma engaged with the local Disability Manager without success. She also engaged with the Council in relation to housing. The Council sourced accommodation but it turned out it was not fire safe. There are currently new units under construction and she thinks that she will be allocated one of these. She said she originally made a submission, which included overnights, but the HSE wrote back to her saying they would not cover nights and asking her to resubmit. She has now resubmitted without overnights. She is still awaiting a response. She described housing and support hours as a kind of chicken and egg situation in terms of which needs to be approved first. Emma feels that interagency work in such situations could be much better. She said that departments do not seem to be talking to each other and she feels that if they did so, it would avoid overspend and further cost.



Andrew's family said that there was no residential place available in the intellectual disability service that Andrew had been attending for years. The family felt that there were no other options at the time other than a nursing home and that this was the best of a bad situation. They thought his stay in the nursing home would be short term as they were informed he was top of the waiting list for a residential place in his day service. However, he still has not been offered a place. His family do not know if the disability service is still actively pursuing a place for Andrew. They said that regular review meetings take place that include the HSE and the disability service. However, they are not provided with updates and they feel that decisions are being made without them being informed. They said that they do not feel that services are actively engaging with them in relation to Andrew's placement and that they have to constantly chase the issue.



Fiona was transferred to a nursing home from hospital 2 years ago. Her advocate said that the HSE said that this would just be for 6 weeks whilst they organised a house in the community. At one point, Fiona was told there was accommodation available and she went out and trialled equipment in the house and made decisions about furniture. She was subsequently told that there was no funding available for a care package and this continues to be the case, despite her hopes being raised a number of times. Her advocate is of the understanding that there is still a house available for Fiona but no care package. She said that an application for a care package is being resubmitted. She thinks this is going through a new process but she is unsure what this is. The advocate feels that Fiona would get a care package quicker if she was in an acute hospital.

Information and Applications for Services

A service that is open and accountable should ensure that information and any advice provided is clear, accurate and complete. Many of the individuals that my Office met with reported some difficulty accessing clear and comprehensive information in relation to what services it may be open to them to access. As outlined in Chapter 2, having all relevant information plays an important role in ensuring that informed consent has been sought and provided.

In Chapter 2, I query whether individuals had all relevant information available to them in a format they understood, when they signed the Nursing Homes Support Scheme form. I also query whether such individuals had clear and comprehensive information available to them in relation to any alternative options that they may have been eligible to apply for. Related to this, individuals under 65 who are living in nursing homes but wish to live in an alternative setting, have advised my Office that they have had difficulty accessing information on what alternatives may be available to them. Some of this may be related to a lack of a case manager or case coordinator, which I will address in more detail below. Related to this, advocacy bodies also informed my Office that they felt it would be helpful if there was a contacts database. Many individuals commented that they found it difficult to establish who they needed to contact in order to get the information they required. Others said that they found it difficult because there was no one person or central source who could provide all the information they wanted.

In their submission to the Department of Health in 2017, as part of the public consultation on home care, ABI stated that families told them that, following a brain injury, they have great difficulty in navigating the services and service providers. The information on services is not readily available in a ‘one-stop-shop’ and families report that it is very often a process of luck or chance encounters. This is also reflected in the IPH’s overview of the Department of Health’s Public Consultation on Home Care (2018). This report stated:

“More accessible information on how to access services across home care was highlighted by respondents: Not enough information and (it is) very hard to get.



At least 5 phone numbers before you get someone who will always give you another number that never works or doesn't get back to you. Then when you do get someone it's "fill out this form and we'll get back to you" (Family member or friend of someone who receives home care). A number of respondents pointed out that this is already a stressful time for patients, families and informal carers and that 'access to home care services are hidden in a maze' (Family member or friend of someone who receives home care); whereby information is critical, especially during points of crises, or when a number of decisions need to be made quickly (such as around hospital discharge processes). One organisation stated 'it's like you're begging, asking for home care' (Advocacy body)".

Lafferty et al (2016) outline how this is also the case for families caring for a person with intellectual disability in Ireland.

My Office asked the HSE whether there is clear information available to the public in relation to what services someone may apply for if they either were born with a disability or have acquired a disability. This was particularly in relation to living arrangements and related supports. The HSE advised that all information related to services is available via the weblink <https://www.hse.ie/eng/services/list/4/disability/>.

This includes information on:

- Children First in Disability Services
- Disability Assessment
- Informing Families
- Neurorehabilitation
- New Directions
- Personalised Budgets for People with Disability
- Progressing Disability Services for Children and Young People
- Time to move on from Congregated settings

- Residential Services
- Other useful links

The HSE stated that, for Children's Disability Services there are clear pathways outlined under the Progressing Disability Services programme. If someone acquires a disability as an adult, application or referral to Disability Services may take place in a number of ways. Individuals with complex needs who present through the Acute Hospital Community Liaison Teams or the Public Health Nursing System are referred to a Case Manager who works with the individual to assess need and refer to appropriate supports.

The HSE also informed my Office of other useful websites and said that the National Advocacy Service for People with Disabilities also provides independent advice and information to people with disabilities in relation to accessing services and any entitlements. The Department of Employment Affairs and Social Protection provides information to people regarding accessing allowances and entitlements or grants specifically available for people with disabilities.

Although it is obvious that there are sources of information available in relation to Disability Services, I am not convinced that there is one clear and comprehensive information source specifically available to individuals who may need alternative living arrangements or related supports due to their disability. For example, there does not seem to be one clear central written information source that outlines options such as home support, personal assistance, rehabilitation, primary care services, residential options and the Nursing Homes Support Scheme in the one forum. I think that it would be very helpful if someone in an acute hospital, or even at home where their circumstances had changed to the point that they cannot continue living at home or elsewhere without support or increased supports, could access this information in one place. For example, this could be in the form of an information leaflet, which would clearly point them towards the pathway for each of the services outlined. I believe that part of the difficulty with currently providing such a source of information is that pathways are not always clear cut and uniform and this will be discussed further below.



Another issue is that eligibility or entitlement to such services is not always clear and therefore, even if this information was available to them, it can be difficult to establish what is actually applicable to them and their particular situation and this will also be discussed further below. This is further compounded by the fact that so many services are discretionary and resource dependent.

Without targeted 'just in time' information on supports, it is nigh on impossible for vulnerable people to navigate this bureaucratic system.

Social Workers, Discharge Planners and Case Coordination

In their submission to the Department of Health in 2017, as part of the public consultation on home care, ABI said that the social workers in the hospital setting were identified as key providers of information on services. In the community setting, where there is a case manager, families identified their invaluable contribution to not only providing information but also offering real practical help in navigating the services and providers at a time in their lives where they are extremely vulnerable. However, they suggest that there is a lack of a comprehensive case management service across the country. From speaking with individuals and advocacy bodies, it is evident that this creates critical difficulties for people in navigating the system.

As outlined by ABI (2017), international best practice guidelines (British Society of Rehabilitation Medicine 2009 Standards for Rehabilitation Services, 2009:9) recommend that people living in the community (with ABI) should have timely and on-going access to a case manager/team to take responsibility for their rehabilitation and for their continuing care and support, who has knowledge of the various specialist and local services available and who works across the range of statutory, voluntary and other independent services to meet the person's needs.

I believe that this point is also applicable to those with other types of disabilities. Case coordination is key in assisting individuals and families with accessing relevant information and making applications for various services. This is particularly

essential in a system where there is not a uniform process or ‘one stop shop’ for applications. This latter point will be discussed further below.

Case coordination may be of benefit at a number of different points. Individuals and families may benefit from it when an individual is ready for discharge from hospital or, as will be discussed in more detail below, individuals who are living in the community, including younger people in nursing homes may also benefit from the assistance of a case coordinator.

My Office asked the HSE if all acute hospitals have medical social workers to assist with discharge planning and, if not, is there any plan in this regard. The HSE responded saying:

“The Report of the Expert Review Group on Delayed Discharges (November 2018) explored this issue. From the qualitative analysis performed, it appears that the level of support and assistance provided to patients and their families regarding a patients’ discharge, can vary significantly. While some hospitals have a Discharge Coordinator and a resource to assist patients with their NHSS (Fair Deal) applications, other hospitals appear to have neither resource.

It was therefore recommended that each hospital assesses whether the support provided is meeting the needs of their patients. Furthermore, level 3 and level 4 hospitals were recommended to consider the appointment of a resource to assist patients completing the NHSS application and one resource (Discharge Coordinator) to assist a patient and their family with the patient’s discharge. Level 1 and level 2 hospitals should have a joint resource which should be available as required. This recommendation is itself indicative of the further issue that the NHSS is all too often the default avenue.

As a follow on to this recommendation, an audit of roles was undertaken and it appears that while a few hospitals have medical social workers involved, the majority of transfers are managed by Discharge Co-ordinators. The NSP 2020 did not make any provision for any increase in staffing; however, and as referenced previously, the HSE is planning via the 2021 estimates process to specifically target persons under 65yrs in nursing home settings. Subject to resources being made available, this programme will integrate across community and acute settings”.



My Office also asked if the HSE had given consideration to the introduction of complex disability discharge planners. It had been suggested to my Office by a number of bodies that such a resource would be of assistance to individuals and their families. The HSE said that, in addition to the above, the HSE Delayed Transfers of Care Implementation Group co-chaired by Acute Hospitals and Community Operations (Services for Older People) has undertaken an audit of the roles currently in place involved in discharge planning and support. As mentioned, some hospitals do not have social work support, but there are Discharge Coordinator roles based in each acute hospital who liaise directly with patients, their families and with community services to safely plan discharges. The winter plan for 2020/21 has detailed submissions within it for further discharge planning and support roles across both acute and community sites that will be working across patient pathways to support complex discharge. These roles will be put in place when funding is approved.

Case coordination is not just required at the start of a journey or when there is an obvious change in circumstances. I will discuss case coordination and its specific impact on people under 65 in nursing homes further below in the section on Follow Up.

Interagency and inter departmental cooperation

As is evident in some of the personal accounts above, difficulties in navigating the system can sometimes arise as the individual may have to link in with different departments and sometimes even different agencies.

The Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services (2019) stated “Many people need to interact with multiple State services in order to receive the health and social care that they need at different stages in their lives. It can be wearying and frustrating to have to deal with many different State services, each handling one aspect of the care needed but with no overall responsibility for providing the integrated package of person-centred measures the individual really needs”. This refers to the fact that not all services are provided by the HSE.

However, even within the HSE, different services are provided through different teams and departments and processes followed by each can differ.

To further complicate this, a number of individuals and advocacy bodies informed my Office that they were advised that they could not access more than one service in terms of Older Persons Services, Disability Services and Primary Care. This has been touched upon previously in Chapter 4, when I referred to difficulties with nursing home residents accessing primary care. When my Office asked the HSE whether individuals can access more than one service in terms of Older Persons Services, Disability Services and Primary Care, the HSE responded as follows:

“The objective of the HSE is to provide a multi-disciplinary team approach that includes the provision of health and personal supports required by service users and incorporates hospital, primary care and community services.

The HSE funds a range of community services and supports to enable each individual with a disability, to achieve their full potential and maximise independence, including living as independently as possible. Services are provided in a variety of community and residential settings in partnership with service users, their families and carers and a range of statutory, non-statutory, voluntary and community groups. Services are provided either directly by the HSE or through a range of voluntary service providers. Additionally, services are provided based on the assessed needs of the individual and so therefore individuals can access more than one service in terms of Older Persons Services, Disability Services, Primary Care as their care needs require”.

However, based on the accounts provided to my Office, this information is not consistent with the experiences of service users.

The individuals trying to access these services may be doing so at a time of their life when they are particularly vulnerable, for example, they may only be coming to terms with a disability or a deterioration in their condition. The European Network on Independent Living (2017) also highlight that, outside of this, application and assessment processes require a certain knowledge of individual rights and entitlements, confidence and assertiveness, which puts disabled people with good education, coming from relatively well-off families in a more favourable position, relative to those with no qualifications or from minority backgrounds.



A number of advocacy bodies suggested to my Office that forms can often be lengthy and complex and can be difficult for individuals to complete.

As is evident in the personal accounts above, issues with inter-agency cooperation and communication can also cause difficulties for service users. For example, individuals have been advised by one agency that they need to apply for housing before a support package can be approved and they have been told by another agency that they have to apply for a support package before applying for housing. Another example is where housing has been allocated and is sitting empty waiting for an individual because a support package has not been approved at the same time. Not only is this frustrating for the individual but it is also an inefficient use of public funds.

A number of individuals advised my Office of how such scenarios can lead to them receiving very mixed messages, which can cause a lot of hurt and upset. For example, at least three individuals were told housing was available and they were actively involved in planning the layout of their interiors down to small details such as where sockets would go, only to be subsequently told that this accommodation would not be available to them, often because a support package was not simultaneously available. This can have a devastating effect on the individual and is totally unacceptable.

The HSE Code of Practice for Integrated Discharge Planning (2008) acknowledges that services cannot work in isolation from each other and it states that effective multi-agency and multi-disciplinary working is essential to manage the patient's journey from preadmission through hospital discharge to the community. However, interagency cooperation seems to remain an issue. Inclusion Ireland (2019), in discussing housing for people with intellectual disabilities, say that one of the biggest issues emerging from its advocacy work is the absence of joined-up services and the poor collaboration between Government departments regarding the availability and co-ordinated delivery of support services.

Steps have been taken in this regard. Strategic Aim 2 of the National Housing Strategy for People with a Disability is to address the need for cooperation and the provision of housing and support service.

