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Deprivation of Liberty relating to Detention in Irish Residential Care Centres for the Older Person; A Legal and Ethical Analysis

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Candidate Dissertation Declaration

I declare that this dissertation, submitted to RCSI for examination in consideration of the award of MSc in Healthcare Ethics and Law, is my own personal effort. Where any of the content presented is the result of related research ore publications this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breech copyright law. Nor has it been taken from other sources except where such work has been cited and acknowledged within the text.

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Abstract

People enter residential care for a wide variety of reasons, with many people stating they would prefer to live in their own homes. However, lack of community resources may lead to an older person entering residential care against their stated will and preferences. Recent case law in Ireland has established that outside of the Mental Health Act (2001) and for infection control purposes the 1947 Health Act, there is no legal provision in Irish healthcare which allows for a person to be detained against their will. The Assisted Decision Making (Capacity) Act 2015 is a key piece of legislation to enable Ireland to ratify the United Nations Convention on the Rights of Persons with Disabilities. Deprivation of liberty safeguards are to be inserted into this Act (part 13) to give statutory provision to ensure that a person lacking capacity is not unlawfully detained. Where a person is under continuous supervision and control, not free to leave, and there is reason to believe that they lack the capacity to make the decision to live in the residential care service this could be seen as a deprivation of their liberty and violation of their human rights under Article 40.4 of the Irish Constitution, Article 5 of the European Convention on Human Rights and Article 14 of the United Nations Convention on Rights for Persons with Disabilities.

This places healthcare providers and healthcare professionals in a very onerous position with regard to vindicating the rights of the older person with regard to living in a residential care services. Duty of care may clash with 'will and preference'. Most healthcare workers appreciate the significance of human rights, but there remains a lack of understanding of how to apply them in day to day practice. To fulfil the requirements to avoid unlawful detention under constitutional and human rights law, the state must future protect home care services for the older person and also introduce legislative safeguards. Healthcare providers and healthcare professionals must open the narrative on deprivation of liberty by using a human rights based approach and establishing the will and preference of the older person in regard to entering or remaining in Long Term Care.

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Chapter 1: Introduction

1.1 Introduction

People enter residential care for a wide variety of reasons, amongst which are increasing care needs, being unable to care for themselves, and the lack of suitable alternative (Donnelly et al., 2016). Where a person is under continuous supervision and control, not free to leave, and there is reason to believe that they lacked the capacity to live in the residential care service, this could be seen as a deprivation of their liberty and violation of their human rights under Article 40.4 of the Irish Constitution, Article 5 of the European Convention on Human Rights, and Article 14 of the United Nations Convention on Rights for Persons with Disabilities (UNCRPD, 2007). Older people have rights that require protection and vindication under the UNCRPD as they develop physical frailty, communication, and cognitive issues due to the aging process and dementia. The UNCRPD creates a paradigm shift for human rights, in that it has a legal basis, and states must act to ensure the rights it enshrines are respected, protected, and vindicated. Where people are obliged to enter residential care, thus being deprived of their right to community living, or not allowed to leave a healthcare facility (detention), the state or healthcare providers could be viewed as being in violation of a number of articles. With regards to the above, Article 5 of the European Convention on Human Rights will be looked at in detail for this dissertation.

The Assisted Decision Making Act (ADMA, 2015) has been ratified but is not yet fully advanced. The projected date for completion for this is the Q4 of 2020 (DoH, 2019). The Safeguarding Proposals, which are to form part 13 of the ADMA, seeks to safeguard the older person, and those with disabilities who lack capacity, from illegal detention in residential care centres, in line with Article 5 of the UNCRPD (2007).

The Draft Heads of Bill for Deprivation of Liberty Safeguards proposals published for public consultation closed in March 2018. These allow for detention in ‘relevant facilities’, i.e. residential care centres for Older People, and Disabilities and Mental Health facilities. Hospitals, Rehabilitation, and Respite Services were excluded from this. There are a number of very challenging aspects to the Safeguarding Proposals,

which in their current state do not sufficiently satisfy the UNCRPD, nor do they align with the ADMA (2015).

1.2 Why do I want to investigate this?

This researcher works as a healthcare professional in a residential care centre for older people. Ireland's healthcare providers are currently in a very challenging legal and ethical hiatus, with regard to care for a person lacking capacity who either does not wish to enter or wishes to leave their residential care service.

The current proposed legislation presents both legal and ethical issues that this writer feels warrant exploration. It is imperative that we in Irish Healthcare begin the narrative on deprivation of liberty, both to ensure that the human rights of those we care for are respected and vindicated, and to avoid costly litigation to an already fiscally burdened healthcare service.

1.3 Methodology

This writer has chosen to use the desk based literature review methodology, as while literature research is focused on acquiring theoretical knowledge about a concept or topic, desk based research is used to gather facts and existing research data that help to answer the research question.

Inclusions: Due to the limitation of word count, this writer will be specifically looking at detention relating to deprivation of liberty in the residential care sector for older persons.

Exclusions: Detention relating to criminal matters, infection control, and Mental Illness. Acute care, rehabilitation, and respite services.

Databases: Westlaw IE, PubMed, Embase, Google Scholar. Courts., ie. Government and Organisation websites.

Limitations: As Deprivation of Liberty legislation has not yet been enacted in Ireland, there is a paucity of information in academic research. The grey literature published by Government Sources, Non-Government and Voluntary agencies is the main source for the information contained in this dissertation.

Keywords used: Detention, liberty, deprivation of liberty, capacity, human rights. Ward of Court, wardship, residential care, older persons and all related synonyms.

1.4 Background

The recent case of AC v CUH & HSE (2018) has established that there is no current legislation that allows Ireland's healthcare providers to detain a person against their will in a healthcare setting outside of the Mental Health Act 2001, S.23.and for Infection Control purposes (Health Act, 1947). Working under the Lunacy Regulations 1871, the Wards of Court system is archaic, where 'incompetents' are placed under the responsibility of the courts system, depriving them of all rights to have any say in self-determination or right to consent to their own treatment. Capacity for this is an 'all or nothing', where the person is either deemed to have the capacity to make their own decisions, or they are not.

Through the proposed Deprivation of Liberty Safeguards (DoH, 2107), the state seeks to ensure that persons with disabilities are not unlawfully deprived of their liberty in residential care centres. however, while there is a statutory provision for nursing homes (SAGE, 2016), unlike other jurisdictions there is lack of a statutory right to homecare in the community. Added to this, the lack of flexible models of care to meet individual's needs in their own homes and lack of adequate homecare service provision risks undermining the state's efforts to avoid unlawful deprivation of liberty, where a person may be forced to seek residential or respite care services or spend a prolonged period in an acute hospital against their stated wishes and preferences (SAGE, 2018).

This chapter seeks to outline the challenges posed to the state; from the rising aging and disability demographic profile, the current policy on state funds and funding, and the community services available to enable an older person or person with disabilities to remain in their own communities.

1.5 Demographics

Globally, current demographic trends mean that each successive cohort of older persons can expect to live longer and, due to declining fertility rates, have fewer adult children as potential sources of support in old age. The share of population aged over 65 across the OECD countries will reach 28% average from 9% in 1960 (OECD, 2017, p.198). While Ireland has one of the youngest populations in Europe, by 2050 the share of the population aged 65 and over is projected to increase by 59%, with the number of people aged 85 and over projected to increase by 97% (CSO, 2018).

As populations age, the potential supply of labour in the economy is expected to decline. On average, across OECD countries, there were 4.2 people of working age (15-64 years) for every older person, which is projected to halve to 2.1 over the next 40 years (OECD, 2017, p. 198). This means that shortfalls in revenue through taxes will make it a challenge for governments to maintain or increase funding for healthcare.

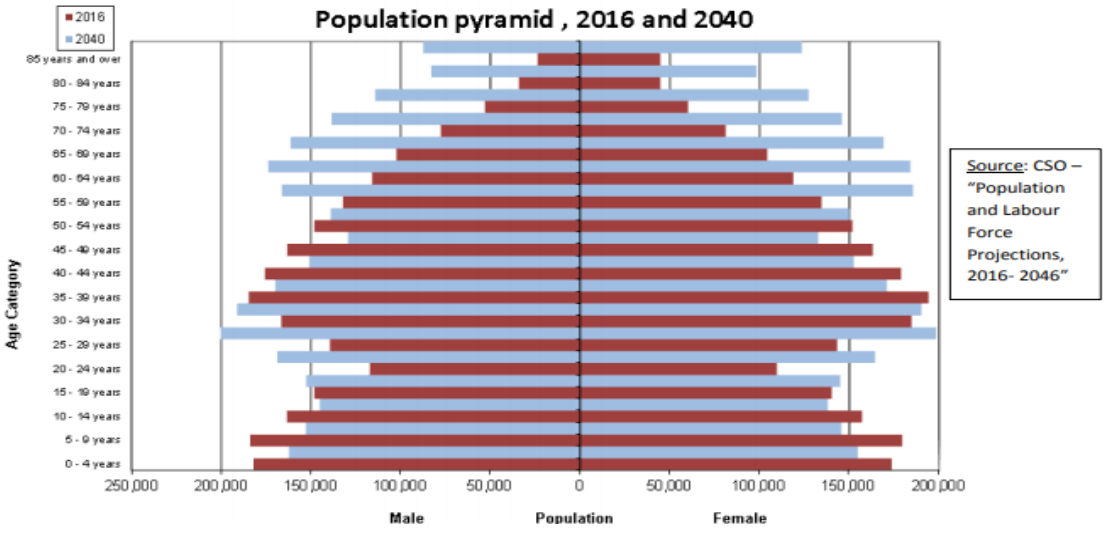
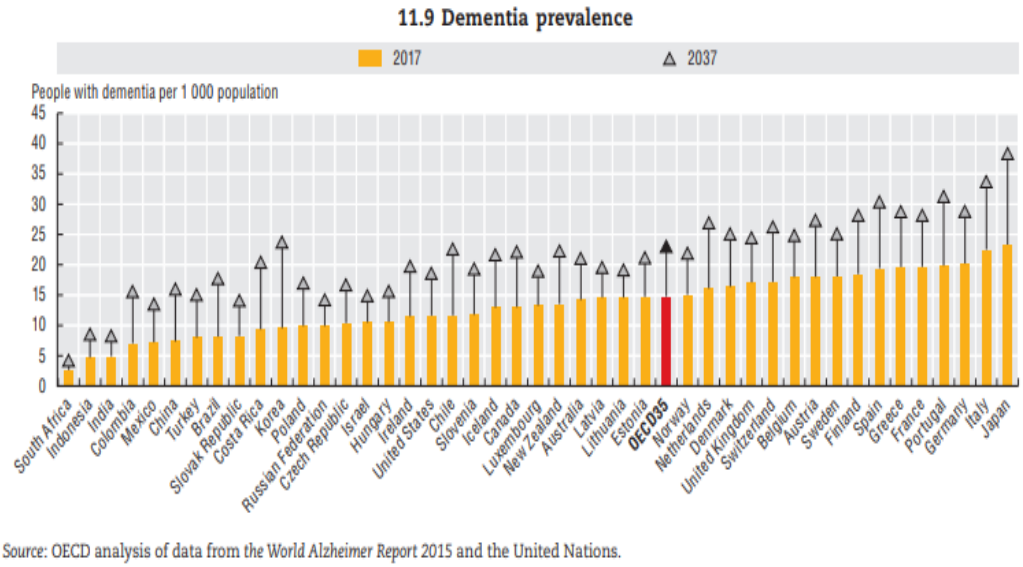


Figure 1.1. Population Pyramid (CSO, 2016)

Those living with a disability have increased by 8% since 2011. By the age of 85 years, 60% of people will have a disability rising to 80% by the age of 93 (CSO, 2016). The increasing demographics mean that there will need to be a radical transformation on

how the needs of those with disabilities will be resourced to satisfy the requirements of the UNCRPD.

Current demographic trends mean that each successive cohort of older persons can expect to live longer and possibly have fewer adult children as potential sources of support in old age. Approximately, 6% of the population of people aged 65 years and older in Ireland are receiving Long Term Care (LTC) in the residential care setting (OECD, 2015), wi*th the* 65 years and over age group showing an increase of 19.1% since 2011. The persons most dependent upon nursing home care are aged over 85, with 56% of nursing home residents being within this age cohort (NHI, 2017). The number of people with dementia in Ireland is rising, with numbers expected to treble to 120,000 by the year 2042, as population ageing continues. The majority of people with dementia live in the community, with 4.6% living in residential care (Cahill et al., 2012). The Alzheimer Society of Ireland states there are approximately 48,000 people living with dementia in Ireland. This number is expected to increase significantly in the coming years, rising to 68,216 people by 2021 and to 132,000 people by 2041 (Alzheimer's Society of Ireland cited in NHI, 2017). This is consistent with OECD (2015) figures.



Source: OECD analysis of data from the World Alzheimer Report 2015 and the United Nations.

Figure 1.2. Dementia prevalence CSO (2015)

This has a cost implication in terms of greater care requirements putting pressure on our Healthcare system. Approximately, 38% of Irish people over 50 years have one chronic disease, and 11% have more than one. As the number of older people increases, the number of people with chronic disease will increase (DoH SoS 2016 – 2019).

There were a total of 643,131 people who stated they had a disability in April 2016, accounting for 13.5% of the population, an 8% increase on 2011 figure (CSO, 2016).

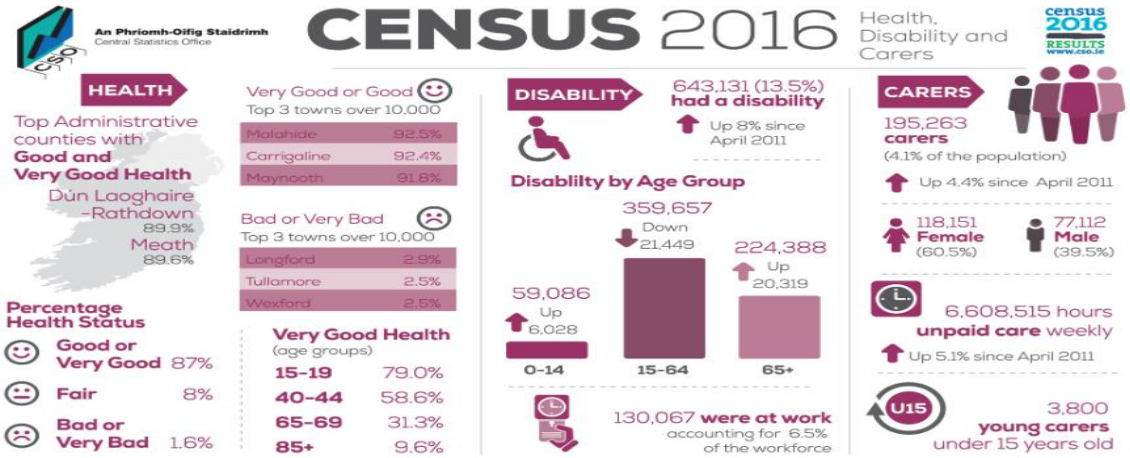


Figure 1.3. Census 2016 Infographic

1.6 Challenges for the Older Person Living in the Community

TILDA (2018) in the Irish longitudinal study of the over 50 year olds in Ireland, and the 'Health and Wellbeing of Ireland's over 50s 2009 - 2016' article reported a number of key findings of great significance for population health for this age group; 57.8% of adults reported problematic housing conditions, most prevalent being damp, mould or moisture. Informal care (care from family or friend) has almost doubled from 5% - 9%, particularly among older adults with frailty (27% to 36%). Also,

> Combined with a 200pc to 300pc increase in prescription charges, new taxes on property, rising energy and medicine costs …the capacity of many older people to develop resilience to economic shocks, even small ones such as any slight changes to utility costs, has been eroded (Walsh, 2019).

