

ERASMUS+PROJECT

Human Rights & Older Age – Where Rhetoric meets Reality

KEY ISSUES FOR OLDER PEOPLE

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It is all about Human Rights

“People with disabilities, both mental and physical, have the same human rights as the rest of the human race...The whole point about human rights is their universal character” Lady Hale (P [2014] UKSC)

OVERVIEW

Key Issues for Older Persons

- Decision Making
- Deprivation of Liberty
- Finances

Legislation on Decision-Making Capacity

The Lunacy Regulation (Ireland) Act 1871

❑ Purpose:

The management of the Estates of Lunatics;

To provide for the visiting and the protection of the property of Lunatics and for other purposes.

❑ Some Definitions

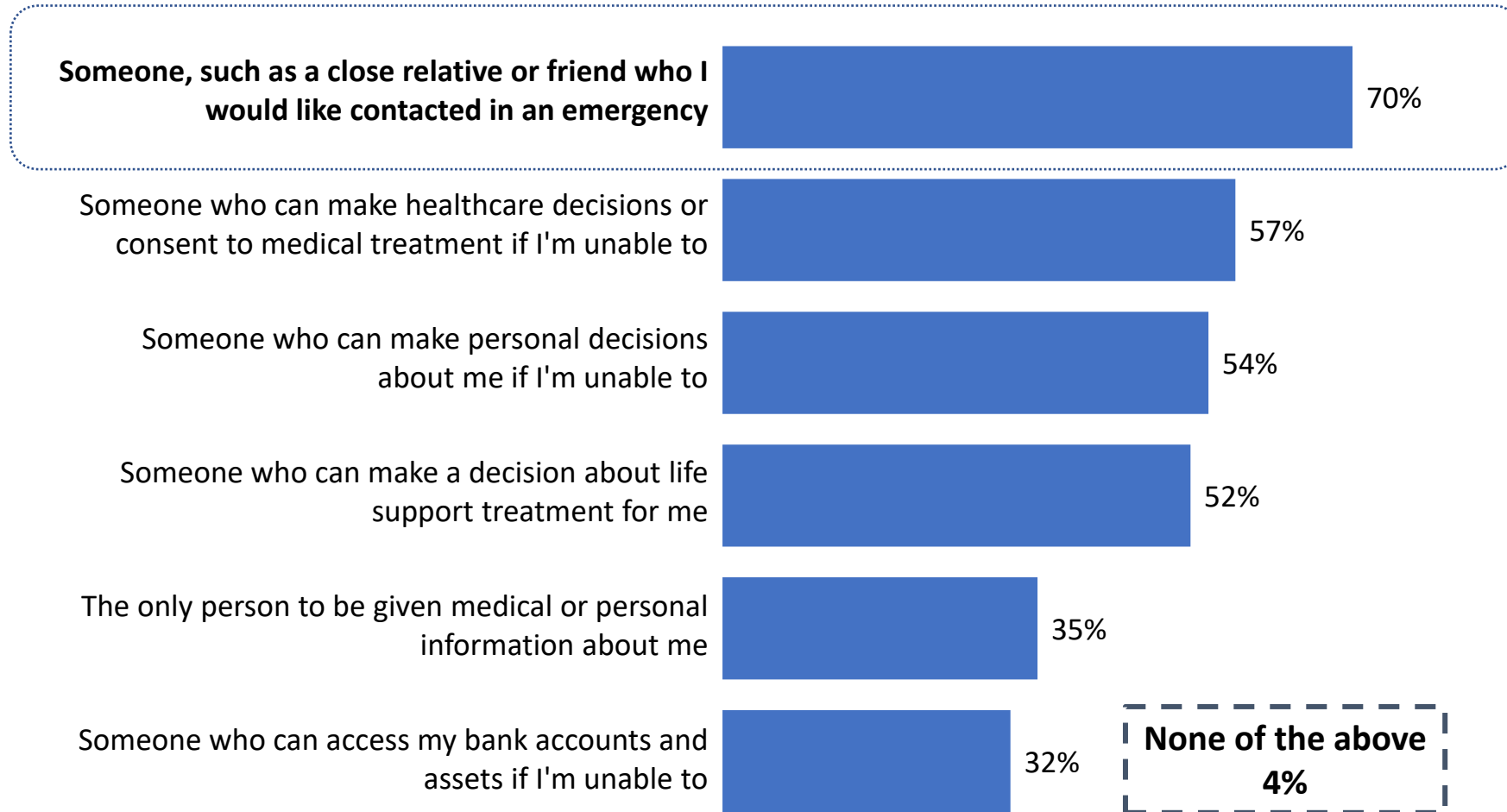
Lunatic: A person of unsound mind/ a person of weak mind