It states that the National Housing Strategy for People with a Disability is “To develop national protocols and frameworks for effective interagency cooperation, which will facilitate person-centred delivery of housing and relevant support services”. However, Inclusion Ireland (2019) suggests that there is scant evidence that these frameworks have been developed or are working in any meaningful way and this also seems to be the experience of a number of individuals and advocacy bodies that my Office met with. Again, this may be a matter of communication.

I could write at length about the issue of housing. However, as previously indicated, the focus of this report is upon services provided by the HSE and Department of Health and therefore comments in this context are in respect of interagency cooperation.

The HSE has advised my Office that:

“In line with the National Housing Strategy for People with Disability Implementation Framework, the HSE, the Disability Umbrella Groups, the NDA and other stakeholders sit on the National Implementation Group and the Oversight Group responsible for the delivery of the Strategy. The Housing Agency chairs the Implementation Group and project manages the implementation of the Strategy. The Department of Housing chairs the Oversight Group.

As part of this work, the Department of Housing has drafted the “National Guidelines for the Assessment and Allocation Process for Social Housing Provision for People with a Disability”, to support and assist local authority housing staff. This document sets out the guidance to housing authorities in relation to the allocation of housing where there may be care supports required. Section 3.1 of this guideline states that,

“As stated previously the Local Authority is responsible for the provision of housing services, while the provision of relevant health and personal social services are the responsibility of the HSE. All individuals can live independently with varying levels of support, both formal and informal. The provision of these supports is not within the remit of the local authority (LA). Whether these supports are in place at the time must not inhibit the assessment process.



However, such supports are required to be in place prior to an individual being offered or taking up alternative accommodation to their current arrangements”.

For those moving from a congregated setting this is dealt with specifically under Section 4.7, Applications from Persons from Institutional Care/Congregated setting which states:

“The LA, HSE, housing association and service provider shall work closely together to deliver on the vision of the A Time to Move on from Congregated Settings, The Vision for Change and the NHSPWD to ensure that the housing need and housing choice of people moving from congregated setting is met.”

The full guidelines can be accessed at: www.housing.gov.ie

This is very helpful but again, it seems that guidance does not always translate into practice on the ground and improvements can always be made in this area

Applications

As outlined above, many of the points in relation to information are also relevant to actual applications for services. For example, there is often no uniform process for this or ‘one-stop shop’ where all applications for services can be made. A case coordinator or someone with extensive knowledge of the system can be helpful in this process. However, it is important to note at this juncture that case coordinators, social workers and discharge planners all have responsibility to their place of work and must also take factors such as patient flow into account, which may not always be easily aligned with the wishes of the individual in relation to discharge.

The process of applying for the Nursing Homes Support Scheme is relatively clear, as it is a statutory scheme with a uniform form and a standard process of allocation. However, other schemes such as home care are not always as straightforward.

In discussing applications for services, individuals and advocacy bodies that met with my Office outlined a number of factors that can make navigating the system more difficult. These include, but are not limited to, a lack of a person or place where applications are made. When applications for different services go to different places, it can take time to establish where to make an application for a service. On top of this, one must establish who to make an application to. As is evident in a number of the personal accounts above, some individuals were confused in relation to whether night time care can be provided at home and, if so, under which service does this fall. The HSE advised my Office that in some CHO Areas night time home care support care packages are provided. However, the provision of night time home care support packages is dependent on specialist needs and available resources and is not routinely provided in all CHO Areas. So, confusion in this regard seems justified. Other individuals reported being directed back and forward between Disability Services and Services for Older Persons.

A number of individuals and advocacy groups highlighted that at times there can be a lack of ownership of the cases of individuals with certain needs. This can arise where there is a dual diagnosis, which was evident in a complaint received by my Office from an advocate, on behalf of someone with both an intellectual disability and a psychiatric condition. When different services are involved, it leaves scope for both services to suggest that the other service may be the relevant service to apply for. The importance of inter-departmental and inter-agency cooperation is discussed above. One of the examples of this issue in terms of ownership that arose in both a complaint to my Office and in my contact with advocacy groups is that of services for people with alcohol related brain injury. One man who met with my Office with his advocate said that he did not know which service he fell under. This does not seem to be uncommon. The HSE highlighted to my Office that the Neurorehabilitation Strategy would support access to services based on clinically assessed need rather than diagnosis. I asked the HSE under what service do individuals with alcohol related brain injuries fall and if this is uniform across the country. I also asked under what directorate does alcohol related brain injury belong in terms of strategy planning and care pathways.



The HSE indicated that health services are provided based on the assessed needs of the individual rather than by diagnosis. It is this clinical assessment that determines the appropriate pathway for services, including Primary Care, Disability Services, Older People's Services and Mental Health Services as appropriate to their care needs. This applies to all people who present to health services, including individuals with alcohol related brain injuries. Again, this currently allows for these individuals to fall between gaps and seems to leave little scope for strategic planning on how to address the specific needs of this group.

Linked to the fact that it can be difficult to establish where to apply for a service is the fact that there is often no standard national process for applying for some services. Again, it can take time and effort to establish how to apply for a service. This also has ramifications for service allocation, which will be discussed further below.

When asked how home care for people under 65 is funded, the HSE advised that, in general, home support services for these individuals are funded through Disability Services. Home supports can also be provided through the generic home help service, which is operated through Older People's Services. With respect to those with acquired neuro-disability who require home care packages to support a discharge home, funding is sought through individual CHO budgets. If funding is not approved, there is currently no process for escalating the request for funding and the person can remain in the acute hospital setting or alternatively, will be placed in long term care.

The HSE is currently engaged with the Department of Health in relation to the development of a statutory home support scheme that will bring all home support services for adults under one heading.

However, in the interim these issues remain and are also applicable to services other than home care and will not therefore be rectified by this process.

Entitlement and Eligibility

Understanding what services an individual is entitled to or eligible for is an essential part of navigating any system and in making an application for services. The current system seems quite complex in this regard, with very little that is black and white or clear cut.

I am of the view that there is a difference between being entitled to a service and being eligible for a service. I will not focus on the semantics but for the purpose of this discussion, I am interpreting entitlement as a definite right to have something, whereas eligibility implies that the individual may meet the criteria to apply for a service but this does not necessarily mean that they will receive this service.

I make this differentiation because in Ireland, people with disabilities do not have any 'entitlement' to certain services. This is important, as I believe that entitlement confers a strong right or statutory obligation, which is less likely to be impacted by factors such as financial, and resource related constraints. In 2002, there was a case before the High Court - O'Brien v South Western Area Health Board. This raised the question of whether the right of an expectant mother, under section 62 of the Health Act 1970, to be provided by her health board with maternity and midwifery services included the right to services for a home delivery. In the course of the case, the High Court had to adjudicate on whether or not cost implications, or the availability of resources, could be invoked by the health board as a qualification on its obligations under section 62. In the event, Ó Caoimh J. found that such a qualification does not apply, stating: "... I accept, that if a clear statutory obligation exists, economic considerations cannot override the requirement of the section and I am satisfied that s.2 of the Health (Amendment) (No. 3) Act 1996 cannot be construed as overriding any clear statutory obligation to provide a specific service."

The 1947 Health Act originally placed responsibility for the delivery of health services on local authorities and this was transferred to the newly created Health Boards by the 1970 Health Act. In 2004 this responsibility was again moved, this time to the centralised Health Service Executive.



Fox (2013) explains that, under the Health Act 2004, the HSE may deliver these services directly or arrange for their delivery. However, she highlights that, other than specifying that health and personal social services do not include any services provided for under the Social Welfare Acts, the legislation does not offer any further direction and that, because of this ambiguity, it is difficult to be precise about what disabled people are entitled to in terms of state support for day, residential or independent living services. My predecessor, Emily O'Reilly (2012) said, in a public address, "...the HSE does not have a statutory responsibility to provide day care services for people with disabilities nor to provide physiotherapy, speech and language therapy or occupational therapy.[I]n the event of these services being curtailed or dropped, people who need them seem not to have any enforceable right to the services. ... [D]ecisions on rationing these services may be influenced by the fact that they are not services which the HSE is legally obliged to provide."

This is further complicated by ambiguity in terms of what constitutes 'care'. HIQA (2017) has highlighted that there is no definition in any of the relevant legislation of what is meant by 'care' or 'care and maintenance'. Other countries have provided a definition of care in their legislation, most often broken down into categories. HIQA suggest that this lack of definition can make assessment of whether appropriate care is being provided more difficult.

There is also a similar lack of clarity in relation to the meaning of community care. Wren et al (2012) highlight that no definition of "community care" appears in Irish legislation and as a result, eligibility for services is unclear. This has been previously acknowledged by the Department of Health (2010) whose expert group stated, "the whole pattern of entitlement to community services is complex and confusing". The European Expert Group on the Transition from Institutional to Community-based Care (2012) define community-based services for persons with disabilities as a "spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution". However, it states that, as is the case for institutional services, there is no common understanding in EU Member States as to what constitutes a community-based service. The Department of Health has informed my Office that a definition of care is not currently being considered by the Department.

In any event, given the necessary emphasis on developing person-centred, human rights based services, the concept of support is more appropriate and will need to be elaborated in the future statutory support scheme.

The issue of entitlement is complex. Some individuals with disabilities have highlighted to me that they are cautious about the concept of entitlement to services. They are concerned that any definite entitlement of people with certain conditions to some services could allow an easier exclusion of others. For example, they suggest that entitlement could become condition focused and this would be restrictive. The Drugs Payment Scheme and the Disabled Drivers and Disabled Passengers Scheme are examples of this. The latter is something that I have repeatedly brought to the attention of the Government.

Keogh for the Expert Reference Group on Disability Policy (2011) also addressed this issue and stated that, in the past, when diagnosis or disability type was used as a simple criterion of eligibility, people with disabilities needed to ‘fit with the available service’ in order to get a service, which can result in some being under-provided for and others receiving over-provision. It stated “Essentially, a simplistic use of classifications such as diagnosis or disability type as proxies for need represents an inefficient way of allocating resources as differences between individuals are not taken into account; rather than the needs of the person determining the allocation of resources, a common label is used instead”.

When asked if people with disabilities have any statutory entitlement to any services, the Department of Health informed my office that HSE Disability Services provide personal and social supports based on the needs of the individual, rather than the provision of services based on a specific diagnosis or condition. However, my question was broader. One can still have a statutory entitlement based on ones needs but this does not seem to be the case in Ireland. The 2001 Health Strategy, ‘Quality and Fairness, A Health System for You’ highlighted the absence of a “statutory framework underpinning access to services within a stated time frame” and it proposed legislation to remedy this. In addressing this issue, I think it is important not to ‘throw the baby out with the bath water’. Keogh for the Expert Reference Group on Disability Policy (2011) discussed resource allocation based on need.



She stated that “The allocation of resources based on need is essential to achieve equity in the provision of supports and services and provision that is fair and transparent. Equity does not mean equality in provision, i.e. that ‘everyone gets the same’. Equity means that access to and provision of service is based on need and implies a bias in provision in terms of those with greatest needs. This is the fairest way to distribute resources in the context of limited resources”. The HSE seems to acknowledge the importance of allocation based on need but my issue here is the fact that there is still no entitlement based on need.

The HSE confirmed to my Office that “There is no legislative entitlement to disability services”. It gave the example of the area of supports within the home. It highlighted that services are provided under Section 61 of the 1970 Health Act which states that “a health board may make arrangements to assist in the maintenance at home of a sick or infirm person or a dependent of such a person.” The Act specifies “may” and therefore the provision of services such as these is discretionary. Furthermore, the HSE stated that Section 61 of the Health Act (1970) goes on to state that “In making a determination under subsection (1), the chief executive officer of a health board shall comply with any directions given by the Minister”. In effect, this means that the provision of personal and social health services is directed by policy rather than legislation. The HSE also said that there is a requirement on the HSE to remain within budget and allocation of service is made on the basis of presenting need and/or associated risk factors. In respect of catering for the needs of individuals with disability who cannot reside at home without supports, the HSE advised my Office that, within Disability Services, current policies are based on the principles of person-centred approaches to ensure, insofar as is possible, that the supports for a person are based on individual assessed need, will and preference and to support people to remain as close to home and connected to their community. However, it pointed out that, as the delivery of supports is contingent on availability of resources and in the absence of multi-annual investment for this sector at present, the response to every individual’s needs is curtailed and tempered by the availability of resources to the HSE.

The consequence of the lack of a statutory entitlement to services and the lack of sufficient resources means that services for person with disabilities are often either unavailable or inadequate, with the exception of the Nursing Homes Support Scheme, which has been established on a statutory basis. This skews the system towards nursing home care. It also means that the application for such support may be more clear and straightforward than for other supports.

This issue of entitlement and eligibility has previously been raised by my predecessor, Emily O'Reilly. In 2010, she completed an investigation into the right to nursing home care in Ireland. This report noted that in July 2007 Mary Harney, Minister for Health and Children stated "Work is under way in my Department on a new legislative framework to provide for clear statutory provisions on eligibility and entitlement for health and personal social services, including appropriate charging mechanisms. The aim is to produce a clear set of statutory provisions that ensure equity and transparency and to bring the system up to date with developments in service delivery and technology that have occurred since the Health Act 1970." In 2008, Mary Harney stated "the current legislation has been in place for many years and there is a need now to have a clear set of statutory provisions that ensure equity and transparency and to bring the system up to date with developments in service delivery and technology that have occurred since the Health Act 1970. Accordingly, work is under way in the Department on a new legislative framework to provide for clear statutory provisions on eligibility and entitlement for health and personal social services. The legislation will define specific health and personal social services more clearly; set out who should be eligible for what services, as well as criteria for eligibility; establish when and in what circumstances charges may be made and provide for an appeals framework.... this is a very complex undertaking as the current legislation has been in place since 1970 [...] Given the complexities around this area, it will be necessary to obtain comprehensive legal advice in relation to the proposed legislation." This seems to remain an issue. The previous investigation was of a different nature and subject matter. However, some of the general discussions about eligibility and entitlement are pertinent to this report and it seems that, aside from the Nursing Homes Support Scheme, the situation has not changed much in this regard between 2010 and 2021.