At a recent conference, it was revealed that the number of older people facing difficulties making mortgage repayments is increasing, where lenders are now dealing with more older clients still paying off mortgages after 65 years of age, giving rise to "age-related difficulties" making repayments, due to a dip in income later in their life (Power, 2019).

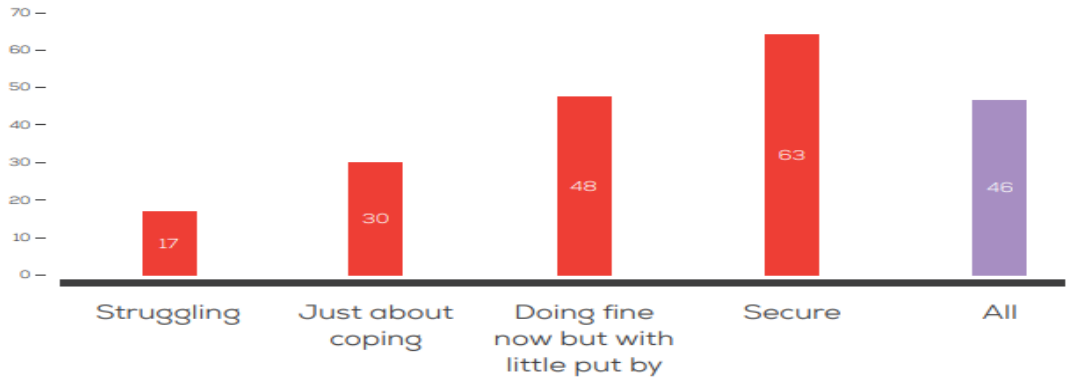


Figure 1.4. Average scores for resilience for retirement among the non – retired population (Competition and Consumer Protection Commission, 2018)

The Irish healthcare system, which was built to tackle episodic diseases or accidental injuries, is currently outdated and ill-equipped to tackle the health challenges of the present and the future (Government of Ireland, 2018). Where the older person cannot get timely access to primary healthcare services, deterioration in health leads to more likelihood of hospital admission. Delayed discharges lead to longer length of stay, where hospital acquired infection, deconditioning, and falls increase the likelihood of requiring Long Term Care (Knowles, 2018).

State formal home care is the Home Care Package Scheme managed by the HSE. This provides for domestic and personal care through home help, as well as higher dependency servicing of needs. In 2015, 47,915 care recipients over the age of 65 received 10.4 million home help hours, with a further 15,272 care recipients aged over 65 receiving a formal home care package (HSE, 2016). According to Murphy et al. (2015), 97% of formal care is publically funded.

Unless there is a radical increase in community healthcare services, many families who are not getting the needed support to care for their older parent or relation may be forced to seek LTC services, without the consent or agreement of the person. Many older persons themselves, unable to source the required care support, may be forced to seek LTC, leading to the risk of *de facto* or arbitrary detention. The majority of residential care services have 24 hour staffing which means that residents are in fact under continuous supervision, with many unable to leave because they have no alternative accommodation. In addition, because staff perceive that they may pose a risk to themselves due to having dementia or other cognitive deficits, and due to a lack of safety awareness, they may prevent them from leaving. These fall within the definition of the deprivation of liberty in the Safeguarding Proposals, but as they are only for those who lack capacity, there are no safeguards to protect them (SAGE, 2018).

Community social workers reported that they were regularly having to advocate for the older person when they wished to live in a manner deemed 'risky' by professionals and family members (Donnelly et al., 2016), with pressure being brought to bear on them to enter residential care facilities; there was also the additional issue that older persons were regularly obliged to go into LTC prematurely because of problems in service availability (Donnelly et al., 2016). The same study found that that older people 'did not receive the level of service that their care needs' assessment indicated, and thus, a worrying consequence of this was unnecessary or premature admission to LTC.

1.7 Meeting the Costs of Community Services

Currently, Ireland is not faring well with regard to social protection for the older person. General Government total expenditure in the European Union on social protection (defined as 'Sickness and disability; old age; survivors; family and children; unemployment; housing; social protection and social exclusion') amounted to an average of 18.8% of GDP in 2017 (Eurostat, 2018). Ireland's contribution to social protection is the lowest in the EU, at 9.5%, raising to nearly 25% in Finland. The group 'old age', which includes pensions, made up the largest part of social protection in all member states and accounted for 10.1% of GDP in the EU in 2017. Ireland recorded

the lowest, at 3.4%, with the highest shares being registered in Greece and Finland (both 13.8%) (Eurostat, 2018).

In Ireland, there is no statutory basis for home care services. Germany, the Netherlands, and Scotland have a national set of standards for home care services, with an independent inspectorate to monitor compliance with the standards. These have a statutory basis (Kiersey & Coleman, 2018). With the highest ever budget of 15 billion for healthcare services, the Irish state has admitted that there are 'fundamental and deep rooted problems' across Irish healthcare services (Government of Ireland, 2018). Formal home care in Germany and the Netherlands appears to be better future protected considering the rising age and dementia demographics. This is funded by compulsory long term insurance and co–payments. Involvement of family members in providing care is encouraged in both countries. In Germany, insurance premiums for home care are higher for childless adults (Kiersey & Coleman, 2017).

The exchequer, where the State gets its funding for payment of state services, is reliant on what can be deemed to be a currently unfair taxation system. Unless there is a dramatic change to the system, the squeeze on the taxpayer will need to increase to an unacceptable level to fund increased community care requirements. Currently, an unfair burden is placed on the 'squeezed middle'. Irish taxpayers enter the 52% rate at a salary level of €70,045. At a salary level of €55,000, an Irish taxpayer pays more tax than in Sweden, Spain, Switzerland, and the US (Irish Tax Institute, 2016). As a consequence, approximately 75% of Irish people have little financial resilience for the future or retirement (Competition and Consumer Protection Commission, 2018). The state's 'Roadmap for Pensions Reform 2018-2023' has recognised this and included a commitment to introduce an Automatic Enrolment pension scheme. Launch of this is expected in 2022 (Competition and Consumer Protection Commission, 2018, p. 10). Not without its critics, this scheme has been castigated as 'unachievable' where Irish workers would have to have 40 years of pension contributions in order to qualify for a full state pension (Pollack, 2019).

As we see from above, delivering high quality health services remains a challenge, with Ireland ranking 10th out of 34 OECD countries for housing affordability, health service, and employment rate (OECD, 2018).

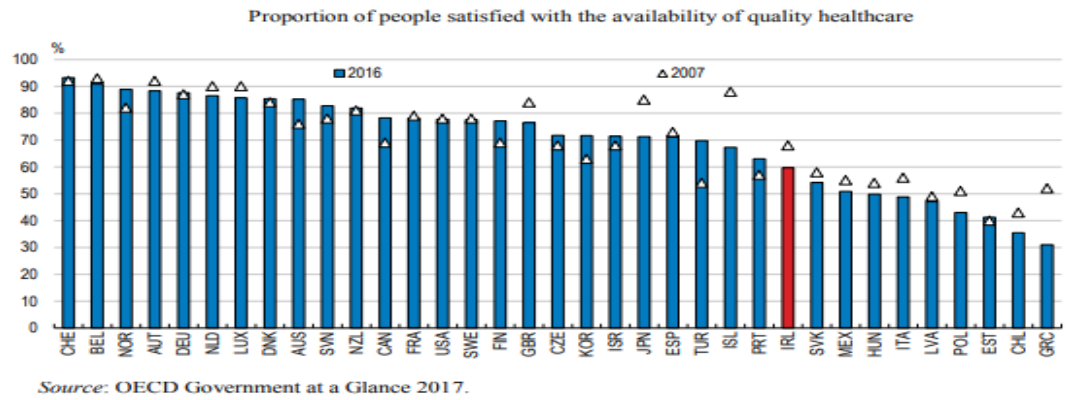


Figure 1.5. Proportion of People satisfied with the availability of quality healthcare (OECD, 2018).

In 2017, Home Care Services alone accounted for €376 million of Healthcare expenditure, with 19,807 people in receipt of a home care package and 46,243 of home help hours (D'Alton et al., 2018). An additional four million hours of homecare is needed to provide for ageing demographics, at a cost of €110 million (Cullen, 2018).

A number of other concerns have been highlighted flagging the inevitable rise in costs to the public purse with regard to caring for people with disabilities and the older person in Ireland. The annual cost of care for older person and the disabled is to double to €4.5bn within three decades, with the current €21bn in income tax needing to rise by 10pc per annum, to pay for care into the future (Lynott, 2019). Estimates from the National Disability Authority show that by 2026, Ireland will need to increase the HSE health and social care budget by a third to cover the increased population living with a disability (National Disability Authority, 2018).

Currently, the state pension is paid from the exchequer takings of the year it falls in. The projected halving of the working age group, coupled with increasing aging demographics, will put a considerable if not impossible pressure on the state to deliver the required community services to avoid a person being forced to resort to residential care services.

1.8 Conclusion

As the OECD and CSO predictors inform us, the share of population over 65 is increasing, with dementia set to rise threefold by 2040. There is a statutory provision for care in residential care services through the Nursing Homes Support Scheme, but no statutory provision for home care, where, through lack of community supports, an older person has to enter residential care. This is in effect *de facto* detention, where they will be under continuous supervision and not free to leave, as there is no suitable alternative provided. As Ireland's contribution to social protection is the lowest in the EU and not sufficient to address current and projected demands, funding community services through the current Irish taxation system is reliant on the 'squeezed middle. The need for increased funding because of rising age demographics and the projected halving of the cohort paying into the exchequer by 2040 ensures that the current system of payment for state funded activities is unsustainable. The very real threat to the state pension will mean even more people will not have community services available to them which may necessitate residential care.

Chapter 2: Human Rights and Legislation Relating to Detention in Healthcare

2.1 Introduction

Liberty has been defined as the right to pursue one's own ends without external interference (Olsen, 2003). 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 5 of the European Convention for Human Rights states that the right to liberty and security of the person is protected, while Article 14 of the United Nations Convention on Rights for Persons with Disabilities (UNCRPD, 2007) protects the right to liberty and security of persons with disabilities. This chapter will explore the human rights and legal issues involved in Deprivation of liberty relating to detention in residential care services in Ireland. The issue of consent will also be explored, as treating a person without their consent (other than in an emergency) is a violation of their rights under common and human rights law

2.2 Legislation in Irish Residential Care

Residential care for the older person in Ireland operates under the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013. The Health Information and Quality Authority (HIQA) is the statutory monitoring body to ensure compliance with regulations under this Act through the HIQA Standards (HIQA(a), 2016). While the Authority has ensured much needed improvements in standards of care for older persons in residential care, it needs to be acknowledged that reaching compliance has required considerable spending by residential care centres. One example of this would be fire regulations, where fire doors had to be installed. Another would be the converting of multi-occupancy rooms to single or double to protect privacy. Currently, there is a significant amount of legislation that healthcare providers must comply with. Some of the more recent such as the Data Protection Act requires considerable use of time and fiscal resources. Data Protection vindicates, to a certain extent, a person's right to privacy, but pressure is also on the providers to balance this right with the rights enshrined in the constitution, legislation, and the UNCRPD, to respect and vindicate the right to liberty.

Legislation Applicable to Healthcare
The Non-Fatal Offenses against the Person Act 2007
The Health Act 2007
Safety Health and Welfare at Work Act 2005 & 2010
Medical Practitioners Act 2007
Nurses and Midwives Act 2011
Health and Social Care Professionals (Amendment) Act 2012
Health (Amendment) Act 2013
Health Service Executive (Financial Matters) Act 2014
Irish Human Rights and Equality Commission Act 2014
Assisted Decision Making (Capacity) Act 2015
Medical Practitioners (Amendment) Act 2017
Civil Liability (Amendment) Act 2017
The Data Protection Act 2018

Figure 2.1. Legislation applicable to Irish Healthcare

2.3 Capacity and Consent

Consent is defined as 'the giving of permission or agreement for an intervention, receipt or use of a service…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…' (HSE National Consent Policy V1.2, 2017). There should be a presumption of capacity unless a trigger exists to give cause to question this. Thus, although presumption can be challenged, the onus to prove otherwise is on the person seeking consent. This includes all people with disabilities, mental health issues, cognitive impairment, or any other disability that affects their daily lives.

The standard of proof is civil i.e. the balance of probabilities but

> in applying the civil law standard of proof, the weight to be attached to the evidence should have regard to the gravity of the decision, whether that is characterised as the necessity for 'clear and convincing proof' or an enjoinder that the court 'should not draw its conclusions lightly (Fitzpatrick & Anor v K & Anor, 2008)

Treating a person without their consent (other than in an emergency) is a violation of their rights under common and human rights law and could result in criminal proceedings. For the consent to be valid, the person must have received sufficient information in a comprehensible manner about the nature, purpose, benefits, and risks of an intervention, not be acting under duress; and have the capacity to make the

particular decision (National Consent policy, 2013). Even before the ADMCA, 2015, capacity to consent favoured the functional approach under HSE policy. Functional capacity can be found in case law (Fitzpatrick & Anor v K. & Anor (2008), and the fact that a person is able to retain information for a short period only does not prevent them from being regarded as having capacity to make the decision.

The "functional" approach recognises that there is a 'hierarchy of complexity' in decisions and also that 'cognitive deficits are only relevant if they actually impact on decision making' (HSE National Consent policy, 2014). The possibility of incapacity and the need to assess capacity formally should only be considered if, having been given all appropriate help and support, a service user is unable to communicate a clear and consistent choice or is obviously unable to understand and use the information and choices provided. Where the person lacks capacity, the healthcare professional should act according to their previous will and preferences (if known). This replaces 'best interest' under the Assisted Decision Making (Capacity) Act.

2.4 Human Rights Law and Liberty

Human rights are the 'distinctive legal, moral and political concept of the last sixty years' (Cruft et al., 2015). These are rights that all human beings possess simply by virtue of their humanity and which can be identified simply by the use of ordinary moral reasoning ("natural reason"), as opposed to the sort of conventional reasons created within particular social or institutional contexts (Cruft et al., 2015).