Next of Kin: shall be construed to refer to the next of kin of a lunatic, and to comprehend his heir or heirs-at-law, and also the person or persons who would be entitled to his estate, or to shares thereof.....

❑ Pre-dated any concept of individual human rights

Which of the following do you feel is the role of your 'Next of Kin'?

(Base: All Adults; n=1,020)



7 in 10 believe that 'Next of Kin' is somebody to be contacted in an emergency. More than half believe 'Next of Kin' is associated with making healthcare or personal decisions on their behalf, if they are unable to do some themselves. Only 4% do not associate the role of 'Next of Kin' with any of the statements.

Older Persons 65+ – Central Statistics Office

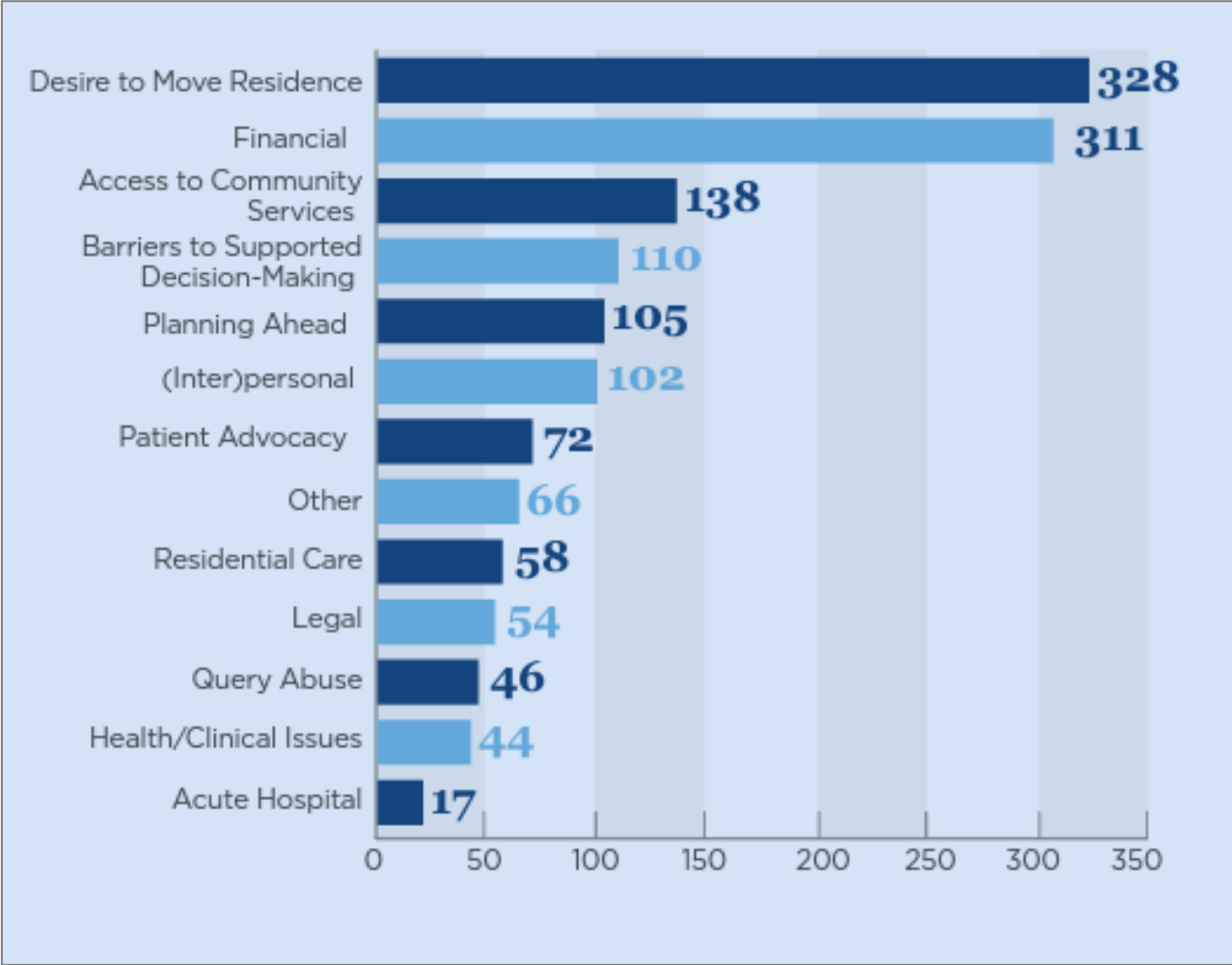
2015	610.3 Thousand	(282.8 Male + 327.4 Female)
2022	768.9 Thousand	(362.3 Male + 406.6 Female)
2031	1,007,000	Estimated
2051	1,597,000	Estimated