The Committee on the Future of Healthcare - Sláintecare Report (2017) highlights that the 2001 Health Strategy, 'Quality and Fairness, A Health System for You' discussed the absence of a 'statutory framework underpinning access to services within a stated time frame' and proposed legislation to remedy this. This has not happened. The Committee suggests that instead, any extension or withdrawal of eligibility has been made on a piecemeal basis.

Assessment

A service that is open and accountable is open and clear about policies and procedures, and ensuring that information and any advice provided is clear, accurate and complete. It explains the criteria for decision making and gives reasons for decisions. This is relevant to the area of assessment as assessment often plays an important role in decision making. The concept of assessment ties in closely with those of entitlement and eligibility, as discussed above. Often, when an application is made for a service, an assessment is completed to identify if the individual is eligible or entitled to that service. The findings of an assessment may play a role in whether a service is allocated. Although, as will be discussed further below, this is not always straightforward.

In the past, assessments have been heavily influenced by the medical model of disability. However, some progress has been made in this regard and it is increasingly recognised that assessments in relation to disability require a holistic approach, which extend beyond the physical condition of the individual. For example, the HSE Code of Practice for Integrated Discharge Planning (2008) states that ensuring service users are discharged or transferred safely and on time requires full assessment of their individual healthcare needs, planning and co-operation of many health and social care professionals. It stipulates that "The purpose of a needs assessment in healthcare is to gather information necessary to bring about change beneficial to the health of the individual by taking account of the physical, psychological, social and emotional needs of the person". However, the ENIL (2017) suggests that, in practice, assessment can still be very medicalised.

It states that “this means that it focuses on a disabled person’s impairment and medical history, rather than on identifying environmental barriers that restrict their participation in society. The assessment is key for determining the type and level of support people receive. Therefore, a medicalised assessment may mean that disabled people’s support needs related to inclusion – rather than just basic needs – are not adequately addressed. Overall, assessment is used by many countries to judge eligibility for services and restrict access, rather than to identify barriers to participation in society. As pointed out by one of the consultation participants: “The assessment is designed in a way to ensure that the majority of people don’t get through”.

In Ireland, where resources are frequently an issue, assessments often form part of a gate keeping system in accessing services and supports. For example, as outlined in Chapter 4, a number of individuals spoke about how they were advised that they could only apply for a personal assistance service to meet their physical needs as opposed to social needs. This was never the intended purpose of the personal assistance service when it was first established. When my Office met with advocacy bodies, it was also suggested that there is a lack of a proper understanding of individual needs. Again, there can appear to be a narrow interpretation of these needs and assessment may not always adequately factor in self-assessment and the views of the individual in relation to their own needs. I believe this will be particularly relevant in the development of the new statutory home care scheme in terms of what ‘care’ it encompasses. Even the use of the word “care” is concerning. People need support in order to live full and engaged lives as valued members of their communities.

Another issue raised by advocacy bodies is that there is a lack of a standardised uniform assessment for individuals for accessing disability services. This has been raised as an issue for some time. The 2005 Report 52 of the C&AG cited concerns regarding the assessment of need in the NIDD and the NPSDD, namely that the assessment process to identify needs is not standardised nor is it independent (service providers make a judgement on the future needs of their current service users). It was noted that the assessment process ‘has been criticised for the tendency to identify needs from a narrow perspective and in terms of capacity to deliver’ (C&AG, 2005, p. 20).



Keogh (2011)) flagged the lack of a standardised needs assessment and the need for an approach to needs assessment that is driven by the person and family (as appropriate), who are centrally involved in the entire process; covers the important domains in a person's life; uses a standardised, reliable process; and is independent of those providing supports and services. The Department of Health (2012) recommended the development of a standardised client assessment. It stated "There are no objective and independent common assessment methodologies in use to allow a nationally consistent dataset to be collected on an individual's current service requirements". It recommended that a common assessment method should be developed or adopted by the HSE and implemented by disability service providers on a national basis to determine the services that are required by an individual.

The need for a common standardised assessment continues to be raised. Keogh & Quinn (2018) noted that there is no standard assessment tool by which persons with disabilities are assessed in terms of their care needs. They suggest that a single assessment tool is required to evaluate an individual's resource allocations based on the individual's goals, the impact of their disability, their family circumstances, their living arrangements and so on. Similarly, the Joint Committee on Health Report on the Provision of Homecare Services (November 2019) highlighted that in respect of home care, there is no standard assessment consistent throughout the CHOs and representatives who attended the Committee meetings noted that there was much ambiguity as to how each individual CHO assesses applicants.

The Disability Act 2005 provides for an 'Assessment of Need', which is an independent assessment of individual needs, a related service statement and independent redress and enforcement for persons with disabilities. The HSE has implemented the Disability Act since 1 June 2007 for children under the age of 5 years. Resulting from a High Court ruling in 2009, all children born since June 2002 have been deemed eligible to apply for an Assessment of Need.

However, there are a number of issues with this. Firstly, this assessment of need only currently applies to children. Secondly, the assessment of needs and related statement of need does not come with an assurance that these needs will be met. Keogh (2011) stated that there was an explicit disconnect between needs and services. Thirdly, the assessment of need has a very specific focus. Keogh (2011)

suggested 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. She stated that "Needs assessment generally refers to a highly structured process to gather information on a person's current abilities, resources, goals and needs. 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.

The Disability Act 2005 gives the individual with a disability the right to an assessment of only their health needs (in the case of children), or health and educational needs (in the case of adults) and by definition, excludes a consideration of the totality of needs of the individual". Keogh (2011) suggested that the Irish Assessment of Need process seems to adopt a rehabilitation/medical perspective, rather than an independent living/person-centred perspective. She stated that the assessment in its current form was not conducive to a policy that enabled the full inclusion of people with disabilities. It also made suggestions as to how an assessment of need should be framed.

The Department of Health has advised my Office that there are no current plans to extend the assessment of need to adults and that the legislation only covers Health and Education. It states that any extension of this remit would not be a matter for the Department of Health.

With the lack of an overall assessment of need, some assessments are developed for specific services. This has highlighted the lack of a standardised assessment process.

Since it was placed on a statutory basis, there has been a form of standardised assessment for nursing home care in place for some time, in the form of the Common Summary Assessment Report (CSAR). However, this in itself has not been ideal. All people under 65 who have been admitted to a nursing home under Fair Deal have had a care needs assessment. The purpose of the CSAR form is to assist in determining if someone needs long term nursing care. This care needs assessment is largely centred around the Barthel Index for Activities of Daily Living.



This index looks at issues like bowel, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, stairs and bathing. This is very much a medical and physical needs focus. As Pierce et al (2018) state “the 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”.

Keogh (2011) distinguished 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. Pierce et al (2018) suggest that the CSAR form belongs in the former category. They also highlight that 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 their sample. Pierce et al (2018) state “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 HSE has advised my Office that the CSAR is a global assessment tool capturing many indicators of need and that it is not exclusively for nursing home care. However, this does not seem to equate with experience on the ground.

There have been developments in relation to the Common Summary Assessment Form and the development of a standardised assessment or single assessment tool. The HSE issued an information document on the Single Assessment Tool (SAT) for Services for Older People. This states that the requirement for a national

single assessment tool stemmed from government strategies, policies and reports (such as Leas Cross Report [O’Neill, 2006], The National Quality Standards for Residential Care Settings for Older People in Ireland’ [HIQA, 2009] and most recently in the government’s Future Health Strategy [DoH, 2012]). It was based on the recognition that “many older people have wide ranging health and social needs and that agencies in Ireland need to work together to reduce fragmentation, so that assessment, care planning, and policy decision-making are effective, co-ordinated, and provide maximum value for money, and meet international best practice standards”. To address this need, a multi-disciplinary, multi-agency SAT Working Group was established to select, pilot and recommend a single assessment tool or suite of tools to be utilised for the assessment of older people nationally. Following pilot programmes, the SAT National Group determined in 2012 that the interRAI suite of tools were the most ‘fit for purpose’ for the Irish context.

The HSE website states that this is a “a comprehensive IT based standardised assessment used to assess the health and social care needs of people (primarily those over the age of 65 years) who may be looking for support under one the following two schemes:

- Nursing Homes Support Scheme (NHSS) – also known as A Fair Deal
- Home Support Services”

This is a positive development as it is an internationally approved standardised assessment, it extends beyond nursing home care and it has a psycho-social component.

There has been a particular absence of standardised assessment for home support. This is also the case for services such as personal assistance. It seems that this may be related to the fact that these have not been placed on a statutory footing. The Single Assessment Tool extends beyond nursing home care. However, concerns still remain in relation to the area of disability and standardised assessment.

The Single Assessment Tool has been developed for older people. As has been identified in this report, although there are overlapping areas, younger people with disabilities and older people do not always necessarily have the same needs and this needs to be recognised.



The HSE has acknowledged that the Single Assessment Tool that is currently in use was developed mainly with an older person focus. However, one of the pilot sites informed us that it has also been using the SAT for assessment of people under 65. It is my understanding that this is without any adaptation, which does not seem appropriate.

The HSE has informed my Office that HSE Disability Services is currently piloting two assessment tools as part of the Personalised Budgeting Demonstration Initiative – Imosphere in Phase one and InterRAI in Phase two. These assessment tools can be modified for younger people or people with certain conditions or who need to be assessed in certain settings. It also said that they may also be in a position to develop a bespoke assessment framework to meet the needs of people under 65 in nursing homes, if they are allocated ring-fenced funding, through the Estimates Process for the HSE's work with this group of people. I am of the view that a standardised assessment process for individuals with a disability should be advanced as a matter of urgency. It is important that this process takes a holistic approach, which comes from an independent living / person-centred perspective.

HSE Disability Services has also introduced a system called the Disability Support Application Management Tool (DSMAT), which enables CHO Areas to record and manage requests for support. The DSMAT provides a consistent listing process for each CHO Area by presenting a detailed profile of the individuals (Adults & Children) who require funded supports outside of the current service quantum. It captures detailed information on home and family circumstance and a detailed presentation profile of the individuals, including specialised profiles of behavioural intensity, key diagnoses, and complex support needs due to the extent and intensity of intellectual and/or physical & sensory disability. The HSE acknowledges that DSMAT gathers information, which only informs an assessment of need. It also acknowledges that some CHO Areas assess clients using a number of mechanisms and assessment tools. The HSE has told my Office that this represents an "indicator of need". However, I would argue that this differs from an assessment of need, as discussed above and it does not negate the need for the development of a standardised assessment process.

I will touch on this issue of assessment further in the section below on Follow Up.

Allocation of Services

As discussed above, individuals have experienced difficulties in navigating the system both in terms of finding the information they need and discovering how to apply for services. Another issue that was flagged was difficulty in understanding how services were allocated once an application has been made. Some of the issues that arise in this regard are similar to some of the issues discussed above. For example, one of the issues that arose was the lack of a uniform or standard process in dealing with applications. Other issues highlighted were a lack of clarity in relation to who makes decisions and how decisions are made. Related to this, was the lack of an appeals process when an individual was not provided with a service they applied for.

Some of these issues seem to have arisen from the manner in which the disability sector has developed.

One example of the above is the Personal Assistance Service. The HSE informs my Office that, at present, each CHO Area has a process to manage applications and referrals for PA Services. In general, services are accessed through an application process or through referrals from public health nurses or other community based staff, although an individual may also contact the CHO Area personally. Individuals' needs are evaluated against the criteria for prioritisation for the particular services and then decisions are made in relation to the allocation of resources. Resource allocation is determined by the needs of the individual, compliance with prioritisation criteria, and the level of resources available. As with every service, there is not a limitless resource available for the provision of home support services and while the resources available are substantial they are finite. In this context, services are discretionary and the number of hours granted is determined by other support services already provided to the person/family.

The local CHO Area would have an application form and decision making process in place and while they may not have a formal right of appeal system, appeals may be reviewed on an individual basis.



There are a few issues with this. The fact that each individual CHO Area has a process to manage applications means that there is no standardised process in place. Linked to this, any assessment of need is also unlikely to be standardised. This allows for inequity and particularly geographical inequity across different CHO areas. Furthermore, there is no formal appeals process, which should be a standard part of any application process. The HSE says that, as Ireland has now ratified the UN Convention, it will be necessary to have a policy on the provision of PA services with an agreed definition, criteria for accessing the service, assessment process and an indication of the level of support that can be provided. In this context, the HSE has established a work stream under the auspices of the National Disability Operations Team to progress this service improvement development. This will lead to a clear national standard application process for PA Services as well as governance procedures and an appeals process. I think this is a positive development and I would suggest that this work should be expedited. However, I also feel that such developments should extend beyond the Personal Assistance Service and that there should be a clear national standard application process, governance procedures and appeals process for all disability services.