Central to Human Rights are the ''right of people to live in freedom and dignity, free from poverty and despair…with an equal opportunity to enjoy all their rights and fully develop their human potential" (UN General Assembly resolution 66/290, 2012), and states must respect and vindicate these rights.

The Constitution of Ireland 1937 was one of the first constitutions in the world to express human rights such as the right to liberty, freedom of expression, freedom of association and freedom of religion. However, the Constitution did not contain certain rights relevant to health care such as the rights to bodily integrity, dignity, privacy, liberty, and autonomy. These personal or fundamental rights are recognised under Article 40.3 of the Constitution. They are unremunerated or unwritten rights:

> The State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen.

The Irish Courts recognised these implied rights in a number of cases during 1965-1995 and were implicit in the Constitution. *McGee v Attorney-General* held that the fundamental rights declared in the Constitution are not created by it but are an acknowledgement that the individual has an inalienable possession of them.

Article 40.4.1 of the Irish Constitution states, 'No citizen shall be deprived of his personal liberty save in accordance with law'. In King v. AG [1981] IR 233, Henchy J. observed that;

> …no citizen shall be deprived of personal liberty save in accordance with law – which means without stooping to methods which ignore the fundamental norms of the legal order postulated by the Constitution.

The European Convention on Human Rights (ECHR, 1950) was signed by Ireland in 1953 but was not incorporated into Irish law until 2003. There are 24 rights and freedoms, which states who have signed up for must protect and vindicate. Those relating to liberty are outlined in Figure 2.2.

Article	Description
Article 1	Places an obligation on all Contracting States to guarantee to everyone within their jurisdiction the rights and freedoms of the Convention.
Article 3	Complete prohibition on subjecting a person to torture or to inhuman or degrading treatment or punishment.
Article 5	The right to liberty and security is protected. The Convention allows a person to be deprived of their liberty in certain circumstances, such as person suffers from a mental disorder or has been convicted of a criminal offence. The Convention provides a person with certain rights when they are deprived of their liberty, for example if a person is arrested, he or she is entitled to know the reasons for the person's arrest.
Article 8	Right to respect for private and family life. This guarantees a right to respect for a person's private life, family life, his home and his correspondence. This right may be interfered with if it is "in accordance with the law and is necessary in a democratic society" for certain interests such as public safety or the protection of health or morals.
Article 9	Freedom of thought, conscience and religion. This right is subject to the same limits for a person's private life, family life, his home and his correspondence.
Article 10	Freedom of expression. This right is subject to the same limits for a person's private life, family life, his home and his correspondence.
Article 14	Prohibition of discrimination. The Convention does not give a right to equality. Instead, the Convention prohibits discrimination. This prohibition may only be relied upon in relation to a particular right, such as the freedom of religion or the right to private life.

Figure 2.2. European Convention on Human Rights relating to Deprivation of Liberty

In relation to privacy, Article 8 of the convention provides that 'everyone has the right to respect for his private and family life, his home and his correspondence' and 'there shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law…'.

Ireland has also ratified the United Nations International Covenant on Civil and Political Rights. Article 17 states;

> No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

While the right to privacy is not expressly defined in the Irish Constitution, the Irish courts have long recognised the right to privacy. McGee v Attorney-General held that the prohibition of the importation of artificial contraceptives by the Criminal Law (Amendment) Act 1935 was an unjustified invasion of the plaintiff's right to privacy in her marital affairs:

> Whilst the personal rights (of the 1937 Constitution, art 40(3) are not described specifically, it is scarcely to be doubted in our society that the right to privacy is universally recognised and accepted with possibly the rarest of exceptions…

Through the HIQA National Standards for residential care services for older people, HIQA 'aims to safeguard people and improve the safety and quality of health and social care services across its full range of functions' (HIQA(a), 2016). While these standards have created very laudable improvements in the standard of care for many older persons, compliance with the standards to a certain extent unavoidably involves an invasion of privacy that would not occur in the person's own home. For example, Standard 1.1 is that a care plan should be in place to answer to the resident's needs.

In order to discern a person's needs, questions need to be asked by staff about what the person eats, drinks, their elimination pattern (daily monitoring and documentation of these as weight loss and constipation can be a common problem for the older person), their recreational and social activities, their spiritual practices, and so on. Monthly weights should be carried out, and where a suspicion of dehydration exists, everything they drink has to be documented. These practices exist to ensure safe care

for the older person, but the fact remains that they do constitute what can be considered very invasive monitoring. In a recent report detailing the results of HIQA inspections, under Regulation 9 Resident's rights, 93% of Services were found to be 'Not Compliant' of the 15 assessed against this Regulation (Healthcare Informed, 2019). Breaches under this right included residents being impacted by noise from other residents, privacy during intimate care being provided by a curtain, use of multi occupancy rooms not supporting privacy for communication and personal care, and residents unable to receive visitors in private.

The lawfulness of detention presupposes conformity with state law and conformity with the purpose of the restrictions permitted by Article 5. The detention of an individual is such a serious measure that it is only justified where other, less severe, measures have been considered and found to be insufficient to safeguard the individual or public interest which might require that the person concerned be detained. The law provides that a person deprived of his or her liberty by detention must be entitled to take proceedings by which the lawfulness of his or her detention must be decided speedily by a court and his or her release ordered if the detention was not lawful. Everyone who has been the victim of detention in contravention of Article 5(1) has an enforceable right to compensation.

For example, in M.S. v. Bulgaria, the applicant was arrested and taken to a prison hospital three times and was allegedly held incommunicado the third time. She complained that her detention was not in accordance with the law and constituted a violation of Art. 5. There was a friendly settlement where the government paid compensation for non-pecuniary damage and legal fees.

Article 5 of the Convention – Right to liberty and security

"1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

(a) the lawful detention of a person after conviction by a competent court;

(b) the lawful arrest or detention of a person for non- compliance with the lawful order of a court or in order to secure the fulfilment of any obligation prescribed by law;

(c) the lawful arrest or detention of a person effected for the purpose of bringing him before the competent legal authority on reasonable suspicion of having committed an offence or when it is reasonably considered necessary to prevent his committing an offence or fleeing after having done so;

(d) the detention of a minor by lawful order for the purpose of educational supervision or his lawful detention for the purpose of bringing him before the competent legal authority;

(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants;

(f) the lawful arrest or detention of a person to prevent his effecting an unauthorised entry into the country or of a person against whom action is being taken with a view to deportation or extradition.

2. Everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons for his arrest and of any charge against him.

3. Everyone arrested or detained in accordance with the provisions of paragraph 1 (c) of this Article shall be brought promptly before a judge or other officer authorised by law to exercise judicial power and shall be entitled to trial within a reasonable time or to release pending trial. Release may be conditioned by guarantees to appear for trial.

4. Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.

5. Everyone who has been the victim of arrest or detention in contravention of the provisions of this Article shall have an enforceable right to compensation."

Figure 2.3. Article 5 of the Convention on Human Rights – Right to liberty and security

With regard to healthcare, the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (UN 1984), ratified by Ireland in 2002, and the United Nations Convention on the Rights of Persons with Disabilities (2007), ratified by Ireland in 2018, are important.

The 2017 report from The Committee against Torture (UN CAT) on their visit to Ireland highlighted concerns in relation to abuses of older persons and persons with psychosocial disabilities in residential care. They stated:

> The Committee is concerned at reports that older persons and other vulnerable adults are being held in public and privately operated residential care settings in situations of de facto detention, and at reports of cases in which such persons were subjected to conditions that may amount to inhuman or degrading treatment, including the improper use of chemical restraints.

They also expressed regret that, although Ireland had enacted new legislation, the Assisted Decision-making (Capacity) Act 2015, which would substantially alter its procedures regarding involuntary confinement in such facilities, the substantive

provisions of this law have not been commenced and, as a result, the Lunacy Regulations (Ireland) Act 1871 continues to be in effect (UN CAT Concluding Observations, 2017).

Interestingly, an addendum to the UNCAT report August 2018 included a comprehensive reply from Ireland on all issues except *de facto* detention of older people in residential care and chemical restraint. Older people were not mentioned at all (UNHR, 2018). The reply stated that 'ongoing progress and implementation' of the UNCRPD would be internally monitored through the National Disability Inclusion Strategy 2017 – 2021. Of note, the strategy does state:

> We will introduce statutory safeguards to protect residents of nursing homes and residential centres, and ensure that they are not deprived of liberty, save in accordance with the law as a last-resort measure in exceptional circumstances.

The timeframe for this was the Q1 2017. Considering the Draft Heads of Bill for the Deprivation of Liberty Safeguards had its public consultation phase closed in March 2018, we are still awaiting progress on this.

2.4.1 The United Nations Convention on Rights of Persons with Disabilities (UNCRPD.2007)

Under the UNCRPD, Article 1 of the convention seeks to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'. It goes on to say persons with disabilities include those who have 'long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'. Articles 3 and 4 refer to the rights of people with a disability to be actively involved, equal to others, in decision-making processes that affect their lives. Article 19 is the right to live independently and to be involved in their communities. Right to life, liberty and security of the person are found in Articles 10 and 14, while equal recognition before the law and legal capacity is found in Article 12.

Outside of the Mental Health Act (2001), and for infection control purposes, in the 1947 Health Act, unlike other jurisdictions, there is no legal provision in Irish healthcare which allows for a person to be detained against their will. Pending

advancement of the Assisted Decision Making (Capacity) Act 2015, which provides a statutory framework for individuals lacking capacity to make legally-binding agreements to be assisted and supported in making decisions about their welfare, their property and affairs, we are currently operating under the Lunacy Regulations (1871). This legal framework for substituted decision making for people deemed of "unsound mind" amounts to a denial of a vulnerable adult's human rights (SAGE, 2017). Yet, in the three years (2012 to 2015), there was a 36% increase in Wardship applications (SAGE, 2017). It is therefore essential that healthcare providers open the narrative on how to address the critical issue of caring for a person with dementia who states they wish to leave and live in their own homes.

In MX v Health Service Executive (2012), the Court noted that the UNCRPD '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'.

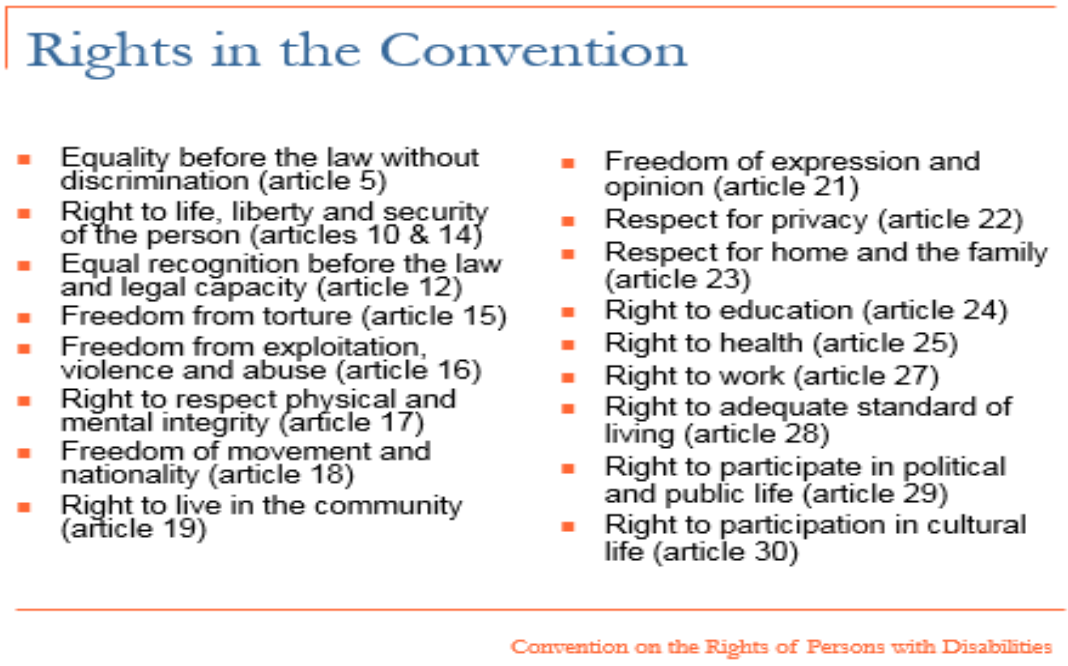


Figure 2.4. Rights under the UNCRPD, 2007

As older people become frail and need support, because of cognitive or physical decline, these fall under the wider conception of persons with disabilities and can benefit from the protection of the convention. It also calls on states *to provide* services to prevent and minimize further disabilities among older people, and to ensure older people with disabilities have access to retirement benefits and poverty reduction programmes. Ireland had signed into the framework of this in 2007 and was the last UN state to ratify it in March 2018. Articles 3, 4, and 19 specifically reference the rights of people with a disability to be actively involved, equal to others, in decision-making processes which affect their lives. The introduction of the Assisted Decision Making (Capacity) Act 2015 and Deprivation of liberty Safeguards to be inserted to the Act are pivotal to this. In addition, the amending of the Mental Health Act 2001 in regards to voluntary detention in Mental Health facilities was also crucial.

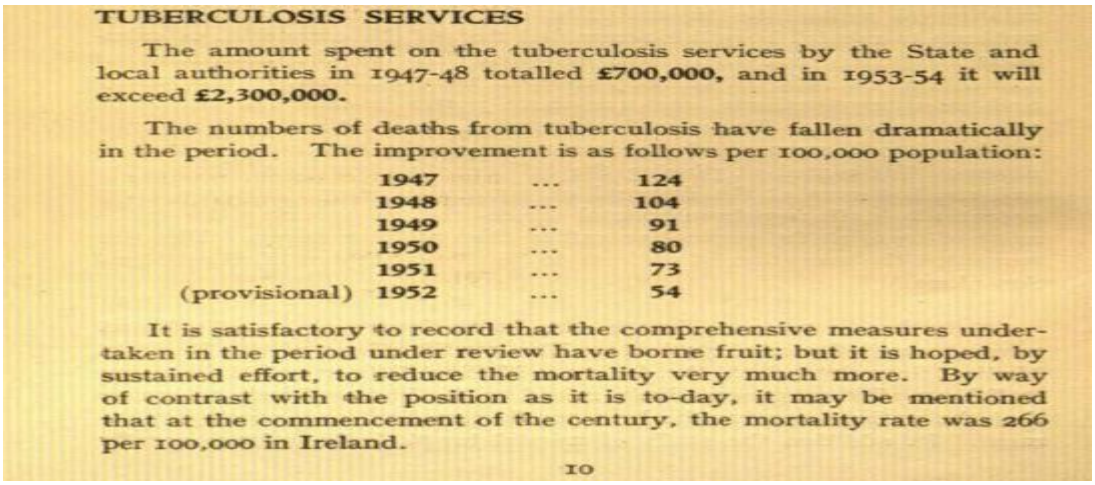
2.4.2 Liberty and Healthcare

Outside of the criminal justice system, there are a number of different circumstances in which an individual may find themselves detained in Ireland.