Total Population:

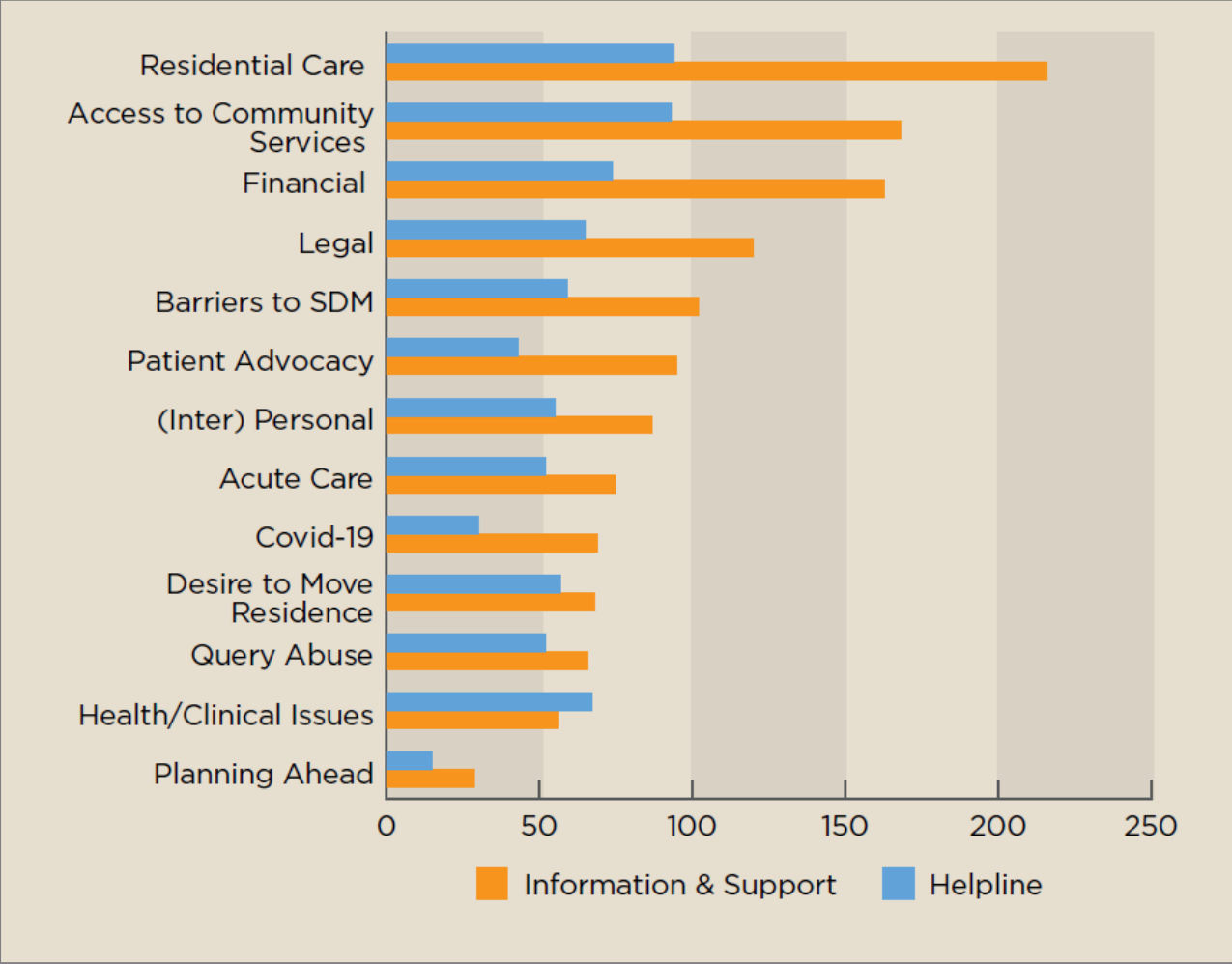
2016 = 4,761,865

2022 = 5,123,536 (Preliminary Results Census 2022)

New Cases by Primary Issue



Information & Support Calls by Issue



Postcards with an Edge



Constitution of Ireland - 1937

Personal rights enshrined in the Constitution include:

- *All citizens shall, as human persons, **be held equal before the law**. This shall not be held to mean that the State shall not in its enactments have due regard to differences of capacity, physical and moral and social function (Article 40.1)*
- *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** (Article 40.3.1)*
- *The State shall in particular, by its laws protect as best it may from unjust attack and, in the case of injustice done, **vindicate the life, person, good name and property rights of every citizen** (Article 40.3.2)*
- *No citizen shall be deprived of his personal liberty save in accordance with law (Article 40.4.1)*

Constitutional Right Recognised

In re Ward of Court (No 2) [1996] 2IR

*The loss by an individual of his or her mental capacity **does not result in any discrimination of his or her personal rights recognised by the Constitution**, including the right to life, the right to bodily integrity, the right to privacy, including self-determination, and the right to refuse medical care and treatment. The ward is entitled to have all these rights respected, defended, vindicated and protected from unjust attack and **they are in no way lessened or diminished by reason of her incapacity***

Council of Europe *Recommendation (99)4 of the Committee of Ministers to Member States on Principles Concerning the Legal Protection of Incapable Adults* February 1999

Respect for Human and Legal Rights

- The fundamental principle underlying all the other principles, is **respect for the dignity of each person as a human being.**
The laws, procedures and practices relating to the protection of incapable adults shall be based on respect for their human rights and fundamental freedoms
- The range of measures of protection should include, in appropriate cases, those which do not restrict the **legal capacity** of the person concerned

European Convention on Human Rights Act 2003