Home care provides another example of deficits in this area. The HSE has advised my Office that in Older Persons Services there is an application process, including an application form, in place. However, in Disability Services there is no uniform national process in place, as CHO Areas generally use their own application process and application form for Home Support Services. The HSE says that the right to appeal decisions is discussed with the service user and /or their family members/ carers. However, given the lack of a uniform application process, there also seems to be a lack of a uniform process in terms of appeals. The fact that a standard process for older persons has been put in place but not for people with disabilities is of concern to me.

I appreciate that the provision of a statutory home support scheme will bring all home support services for adults under one heading and this process will include guidance and the tools to be used including forms, letters and appeals process. However, I feel the deficits in this regard to date highlight how people with disabilities have not always been treated fairly.

Furthermore, even a standard application process does not always ensure a standard model for decision making or service allocation. Each CHO and their respective care group management system carries decision making responsibility for assessment and decision making regarding home care packages. Again, placing home care on a statutory basis may assist in streamlining this. At present, in some CHO Areas there are Home Care Forums in place that make decisions in relation to all applications for Home Support. However, in other CHO Areas, decisions are made by the Case Manager or Disability Manger, who can approve Home Support hours within existing funding levels, or through business cases escalated to the Head of Social Care or other appropriate management structure. The HSE says that approval is generally based on clinically assessed needs and priority scoring and CHO areas are encouraged to use the Disability Supports Application Management Tool (DSMAT) as it provides a consistent listing process for each CHO Area by presenting a detailed profile of the individuals (Adults and Children) who require funded supports. However, this is not used throughout the HSE. Applications requiring approval are also subject to available resources, which will be discussed further below. The Joint Committee on Health Report on the Provision of Home Care Services (November 2019) also noted that there is no standard assessment consistent throughout the CHOs and representatives who attended the Committee meetings noted that there was much ambiguity as to how each individual CHO assesses applicants. It stated “there is no standardisation of assessment and many inconsistencies exist between various CHOs regarding eligibility of services”.

A number of individuals and advocacy bodies expressed frustration to my Office in relation to this process. They said that they have difficulty in establishing who is making the decision in relation to their application. One individual highlighted that they would have liked the opportunity to make personal representation in relation to their case to the person who makes the decision as they felt that their situation continued to become more depersonalised as it was escalated. They said it feels like they are “talking to smoke”. Others spoke about frustration at being constantly advised that their case was being passed on to another level without a full understanding of why this was the case or what the decision making process involved.



Disparities in allocation relate not just to processes but also to funding. As outlined above, Home Care Packages are provided locally within a given CHO Area and each CHO has a budget for Disability Services on an annual basis and has to plan and deliver services within its allocation in accordance with the HSE National Service Plan. Timonen et al (2012) observed that expenditure on home care services also varies significantly by geographical area, which creates egregious inequity in the availability of home care and access to services is, to a greater extent, determined by geographical location than by need. There has been some acknowledgment by the Government of the flaws in this system. The HSE wants to move towards a system of multi-annual funding resources, as per the Programme for Government. This would mean that funding is given for more than a year, which allows for better service planning and provision.

It is relevant to note that in 2004, the Government issued a statement in relation to multi-annual funding for disability support services. It stated “A multi-annual capital investment programme for disability-specific services will be developed within the overall system of five-year multi-annual capital envelopes that was introduced in Budget 2004. This was a major change in the treatment of capital spending. It provided for a rolling investment programme and a structured and planned approach to capital spending”. Proposed actions need to be fully implemented in order to create change.

The question also arises as to whether multi-annual funding will address all inequities in terms of funding in Disability Services. I fully appreciate that channelling funding through individual CHO areas provides for some autonomy locally. However, I would suggest that it can also lend itself towards inequity at times, particularly if funding is not directly linked to levels of need. This was highlighted to me by a number of advocacy bodies. For example, as outlined above, home care packages are provided locally. It seems that if there is a large demand for these services in an area due to a number of people with high dependency, then funding is more limited. The NRH suggested that a national funding source and process for complex home care packages could be helpful in this regard.

Similarly, ABI (2017) stated “There are a number of people with ABI with complex needs who require intensive home care packages (as currently exist for people with dementia) where there is a comprehensive package of support put in place to enable the person to live at home. The provision of such intensive home care packages needs a national framework and should be streamlined and centralised, with its own separate budget. One assessment process should apply which should be open and transparent.”

This would mean that the process would be streamlined and also that funding could be more based on individual need and priority on a national basis as opposed to resources available within any particular area. There is a commitment in the Programme for Government to increase capacity across all aspects of care and to continue investment in healthcare infrastructure and equipment, together with the recommendations of the Capacity Review, in line with Project Ireland 2040. However, this does not necessarily address this particular issue. The HSE also highlights that work is also currently ongoing to develop and implement a national home support scheme that will encompass all home support measures for adults including home care packages. Whilst the detail of this is still in its infancy, the scheme will be based on a standardised assessment of need that over time will ensure resources can be allocated equitably based on need and agreed prioritisation criteria to eliminate geographical inequity. As is evident above, I fully support the notion of standardised assessment but I would suggest that in order to fully eliminate geographical inequity, there needs to be more detailed exploration of funding models. As part of this investigation, my Office met with a number of different acute hospitals. There appeared to be disparity in how hospitals accessed funding for home care packages. Some hospitals seemed to be provided with set amounts for certain periods of time by CHO areas, where others seemed to apply on a case by case basis. This in itself highlights how the system is not streamlined and can be difficult for any professional to interpret, whatever about an individual who is trying to navigate the system.

Some of the issues in this regard seem to be related to the fragmented manner in which disability services in Ireland have developed. Disability services are delivered through a mix of HSE direct provision, non-statutory section 38 and 39 service providers, and private providers.



The structure of Disability Services in general obviously impacts on funding and allocation of services. In the Value for Money and Policy Review of the Disability Services 2012, it was noted that while the National Disability Unit of the HSE had lead responsibility for the planning, monitoring and evaluation of the Disability Services Programme nationally, it had no authority over resource allocation matters or operational service delivery. Responsibility in these areas lay with the HSE Regional Directors of Operations and the Integrated Service Area Managers. The Governance and Management structure within the HSE has changed since the publication of the Value for Money and Policy Review of the Disability Services 2012. In 2013, the Community Healthcare Structure was implemented whereby the former 18 service delivery areas were reconfigured into nine with a National Office in Dublin. Disability became part of the Social Care Directorate and was divided in two, in terms of service delivery - Operations and Strategy & Planning. Each Chief Officer has responsibility for all community services provided within their Community Healthcare Area and is required to provide those services within their annual allocated budget (resource). As highlighted above, I am of the view that a more innovative approach may need to be considered.

The HSE has advised my Office that the clinical lead will provide clinical leadership and guidance to effect the development and implementation of best practice care / support pathways and models providing a coordinated approach to integrated, person-centred, support for all people with a disability that is sustainable into the future. Through alignment with Sláintecare, the clinical lead and new clinical programme will support the development of a model of support for people with disabilities (and related programmes) that reflects alignment of community care/ support for people with disabilities, maximising access to those models and supports. Furthermore, the HSE has a Head of Operations Disability Services and a Head of Disability Strategy and Planning. These are national posts. I would again suggest that some funding structures may benefit from a more national approach in terms of ensuring equity in allocation of services, based on individual need. Smith et al (2019) suggest that in the absence of a national resource allocation system that relates supply to population need, it is likely that inequalities persist.

The HSE has highlighted that Sláintecare envisages implementing devolved budget allocations and operational key decision making at local level. I appreciate that a more national approach to funding allocation may not be in keeping with this. I would suggest that the answer to this may be in ensuring that devolved budget allocations are closely linked to need and that there is an interface between national services and local services. There also needs to be some level of flexibility in catering for fluctuating need and emergency situations. There should be a standardised, person-centred assessment of need as opposed to a more local approach. It is important that the allocation of services is not based on a 'post code lottery'.

Another issue highlighted to my Office was the difficulty that individuals have with future planning. For example, as outlined above, my Office met with the parents of a 40-year-old man who lives with them at home. He has a physical disability and some level of intellectual disability. His parents are in their 70s and they both have health problems. They are trying to put a long term plan for their son in place. A nursing home has been suggested as a possibility but they do not want this for their son. They remain concerned that their son will end up in a nursing home if something happens to them as they have been unable to put any alternative plan in place. They were told that this would be what happened, although the HSE advised my Office that it would not be supportive of this approach. This is a complex matter and I will discuss the concept of "deprioritisation" further below. Although I support a system of allocation based on need, this is not entirely straightforward as it can make forward planning more difficult as immediate need is often the focus. This can cause an extremely stressful and upsetting situation for families who are caring for family members and trying to plan for their future. It seems that the general answer to these issues lies within overall service capacity and provision. It seems that this is something that the Government and HSE is mindful of but I think it is important to highlight once again the personal stories behind those impacted by a service that does not seem to have adequate capacity. Understandably, finances are limited and I appreciate that this is particularly pertinent in the times we are in but it is important to highlight individual experience within this context.

A national, standardised approach to the assessment of need would allow for the development of a comprehensive picture of resource shortfalls across support services and would provide the basis for effective future planning.



Follow Up

Some of the discussions above are particularly relevant for people first entering the system and initially accessing disability services. As outlined above, the system is difficult to navigate, particularly at a time when an individual may be vulnerable. This is pertinent to the issue of people under 65 living in nursing homes as this experience may have played a role in their admission into a nursing home. However, difficulties in navigating the system are also more immediately relevant to younger people in nursing homes, particularly those who are actively pursuing a change in their living arrangements.

One of the big issues that arose when my Office met with younger individuals in nursing homes and also with advocacy bodies is an overall lack of follow up when a younger person is admitted to a nursing home. The HSE advised my Office that each CHO area is encouraged to actively review each placement in nursing homes. However, this often does not seem to be translated into practice.

The Value for Money and Policy Review of the Disability Services 2012 recommended that an adult's requirements for supports and services should be re-assessed at the individual's request, at key transition periods or following a change in the individual's health or personal circumstances, but in any event not less than once every 3 years. This is to ensure that services are responsive to the changing needs of the individual. This re-assessment process should be practical and capable of being integrated into an agency's person-centred planning and staff utilisation and deployment planning processes.

My Office asked the HSE if the situation of all people under 65 in nursing homes is automatically reviewed at regular set periods, by the HSE as opposed to the nursing home, and, if so, under what process. The HSE advised my Office that under HIQA Standards, all designated residential centres must undertake a review/assessment of the care needs of every resident, regardless of age. This review is ordinarily carried out by the service provider who is contracted by the HSE to provide services in accordance with service arrangements. However, in some CHO Areas, the HSE will endeavour to review and possibly reassess service users who are known to them or who receive additional funding/supports from Disability Services on a regular basis.

For example, in one CHO Area, HSE Disability Services have reviewed a number of the under 65 nursing home placements in terms of reassessing needs, sourcing additional resources or planning to source appropriate alternative accommodation options. However, this is not uniform across all CHO Areas. I am of the view that in such cases, it is not appropriate for a nursing home to carry out this particular assessment and that regular review by the HSE should be standard for all younger residents in nursing homes.

A number of individuals advised my Office that when they were admitted to the nursing home, their contact with the HSE largely stopped. Others reported having caseworkers of some sort but described minimal contact. The importance of case coordination is referred to above. The main support in this regard often seems to be provided by the National Advocacy Service. Mainly people spoke about having to “chase” professionals. This involved numerous phone calls and much initiation on the part of the individuals or their advocates. One man felt he was at a disadvantage as he feels that he has no one to “nag” in the HSE about his case and he feels that he misses out in this regard. It seemed to be a common view that some sort of persistent approach on the part of the individual and/or their advocate was necessary to progress their case.

A lack of regular automatic review is problematic on a number of levels. One of these is that it does not take into account the potential for change in individuals. By change, I am referring to both change in needs but also change in ability, to include both reduced or increased support requirements. To ignore ability and potential for improvement means reversion to a very medical model of care. For example, my Office asked the HSE if the Common Summary Assessment Report for nursing home care caters for potential for rehabilitation and other potential future changes in an individual’s condition. The HSE stated that to be eligible for the Nursing Homes Support Scheme a determination must be made to confirm that an applicant needs nursing home care. The care needs assessment is carried out by appropriate health-care staff using a standardised common summary assessment report (CSAR) and considers healthcare needs and family and social supports of an applicant. The CSAR was developed for this specific purpose. It is used to determine the need for long term care rather than rehabilitation.



To me, this seems to ignore potential in younger people in nursing homes and highlights even further the need for regular reviews. Farrell (2013) states “Strong evidence emerged from this survey that once the person was placed in the nursing home there was no perceived system or practice for a thorough external review of the placement, unless the person’s health or behaviour deteriorated, to check how the person was progressing or what supports the person needed”.

Linked to this is the concept of person-centred planning. Farrell (2013) suggests that there should be a mechanism for a regular independent person-centred review of the funded placement for those currently in nursing homes, which must include the person, their advocate and/or family member. This concept of a person-centred approach and person-centred planning is relevant to much of this report. Navigating a system becomes much easier if it is person-centred. A person-centred approach is a key tenet of the HSE’s Transforming Lives programme. The National Disability Authority supported the HSE to develop a National Framework for Person-Centred Planning, in response to an identified need for a more consistent approach to person-centred planning in Ireland. HIQA’s National Standards for Residential Services for Children and Adults with Disabilities (2013) states that a person-centred approach to service is one where services are planned and delivered with the active involvement and participation of people who use services. The NDA Guidelines on Person-Centred Planning in the Provision of Services for People with Disabilities in Ireland (2005) states that in practical terms, this means that all planning around the design, development and delivery of all services for people with disabilities should be both based on and actively involve the individuals availing of these services and each of those individuals’ unique characteristics, capabilities, needs and wishes (that is: conducted in a person-centred way). A person-centred plan is not a plan for person-centred service provision (a ‘service plan’ as such) but is, rather, a personal, overall life plan for an individual. It is different to individual programme planning, which is characterised by a synchronised and standardised approach to addressing identified needs. The NDA states that person-centred planning requires a flexible and responsive approach to meeting an individual person’s needs and changing circumstances, guided by the principles of good practice rather than a standard procedure.