1. Pursuant to statute where an individual may be detained statutorily and, in the case of wardship, in tandem with an order of the Court: The Lunacy Regulation (Ireland) Act 1871 and the Mental Health Act 2001. For Infection control purposes under the 1947 Health Act.
2. Pursuant to the inherent jurisdiction of the Court; under Article 40.3 of the Constitution where the Court may find that the personal rights of an individual are endangered e.g. where they require medical treatment but does do not have capacity to consent to it, necessitating the intervention of the Court.
3. *De facto* detention where an individual is unable to leave a residential or institutional care setting, although there is no statutory detention or Court order of detention.

The Mental Treatment Act, 1945, co-ordinated and modernised the legal code under which mental treatment was afforded. The Tuberculosis (Establishment of Sanatoria) Act, 1945, gave power directly to the Minister for Health to build regional sanatoria to deal with the tuberculosis problem (DoH, 1953). The Health Act 1947 gave statutory

powers for Medical Officers to detain and isolate persons suspected of having an infectious disease.



TUBERCULOSIS SERVICES

The amount spent on the tuberculosis services by the State and local authorities in 1947-48 totalled **£700,000,** and in 1953-54 it will exceed **£2,300,000.**

The numbers of deaths from tuberculosis have fallen dramatically in the period. The improvement is as follows per 100,000 population:

	1947 ...	124
	1948 ...	104
	1949 ...	91
	1950 ...	80
	1951 ...	73
(provisional)	1952 ...	54

It is satisfactory to record that the comprehensive measures undertaken in the period under review have borne fruit; but it is hoped, by sustained effort, to reduce the mortality very much more. By way of contrast with the position as it is to-day, it may be mentioned that at the commencement of the century, the mortality rate was 266 per 100,000 in Ireland.

10

Figure 2.5. Department of Health Cursai Slainte Health Progress 1947 – 1953 P.10 (DoH, 1953)

2.5 The Mental Health Act 2001

The Mental Health Act of 2001 replaced the Mental Treatment Act 1945. It did not come into force until 2006 after being a bill since 1999 following 108 amendments (Keys, 2002). Its provisions are to provide for the involuntary admission of people suffering from mental disorders. Under the Act, “mental disorder” means mental illness, severe dementia, or significant intellectual disability. Involuntary admission can be made for people who are considered a danger to themselves or others, where the judgement of the person is so impaired that without treatment their condition would severely deteriorate, or where the reception, detention, or treatment is likely to benefit the person (Section 3.1 of the MHA). Voluntary patients are ‘a person receiving care and treatment who is not the subject of an admission order’. The MHA makes no provisions for voluntary patients who do not refuse admission. Section 23 of the Act provides for involuntary detention:

> Where a person (other than a child) who is being treated in an approved centre as a voluntary patient indicates at any time that he or she wishes to leave the approved centre, then, if a consultant psychiatrist, registered medical practitioner or registered nurse on the staff of the approved centre is of opinion that the person is suffering from a mental disorder, he or she may

> detain the person for a period not exceeding 24 hours or such shorter period as may be prescribed, beginning at the time aforesaid.

It is worth noting at this point that in HL V United Kingdom in the European court of Human Rights (2004) – the Bournewood case – the ECHR found that the voluntary admission of a man who lacked capacity to consent or decline voluntary treatment amounted to a breach of Article 5 and 4 of the European Convention on Human Rights. Because of this ruling, the Mental Capacity Act (2005) for England and Wales was amended with the addition of Deprivation of Liberty Safeguards, whereby when admitting a person who lacked capacity to consent to treatment an application had to be made through the courts.

In AM v Health Service Executive Supreme Court (2019), Justice John MacMenamin stated that the demarcation line between wardship and the Mental Health Acts is shown by s.283 of the 1945 Act.

> (T)he statutory intention is, then, explicit; neither the 1945 (Mental Health) Act nor its successors are to remove or delimit the wardship jurisdiction of the High Court and Circuit Court.

2.6 The Lunacy Act 1871. Wards of Court System

This is an Act to 'amend the Law in Ireland relating to Commissions of Lunacy, and the proceeding under the same, and the management of the Estates of Lunatics; and to provide for the visiting and the protection of the Property of Lunatics in Ireland; and for other purposes' (Chapter XXII of Lunacy Act 1871 sic). This legal framework for substituted decision making for people deemed of "unsound mind" amounts to a denial of a vulnerable adult's human rights; nonetheless, from 2012 to 2015, there was a 36% increase in wardship applications (SAGE, 2017). In 2016, 234, or 81% of those admitted to wardship were due to dementia and age related illness (National Safeguarding Committee, 2017). In 2017, there were 2909 wards of court (The Office of the Accountant of the Courts of Justice, 2017). A committee, typically including a family member, is appointed to make recommendations on matters relating to welfare and property (Joint Committee on Justice and Equality, 2018). Of considerable concern is that neither wards nor their families have access to legal redress within the courts

system, with the cost of legal expertise being prohibitive for many (Joint Committee on Justice and Equality, 2018)

Table 1. Reasons for Wardship

Reason person admitted to Wardship	2014	2015
Elderly or mentally infirm	159 (36%)	155 (36%)
Learning or intellectual disability	122 (28%)	122 (28%)
Psychiatric illness	95 (22%)	96 (22%)
Acquired brain injury	54 (12%)	55 (13%)
Minor	6 (1%)	5 (1%)
Residential abuse	2 (≈ 0%)	2 (≈ 0%)
Total	438	435

Source: Courts.ie website.

Figure 2.6. Reasons for Wardship Joint Committee on Justice and Equality (2018)

The wardship of the court's jurisdiction can be traced back to medieval times. The jurisdiction was seen as the delegated exercise of a "*parens patriae"* power, originally vested in the Crown as part of the Royal prerogative (Costello, 1997, cited in AM v Health Service Executive, 2019). Subsequently, by a series of enactments, The Lunacy Regulation (Ireland) Act, 1871, the Lunacy (Ireland) Act 1901, the Government of Ireland Act 1920, the Courts of Justice Act 1924, the Courts of Justice Act 1936, and the Courts (Supplemental) Provisions Act 1961), wardship jurisdiction became vested in the Lord Chancellor of Ireland, then to the Chief Justice of Ireland, and finally to the President of the High Court. Currently, the President of the High Court is empowered to assign another judge of the High Court to perform these functions (AM V Health Service Executive 2019).

"Ward" is defined by Order 67, Rule 1 of the Rules of the Superior Court as;

> a person who has been declared to be of unsound mind and incapable of managing his person or property and includes, where the context so admits, a person in respect of whom or whose property an order has been made under section 68 or section 70 of the Lunacy Regulation (Ireland) Act 1871.

The court must also be satisfied that it is appropriate and necessary to make the person a Ward of Court in order to protect his or her person and or property. The recognition of the ward's human rights have been established in case law (Re a Ward of Court (No 2) [1996] 2 IR 79). C.J Hamilton stated:

> The loss by an individual of his or her mental capacity does not result in any diminution of his or her personal rights, recognised by the Constitution…The ward is entitled to have all of these rights respected, defended, vindicated and protected from unjust attack and they are in no way lessened or diminished by reason of her incapacity.

However, as we will see from Case law Ward of Court examples in the next section, protection and vindication of the person's rights does not appear to have been fully adhered to.

2.7 Ward of Court Judgements

One very controversial case was that of W.D in August 2018 reported in the media (W.D, 2018), which was not available on court records. A man in his 60's with epilepsy wished to go to live in his own home after being transferred to a nursing home from the acute hospital to where he was admitted. He was made a ward of court by Justice Peter Kelly who found that he lacked the capacity to make his own healthcare decision in regard to being allowed live in his own home and that detention in a nursing home was appropriate care for him. He had been regularly admitted to the acute care services following episodes of epileptic seizures and hospital staff, concerned for his health and safety, discharged him to a nursing home. SAGE Advocacy who supported the man in his bid to be allowed care for himself expressed bitter disappointment in a statement to RTE news, stating that the man 'has lost his legal identity, his rights as a citizen and his ability to choose where he lives based on legislation dating from 1871'. SAGE stated that they had tried to engage with the HSE to plan for a safe discharge for him, but this did not happen. In a statement, a spokesperson for the HSE said: 'The Ward of Court process offers significant additional protections to vulnerable people'.

In the case of A.M v Health Service Executive, AM following conviction for serious assaults and manslaughter was detained in the Central Mental Hospital (CMH) in a high security Unit. On completion of the sentence, he could not be released due to the risk his mental illness posed to the public and himself. A temporary detention order was made pending Ward of Court petition. The HSE sought to have him taken into wardship, claiming that there was no other way to have him legally detained in the CMH. If detention was to be under the Mental Health Act 2001 (MHA), AM would have to be transferred to an approved centre (other than the CMH), where under section 10

he could be admitted as an involuntary patient and then transferred to the CMH under section 21. The director of the CMH swore an affidavit stating that no other centre was prepared to take him, which is why they were making the Ward of Court application. The council for AM stated that this would circumvent the provisions and safeguards of the Mental Health Act 2001 for AM. AM was subsequently made a Ward of Court on the basis that there were six monthly reviews and sufficient protections under the Lunacy Regulations. Mr Justice MacMenamin said that to admit AM into wardship was appropriate in this case, and that even though he was admitted into wardship, the essential safeguards and protections, as regards procedural rights, and as reviewed by the courts, consent and treatment could be no less than if he had been admitted to the CMH under the Mental Health Acts.

In P.L. v Clinical Director of St. Patrick's University Hospital, January 2012, the appellant was a voluntary patient in St Patricks Hospital in 2011, having admitted himself following a psychotic episode. In September, he expressed a wish to leave but was detained under a renewal order affirmed by the Mental Health Tribunal until October 2011 when it was then revoked, meaning he was still a voluntary patient. He was detained in a locked ward, limiting freedom of movement. The attending psychiatrist believed that following a period of not taking his medication, acute symptoms of psychoses were re-emerging and they decided to make an order under section 23 of the 2001 Act, pursuant to an assessment for the purposes of section 24 of the Act. A second doctor's opinion (as is required under section 24 of the Act) did not believe the man should be detained under section 23, noting that he had agreed to engage in further treatment as a voluntary patient. He was returned to a locked ward. The appellant argued that there was no legal basis to detain him. The hospital argued that it was necessarily implicit in section 23 of the Act that they could refuse to allow a voluntary patient to leave in in order to obtain an initial assessment that they are suffering from a mental disorder, and without having to invoke section 23. Judgement in the Court of Appeal was that a voluntary patient could not be detained against their wishes.

Part 6 of the Assisted Decision Making (Capacity) Act 2015 (ADMCA) makes provision for a review of all existing wards of court within at least three years from the date of

commencement of the Act. In its review of the wardship system, the National Safeguarding Committee (2017) have suggested that, as the Lunacy Regulations (Ireland) Act 1871 remains on the statute book, its statutory provisions need to be interpreted and applied in accordance with the provisions of the European Convention for the Protection of Human Rights and Fundamental Freedoms, as required under the European Convention on Human Rights Act 2003, and in line with the spirit of the UN Convention on the Rights of Persons with Disabilities, which is provided for in the Guiding Principles of the Assisted Decision-Making (Capacity) Act 2015 (National Safeguarding Report 2017). The committee identified a number of serious issues in relation to human rights with the continuance of the Wards of Court system.

2.8 The Assisted Decision Making (Capacity) Act 2015

The Assisted Decision Making (Capacity) Act 2015 (ADMCA) is a key piece of legislation to enable Ireland to ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), reforming Ireland's existing capacity legislation, the Lunacy Regulations (Ireland) Act 1871. While these are now repealed under the Act, the existing wardship system is still in place. The ADMCA places a statutory onus on healthcare professionals to support people to make their own decisions and establishes a legal framework to support decision-making by adults who have difficulty now, or may have difficulty in the future, in making decisions without help. In some limited circumstances, it allows for a court appointed decision-maker, with legal oversight.

Places a legal obligation on everyone, including health and social care staff, to support a person whose capacity is in question, or who may lack capacity to make their own decisions.
Assessment of a relevant person's capacity should only be done after all practicable steps and efforts to support the relevant person to make his or her own decision have been taken.
Affirms a flexible 'functional' definition of capacity, whereby capacity is assessed only in relation to the matter in question and only at the time in question. Therefore, 'blanket' assessments of a person's capacity should not be made – the assessment must relate to the particular decision to be made ('issue-specific') and at the time the particular decision is to be made ('time-specific').
Recognises that a person's capacity can fluctuate so he or she may appear to lack capacity in relation to a certain decision on one day but have capacity in relation to the same decision on a different day. The functional approach of assessing capacity on a time-specific and issue specific basis is of particular assistance in relation to the assessment of a relevant person with fluctuating capacity.
Where health and social care staff must make an intervention on behalf of the person due to their lack of capacity and the urgency of the situation and decision required, staff must seek to establish the will and preference, the belief and values of the person, and these must inform any intervention

Figure 2.7. Summary of main provisions of the 2015 Assisted Decision Making (Capacity) Act

The main provisions are recognition of fluctuating capacity (may change from day to day for the same decision) and functional capacity (issue specific and time specific).

A Decision Support Service (DSS) is provided for to raise public awareness of the Act, providing information to people in relation to their options for exercising their capacity, and information and oversight to the legally recognised persons under the Act. The DSS can also make recommendations to the Minister on any matter relating to the operations of the Act.

Where healthcare staff seek to make an intervention on behalf of a person who lacks capacity, they must establish the will, preference, beliefs, and values of the person before proceeding. The Act allows for a person, whose decision making ability may be in question, to have support from a trusted family member or friend (an 'intervener'). This can be a 'Decision Making Assistant' (who will help them make a decision), or a 'Co – Decision Maker' (who will make the decision with them). Where the person has not make an Advanced Healthcare Directive or created an 'Enduring Power of Attorney' an application to the court is necessary. The court will then either make the decision if the issue is urgent, or appoint a 'Decision Making Representative'. The Act also legislates for Advanced Healthcare Directives' where the person can make decisions in advance of their care wishes and appoint a person as their 'Decision Making Representative. These have been recognised in common law for some time (Re a Ward of Court (No 2) [1996] 2 IR 79).

Lastly, where under the Powers of Attorney Act 1996 a person can create an enduring power of attorney appointing a person, known as an attorney, to make decisions on their behalf relating to property and finance or personal care or both, the ADMCA allows someone to also appoint an attorney in relation to some health care matters. This only comes into action where the person lacks capacity.