The HSE developed a National Framework for Person-Centred Planning in Services for Persons with a Disability in 2018. In this document, the HSE adopts the following description of person-centeredness:

”an approach to practice established through the formation and fostering of healthful relationships between all providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development” (Adapted from McCormack & McCance, 2016:3[1]).

A person-centred approach may involve some level of positive risk management, which I previously alluded to in the context of informed consent and the right to self-determination. This is acknowledged by the HSE. A lack of regular updated automatic review does not qualify as a person-centred approach.

Another issue that may fall under follow up but is also relevant to general applications relates to how funding is managed. This was in part discussed above. It seems that there are what I would describe as ‘funding silos’. By this, I mean that funding for a particular service comes from a particular budget for a particular reason and there is no flexibility in this regard. One of the most obvious examples of this is ‘top ups’. There are persons with a disability under the age of 65 years who are resident in nursing homes under the Nursing Homes Support Scheme (Fair Deal) and who are in receipt of additional payments from Disability Services, as the weekly cost is in excess of the Fair Deal limit, due to the specialised nature of the care involved. These additional payments are managed on a case by case basis, depending on the needs of the individual and in line with individual preference and available resources. Funding comes mainly from local Disability Service budgets.

At present, the CHO Areas oversee/manage additional payments in a number of different ways. The HSE states that in line with Disability Service Improvement, the National Disability Operations Team has established a work stream to develop and implement a standardised process in this area, which will include formal guidance, governance arrangements and an appeal structure.



Although I fully understand the benefit of these top up payments, I have a number of issues with them. Firstly, the seemingly discretionary nature of them with a non-standardised process of application and allocation is of great concern. Hopefully the National Disability Operations Team's new work stream will deal with this as a matter of urgency. My views in relation to deficits in standardised processes are quite clear in the section above on service allocation.

My issue in the context of this section is the aforementioned problem of 'funding silos' and how they impact on service provision. Whereas top ups are available in relation to nursing home care, they do not seem to be transferrable to home care or related services. This lack of transferability seems to be a broader issue in relation to funding and a number of advocacy bodies commented that funding does not always 'follow the person'. My Office asked the HSE to what extent does funding follow the person and, if there is transfer between different services or support, does the funding move with the person. The HSE again advised that there is no uniform policy in this area and the practice within CHO Areas varies from area to area and from service provider to service provider. For example, with the Personal Assistance Service, the HSE advised that while some CHO Areas indicate that Personal Assistant funding will follow the person if they transfer between different services or supports, other CHO Areas suggest that a full review of the needs of the service user will be undertaken if a transfer between services takes place. I have discussed inter-agency and inter-departmental cooperation and I would like to highlight it again at this juncture. I believe that if someone is in receipt of a service and they do receive a review, they should not have to start from scratch in applying for funding for alternative services. This is excessively bureaucratic.

Deprioritisation

The HSE has advised my Office that allocation of services is based on need. I fully support needs based allocation in disability services. However, as referred to above, the interpretation of this can cause some complexities. Many of the individuals who my Office met with, who were actively trying to move from a nursing home, felt that they were deemed to have a lower level of need as they were considered 'safe' in the nursing home.

They felt that their placement in a nursing home meant that they were deprioritised and this meant they were caught up in a scenario where they could not advance their case.

The HSE informed my Office:

“It is not the policy of the HSE to deprioritise any individual under 65 admitted to a nursing home for any alternative supports. Each individual’s situation and care needs are unique and therefore an individualised person centred approach is required. The will and preference of the person is a priority and a person may choose to leave a nursing home at any time. Some CHO areas report that some individual service users are admitted to nursing home care on a short-term/interim basis as part of a transitional care plan from Acute Care to return home or alternative specialist accommodation. Some service users’ needs are more complex and intensive requiring substantial care input. All requests for alternative supports for people with disabilities are managed on a case by case basis and in the context of severely limited resources. Each CHO Area is encouraged to use the DSMAT system as it aims to deliver services in an equitable and targeted manner to where the highest need is.

Additionally, each CHO Area is encouraged to actively review each placement in nursing homes. Requests for additional supports and/or request for alternative placement options, particularly where these are deemed more appropriate for service users must be considered on a case by case basis taking in the circumstances, support needs and will and preference of the individual within available resources. The HSE does not have capacity to meet all needs and requests. Decisions made endeavour to mitigate presenting risks.

It must be noted that this area is a significant area of need and is highly resource intensive. This deficit reflects the growing population of people with disabilities, longer life expectancy and more complex needs presenting, along with a lack of structured investment in residential and home supports over a number of years. A suitable Case Management Model to deal with individual cases is required and can be included in the Estimates Process.”



I would like to clarify that I am not saying that the HSE is intentionally deprioritising these individuals for services. However, I do feel that the system, as it currently operates, inadvertently leads to this as an end result. These individuals seem to be caught in a cycle that is very difficult to exit. At least two individuals my Office met were admitted to a nursing home on an emergency basis due to safeguarding concerns at home. However, now they are resident in the nursing home, it seems very difficult for them to access an alternative.

Integrated Care Pathways

According to the HSE's webpage, the HSE is leading a large-scale programme of work to develop a system of Integrated Care within health and social care services. This is a long-term programme of change and improvement for health and social care services, and will involve people at every level of the health service working together to create improved experiences and outcomes for the people in our care. Integrated care has the patient perspective as an organising principle of service delivery. The HSE states that integrated care is not a new concept and arises from the consequences of fractures in systems and delivery that allow individuals to 'fall through the gaps' in care – e.g. primary/secondary care, health/social care, mental/physical health care. The WHO has provided a framework including five inter-dependent strategic directions to support people-centred and integrated health services with key actions (WHO/HQ, 2015).

1. Empowering and engaging people
2. Strengthening governance and accountability
3. Reorienting the model of care
4. Coordinating services
5. Creating an enabling environment

Given that integrated care is an approach that targets fragmentation of services and preventing people from falling between the gaps, the question arises as to whether an integrated care approach to disability services would benefit the service user and lead to a system that is easier to navigate.

The HSE is introducing four Integrated Care Programmes being rolled out on a phased basis. These are:

- Integrated Care Programme for Older Persons
- Integrated Care Programme for Children
- Integrated Care Programme for Patient Flow
- Integrated Care Programme for Prevention and Management of Chronic Disease

Work done within some of these programmes is already addressing some of the issues identified in this report for the target groups of the programmes. For example, in its submission to the Department of Health's consultation on home care services, HIQA (2017) stated:

“The development and enhancement of integrated care is a necessary development in Ireland's health and social care services. The lack of availability of adequate homecare services is often cited as a reason for delayed discharges from acute hospital beds. Our own research has also shown that the alternatives to long-term residential care are underdeveloped in Ireland. Fostering greater integration between primary, community and acute care would improve the options available to people and relieve pressures and bottlenecks throughout the system. What this means for the individual who needs care is that they will experience a continuum of care that is seamless. HIQA notes the work being done by the HSE's Integrated Care Programme for Older Persons in this regard. This type of programme offers a framework by which homecare can form a key part of a suite of services for older people, allowing them to remain in their homes and communities to the greatest extent possible”.



HIQA highlighted that not all recipients of home care are older people and it suggested that the development of integrated care programmes for people with disabilities (intellectual, physical and sensory), mental health issues and substance abuse/addiction problems is also encouraged.

Similarly, ABI (2019) discussed the HSE Integrated Care for Older People and the 12 pioneer sites. It suggested that an integrated care approach is a disruptor in the system and one where the population's needs are prioritised over the organisation's needs. It stated that we must learn how to do integrated care and we need to have resources in the system to facilitate this change led nationally with local systems co-designing and co-creating the response.

A more integrated service may address some of the issues highlighted in this chapter.



5.1 Finding

This group of people need support to enable them to understand and navigate the system, to have their wishes and preferences identified and acted upon and to have their voices heard.

5.1 Recommendations

- a. *A case coordinator (key worker) should be appointed by the HSE for each individual included in the national database.*
- b. *A comprehensive information package should be drafted by the HSE aimed specifically at these individuals. This should include relevant points of contact, an outline of rights and entitlements as well as a road map as to how to apply for and access any relevant support schemes and services such as relevant NGOs, the National Advocacy Service etc.*



5.2 Finding

The HSE has indicated that each CHO Area is encouraged to actively review each placement in nursing homes and that requests for additional supports and/or alternative placement options should be considered. The HSE says that, in this regard, the assessment process of individual needs should be supported by a suitable Case Management Model. The Department of Health has told my Office that it agreed that a care and case management approach should inform the approach to assessing the need for placement and that there should be provision for a review of such placements and consideration of requests for additional supports and/or alternative placement options.

5.2 Recommendation

A Case Management Model should be drawn up by the HSE and rolled out through each CHO Area within twelve months of the publication of this report.

Chapter Six: Policy and Human Rights

Human Rights

I have referred a number of times to the movement from a medical model of disability to a social model of disability. There are ongoing changes in disability discourse. Similarly, and in parallel with this, there has been ongoing developments in the area of human rights. IHREC (2015) defines human rights as “the basic rights and freedoms that belong to everyone. International law, including treaties, contain the provisions which give human rights legal effect”. I do not propose discussing human rights in great detail as this is more appropriate to the Irish Human Rights and Equality Commission as Ireland’s national human rights and equality institution.

However, the work of Ombudsman offices across the world involves a strong focus on human rights and my Office is no different. The Venice Principles on the Protection and Promotion of the Ombudsman Institution were recently adopted by the UN as the global principles governing Ombudsman offices. The General Assembly motion adopting them was co-sponsored by Ireland. Article 1 of the Principles states that “Ombudsman Institutions have an important role to play in strengthening democracy, the rule of law, good administration and the protection and promotion of human rights and fundamental freedoms.” Furthermore, Section 42 of the Irish Human Rights and Equality Commission Act 2014 places a positive duty on public sector bodies to have regard to the need to eliminate discrimination, promote equality, and protect human rights, in their daily work. This is applicable to not only my Office but also to the Health Service Executive and the Department of Health.



When it comes to the rights of persons with disabilities, the UN Convention on the Rights of Persons with Disabilities is one of the key human rights instruments for the protection of these rights and it embodies the social model of disability. On 13 December 2006 the General Assembly of the United Nations adopted the Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD was opened for signature in March 2007 and came into force on 3 May 2008 following the 20th ratification. The Convention covers both civil and political rights (such as the promotion of equality and protection from discrimination, the right to freedom from exploitation, violence and abuse, and participation in political and public life) and economic, social and cultural rights (such as the right to education, work and adequate standard of living).

Many of the articles of the UNCRPD are interrelated. However, the article that arguably has most direct relevance to the issue of younger people in nursing homes for older people is Article 19 of the Convention which 19 states:

“States Parties to the present 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.

Many of the articles of the UNCRPD are interrelated and in a general comment on Article 19, the United Nations (2017) stated “Article 19 is one of the widest ranging and most intersectional articles of the Convention and has to be considered as integral to the full implementation of the Convention”. It said that Article 19 entails civil and political as well as economic, social and cultural rights and is an example of the interrelation, interdependence and indivisibility of all human rights. The right to live independently and be included in the community can only be realised if all economic, civil, social and cultural rights enshrined in this norm are fulfilled.

For example, Article 19 is underpinned by one of the general principles of the CRPD set out in Article 3, namely, the ‘full and effective participation and inclusion in society’. Furthermore, articles such as Article 12, which addresses equal recognition before the law, is relevant to some of the issues discussed in Chapter 2 on informed consent. Article 9 deals with ensuring accessibility, Article 25 deals with the right to quality health services and Article 26 deals with habilitation and rehabilitation. All these Articles are relevant to this report.

Ireland, Disability and Human Rights

Ireland was the last Member State of the European Union to ratify the convention. Ireland signed the Convention in 2007 and further to its ratification in March 2018, it entered into force from 19 April 2018.

Ireland has not ratified the Optional Protocol to the Convention, a separate instrument which would allow for individuals and groups of individuals to take a complaint to the UN Committee on the Rights of Persons with Disabilities in the case of an alleged violation of their rights. This also means that the UNCRPD is not justiciable in an Irish Court.

The Department of Health sought an update on the ratification of the Optional Protocol to the Convention from the Department of Justice and Equality, which provided the following response:



“Originally, it was intended to ratify the Protocol at the same time as the Convention. However, the focus at the time was to ratify the Convention itself as a first step.

Therefore, the Optional Protocol to the Convention was not ratified at this time with a commitment given to ratify the Protocol as soon as possible following completion of Ireland’s first reporting cycle. The reasoning was that this would provide an opportunity to identify areas for improvement and any actions needed for a high level of compliance.

Work is continuing on the final legislative reforms needed for the highest possible level of compliance with the Convention’s requirements”.

IHREC states that, although Ireland has ratified a number of international human rights treaties, under Irish law, an individual can only engage the protections afforded under human rights law that has been incorporated into national law, such as for example the rights protected under:

- the Irish Constitution
- the European Convention of Human Rights Acts 2003 and 2014, and
- where EU law is applicable, the EU Charter of Fundamental Rights

This means that although Ireland binds itself in international law upon ratifying a human rights treaty, it only gives effect to the provisions of that treaty in domestic law through Acts of the Oireachtas, or where a treaty right is already provided for under the Irish Constitution. However, IHREC highlights that this lack of incorporation of the UNCRPD into Irish law does not, however, mean that these standards cannot be raised in legal argument. IHREC states that the Irish Courts can, and have attached a form of persuasive authority to unincorporated international human rights instruments. In *M.X. v Health Service Executive* (2012) IEHC 491, the High Court regarded the Disability Convention as “a helpful reference point for the identification of “prevailing ideas and concepts”, which are to be assessed in harmony with the constitutional requirements of what is “practicable” in mind.”

Parker and Clements (2008) also suggest that the right to independent living is not a new right under the UNCRPD. They highlight that the United Nations Handbook for Parliamentarians, 'From Exclusion to Equality, Realizing the Rights of Persons with Disabilities' stresses that the Disability Rights Convention is not intended to create new rights rather it 'complements' existing human rights treaties and: '... clarifies the obligations and legal duties of States to respect and ensure the equal enjoyment of all human rights by all persons with disabilities'. They say that this suggests that Article 19 has not created a new right. Rather it is intended to provide a clarification of the obligations on States to ensure disabled people's full and equal enjoyment of this right. Fox (2013) similarly suggests that the core elements of the right to independent living are inherent in pre-existing international human rights and, in this way, they can be detected in Irish law.

In Europe, the key legally binding human rights treaties are the European Convention on Human Rights ('the ECHR') and the European Social Charter. The ECHR sets out a range of civil and political rights while the European Social Charter addresses economic, social and cultural rights. As part of the Good Friday Agreement signed in 1998 the Irish Government agreed to incorporate the ECHR into Irish legislation leading to the passing of the European Convention of Human Rights Act in 2003. The passing of the Lisbon Treaty also marked progress in the status of human rights within the EU with the elevation of the place of the Charter of Fundamental Rights to that of equal value to the Union treaties, and the commitment to accession to the European Convention on Human Rights (ECHR) by the EU.

The EU Charter of Fundamental rights does not specifically refer to the right to independent living but Article 5 refers to the right to liberty and security of person, Article 8 centres on the right to private and family life, Article 20 involves equality before the law and Article 26 covers integration of persons with disabilities. It states "The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community".



The Council of Europe Commissioner for Human Rights (2012) recommended that member states of the European Council should review their legislation and policy in the light of Article 19 of the UN Convention on the Rights of Persons with Disabilities, with a view to ensuring that everyone with disabilities enjoys an effective right to live independently and be included in the community, irrespective of the nature of the impairment.

MDAC (2011) give examples of a number of cases where the CRPD has been referred to in court cases in Europe. In *Glor v. Switzerland* (2009) the European Court of Human Rights (ECHR) made explicit reference to the CRPD as the basis for the “existence of a European and universal consensus on the need to protect persons with disabilities from discriminatory treatment”, despite the fact that Switzerland had not yet signed the Convention. The ECHR’s judicial decision in *Kiss v. Hungary* (2010) made mention of the CRPD and although not specifically referencing the CRPD, the *Shtukaturov v. Russia* (2008) decision was nonetheless harmonious with its principles. The judgment in *AH v. West London Health Trust* (UK, February 2011) referenced the CRPD directly, concluding that Article 13 of the CRPD “reinforced” the applicant’s Article 6 ECHR rights.

I believe that although Ireland has not yet ratified the Operational Protocol to the UNCRPD, it still provides essential guidance and Article 19 is extremely important in the context of this report. In terms of a more general focus on human rights, HIQA (2019) has published *Guidance on a Human Rights-based Approach in Health and Social Care Services* and I believe the tenets of this guidance also tie in with this report and provide relevant helpful guidance.

Policy in Ireland

Historically, the manner of the evolution of Disability Services in Ireland meant that in the early years of the provision of services, policy was not a priority. Linehan et al (2014) state that the historical development of services for people with disabilities in Ireland can be traced to an edict by the Westminster Parliament in the early 19th century not to provide ‘outdoor relief’ to those in need.

Assistance would be provided only to those who entered workhouses, thereby excluding those who remained in the family home. They state that, after political autonomy in 1922, the Irish state assumed responsibility for providing supports for those in need: for example, those with intellectual disabilities, epilepsy, or mental health difficulties, as well as unmarried mothers and their children. However, the State had few resources and was enmeshed with the Catholic Church, in line with the Irish Constitution. The Church came to dominate health and social care service provision in 20th century Ireland, including provision for those with intellectual disability and the Irish state adopted a hands-off approach, delegating many aspects of health, social care and education, to religious orders, with little oversight. Linehan et al (2014) state that since the publication of Needs and Abilities in 1990, a raft of policies have been developed aiming to transform disability services from a traditional, and congregated model of care, towards a model whereby people with disabilities are supported to live a life of their choosing within their own local communities.

Internationally, there has been a general move in society from a medical model of disability to a social model. Banks et al (2018) explain that the medical model focuses on the individual's particular impairment and health needs as the factors that are disabling. The social model views the way society is organised as being disabling rather than the individual's impairment itself; for example, physical and attitudinal barriers. Banks et al (2018) suggest that we have a lot of work to do to make this shift in Ireland, where the approach to disability remains stubbornly grounded in the medical model as is evidenced by the location of disability support services within the Health Service Executive. However, policy in this area has been evolving for a number of years. The central aim of current disability policy in Ireland is to support people with disabilities to live ordinary lives in ordinary places. There has been an increased focus on autonomy and self-determination. This has led to an increased interest in areas such as independent living. This aspiration is articulated in numerous government policies and strategies over the past two decades. It is not within the scope of this report to discuss all these policies and strategies. However, I will refer to some of the more significant and relevant ones below as I believe that the recommendations in this report are in line with previous policy.



1990

- *Needs and Abilities: A Policy for the Intellectually Disabled – Report of the Review Group on Mental Handicap Services*

This report indicated a preference towards the development of community based services. It made detailed recommendations for discontinuing residential provision that is not domestic in scale. It proposed a range of community based alternatives, including forms of adult foster care, and supports for families to enable them to maintain their family member in a home situation.

1994

- *Shaping a Healthier Future: a strategy for effective healthcare in the 1990s*

One of the objectives of this strategy placed an increased emphasis on the most appropriate care. It promised greater sensitivity to the right of the consumer to a service which responds to his or her needs in an equitable and quality-driven manner and in an appropriate setting. This strategy focused not just on 'health gain' but also on 'social gain'.

1996

- *Towards an Independent Future: Report on the Working Group on Health and Personal Social Services for People with Physical and Sensory Disabilities*

This report also signalled a move away from large institutions, towards small living units and mainstream housing provision. It stated that the objectives of health and personal social services for people with disabilities should be to enhance their health and quality of life, for example, by enabling them to live as independently as possible in the community, providing services in a manner that respects the right of service users to have a say in the services they receive and ensuring service provision is respectful of the dignity of the service user as well as equitable, accessible, appropriate and available within a reasonable period of time.

- *A Strategy for Equality Report of the Commission for the Status of People with Disabilities*

This report was instrumental in proposing a rights-based approach to disability in Ireland. This strategy said that people with disabilities should have the right to participate in all areas of Irish life to the fullest extent possible, and that individually and collectively (and where appropriate, their families and friends) they have the right to influence decisions which affect their lives. People with disabilities have the right to be able to achieve their full potential. They have the right to make their own decisions and choices regarding the conditions of life best suited to their circumstances. They also have the right to quality services which meet their needs at all stages of life and they must not be dependent on charity or voluntary effort.

2001

- *Quality and Fairness: A Health System for You*

The vision of this strategy was “A health system that supports and empowers you, your family and community to achieve your full health potential. A health system that is there when you need it, that is fair, and that you can trust. A health system that encourages you to have your say, listens to you, and ensures that your views are taken into account”. This strategy highlighted that access to healthcare should be fair and the system must respond to people’s needs rather than have access dependent on geographical location or ability to pay. It states that health and social services must be personalised as individuals differ in many ways. It suggests that services must adapt to these differences rather than the individual having to adapt to the system. It states “Groups such as the elderly, people with disabilities, people with mental illness, and those with chronic illnesses, expect to be able to enjoy a reasonable quality of life. In the future, services will be planned to meet these expectations and the ‘whole person’ perspective.” Its first objective is to place the patient at the centre in the delivery of care. Its second objective is that appropriate care is delivered in the appropriate setting. It states that the underlying principle will be concerned with ‘the right care in the right place at the right time’.



2004

- *The National Disability Strategy*

This was launched with the overall aim of supporting equal participation of people with disabilities in society. It comprised four elements, one of which was six sectoral plans whereby six Ministers were required to draw up Sectoral Plans as follows — Minister for Health and Children, Minister for Social and Family Affairs, Minister for Transport, Minister for Environment, Heritage and Local Government, Minister for Communications, Marine and Natural Resources and the Minister for Enterprise, Trade and Employment. It provided for an investment programme to build capacity in priority areas of support services for people with disabilities.

2006

- *Sectoral Plan of the Minister for Health and Children*

This outlined the plan context and advised that health policy is guided by the principles of equity, people-centredness, quality and accountability, as set out in Quality & Fairness – A Health System for You.

- *Towards 2016: A Ten Year Framework Social Partnership Agreement*

The implementation of the National Disability Strategy was the agreed focus of disability policy under the Partnership Agreement Towards 2016. The following vision for persons with disabilities is set out in Towards 2016: “The parties to the agreement share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families as part of the local community free from discrimination”. The vision of this framework included “Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential.”

- *A Vision for Change: Report of the Expert Group on Mental Health Policy*

In drawing up this policy, the Expert Group considered the various core values that are intrinsic to the design and delivery of a quality mental health care service: services should be person-centred and adapted to each individual's needs and potential. It recommends:

- The involvement of service users and their carers should be a feature of every aspect of service development and delivery;
 - A plan to bring about the closure of all mental hospitals should be drawn up and implemented, the need for services to be built around responding to the practical needs of its users;
 - The need to recognise that service users are primarily held back from recovery by practical problems of living rather than by their symptoms;
 - The need for integration into mainstream community life to be the ultimate goal of recovery, to be achieved through involvement of users and carers with an expanded range of service structures that link well to primary care, local voluntary organisations and relevant community agencies. Services should be accessible, user-friendly, and available when individuals need them most.
- *Long Term Care Report - Report of the Long Term Working Group*

This report was finalised by the working group at the end of 2005 and submitted to Government in January 2006. While the report's proposals were not formally endorsed by Government, its analysis and recommendations have informed subsequent decisions, including the Fair Deal policy on Long Term Nursing Home Care. The Group proposed the adoption of the following principles as the basis for future policy:

- All relevant public services should be designed and delivered in an integrated manner around the needs of the care recipient, based on a national standardised needs assessment;
- The use of community-based care should be maximised;
- The important role of family carers should be recognised and supported;



- Where community-based care is not appropriate, quality residential care should be available on an equitable basis in accordance with financial circumstances and as between public and private provision;
- There should be appropriate levels of co-payment by care recipients based on an assessment of financial resources;
- Policy must evolve effectively in response to demographic, labour market and social changes in Ireland;
- Any model adopted must be financially sustainable over the long-term.

2007

- *National Action Plan for Social Inclusion (2007–2016)*

This was closely aligned to ‘Towards 2016’. This plan acknowledges that people with disabilities are at significantly greater risk of social exclusion and it endorses a vision, with associated agreed actions, where ‘every person with a disability would be supported to enable them, as far as is possible, to lead full and independent lives, to participate in work and in society, and to maximise their potential’. Implementation of the National Disability Strategy 2004 is regarded as integral to attaining this vision.

- *HSE Transformation Programme 2007-2010*

The values espoused in this programme further cemented and confirmed the importance of a truly person-centred approach, where each individual receives services based on need and where he or she is an active participant in decisions relating to the management of their condition and health needs.

2008

- *Department of Health and Children Statement of Strategy 2008 – 2010*

This included as one of its objectives “To help people with disabilities to achieve their full potential including living as independently as possible”.

- *National Strategy for Service User Involvement in the Irish Health Service*

This was published by the HSE and the Department of Health. One of the guiding principles was that service users should be centrally involved in their own care. Involvement must be based on inclusion, diversity and equity – health services must engage socially excluded groups including those who are socio-economically disadvantaged, ethnic minorities and Travellers, people with disabilities, lesbian, gay, bisexual and transgendered people, children, young people and older people and users of mental health services.

2011

- *National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011– 2015*

The HSE and Department of Health published this document. The vision proposed is that people presenting with neuro rehabilitation needs are supported to participate as fully as possible in the social and economic life of their community and have access to a range of quality services and supports so as to enhance their quality of life and well-being. This policy states that most people with disabilities prefer and expect to remain in their own homes, wherever possible, and receive care and support services locally. This policy is referred to in Chapter 4.

- *National Housing Strategy for People with a Disability 2011–2016*

This strategy was published in 2011 by the Department of the Environment, Community and Local Government. A National Implementation Framework was published by the Department of the Environment, Community and Local Government and the Department of Health in 2012. This strategy was affirmed in Rebuilding Ireland and extended to 2020. The vision of this strategy is to: “facilitate access, for people with disabilities, to the appropriate range of housing and related support services, delivered in an integrated and sustainable manner, which promotes equality of opportunity, individual choice and independent living”.