Part 2 of the ADMCA sets out a number of guiding principles to be followed:

- There is a presumption of decision-making capacity, unless the contrary is shown,
- No intervention can take place unless it is necessary,

- Any act done or decision made under the Act must be done or made in a way which is least restrictive of a person's rights and freedoms,
- Any action done or decision made under the Act in support or on behalf of a person with impaired capacity must give effect to the person's will and preferences.

Lunacy Act 1871	ADMA 2015
Legal capacity: Binary choice – person has capacity or no capacity	Decision making capacity: Functional and fluctuating. Must be supported in as much as is practicable.
No 'court friend' / advocate	Provides that where the Respondent has not instructed a legal practitioner, they may be assisted in Court by a decision-making assistant, co- decision-maker, decision-making representative, or designated healthcare representative. Where there is no such assistance available, then they may nominate 'another person', who the Court must be satisfied is suitable, willing and able, to assist the Respondent. The Court is entitled to hear submissions from this person. Where no assistance is available to the Respondent from any of the above assistants, and where the Respondent has not instructed a legal practitioner, the Court may appoint a Court friend.
No legal representation	Amends the Civil Legal Aid Act 1995 to provide that a Respondent is entitled to legal aid.
No right to be in court	Provides for the right of the Respondent to be in Court during proceedings that he or she is a party to.
Will and preference, feelings, beliefs and values not taken into account. Voice of respondent not heard	Will and preference provided for through decision making representatives as above.

Figure 2.8. ADMCA and Lunacy Act Comparisons

The primary responsibility for implementing these new statutory provisions rests with the Department of Justice and Equality and the Department of Health, with responsibility for managing the new decision-making regime under the auspices of the Mental Health Commission. A budget of €3 million has been provided for the establishment of the Decision Support Service (Department of Justice and Equality, Press release October 2018). This is out of a total budget for this department of €2.79 billion. It was intended that the service will be up and running at the beginning of 2019 (Joint Commission of Justice and Equality, 2018).

However, advancement of this Act has been very slow, with decision support services not yet set up and further amendments required. While the Act places a legal

obligation on healthcare professionals to support a person whose capacity may be in question to make decisions in regard to their own care, healthcare services are currently in a hiatus and unsure of how to proceed when caring for a person who may lack capacity. Caught between the Lunacy Act 1871 and the not yet fully commenced ADMA, 2015, and a requirement to fulfil the rights of persons with disabilities under the UNCRPD, there is considerable confusion. A draft guide was circulated for healthcare professionals with consultation closed April 2017. To date, this - the 'Assisted Decision-Making (Capacity) Act 2015 A Guide for Health and Social Care Professionals' - has not been circulated two years later. And there is a concern that, while ratification is outstanding for the ADMA, the principles established in the UNCRPD, which recognises the rights of persons with disabilities as fundamental human rights, are given no recognition in the current wardship system (National Safeguarding Committee, 2017).

Thus, while the ADMA states that people who are existing Wards Of Court will have their capacity reviewed to bring them in line with the ADMA, it does not grant rights to legal aid or other representation in the reviewing court (SAGE, 2017).

2.9 Clinical Negligence and Duty of Care

Negligence is defined by Mills (2007, p.40) as 'doing - or failing to do – something in such a way that your act or omission falls below the standard of care you owe to your neighbour causing him harm. Legally speaking ones neighbour is any person whom one can reasonably foresee as being affected by ones acts or omissions'. In Blyth v Bermingham Waterworks Company (1856):

> (T)he omission to do something which a reasonable person, guided upon those considerations which ordinarily regulate the conduct of human affairs would do, or doing something which a prudent person would not do

Three elements must be proven, based on the balance of probabilities, in order for a negligence action to succeed. There must be an existence of a duty of care or a duty to take care, a breach of that duty (failure to reach the required standard of care), and causation (harm or damage is caused to the plaintiff by a breach of that duty) (Mills, 2007, p.139).

In Irish law, a duty of care arises where there is proximity between the parties in a legal sense, where any damage caused by one party to another is foreseeable, and where there is no strong public policy that would create an exception. A duty of care is invariably present in any therapeutic relationship established between the patient and clinician (Mills, 2007, p.140). The requirement of the healthcare professional to act in the 'best interest' of the patient is by statute under the Mental Health Act 2001 s.4, having previously been established in case law (Re MB (Medical Treatment) (1997) 2 FLR 426, CA. & Re A (Male Sterilisation) (2000) 1 FLR 549). This is being changed by the Assisted Decision Making (Capacity) Act to a principles-based approach, as outlined previously. Of note, it is established in Strasbourg and domestic jurisprudence that in certain 'well-defined circumstances', Article 2 will impose 'a positive obligation on [state] authorities to take preventative operational measure' to protect the life of an individual (Osman v UK, (2009) 29 EHRR 245 at 115).

As outlined previously, many healthcare professionals adopt a 'risk averse' approach when it comes to care of the older person in the community, where the wishes of the older person to live at home in 'risky' situations were 'often' ignored and residential care encouraged (Donnelly et al., 2016). In part, this is because of the moral and legal 'duty of care'. It is also because of fear of litigation. However, as can be seen from the AC v CUH & HSE (2018) case, where the health and social care professionals act in a patient's 'best interests' fulfilling their duty of care, the law may still react unfavourably to detaining a patient unable to take care of themselves outside of the statutory provisions allowed.

In this landmark case for Ireland, the Court of Appeal ruled that a hospital had no lawful power to restrain a patient in hospital against his or her wishes, notwithstanding that the restraint may have been in the patient's best interests. AC was admitted to Cork University in 2015 twice, following falls, where she sustained a fracture of one hip, and then the other. From 2016, she was bed bound, incontinent, and at significant risk of pressure ulcers having become fully dependent on staff for all of her care. The multidisciplinary team felt she lacked capacity to make her own healthcare decisions and subsequently refused to discharge her to the care of her children, as there were safeguarding concerns also in the way her son and daughter interacted with their

mother and the staff in the hospital. AC, that July, signed a letter stating that she wished to return to the home of her son and that associated costs for her care at home would be paid for by the HSE. CUH were of the view that AC did not have the capacity to understand the implications of her being discharged on her health and well-being and refused to discharge her. The help of the Gardaí was sought to prevent her family removing her. AC's son made two unsuccessful applications to the High Court into the legalities of her detention. AC was taken into wardship. A subsequent application to the Court of Appeal was granted, and the court concluded that AC was unlawfully detained, with the judge stating:

> The fact remains, however, that CUH had no power to prevent Ms. AC from leaving the premises once she expressed her wish to do so. In this context it mattered not that this decision to refuse permission to leave was considered to be in her best interests.

Moreover, Justice Hogan further elaborated by saying,

> ….there is, simply, no "half way house" between liberty "unfettered by restraint and an arrest". Yet if the power to restrain contended for by CUH in the present case were to be admitted, it would mean ……..the personal liberty of tens of thousands of vulnerable, elderly patients suffering from dementia and residing in institutional care through the State – would be reduced to a half-way house of ambiguity, variable and inconsistent grants of permission and subjective paternalism on the part of clinicians, nurses and care-givers

This judgement has naturally caused great concern amongst the medical profession and is in direct opposition to standard practice for treating a person who lacks capacity. In the Medical Council's guidelines for treating a person who lacks capacity to make a decision and there is no person with the legal authority to do so for them, the doctor will have to decide what treatment option is in the patient's best interests. However, of note in the ADMCA, the principle of 'best interest' is not mentioned, replaced instead by 'will and preference'. The 'best interest' approach is also in place under the IMC, 2016, NMBI, 2014 and SWRB, 2011 for doctors, nurses and social workers (discussed further in the Ethics chapter).

It is not without reason that many healthcare professionals in Ireland fear medical negligence claims. The financial statements of the State Claims Agency indicate claims settlements on behalf of state agencies in 2018 totalled €354 million (Committee of

Public Accounts Debate, 2019). Personal injury costs to the state increased from around €100m in 2012, to €250m in 2016 (RTE, 2018). The state has settled two very tragic personal cases against the HSE recently. In the first, for alleged negligence and breach of duty, a 19 year old boy discharged from psychiatric services fatally stabbed his little brother, then himself. This was settled for an undisclosed sum (Healy and Begley, 2019). The second case involved a gentleman who was on day release from a psychiatric hospital. He ran from his mother and entering a multi-storey car park, fell from the first floor of a car park, sustaining 'horrific' injuries to his spine, whereupon the HSE admitted liability and a settlement of €7.25 million followed (Healy, 2019).

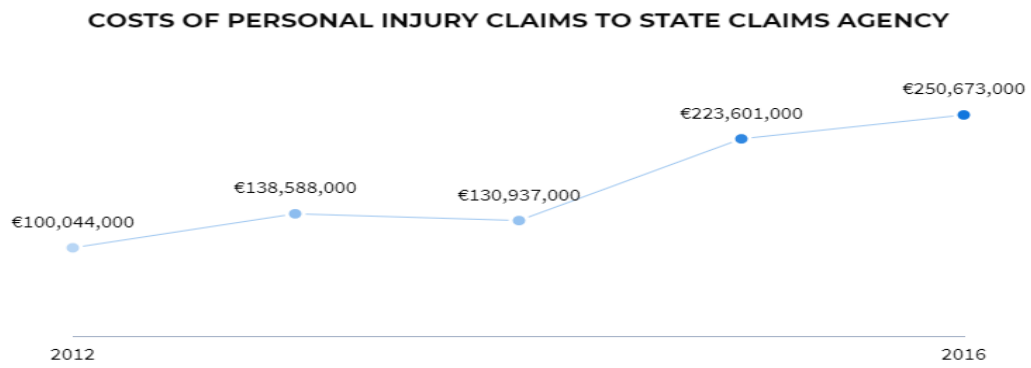


Figure 2.9. Costs of Personal Injury Claims to the State Claims Agency (RTE, 2018)

2.9 Conclusion

The current legal framework in Ireland under the 1871 Lunacy Act and Wards of Court system fails to protect and vindicate human rights under the UNCRPD. It is inadequate in protecting the interests of people with impaired capacity and fails to empower them to maximise their potential. The Assisted Decision Making (Capacity) Act has great potential to improve healthcare decision-making for people with capacity impairments. The fact that the Act was ratified in 2015 and has yet to be fully commenced is of great concern, however. The Office of the Decision Support Services has an allocation of only €3 million to fully implement the ADMCA, educate healthcare professionals and the public and advise people on their rights in relation to capacity.

The question now of course is whether it is possible to achieve all of this with the sum allocated.

The right to liberty is enshrined in the Irish Constitution, the European Convention on Human Rights and the UNCRPD. Outside of the Health Act 1947 and Mental Health Act, 2001, there is no statutory provision for detention of a person in a healthcare facility. Ireland's current framework for substituted decision making for a person lacking capacity, in the form of the Lunacy Act 1871, depends on making people a 'Ward of Court' where the court committee makes decisions on their behalf , is unconstitutional and deprives a person of any say in their own lives. The ADMCA 2015 seeks to address this. Progression of the Act is dependent on a number of amendments including Deprivation of Liberty Safeguards, which will form part 13 of the Act and seeks to ensure that a person lacking capacity will not be detained against their wishes unlawfully in approved centres.

Legislation in relation to deprivation of liberty and related safeguards, which will form Part 13 of the Assisted Decision-Making (Capacity) Act 2015 [ADM Act 2015] to prevent unlawful interference with the right to liberty, should be focussed on human rights and adhere to human rights principles and standards, particularly as the right to liberty is a convention right under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the European Convention on Human Rights (ECHR).

Health and social care professionals are currently in a very challenging hiatus awaiting the Deprivation of Liberty Safeguards. Many older people may be admitted to residential care against their wishes because of lack of community supports, or at the behest of their families who are under pressure to provide care for them. Where they wish to leave and there is a concern that they may not be able to care from themselves and may suffer adverse consequents, the professionals, notwithstanding their moral and legal obligations under duty of care, fear litigation on charges of negligence.

Chapter 3: Deprivation of Liberty in Irish Residential Care for the Older Person

3.1 Introduction

SAGE Advocacy have been cited in the media as saying up to 1000 people may be held against their wishes in places of care in Ireland (extrapolated from UK and European studies and applied to Ireland in reference to its population and age demographic) (Crosson, 2018). In a 2012 NCPOP survey (Drennan et al., 2012) on staff-resident interactions and conflicts in nursing homes, one of the most frequently reported conflicts was that of preventing an older person from leaving the home in which they were receiving care. De facto detention, where people are unaware of their right to leave of their own accord, or where the doors are locked to prevent "wanderers" from absconding, appears to exist in some cases (National Safeguarding Committee, 2017).

3.2 Deprivation of Liberty Draft Heads of Bill

To fulfil the state's obligations under the UNCRPD, legislative clarity on the issue of deprivation of liberty in residential centres for older people, people with disabilities, and mental health issues is needed. The Assisted Decision-Making (Capacity) Act 2015 and the Mental Health Act 2001 do not provide a procedure for admitting persons without capacity to relevant facilities when they will be under continuous supervision and control and will not be free to leave. They also do not provide procedural safeguards to ensure that these people are not deprived of their liberty unlawfully (DoH, 2017). The Draft Heads of Bill were out for public consultation from December 2017 – March 2018 and propose to insert a new part, Part 13, into the Assisted Decision-Making (Capacity) Act 2015. The purpose of the provisions are to establish a procedure for admitting a person who is reasonably believed to lack the capacity to make the decision to a relevant facility and also to establish a procedure for a person living in a relevant facility who is reasonably believed to lack the capacity to leave, or continue living in, the relevant facility. They seek to ensure the legislative provisions are aligned with Article 14 of the UNCRP, which apply where a person is or will be under continuous supervision and control and is not or will not be free to leave; and

there is reason to believe that the person lacks capacity to make a decision to live in the relevant facility (DoH, 2017). These do not apply to wards of court, which can be viewed as discriminatory.

European and Irish jurisprudence determines that deprivation of liberty includes both an objective and a subjective element. The objective element is where the person is under continuous supervision and control and not free to leave, while the subjective element is whether the person consented to their confinement (DPP v Pringle, McCann and O'Shea, Unreported, 22 May 1981, pp. 98–100, cited in IHREC, 2018).

Application is to be made to the Circuit Court if there is reason to believe the person lacks capacity and there is no other person with legal authority to make the decision (part 5 ADMCA). The court can then either make the decision to admit or appoint a Decision Making Representative to do so. The provisions will apply to residential centres for persons with disabilities, nursing homes, and mental health facilities, where a person has mental health issues but is not suffering from a mental disorder and so cannot be involuntarily detained under the Mental Health Act 2001. Unlike the UK, Hospitals, rehabilitation, and respite services are not included in this provision. With almost 19% of applications coming from hospitals in England for the year 2017 – 2018, this is a very concerning omission (Appendix 1 contains the full explanations for each head).