This strategy outlines a plan for providing housing and accommodation to people with physical and or sensory disabilities, intellectual disabilities and those with mental health issues. The strategy sets out the following vision for facilitating independent living: The range of supports necessary to enable people with a disability to live independently in their own homes can be extensive and range from physical adaptations to make homes accessible to the provision of healthcare related supports. The types of supports required will vary according to the nature of disability and personal preference and should be delivered in an integrated manner. The provision of necessary supports must be assured by the responsible agencies and underpinned by agreed service plans.

- *Department of Health Statement of Strategy 2011-2014*

The first strategic objective in this document is to support people to lead healthy and independent lives. The third objective is to create a more responsive, integrated and people-centred health and social care service.

Under programme 6 – Specialised Care Services, this strategy states that the DOH wants to achieve provision of “a wide range of long-term supports and services aimed at ensuring that people who need long-term services and care can achieve their full potential and enjoy a high quality of life in the workplace, and within their own homes and communities. This goal encompasses and reflects Government’s policy objectives for particular care groups as set out below. In terms of disability services, it states “To help people with disabilities to achieve their full potential including living as independently as possible”.

- *Time to Move on from Congregated Settings – A Strategy for Community Inclusion*

This strategy will be discussed in more detail below. Overall, it promotes a move from congregated settings to community living.

2012

- *HSE Value for Money and Policy Review of Disability Services in Ireland*

This review proposed a fundamental change in approach to the governance, funding and focus of the Disability Services Programme, with the migration from an approach that is predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports.

- *Transforming Lives Programme*

Transforming Lives is the reform programme to implement the recommendations of the Value for Money (VFM) & Policy Review of Disability Services in Ireland.

- *New Directions: Review of HSE Day Services and Implementation Plan 2012-2016*

This set out a proposed new approach to adult day services for people with disabilities. This new approach involves delivering 12 supports, which are collectively called New Directions. This was one of the key policy documents contained in the HSE Transforming Lives Programme. It sets out an approach to day services that envisages all the supports available in communities that will be mobilised so that people with disabilities have the widest choice and options about how to live their lives and how to spend their time. It proposes that ‘day services’ should take the form of individualised outcome-focussed supports to allow adults using those services to live a life of their choosing in accordance with their own wishes, needs and aspirations. Although focused on day services, its main principles were based on meeting service users’ own wishes, needs and aspirations.

2015

- *Building a high quality health service for a healthier Ireland - Health Service Executive Corporate Plan 2015-2017*

The ambition in this plan is that for those in society who have care needs, the HSE will support them to live as independently as they can, including older persons and people with disabilities, by providing a range of supports suited to their individual needs. One measure of this is fewer people with a disability living in congregated group residential settings.



The HSE aims to provide integrated services that meet the highest standards, where people are treated with respect and dignity and can live as independently as possible.

2016

- The Department of Health Statement of Strategy 2016-2019

This statement of strategy quotes Minister Simon Harris as saying “Actions in this Strategy are aimed at addressing these challenges by improving health and wellbeing and supporting independent living, delivering high quality and safe care which is more responsive, integrated and person-centred, and better managing our health services”. This strategy states “The Department is conscious of its responsibility in ensuring that the principles of the Public Sector Duty in relation to human rights and equality are embedded across the work of the Department. An example of this is the Department’s commitment to the creation of a more responsive, integrated and people-centred social care system which (amongst other things) supports the full and effective participation of people with disabilities in society on an equal basis with others, in accordance with the United Nations Convention on the Rights of Persons with Disabilities.”

This strategy also states “Independent Living enabling and supporting people to live independently and lead active lives in their communities can make a real difference for a person, allowing older people or those with a disability or illness to achieve their full potential. This requires an early intervention approach and the provision of care and services on a personalised basis”.

2017

- *HSE Operational Plan for Social Care 2017*

This plan made reference to decongregation but not to under 65s in nursing home. One working group did have the task to: “Review current residential provision to determine and agree recommendations in relation to the appropriate model of service for individuals with significant specialist care needs”.

- *The National Disability Inclusion Strategy (2017-2021)*

The aim of this strategy is to take a whole of Government approach to improving the lives of people with disabilities both in a practical sense, and also in creating the best possible opportunities for people with disabilities to fulfil their potential.

This strategy gave priority to a number of areas, including examination of the recommendations of the report of the Personalised Budgets Task Force, with a view to introducing the option of availing of a personal budget as one approach to individualised funding. It also gave priority to full implementation of the Transforming Lives programme, with particular reference to advancing the Time to Move On agenda (decongregation), the New Directions programme (reforming adult day services), and the move towards person centred planning for residential and day services. It dedicates a section to disability and supporting individuals to lead a fulfilled life of their choosing. A further section is dedicated to living in the community.

2018

- *National Development Plan for 2018-2027*

This committed to continuing to support the capital programme for people with disabilities, which consists of the purchase and adaptation of houses in the community along with the replacement of long-term residential care units.

- *HSE National Service Plan 2018*

This again stated that disability services focus on enabling people with disabilities to achieve their full potential, living ordinary lives in ordinary places, as independently as possible while ensuring that the voices of service users and their families are heard, and that they are fully involved in planning and improving services to meet their needs. It stated that disability services have a significant programme of reform which is informing a new model of service provision. It identifies resourcing as an issue and states that as the HSE move through its programme of reform and consolidation of the disability sector, an increasing challenge has been striking the appropriate balance in relation to the competing need for resources across the national policy objectives.



2019

- *HSE National Service Plan 2019*

This states that disability services focus on supporting and enabling people with disabilities to maximise their full potential, living ordinary lives in ordinary places, as independently as possible. Disability services strive to ensure the voices of service users and their families are heard, and are fully involved in planning and improving services to meet their needs. It identifies issues in relation to resourcing and funding, similar to the previous year. It states that, a critical challenge for 2019 and future years will be the development of a more sustainable model of service and supports which achieve these key policy objectives within the resources available. In this context, a particular challenge in 2019 will be to maximise the capacity of the service to respond to residential care needs. This plan outlined steps to be taken in implementing policies such as ‘Time to Move On’.

As well as the above policies, some of the relevant legislation introduced during this period included:

- Various Health Acts
- Equality Legislation
- Disability Act 2005
- Nursing Homes Support Scheme Act 2009
- Irish Human Rights and Equality Commission Act 2014
- Assisted Decision-Making (Capacity) Act, 2015

Policy at a European Level

Policy developments in Ireland were also underpinned by broader European policy and strategy in relation to disability. These included:

- *Council of Europe Action Plan 2006 – 2015*

This stated that, “people with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community.”

- *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*

This strategy pledged to realize the full participation of people with disabilities in society by “providing quality community based services including access to personal assistance”, promoting the transition from institutional to community-based care and supporting national efforts to achieve these ends. It followed the spirit of the CRPD and lists participation as one of its eight main areas of action. Participation includes the right to choose where and how to live, with one objective under this area being to “achieve full participation of people with disabilities in society by providing quality community-based services, including access to personal assistance.”

- *Human Rights: A Reality for all Council of Europe Disability Strategy 2017-2023*

The overall goal of this strategy was to achieve equality, dignity and equal opportunities for persons with disabilities. It stated that this requires ensuring independence, freedom of choice, full and effective participation in all areas of life and society, including living in the community.

Policy and Reality

As is evident, all the above policies support the concept of participation and choice and advocate for the right to independence. However, it would seem that policy does not always translate to direct action on the ground and the expression of an ideal in policy does not always impact on the day to day lived experience of those who should be impacted by the policy. It is not unreasonable to conclude that we have no shortage of vision, but fall well short in delivery.



The European Union Agency for Fundamental Rights (2018) discusses a gap between rhetoric and reality concerning deinstitutionalisation for persons with severe impairments and complex needs. Similarly, the Centre for Disability Law & Policy (2007) states that while the issue of independent living for people with disabilities has been addressed and highlighted as a desirable goal in a number of policy documents, there has been no definitive statement of a policy imperative to move away from providing support in segregated residential institutions to independent living in the community. It states that the right to ‘independent living’ in Ireland has no legal status in the Constitution, in statute or in administrative law. This was written prior to the publishing of “Time to Move on from Congregated Settings” in 2011.

In 2012, NESAC commented “There is..... a gap between this top-level vision and the service reality on the ground that has created a complex sectoral landscape, characterised by unevenness in terms of the quality of care”.

Obviously, when it comes to the specific issue of decongregation, the publication of the policy ‘Time to Move On from Congregated Settings’ in 2011 was an important development in Ireland. At that time, the HSE found that over 3,000 people with a disability were living in congregated settings. The report recommends that people who live in congregated settings should move to their own homes in the community with the support they need. It stated that congregated settings are where 10 or more people with a disability live together in a single living unit or are placed in accommodation that is campus based. In most cases, people are grouped together and often live isolated lives away from the community, family and friends. It observed that many people experience institutional living conditions where they lack basic privacy and dignity. The report recommends that people who live in congregated settings should move to their own homes in the community with the support they need. Obviously this is in keeping with the overall premise of this report, which is that people should have the right to choose where they want to live.

There have been delays in the implementation of ‘Time to Move On’ and people are still residing in congregated settings in Ireland today.

Even in the HSE's 2016 progress report on the implementation of Time to Move On from Congregated Settings: A Strategy for Community Inclusion, the HSE acknowledged that the overall number of transitions completed was less than planned. This lag continues although I appreciate that steps are being taken to try address this. I am concerned about these delays and although it is not the specific subject of this report, I nevertheless think it is important to highlight my concerns in this regard. It is an issue which I intend addressing in a future report. The vision of 'Time to Move On' is in keeping with the general premise of this report. However, "Time to Move On" explicitly excluded nursing homes in its scope. I appreciate the reasons for this and that, as with any report, including this report, there has to be some limitations to scope. However, I am of the view that this has potential ramifications. Whereas, there is a specific policy and strategy in place for moving individuals from traditional institutions into the community, there seems to be no definitive statement of a policy imperative or procedures to cover the placement of individuals under the age of 65 in nursing homes. This suggests that this particular area is of lower priority in terms of policy and procedures and I would suggest that this is reflected in some of the other chapters within this report.

The lack of priority in this area is evident in the follow up of the one recommendation in "Time to Move on from Congregated Settings" which referred to this issue. This strategy recommended that: "The HSE should initiate a review of large residential settings for people with disabilities which were outside the scope of the Working Group, for example, people inappropriately placed in Nursing Homes. The aim of the review should be to ensure that residents in these settings can access community-based support and inclusion, in line with the Working Group's proposals for residents of congregated settings. A number of people with disabilities are still living in mental health settings, and their accommodation and support needs fall within the remit of Vision for Change proposals. The Working Group recommends that this group should be given top priority in the Vision for Change implementation process and be moved to appropriate community settings in line with the recommendations in this Report".



This was written in 2011 yet the HSE has advised us that there has been no timeframe set to deal with these recommendations. Without such a policy, there are no specific pathways to enable individuals under 65 to move from nursing homes into the community. There is also no imperative to prevent new admissions. This is a feature of ‘Time to Move On’, which recommends that there should be no new admissions to congregated settings and advocates for an approach that involves both preventing new admissions and the transition of current residents. Both are approaches which I feel could be drawn upon in looking at people under 65 in nursing homes. I would also suggest that the lack of a specific policy for individuals under 65 in nursing homes feeds into the concept of deprioritisation discussed in Chapter 5. I am not in any way suggesting that this group should be enabled to move on before those in more traditional congregated settings. I fully support the move from congregated settings to enable people to live in the community and I have been quite vocal in this regard. However, due to a lack of specific policy for individuals under 65 in nursing homes, it seems that these individuals are given lower priority than individuals in congregated settings and other settings in terms of placement as they are considered to have a placement. This endorses a system where, once an individual is placed in a nursing home, it is very difficult to source alternative accommodation as they are, in reality, treated as a low priority. This has been clearly articulated by the HSE in most of the individual complaint responses to this Office in relation to this issue.

While there have been some positive developments, I would suggest they are not enough and are not yet impacting the day to day lives of individuals.

The Department of Justice and Equality: Roadmap to Ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2015), under further actions required under article 14 of CRPD, stated “Clarity on issue of nursing homes and care homes for people with intellectual disabilities. The Department of Health is considering the issue further and will seek further legal advice. The Department of Justice and Equality is open to taking the necessary amendments forward as part of the Equality/Disability Miscellaneous Provisions Bill”.

I appreciate that the 2020 Programme for Government: Our Shared Future has stated that it will “Reduce and provide a pathway to eliminate the practice of accommodating young people with serious disabilities in nursing homes”. The HSE has also advised my Office that it is actively planning to provide for an intervention programme for persons under 65 years with a disability, which is being planned for via the 2021 estimates process. These are new developments, which are very much welcome and a definite step in the right direction. However, I believe that a specific policy needs to be drawn up in relation to this particular issue. The HSE acknowledged to my Office that “there is no specific comprehensive policy framework that exclusively targets Nursing Home Settings where under 65s are concerned. This was noted and identified as a policy gap in Ireland in the 2017 reports completed by the Fundamental Rights Agency”.

I believe that such a policy would provide for designated pathways to deal with this issue. It would also strengthen the case for ring-fenced funding to address this matter, as I am concerned that, without this, it will never be provided with any level of immediacy. I would suggest that despite extensive media coverage on individual cases and strong advocacy from a number of different bodies, from a policy perspective, the plight of individuals under 65 in nursing homes has remained a relatively invisible systemic issue.