DOL Draft Heads of Bill
Heads 1 Definitions
Head 2 Application and Purpose
Head 3 Person's Capacity to Make a Decision to Live in a Relevant Facility in Advance of an Application to enter the Relevant Facility
Head 4 Procedure for Routine Admission of a Relevant Person to a Relevant Facility
Head 5 Procedure for Admission of a Relevant Person to a Relevant Facility in Urgent Circumstances
Head 6 Procedure for making an Admission Decision
Head 7 Persons Living in a Relevant Facility
Head 8 Transitional Arrangements for Existing Residents on Commencement of this Part
Head 9 Review of Admission Decisions
Head 10 Chemical Restraint and Restraint Practices

Figure 3.1 Draft heads of Bill Deprivation of Liberty: Safeguard Proposals (DoH, 2017)

3.2.1 Draft Deprivation of Liberty Heads of Bill Challenges

There are an estimated 25,000 people under wordship and living in residential care that will be due for review (Jenkins, 2018). This will create an onerous task for the circuit court system, healthcare providers, and the office of the Decision Support Services. As there is not a statutory right for home care services, the state's obligation to implement a process to ensure a person is not unlawfully deprived of their liberty may be undermined (SAGE, 2018).

In its July 2019 report on the safeguarding submissions received (DoH, 2019), the Department of Health stated that a total of fifty one responses to the Draft Safeguarding proposals were submitted. Thirty seven were from organisations such as state agencies, advocacy groups, healthcare providers, academic institutions, and other voluntary sector organisations (see Appendix 2 for full list of organisations). As

there were twenty seven questions pertaining to the thirteen draft heads, as well as three general questions, there is not sufficient word space to outline all here. Thus, this writer will detail some of the main issues as examples to show how complex the process of implementing the safeguards is going to be. Of note, while the Draft Safeguard proposals do not include acute care hospitals, rehabilitation, or respite services (a source of concern for many respondents), the DoH states that due to the AC v CUH case, acute care hospital may now be included.

Clarification was called for on the meaning of the phrase 'not be free to leave' and a definition of 'continuous supervision and control'. There was strong representation to include independent advocacy and the fact that wards of court are not included is seen as discriminatory and not in line with the UNCRPD or the ECHR. Respondents suggested that the introduction of a tribunal system or provision of advocacy services would be more practicable than going through the courts, as the existing resources of the court services and Decision Support Service resources were insufficient.

There was a call for greater emphasis to be placed on respecting the will and preference of the relevant person, in accordance with the guiding principles of the ADMC Act regarding the procedure for making an admission decision. Also, recommendations were made to incorporate a risk assessment into the procedure, giving due emphasis to ensuring the necessity and proportionality of the admission decision. This harks back to the caution in Justice Hogan's comment in the AC v CUH & HSE case;

> …variable and inconsistent grants of permission and subjective paternalism on the part of clinicians, nurses and care-givers.

Concern was expressed that consent and capacity in the draft heads does not form part of the substantive procedures set out in Heads three to eight. These focus on a lack of capacity rather than capacity building, in line with the ADMCA 2015. Consent is only referred to in Head eleven (IHRC, 2018). Article 12 of the UNCRPD states that denying person with disabilities legal capacity and detaining them in institutions against their will, without their consent or that of a substitute decision-maker, constitutes arbitrary deprivation of liberty, in violation of Articles 12 and 14 CRPD (CRPD, 2014).

The draft heads propose that a person may only be deprived of their liberty either to protect an individual from significant harm or to prevent an imminent risk of significant harm to an individual's health and welfare or that another person (IHRC, 2018). The interpretation of 'significant harm' can vary depending on who is carrying out the assessment. As per the Donnelly et al. (2016) study, community social workers found that they were regularly having to advocate for people whose family members or other healthcare professionals deemed that they were living in 'risky' situations and that residential care was the most suitable option. An assessment of the person's needs and how these needs can be met should be fully explored in the context of all options, and this should be communicated to the person to enable them to make their own decision about care and treatment (SAGE, 2018).

The DoH cautioned in its report that there is a need to design an approach that is workable and practicable, citing the Office of the Public Advocate, Victoria, where they found that 'one of the major challenges arising is to develop 'appropriately robust safeguards for liberty and contributes tangible benefits to people's lives without being excessively bureaucratic or practically unworkable' (Office of the Public Advocate, 2017).

Given the myriad of issues, it is worth looking at how other jurisdictions have introduced Deprivation of liberty Safeguards. As examination of all other jurisdictions cannot be facilitated in this thesis due to word space, and so this writer will look to England and Wales, as these are similar to our own judicial and health system.

3.3 Deprivation of Liberty in England and Wales

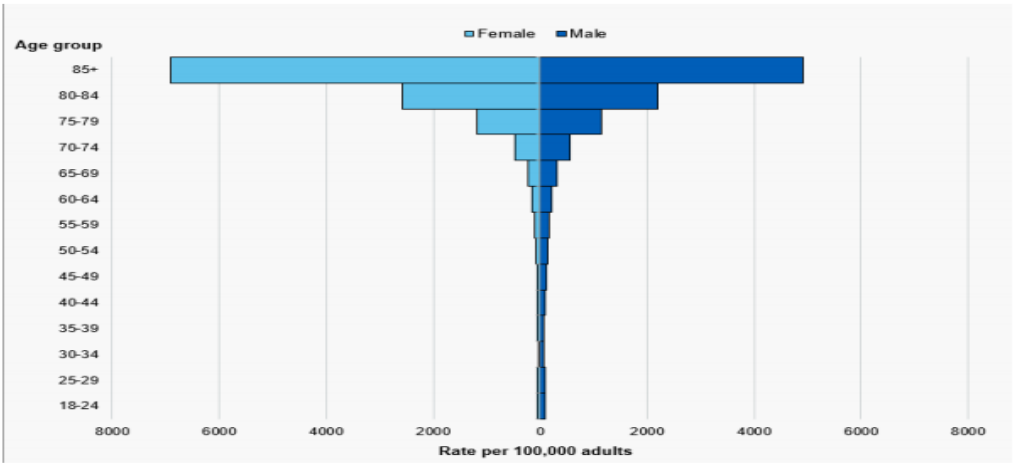
There are around 300,000 people over 65 in residential care in the UK, with many suffering from dementia (Bowcott, 2019). Deprivation of Liberty Safeguards were introduced in 2007 as amendments to the Mental Capacity Act 2005. As a result of the ruling in the Bornewood case mentioned previously under the Mental Health Act 2001 section, the Mental Capacity Act (2005) for England and Wales was amended with the addition of Deprivation of Liberty Safeguards, whereby when admitting a person who lacked capacity to consent to treatment an application had to be made through the courts.

Once the local authority confirms that an application should be pursued, the following six assessments must be made: Age, Mental Capacity, Mental Health, No Refusals Assessment, Eligibility Assessment, and Best Interests Assessment. Where all six requirements are met, the application is granted and the individual can be legally deprived of their liberty by the hospital or care home. If any of the six requirements are not met, an authorisation cannot be granted (NHS Digital, 2018). This has been criticised as a highly bureaucratic process, leading to many delays (Bowcott, 2017).

The DoLS Code of Practice states that a standard DoLS application should be completed with 21 days of the local authority receiving the application. Nationally, the proportion of standard applications that were completed within 21 days fell from 23.3% in 2016-17 to 21.7% in 2017-18 (NHS Digital, 2018). The age profile escalated dramatically for the age group 85 and over.

Mental Capacity Act 2005, Deprivation of Liberty Safeguards, England, 2017-18

Figure 1.1: Proportion of individuals with at least one DoLS application per 100,000 adults in England, by age group and gender

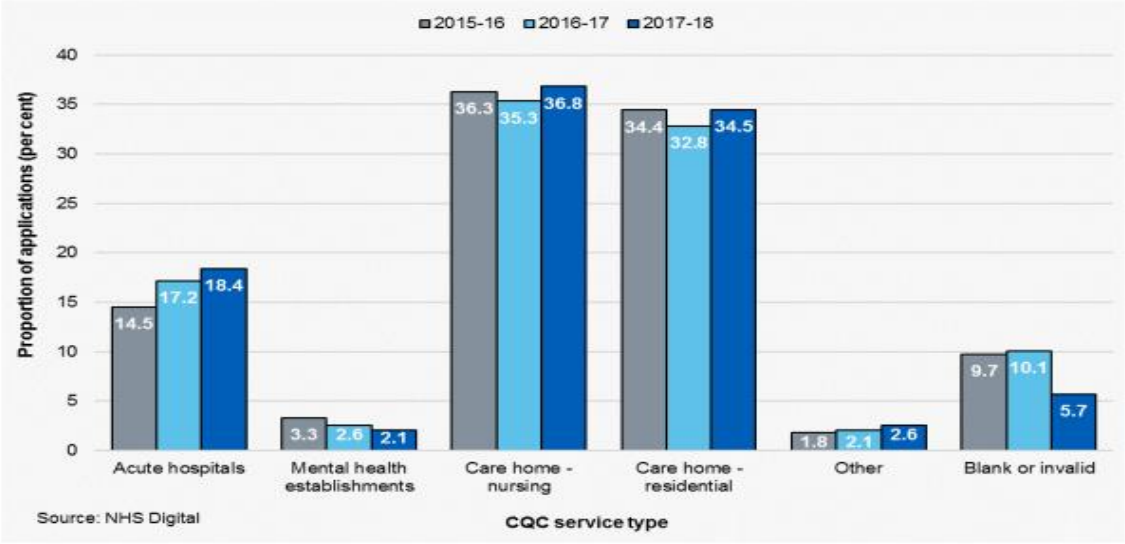


Note: Population data source: Office for National Statistics (ONS)

Figure 3.2. Mental Capacity Act 2005 Deprivation of Liberty Safeguards England 2017 - 2018

71.3 % of applications came from Nursing and other Residential Care homes 2017 – 2018, and acute hospitals accounted for 18.4%.

Figure 2.7: Proportion of applications (per cent) received between 2015-16 and 2017-18 by CQC service type in England



Notes: Proportions (percentages) are based on the unrounded figures. Please see Annex C Table 2 to view 2017-18 data in further detail.

Figure 3.3. Proportion of applicants (%) received between 2015-2016 and 2017 – 2018 by CQC service type in England

In 2014, the Supreme Court judgment in two cases: P v Cheshire West and Chester Council and P & Q v Surrey County Council, led to what's known as the 'acid test'. The Supreme Court decided that, when an individual lacking capacity was under continuous or complete supervision and control and was not free to leave, they were being deprived of their liberty. This has led to a 'considerable increase' in the number of people in England and Wales who are considered to be deprived of their liberty (The Law Society, 2015). As a result, while there were 13,700 applications for deprivation of liberty in England in 2013-14, by 2015-16 that figure had risen to 195,840. Overburdened local authorities were unable to carry out checks within the period required or even at all (Bowcott, 2017). There were 227,400 applications for DoLS received during 2017-18, with almost three quarters relating to people aged 75 and over (NHS Digital, 2018).

Figure 2.1 Time series of number of applications in England

	Applications received	Year-on-year change
2013-14	13,715	-
2014-15	137,540	123,825
2015-16	195,840	58,300
2016-17	217,235	21,395
2017-18	227,400	10,165

Source: NHS Digital

Figure 3.4. Time Series of Applications in England

In the UK, the Court of Protection Rules provide that, if the protected party (that is the Respondent or vulnerable person) becomes a party to proceedings, all documents served on them must be served on his or her litigation friend or other person authorised to conduct proceedings on his or her behalf (The Court of Protection Rules 2007, as amended in 2015) These also provide that, if a party lacks litigation capacity, then the Court of Protection appoints a 'litigation friend' to carry on the proceedings on his or her behalf.

With regards to Wye Valley NHS Trust v Mr B (2015),

> ….the European Convention make[s] clear, a conclusion that a person lacks decision-making capacity is not an 'off switch' for his rights and freedoms. To state the obvious, the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important

This Act is now again under review as the increase in applications caused by the widening of the definition of liberty in the Bournewood case have caused considerable back-logging in the courts. The draft amendment suggests returning the decision to the healthcare provider and professionals. Much controversy has been caused, to date, regarding this with The Law Society, with mental health charities and politicians accusing the Department of Health and Social Care of rushing through legislation that would remove independent scrutiny of the monitoring process to ensure that residents were not subjected to excessive restrictions (Bowles, 2019).

3.4 Conclusion

The proposed Deprivation of Liberty Safeguards are a very welcome advancement for human rights for the older person in Ireland regarding residential care. However, the

draft proposals require considerable amending if they are to encompass the rights protected under the ECHR and UNCRPD conventions. As we have seen from the practice in England and Wales, the involvement of the courts and the sheer numbers of people requiring deprivation of liberty reviews led to a considerable backlog of cases, with the complexity of the number of assessments required compounding the delays.

While we await the DoH progress on this, it is important that a human rights based approach is taken for addressing deprivation of liberty for older people in residential care, and the ethical issues involved are of paramount importance.

Chapter 4: Ethical Issues Arising with Deprivation of Liberty in Residential Healthcare

4.1 Introduction

Frequently, the question of entering Long Term Care arises under very stressful circumstances for the person concerned. They may be unwell either in hospital or their own homes and feel under pressure to make the decision to enter into care. It could be a case that they feel guilty knowing that their spouse or children are carrying the burden for their care. Likewise, financial stressors and lack of community supports may be clouding their judgement. Bioethics, as a discipline, helps health professionals and public policymakers to apply critical thinking to recognise and respond to moral dilemmas in health care. They provide principles and moral rules with which to navigate through these dilemmas (Kass, 2001). The four principles, as described by Beauchamp and Childress - Autonomy, Beneficence, Non-maleficence and Justice - clearly appear to be an answer to our moral norms. Therefore, I will use these principles in this chapter to explore the issue of deprivation of liberty for the older person in residential care in Ireland.

4.2 Ethical Guidelines for Healthcare Professionals

The fundamental values of medical ethics, such as compassion, competence and autonomy 'provide a sound basis for analysing ethical issues in medicine and arriving at solutions that are in the best interests of individual patients' (World Medical Association, 2015, p.28).

The Irish Medical Council Guide to Professional Conduct and Ethics for Registered Medical Practitioners (IMC, 2016) for doctors states that patients must always be treated with respect. A patient must not be discriminated against on any grounds including age and disability and that consent must be obtained prior to any medical treatment. There is a duty to presume and maximise capacity and that capacity may fluctuate. In addition, that lack of capacity to make a particular decision does not mean a lack of capacity to make this decision or another decision in the future. Thus, there is

a duty to act in the best interests of patients and a responsibility to engage and advocate with the relevant authorities to promote the provision of suitable healthcare resources and facilities. It is noteworthy then that the 'best interest' duty has not been changed to 'will and preference' to align it with the 2015 ADMCA. While family members or carers may understandably wish for information from the doctors, the guideline also outlines under 'Disclosure' that information on their patient who lacks capacity should only be shared if the failure to do so would put that person or another in danger or if it is in the patient's best interest.