This is not a new issue. As far back as 2002, the ERHA, as it was then known, stated “Of immediate concern to Health Service Providers is the lack of appropriate accommodation for people who fall into the young chronically disabled category. At present some people are living in inappropriate accommodation such as Nursing Homes where the emphasis rests on nursing care rather than on social input, and in the community where geographical location and inadequate transport contribute to social isolation. It follows that many young chronically ill men and women are unable to enjoy a full life. A substantial number of those living in the community are living with their families, who experience enormous pressure due to the limited support available to them”.



The lack of focus on this issue is reflected in the way it is represented in statistics. Accurate statistics are required for the management and planning of any service. It is not possible to develop a comprehensive plan to address an issue if the exact prevalence of that issue is not fully known. Statistics play an essential role in capacity planning. O'Farrell (2013) states that it appeared that residents with intellectual disabilities or physical disabilities were not on the relevant HSE databases, such as the National Intellectual Disability Database (NIDD) or the National Physical and Sensory Disability Database (NPSDD) and therefore the person and their support needs were not identified in national planning systems, as would generally be the case if they were in receipt of services from disability providers.

While being on the NIDD or NPSDD is no guarantee of getting an appropriate service, it did ensure that the person is identified, has a Personal Identification Number (PIN), and was logged as having quantified and costed support needs. This gap in information was noted in the Time to Move on from Congregated Settings Report, the Housing Strategy Report and by the Disability Federation of Ireland. There has been some progress in this regard and the NIDD and NPSDD were decommissioned in 2018. The National Ability Support System (NASS) was introduced in their place. The NASS is a national database that records information about disability-funded services that are received or required as a result of an intellectual disability, developmental delay, physical, sensory, neurological, learning, autism spectrum, speech/language disability arising from disease, disorder or trauma. Mental health as a type of disability is also recorded on NASS where an individual is in receipt of a disability-funded service. This may come about where the individual has more than one type of disability or where no suitable mental health service is available. The purpose of NASS is to gather information to aid the planning, development and organisation of disability-funded services. A person is eligible to be registered on NASS if they receive or require (in the next 5 years) a disability-funded service.

However, when asked if the HSE hold statistics on the number of individuals under the age of 65 who are placed in nursing homes and, if so, whether there is any breakdown of these statistics available, the HSE informed my Office that there were 1,320 clients under 65 years of age supported by the Nursing Homes Support Scheme as at 30 June 2020. The HSE confirmed that it does not have data on residents who may self-fund or are funded from another source. I would suggest that an audit should be done of the number of people under 65 in nursing homes in order to establish accurate statistics. These may not vary greatly from the numbers identified but I think that all placements should be identified and documented.

Other countries have taken measures to address the specific issue of younger people in nursing homes for older persons. In 2006, the Council of Australian Governments (COAG) agreed that the Australian Government, States and Territories would, from July 2006, work together to reduce the number of younger people with disabilities in Residential Aged Care. The Young People in Residential Aged Care Programme was subsequently introduced. This was a five year programme to assist younger people with disability living in or at risk of entering residential aged care throughout Australia. The three objectives of this programme were:

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.



Participation in this programme was voluntary and initial priority was given to people under 50 years of age. This initiative was incorporated into the National Disability Agreement when it came into effect in January 2009. Commonwealth Government funding for the YPIRAC initiative is ongoing as part of the National Disability Specific Purpose Payment to state and territory governments for increased and improved specialist disability services. At the October 2011 meeting of the Standing Council on Community, Housing and Disability Services, Ministers agreed to a continued effort to meet each of the objectives under the YPIRAC initiative and agreed to achieve better connections with mainstream services for younger people with disability in, or at risk of entering, residential aged care. On 22 March 2019 the Government announced it had developed a national action plan to take concrete actions to reduce the number of younger people living in aged care and to help them access more age appropriate housing and supported living options. The action plan has the following goals:

- * Support those already living in aged care aged under 45 to find alternative, age appropriate housing and supports by 2022, if this is their goal;
- * Support those already living in aged care aged under 65 to find alternative, age appropriate housing and supports by 2025, if this is their goal; and
- * Halve the number of younger people aged under 65 years of age entering aged care by 2025.

This is a good example of how policy can promote active change in this area and the importance of having specific goals. It also includes a focus on improving the current situation for younger people living in nursing homes whilst also focusing on a move towards alternative settings. I think this two pronged approach is essential as realistically, transitions from nursing homes will not be immediate for most people and it is important that any policy looks at their present situation and addresses some of the issues discussed in this report, particularly in Chapter 3 and Chapter 4.

As indicated above, the ‘Time to Move On’ report stated that congregated settings are where 10 or more people with a disability live together in a single living unit or are placed in accommodation that is campus based. In most cases, people are grouped together and often live isolated lives away from the community, family and friends. Many experience institutional living conditions where they lack basic privacy and dignity. It explicitly excluded nursing homes from this report and again, I fully appreciate this in the context of the parameters and scope of the report.

However, I would suggest that, in the context of this report, it would be remiss of me to not dig deeper into definitions of institutionalisation and de congregation. At the very outset of this discussion, I would like to make clear that I am in no way comparing nursing homes to the old style institutions. The living conditions and quality of care are clearly of a different order. However, they are clearly a form of institutional care and are inappropriate for people under 65 and it is likely that many of their older residents would also wish to be supported in their own homes if this option was available to them.

Where this question most obviously arises is when a younger person is moved from a congregated setting under ‘A Time to Move On’ to a nursing home. Statistically, the numbers in this regard are quite low. The HSE informed my Office that data gathered prior to 2015 was not sufficiently validated to provide use as information in this regard. However, from 2015-2019 a total of 72 people have transitioned to nursing homes. Of these 18 were under 65 years of age, 44 were over 65 years of age and the date of births for the remaining 10 people was not confirmed. Obviously, I do not know the individual circumstances of these individuals and so I can only comment generally but I would suggest that the transition of a younger individual from a congregated setting to a nursing home defeats the purpose of the initiative.

The European Union Agency for Fundamental Rights (2017) highlights that here is no internationally accepted definition of deinstitutionalisation. The UN Office of the High Commissioner for Human Rights (OHCHR) has described it as “a process that provides for a shift in living arrangements for persons with disabilities, from institutional and other segregating settings to a system enabling social participation where services are provided in the community according to individual will and preference.”



In an Irish context, McCarron et al (2018) state that an important consideration is what constitutes an institutional setting and what constitutes a community setting when decongregation occurs. They state that, in current Irish Government policy, best-practice community living arrangements are those with four people or fewer living in a single unit. However, in most of the available literature, the concept of deinstitutionalisation has been applied more broadly and refers simply to leaving an institution (e.g. a long-stay hospital), even if the individual with intellectual disability moves to a setting with more than four beds, and in some older studies this includes settings such as nursing homes.

In Mansell et al's study (2007), the European Commission defined a residential institution as an establishment in which more than 30 people lived, of whom at least 80% were mentally or physically disabled. It included nursing homes. Inclusion Ireland (2018) argues that deinstitutionalisation involves more than just the closure of large, residential settings. It states that it is about removing institutional cultures and practices and ensuring that accessible, inclusive housing, services and supports are available to persons with disabilities in community settings. It highlighted an institutionalised model of care, which involves being characterised by rigid routines, little opportunity to make decisions and paternalistic approaches. The European Expert Group on the Transition from Institutional to Community-based Care (2012) also discusses the concept of institutional culture. It defines an institution as any residential care where:

- residents are isolated from the broader community and/or compelled to live together;
- residents do not have sufficient control over their lives and over decisions which affect them; and
- the requirements of the organisation on itself tend to take precedence over the residents' individual needs.

The European Union Agency for Fundamental Rights (2018) outlined both physical and cultural characteristics of institutional settings:

Physical characteristics of institutions

- large buildings
- isolated / remote locations
- segregation - only people with disabilities
- large groups of non-family members living together
- long length of admission / residence
- compelled to live together
- sharing room and personal space.

Cultural characteristics of institutions

- lack of privacy and intimacy
- lack of liberty and expression of wishes
- lack of accountability
- strict schedule / regime and predefined procedures and activities
- block treatment defined by one size fits all; individual's lack control over daily activities
- rules and interest of the institution take precedence over the will and preference of the client
- division between staff and users - medical model of care reducing individuals to their diagnoses/impairment
- no choice of support personnel
- place of residence contingent on care provision.



The Report of the Ad Hoc Expert Group on the Transition from Institutional to Community based Care (European Commission: 2009) suggests that there can be replication of institutional culture in community-based services. They state “Typical characteristics of “institutional culture” have been described and analysed by pioneering researchers some four decades ago. It has long been argued that institutional care segregates users and tends to be characterised by depersonalisation (removal of personal possessions, signs and symbols of individuality and humanity), rigidity of routine (fixed timetables for waking, eating and activity irrespective of personal preferences or needs), block treatment (processing people in groups without privacy or individuality) and social distance (symbolising the different status of staff and residents)”.

Similarly, the United Nations Committee on the Rights of Persons with Disabilities (2017) General comment No. 5 (2017) on living independently and being included in the community stated “Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment”.

ENIL (2017) and the Council of Europe Commissioner for Human Rights suggest that in decongregation, the focus on community services is as important as the focus on institutions. ENIL (2017) states “, this term is wrongly used as synonymous with transforming large residential institutions into contemporary institutions, or closing large institutions without putting in place alternatives, rather than ensuring equal access to services and support in community. While the closure of large residential institutions is essential, it is not sufficient to ensure that disabled people can live independently and be included in the community.

Without support in the community and accessible and affordable mainstream services – including housing - disabled people leaving institutions will not be able to participate in society on an equal basis with others”.

The World Health Organisation (2011) defines an institution as “any place in which persons with disabilities, older people, or children live together away from their families. Implicitly, a place in which people do not exercise full control over their lives and their day-to-day activities. An institution is not defined merely by its size.”

It is clear that nursing homes fall in some way into the above definitions, particularly in the context of Chapter 3. Inclusion Ireland (2018) states “Discussion on what constitutes deinstitutionalisation and community living in Ireland needs to become broader and take into account the many people with disabilities experiencing institutional life outside of so-called congregated settings”.

Again, there seems to be a lack of clarity in the Irish context. HIQA (2017) states that definitions of a designated centre and a nursing home are somewhat broad and can be open to interpretation. They comprise a number of key terms including:

- institution
- residential service
- care and maintenance
- dependent person

Nowhere in the relevant legislation is there a specific definition of residential services. HIQA’s interpretation of this term in relation to disability services, in line with the most recent HIQA guidance document, is as follows:

A ‘residential service’ is one that is comprised of both accommodation and care/support services provided to people with disabilities living in residential settings, on a short or long term basis, whether or not it is their sole place of residence.

The Health (Nursing Homes) Act, 1990 provides the following definition for a dependent person:



“dependent person” means a person who requires assistance with the activities of daily living such as dressing, eating, walking, washing and bathing by reason of—

- a) physical infirmity or a physical injury, defect or disease, or
- b) mental infirmity.

The Department of Environment, Community and Local Government’s national guidance for the assessment and allocation process for housing provision for people with disability (2014) states that people with disabilities:

“Shall not be deemed adequately housed when their current address is a congregated setting, institution, hospital/nursing home, community-based group home, or when they, although an adult, remain in the family home due to their personal circumstances and/or support needs, including their need for adapted living conditions where the family home is unsuitable”.

Finally, I would like to comment that, as per the scope of this report, I have focused on policy that generally falls under the remit of the HSE and the Department of Health. I would suggest that ultimately, to adequately address this issue, policy will require a unified approach across all government departments. In chapter 5, I discussed the impact of failures in inter-agency cooperation. The same applies at a policy level. Any effort to address this issue or any issue that relates to disability must be looked at from a whole of government perspective.



6.1 Finding

The framing of policy in respect of people under 65 in nursing homes needs to be underpinned by a rigorous objective assessment of their needs, both at an individual and an aggregated level. This is also necessary in setting targets, assessing progress against them and meeting policy objectives.

6.1 Recommendation

A full comprehensive national survey of persons under 65 in nursing homes should be undertaken by the HSE and completed within twelve months of the publication of this Report with all information collated on a centralised database. This database should be regularly updated.



6.2 Finding

While it is important to address the situation of persons under 65 currently in nursing homes it is equally important that appropriate measures be put in place in order to reduce the possibility, in so far as is practicable, to prevent others under 65 ending up in the same situation. It is acknowledged that, in a very small number of cases, a nursing home may be the most appropriate placement, provided that this is the will and preference of the individual.

6.2 Recommendation

- a. *An alert system should be put in place by the HSE throughout the health sector, but in particular in the acute hospital sector, to identify in future, at the earliest possible stage, individuals under 65 who, because of their circumstances, may end up in long term residence in a nursing home. The details should be notified to the national database (see 1 above) and an action plan should be put in place to avoid long term placement in a nursing home if that is the individual's preference.*



- b. A date should be set after which there will be no long term admissions to nursing homes by people under 65 unless it is their express wish to be so admitted and a plan developed to ensure that the necessary resources are made available to achieve this.*

6.3 Finding

This investigation has identified a specific systemic issue of concern which is adversely affecting a particular group of people. From a policy perspective and in terms of resolving this issue there needs to be a definitive policy framework put in place which acknowledges the issue and commits to its resolution within a reasonable timeframe. An example of an analogous policy document would be Time to Move On from Congregated Settings.

6.3 Recommendation

That the Department of Health, in consultation with the HSE, draw up and publish an overarching policy framework to remedy the situation of persons under 65 in nursing homes. This should be done by the end of 2021.



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