For nurses, there is a duty to promote and protect autonomy. The Nurses Professional Code of Conduct and Ethics (NMBI, 2014) Principle 1 (respect for the dignity of the person) is drawn directly from the Universal Declaration of Human Rights. Nurses are obliged under this to 'respect each person's right to self-determination as a basic human right…the requirement of informed consent is key'. Also, it is presumed that all adults have capacity to make health care decisions, therefore a person must not be discriminated on any grounds including age and disability.

The Social Workers Registration Board (SWRB, 2011) have a statutory provision for their Code of Professional Conduct and Ethics. The Code of Professional Conduct and Ethics for Social Workers by-law 2011 states:

> Social Work is a profession based on principles of human rights and social justice that work to empower individuals, groups and communities to develop their full potential and wellbeing…Particular emphasis is placed on meeting the needs of vulnerable and marginalised individuals and groups.

The ethical codes include upholding human rights in practice by respecting the right to self-determination and promoting the right to participation, to seek informed consent, and to treat with respect and dignity all people regardless of age, gender, disability and all other groups at risk of discrimination. There is also the requirement to always act in the person's 'best interest'.

Under the ADMA and UNCRPD, healthcare professionals have a number of ethical obligations to the person they are looking after. However, the reality of time constraints and lack of resources in decision making training reveals a stark contrast between the guidelines for addressing ethical challenges and their efficacy in practice.

An ‘ethical challenge’ thus arises when there is doubt, uncertainty, or disagreement about what is right or good (Landeweer et al., 2011). Hem et al. (2014) caution that precise knowledge about ethical challenges ‘is necessary for those who want to develop ethical support in health care’. It has also been noted that, while much of the work carried out by health and social care professionals involves the observation of human rights, to date there remains a lack of understanding about the application of these in their day to day work (HIQA, 2019).

4.3 Autonomy

The concept of autonomy is not new. J.S Mills in 1859 wrote: ‘Over himself, over his own body and mind, the individual is sovereign’. Autonomy, or self-determination, has been defined as ‘the capacity to make decisions and take actions that are in keeping with one’s values and beliefs’ (HSE National Consent policy, 2014). The ethical rationale behind the importance of consent is the need to respect the service user’s right to self-determination and to decide what happens to their own body. Should a person then refuse to enter or wish to leave residential care, where they have capacity they have the right to make this decision, even if deemed ‘unwise’ by the healthcare professionals. However, the real ethical dilemmas arise when the person lacks capacity. Previously, this decision was to be made by the healthcare professionals under the ‘best interest’ approach. This is now replaced by ‘will and preference’.

Where capacity is lacking, admission or detention must be under a procedure prescribed by law. Currently, while we are awaiting the Deprivation of Liberty Safeguards, there is no procedure prescribed by law, save the Lunacy Act and Mental Health Act 2001. However, where decision making capacity is lacking, any intervention decided on by a health or social care practitioner must be justifiable and proportionate, weighing up the risk to others and the risk to the person’s own wellbeing and safety (HIQA, 2019). Capacity, then, must be continuously reviewed, as it can fluctuate.

We have many strong drivers to ensure autonomy, as the care facilities are regulated by HIQA, of significance is Principle 1 of the Standards is to ‘Provide care and support to promote autonomy and an excellent quality of life for people living in the service’ (HIQA (a) Guidelines, 2016). HIQA have also published guidelines for supporting

people's autonomy (HIQA (b) 2016). The various policies, procedures, and guidelines required in residential care services to ensure compliance with various legislative instruments to a certain extent, curbs autonomous choices for residents.

Health and Safety Regulations means that many residential care facilities will not allow pets to be kept because of danger of the resident or another getting bitten or scratched and for infection control purposes. This has been a great source of distress for some older persons who have missed their pets. Food Hygiene means that residential care services cannot allow certain foods such as soft eggs or cooked food to be brought in from outside, as there is no traceability should there be an outbreak of gastroenteritis. Where a resident has a high risk of falling, they have their freedom of movement limited, whereby walking on their own is discouraged. In some cases, exit alarms sound each time the person stands up or exits their bed, whereupon staff may get them to sit down or return to their beds. This is physical restraint.

The issue of respecting the right of the person with dementia to autonomous decision making is a complex one. When the person wishes to leave the facility and return to their own home, several factors need to be taken into account. Where it is clear that the person is unable to take care of themselves and there is a risk to their safety, the healthcare professional does have a statutory duty of care, and consent is central to respecting autonomous decision-making.

The primacy of autonomy has been challenged by some healthcare professionals. Makay (2017) states that 'adult safeguarding often creates a tension for welfare practitioners between promoting an adult's autonomy and their duty to try to protect them from harm' and that 'choice, autonomy and capacity are interconnected concepts; and that they can be compromised by a range of personal, relational and environmental factors'. Braye et al. (2017) suggest a more nuanced, situated and relational approach to autonomy, which can enable practitioners to move away from dichotomous interpretations of the moral imperatives.

4.4 Beneficence and Non-Maleficence

Whenever we try to help others, we inevitably risk harming them (Gillon, 1994). Therefore, the principles of beneficence and non-maleficence will be discussed together. Beneficence involves balancing the benefits of treatment against the risks, non-maleficence means avoiding the causation of harm. The most pertinent example of this is as described in the autonomy section, where in the interest of providing safe care to a resident, privacy is compromised. Another would be the curtailment of movement due to high falls risk.

There appears to be a lack of participation by healthcare professionals in advocating for human rights on behalf of the older person. Despite the HSE National Consent policy (2014), stating that no person can give or refuse consent on behalf of another person who lacks capacity to consent unless they have specific legal authority to do so, two years later social workers working with older people have reported that only 61% of people in a sample of cases were involved in decision-making about their care, with involvement being described as tokenistic in some cases (Donnolly et al., 2016). It is a challenge to understand why this is, but according to Carriere (2019), how we perceive external threats significantly impacts how we value human rights and civil liberties for both ourselves and for others.

Human rights violations have a 'demonstrable' impact on psychological health (Johnston et al., 2009). As outlined previously through the National Safeguarding Committee 2017 review, one of the most frequently reported conflicts between nursing home residents and staff was that of staff preventing a resident from leaving the nursing home (Drennan et al., 2012). In a 2012 NCPOP survey on staff-resident interactions and conflicts in nursing homes, it was found that one of the most frequently reported conflicts was that of preventing an older person from leaving the home in which they were receiving care.

Physical restraint involves use of locked wards or use of physical force and is only allowed through policy as a last resort, and only to protect that person or others from harm (HSE, 2011). There is no statutory provision for this currently in Ireland. This means that care staff are in violation of the resident's right to liberty and could be viewed as committing assault under the Non-Fatal Offences against the Person Act

1997. Head 10 of the proposed Deprivation of Liberty Safeguards Prohibits the use of 'chemical restraint' for non-therapeutic reasons in the context of deprivation of liberty and use of restrictive practices except for exceptional circumstances.

However, of note in the Assisted Decision Making guide that was out for public consultation in April 2017, it states that where the person may suffer serious harm, even death, as a result of his or her own decision if their own will and preference is followed, staff must clearly document every effort they have made with the person, how risks and consequences were communicated, that they have followed the principles of the 2015 Act, and have acted in good faith and for the benefit of the person. It presents serious ethical and legal challenges to any healthcare professional to determine where a person with dementia, who had poor safety awareness and who posed a very real threat to themselves, can have their will and preference followed.

4.5 Justice

The principle of justice involves fair adjudication between competing claims of rights. Gillon (1994) divided justice into three categories: fair distribution of scarce resources (distributive justice), respect for people's rights (rights based justice), and respect for morally acceptable laws (legal justice).

Under fair distribution of scarce resources, consideration needs to be given as to how these resources are shared. The current system of state home care is reliant on physical needs using the Barthel index (Donnelly et al., 2016). Where a person with dementia may not have high dependency needs in regards to physical care, they may need more supervision hours to protect them from harm while living in their own homes.

> For those with mental health issues and/or cognitive impairment/dementia, assessment often did not capture what supports they may have needed to live well at home and needs were understood within the narrow parameters of 'physical care needs' (Donnolly et al., 2016).

There is not equal allocation of funding to protect specific rights under the UNCRPD; for example, in relation to data protection (privacy) versus deprivation of liberty. A budget of €3 million has been allocated for the Office of the DSS, and this office, through its Director, has responsibility for:

1. implementing the important changes brought about by the Assisted Decision-Making (Capacity) Act of 2015,
2. informing the public about the Act, and about the supports available through the DSS to those who require assistance with their decision-making,
3. establishing and maintaining panels of suitable people willing to act as decision-making representatives, court friends, and special and general visitors,
4. handling complaints against decision-making assistants, co-decision makers, decision-making representatives, attorneys with enduring powers of attorney and designated healthcare representatives.

The Office of the Data Protection Commissioner will receive €15.2 million next year, a 30 per cent increase on its funding for 2018. This facilitates building a regulatory authority that is fit for purpose in terms of our national and global responsibilities under the General Data Protection Regulation (Edwards, 2018).

A widely accepted definition of public health is 'the science and art of preventing disease, prolonging life, and promoting health through the organized efforts of society' (Detels, 2009 cited in Aikin, 2015). It centres on the health of the population as opposed to the individual. Public health has been defined as 'what we, as a society do collectively to assure the conditions in which people can be healthy' (IOM, 1988). Informed consent and individual decision-making may be less important factors in promoting public health than in other areas of healthcare (Dawson, 2011).

The Irish healthcare system is not currently able to deliver safe and effective services throughout. Across all sectors, there are staffing issues which require considerable financial input. The Acute Hospitals and Mental Health Services are competing with Care of the Older Person Services for increased funding, with a shortage of consultants creating serious concern. While arguably fair distribution of scarce resources means the benefit of the many as opposed to the few, state protection of vulnerable groups such as older people living in the community is required under Human Rights. The UNCRPD has been ratified and serves to enable this.

With 97% of formal home care being publically funded, the cost of this is falling back on the taxpayer. The evidence tells us that the age demographic is increasing. This will

place an unfair and unstainable burden on the public purse. To date, the state has adopted a *laisez faire* approach. Following the example of Germany, the Netherlands, and Scotland the statutory provision for home care services through compulsory private insurance and co-payment would appear to create a fairer and more sustainable model of financing.

Under respect for people's rights, Article 19 of the UNCRPD is on the 'right to live independently and be included in the community'. Yet as discussed previously, there are not sufficient community resources for all older people to receive the home help hours that many require them to remain in the community. This is an unjust breach of their human rights, but considerably more financial resources are needed to provide the appropriate community services and home help hours. The review of people under current wardship and proposed review of an estimated 25,000 people in residential care, in light of the anticipated deprivation of liberty amendments to the ADMCA 2015, will also require considerable resources (Jenkins, 2018). Yet as previously discussed, the tax burden in Ireland is a very unfair system, especially on an already 'squeezed middle'. The unpalatable reality is that, unless there are increases to taxation and a radical change to the current state pension scheme, more people will be forced to enter into residential care against their wishes.

Inequalities of care for the older person have radically changed over the years. For example, in the early 1970s, 'many, if not most, of the coronary care units around the UK had adopted an age limit for admission where patients over the age of 70 years were not admitted following acute myocardial event on the basis that they could not cope with all age groups but also the lack of evidence of benefit in older people' (Rai & Abdulla, 2012). This was subsequently reversed when studies showed that this age group could indeed benefit from ICU admission.

Under respect for morally acceptable laws, state governance in regard to fulfilling the human rights of our older person's protection of the right to self-determination and avoidance of illegal detention has been remarkably slow. Ireland continues to operate under the 1871 Lunacy Act in regard to decision making for a person lacking capacity, and the Assisted Decision Making Act 2015 had been a bill since 2011. Thus, it seems astounding that eight years later it is still not yet fully commenced. The state's

intention to introduce statutory safeguards to protect residents of nursing homes and residential centres, and to ensure that they are not deprived of liberty, save in accordance with the law (part 13 of the ADMCA), is thus facing considerable challenges with progression. Following the March 2018 public consultation phase for the Draft heads of Bill for Deprivation of liberty safeguards, according to the DoH, 2019 report, the timeline for this is the Q4 of 2020. Essentially, if this is the case, the ADMCA will have taken nine years to bring it into operation. While Ireland signed into the UNCRPD in 2007, it did not ratify it until 2018; eleven years later.

4.6 Conclusion

As per the HIQA (2019) **'**Draft Guidance on a Human Rights-Based Approach to Care and Support in Health and Social Care Settings' (for Public Consultation), there remains a lack of understanding amongst health and social care professionals on how to apply human rights in their day to day work. Time constraints have also been identified through the literature as a barrier. Many older people state they would prefer to live at home (Donnolly et al., 2016, HIQA, 2019). In addition, Drennan et al. (2012) found that one of the greatest conflicts between staff and residents was of staff preventing a resident leaving the nursing home. Yet with no statutory provision to detain a person in a healthcare facility outside of the Mental Health Act 2001 and for infection control purposes, healthcare professionals and providers are in a legal hiatus. Personal autonomy is compromised simply by entering into residential care due to various legislative provisions that must be adhered to. Of concern in wishing to protect a person from harm in relation to detention, the question of physical and psychotropic ('chemical') restraint arises where they attempt to leave.

Chapter 5: Conclusion

5.1 Conclusions

In chapter one, the researcher introduced the subject of deprivation of liberty in the older person residential care setting. It was outlined that, where a person is under continuous supervision and control, not free to leave, and lacks the capacity to make the decision to enter into or leave the facility, this could be seen as a deprivation of liberty, thus violating their rights under the Irish Constitution, the ECHR, and the UNCRPD. Working under the archaic Lunacy Regulations 1871, there is currently no legislative provision outside of the Mental Health Act and the Health Act for infection control purposes that allows healthcare providers to detain a person lacking capacity against their will. The proposed Deprivation of Liberty Safeguards to be inserted into the ADMA seeks to provide guidance to healthcare professionals to ensure that unlawful detention does not occur.

As the OECD and CSO predictors inform us, the share of population over 65 is increasing, with dementia set to rise threefold by 2040. There is no statutory provision for home care services, thus enabling a person to remain living in the community. The state is not responding well to its commitment on rights for the older person, with contribution to social protection being the lowest in the EU and not sufficient to address current and projected demands. Funding community services through the current Irish taxation system is reliant on the 'squeezed middle. The need for increased funding because of rising age demographics and the projected halving of the cohort paying into this by 2040 ensures that the current system of payment for state funded activities is unsustainable. In addition, the very real threat to the state pension may necessitate residential care for even more people. Other countries such as Germany, the Netherlands, and Scotland have addressed this by introducing compulsory long term care insurance and co-payments.

In chapter two, the researcher looked at deprivation of liberty in the healthcare setting under human rights law and current legislation in Ireland. The right to liberty is enshrined in the Irish Constitution, the European Convention on Human Rights, and the UNCRPD. Outside of the Health Act 1947 and Mental Health Act 2001, there is no

statutory provision for detention of a person in a healthcare facility. The current legal framework in Ireland under the 1871 Lunacy Act and Wards of Court system is unconstitutional and fails to protect the interests of people with impaired capacity. The Assisted Decision Making (Capacity) Act seeks to address this by placing a statutory onus on healthcare professionals to support people who lack capacity to make their own decisions. It establishes a legal framework to support decision making by these adults.

In chapter three, the current status of Deprivation of Liberty in older person residential care services was examined, with an analysis of the proposed Deprivation of Liberty Safeguards. Analysis of these has shown that there are a number of very challenging aspects to the safeguards, which in their current state do not sufficiently satisfy the UNCRPD, nor do they align with the ADMA (2015). This is a very complex process and an approach needs to be designed that is both appropriately robust without being excessively bureaucratic or practically unworkable, as seen in other jurisdictions. There are currently no guidelines in place for healthcare providers to address deprivation of liberty challenges, yet they are still open to litigation. As per Justice Hogan's comment in the AC v CUH & HSE case, regarding '…variable and inconsistent grants of permission and subjective paternalism on the part of clinicians, nurses and care-givers'. It is imperative therefore that healthcare providers start to address this.

In chapter four, the ethical issues arising from deprivation of liberty was explored using the four principles approach. Although most healthcare workers appreciate the significance of human rights, there remains a lack of understanding of how to apply them in day to day practice. Preservation of personal autonomy, and balancing this with professional autonomy, is becoming more of a challenge for residential care facilities where duty of care may clash with will and preference. It is imperative that Organisations recognise this challenge and implement meaningful change. All of the Professional Codes of Conduct and Ethics (SWRB, 2011, NMBI, 2014 and IMC, 2016) refer to acting in the 'best interest' of the person. This paternalistic wording needs to be changed to acting according to the person's 'will and preference', as stated in the ADMCA, 2015. State protection of vulnerable groups such as older people living in the

community is required under Human Rights. This has not been reflected, to date, either in state policy or funding.

5.2 Recommendations

The state must address the reason many people are forced into residential care in the first instance. State contribution to social protection should be increased in line with the majority of other countries in the EU. There should be statutory provision for home care services. As the current model of payment into the exchequer for funding this is unsustainable, consideration should be given to following other countries such as Germany, the Netherlands, and Scotland, where home care is funded by compulsory long term insurance and co-payment.

Progression of legislation with regard to decision making for the person who lacks capacity has been disappointingly slow, to date, notwithstanding the complexity of the ADMA awaiting the Deprivation of liberty safeguards. To fulfil the requirements to support decision making for those lacking capacity, and avoid unlawful detention under constitutional and human rights law, the state must future proof home care services for the older person and introduce legislative safeguards. Healthcare providers and healthcare professionals must open the narrative on deprivation of liberty by establishing the will and preference of the older person with regard to entering or remaining in Long Term Care.

All healthcare services that work with older persons, acute care hospitals, and rehabilitation and respite services should be included in the Deprivation of Liberty Safeguards. If this does not happen, then there is a danger that unlawful detention will occur in these facilities.

Education and training for healthcare professionals and healthcare providers on how to apply ethical codes of practice in their day to day work is essential in contributing to vindicating human rights for the older person and avoiding illegal detention. Inclusion of guidelines on how to use the safeguards, with particular reference to the applications process, is needed to standardise practice and mitigate variance in practice.

Healthcare providers should start addressing cases where a person lacking capacity wishes to leave the residential care service. This researcher would propose multidisciplinary meetings that are underpinned by the four principles of autonomy, beneficence, non-maleficence, and justice. Namely, the residents' will and preference discussed under autonomy, consideration of risk versus benefit, and sourcing community resources under beneficence and non-maleficence; and what the provider's responsibilities under the Health Act 2007 regulations 2013 are, and what is available by law to support the resident and the healthcare provider to reach a decision. This researcher has presented this concept at conference (see Appendix 3 for the conference poster presented at the Nursing and Midwifery Conference September 2018).

There will need to be considerable state resources allocated to enable the DSS Office to manage the sheer number of reviews required in the timeframes given and to increase the capability of the Circuit Courts to process reviews of these and the Wards of Court reviews.

This dissertation contributes to what is currently a very shallow pool of legal and ethical analysis with regards to deprivation of liberty in the residential care setting in Ireland. It shines a light on the ethical and legal issues involved with deprivation of liberty for older persons, healthcare professionals, and healthcare providers and suggests how these could move forward with vindicating older person's rights in the healthcare services, pending implementation of the Deprivation of liberty safeguards and associated guidelines.

As academic research in this area is limited, this researcher is of the opinion that further research would be of great importance. This could be through a PHD, further qualitative and quantities studies as to why older people enter to residential carer and what enables could help them return to community living. This would be of great benefit to determining the status of deprivation of liberty potential in Ireland.

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Appendices

Appendix 1 Synopsis of Deprivation of Liberty Safeguarding Proposals (DoH, 2017)

	Proposed Deprivation of Liberty Safeguards Heads of Bill
Heads 1 Definitions	Deprivation of liberty definition captured in that of admission and admission decision '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'.
Head 3 Person's Capacity to Make a Decision to Live in a Relevant Facility in Advance of an Application to enter the Relevant Facility	Provides where healthcare professional determining a person's requirement for residential care (likely to result in deprivation of liberty) has concerns about an individual's capacity to make the decision, they must notify people specified by the person of concern, affording them opportunity to make application to court under Part 5 of the ADMCA for declaration that person lacks capacity to make the decision.
Head 4 Procedure for Routine Admission of a Relevant Person to a Relevant Facility	Provides that the person in charge (PIC) shall not admit a relevant person to a relevant facility where they will be deprived of liberty without: (i) evidence that the court has made an admission decision; or (ii) evidence that a third party has legal authority (Decision-Making Representative or Enduring Power of Attorney) to make this decision and that third party made an admission decision.
Head 5 Procedure for Admission of a Relevant Person to a Relevant Facility in Urgent Circumstances	Provides that the PIC can, on basis of medical evidence, authorise a temporary admission-decision in instances where there's imminent risk of significant harm to person's health/welfare or to another person - and there's concern that person lacks capacity to make decision. PIC must notify people specified by the person affording them opportunity to make an application to court for admission-decision. Where no

	Proposed Deprivation of Liberty Safeguards Heads of Bill
	application made within specified time-period, PIC must contact the Director of the Decision Support Service (DSS) requesting that appropriate person be assigned to the relevant person to make application on their behalf.
Head 6 Procedure for making an Admission Decision	Sets out the procedure for making an admission-decision. Under the European Convention on Human Rights, any decision to deprive a person of their liberty requires medical evidence.
Head 7 Persons Living in a Relevant Facility	*(i) Person who is living in a relevant facility before or after commencement of this legislation and wishes to leave it* shall not be prevented from doing so. If reason to believe person lacks capacity to make decision, PIC may temporarily prevent them leaving. Procedure under Head 5 to be followed. *(ii) Person who after commencement of this legislation had capacity to live in a relevant facility and may now lack capacity. PIC* must notify people specified by the person of this belief, affording them opportunity to make application to court for admission-decision. Where notification of application not received by PIC within specified time-period, PIC contacts the Director of the DSS and requests appropriate person be assigned to make application on person's behalf. Requirement to apply to court does not apply in cases of fluctuating capacity or nearing end of life. *(iii) Person who previously lacked capacity and may have regained it* If PIC believes person may have regained capacity to make decision to live in relevant facility, they must notify the appropriate Decision-Making Representative or Attorney. Will

	Proposed Deprivation of Liberty Safeguards Heads of Bill
	allow application to be made to court for review of court declaration that person lacked capacity. Where notification of this application not received by PIC within specified time-period, they shall contact the Director of DSS requesting an appropriate person be assigned to relevant person to make application on their behalf.
Head 8 Transitional Arrangements for Existing Residents on Commencement of this Part	Provides where there's reason to believe a person lacks capacity to make a decision to continue to live in the relevant facility, PIC shall notify people specified by the relevant person of their belief. Affords opportunity to make application to court under Part 5 of the ADMC Act. Where notification of such an application not received by PIC within specified time-period, they shall contact the Director of the DSS requesting an appropriate person be assigned to the relevant person to make application on their behalf.
Head 9 Review of Admission Decisions	Provides for the review of an admission decision.
Head 10 Chemical Restraint and Restraint Practices	Prohibits the use of chemical restraint for non-therapeutic reasons in the context of deprivation of liberty and use of restrictive practices except for exceptional circumstances.

Appendix 2: Organisations from which submissions were received (DoH, 2019)

- Acquired Brain Injury Ireland
- Alzheimer Society of Ireland
- Catholic Institute for Deaf People
- Central Remedial Clinic
- Centre for Disability Law and Policy, National University of Ireland, Galway
- Citizens Information Board
- College of Psychiatrists of Ireland
- Disability Federation of Ireland
- Dublin Solicitors' Bar Association
- Family Carers Ireland
- Health Information and Quality Authority
- HSE Assisted Decision Making National Office
- HSE National Safeguarding Office
- HSE Older Persons' Services
- Inclusion Ireland
- Irish Association of Social Workers
- Irish Council for Civil Liberties
- Irish Hospice Foundation
- Irish Human Rights and Equality Commission
- Irish Mental Health Lawyers Association
- Irish Nurses and Midwives Organisation
- Law Society of Ireland
- Mental Health Commission
- Mental Health Reform
- Multiple Sclerosis Society of Ireland
- National Advocacy Service for Older People with Disabilities
- National Clinical Programme for Older People
- National Dementia Office[54]

- National Disability Authority
- National Rehabilitation Hospital
- Nursing Homes Ireland
- Psychological Society of Ireland (Division of Neuropsychology)
- Rehab Group
- Safeguarding Ireland[55]
- SAGE
- Saint John of God Community Services
- St. Patrick's Mental Health Services
- St. Luke's Nursing Home, Cork

Appendix 3 Conference Poster Addressing the Issue of Deprivation of Liberty in a Residential Care Centre for Older Persons South Co Dublin Ireland

Addressing the Issue of Deprivation of Liberty in a Residential Care Centre for Older Persons South County Dublin Ireland

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Background

Ireland has a rapidly aging population. The *65 years and over age group* has risen by 19.1% since 2011 (CSO, 2016). For a person who lacks capacity, there are currently no adequate legal safeguards and procedures to prevent the person being *de facto* detained in a residential care setting. Residents who display exit seeking tendencies, or state that they want to leave can present ethical and legal dilemmas for Service Providers of Residential Care Services for the Older Person (and Intellectual Disability), where duty of care may conflict with the service users stated wishes.

The recent case of A.C vs CUH & ors in the Court of Appeal has identified that there is no statutory or common-law power to detain a patient in hospital (outside of the application of the Mental Health Act 2001). Article 40.1 of the Constitution provides that all detention must be in accordance with law.

Aim

To implement a standardised discussion format for our Organisation to ensure that no resident with the capacity to make a decision to leave was deprived of this right and thus unlawfully detained. A person with capacity is lawfully entitled to make what we may deem an 'unwise' decision'. For those who lack capacity the service must evidence that they are acting in the best interests of the person, acknowledging if necessary that this is not their stated wish.

Quality Improvement Driver

The number of people with dementia in Ireland is expected to more than double by 2036. Existing legislation in the form of the Assisted Decision-Making (Capacity) Act 2015 and the Mental Health Act 2001 do not provide a procedure for admitting persons without capacity to relevant facilities in which they will be under continuous supervision and control and will not be free to leave, nor do they provide procedural safeguards to ensure that such persons are not unlawfully deprived of their liberty.

While the vast majority of people entering Residential Care do so of their own free will, lack of legislation places an onerous burden on Residential Care facilities where due to lack of community services, or personal circumstances a limited amount of older persons may enter Residential Care believing that there is no alternative.

It is imperative that Residential Care services open the narrative of autonomous decision making with residents who express the wish to leave the service. Where it's determined that there is a lack of capacity to make this decision, the service must evidence what procedural safeguards were in place to avoid unlawful detention.

Method

A 'Deprivation of Liberty' IDT (MDT) form was developed which enabled discussion under the 4 Principles of Medical Ethics; the residents' desire to exit seek and capacity issues were addressed under Autonomy. Beneficence and Non maleficence covered what had been done to care for the resident and what was required to avoid harm. Justice addressed duty of care and the Organisation's legislative and Regulatory obligations with particular reference to the procedural safeguards that were in place.

Deprivation of Liberty IDT Form

Resident's Details

Name:
MRN:
DOB:
Admission date:
Relevant Diagnosis:
Designated Advocate:

Has the resident and or the Designated Advocate been invited to attend this meeting? Yes No Declined

Outline the issues of concern that gave rise to this meeting:

Autonomy: Individuals must be respected as independent moral agents with the right to choose how to live their own lives.

Resident's Autonomy

What does the resident say they want in this regard?

Capacity: Must be presumed unless a trigger exists to indicate otherwise.

Is the resident able to communicate a clear and consistent choice or are they unable to understand and use the information and choices provided?

Measurement of capacity required? Yes No

What evidence is there to support the capacity outcome?

Does the resident have the capacity to make this particular decision? Yes No

Organisation Autonomy

What are the duties of the Organisation under Legislation and Regulation?

Beneficence: one should strive to do good where possible

What has been done to ensure safe and appropriate care for this resident?

What further actions can be taken to provide safe and appropriate care?

Are there services available that can cater for the resident's current needs in the community?

Non - maleficence: one should avoid doing harm to others

What are the risks involved for the resident?

Can these risks be mitigated against?

Justice: people should be treated fairly, although this does not necessarily equate with treating everyone equally.

What are the rights of the resident under Legislation and Regulation?

What are the rights of the Organisation under Legislation and Regulation?

Meeting Outcome

Outcome

While the piloting of this form has enabled comprehensive and robust adherence to human rights for two residents thus far, this is an area fraught with legal and ethical challenges. We are confident that the current iteration has served to avoid unlawful detention and will form the framework for 'Deprivation of Liberty' discussions in the Organisation pending advancement of the Deprivation of Liberty Bill (2018).

Note on Legislative Progress in Ireland

The Department of Health has prepared draft Heads of Bill (2018) on deprivation of liberty safeguards which will form a new part of the Assisted Decision-Making (Capacity) Act 2015. The provisions will apply to residential centres for persons with disabilities, nursing homes and some mental health facilities. This is to align with the UNCRPD 2007 and 'seeks to ensure that persons with disabilities - including dementia and frailty are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law'. Also that the existence of a disability shall in no case justify a deprivation of liberty.

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A.C v CUH & ors
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