- ECHR signed in 1950 (Ireland one of the founding members of Council of Europe)
- ECHR incorporated into Irish law in 2003
- Irish Courts must now interpret Irish law in a way which gives effect to the State's obligations under the ECHR regardless of whether legislation pre or post 2003
- Every organ of the State must perform its functions in a manner **compatible with** the State's obligations under **the ECHR**
- Judicial Notice must be taken of:
 - Any declaration, decision, advisory opinion or judgment of the European Court of Human Rights
 - Any decision or opinion of the European Commission of Human Rights
 - Any decision of the Committee of Minister of the Council of Europe

UNCRPD Article 12 – Core provisions in relation to Irish legislation

- ✓ State Parties reaffirm that persons with disabilities have the right to recognition everywhere **as persons before the law** (Art 12.1)
- ✓ State Parties shall recognise that persons with disabilities **enjoy legal capacity on an equal basis with others in all aspects of life** (Art 12.2)
- ✓ State Parties shall take appropriate measures to provide access by persons with disabilities to the **support they may require in exercising their legal capacity** (Art 12.3)
- ✓ State Parties shall ensure that all measures that relate to the exercise of legal capacity **provide for appropriate and effective safeguards to prevent abuse** in accordance with international human rights law (Art 12.4)

Council of Europe *Recommendation on the Promotion of Human Rights of Older Persons (2014)*

To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all older persons, and to promote respect for their inherent dignity.

*Older persons ... are entitled to lead their lives independently, in a self-determined and autonomous manner. This encompasses, inter alia, the taking of independent decisions with regard to all issues which concern them, including those regarding their **property, income, financial, place of residence, health, medical treatment or care...** (Para 9)*

Assisted Decision-Making (Capacity) Act 2015

Key elements

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Assisted Decision-Making (Capacity) Act 2015

- Enacted in December 2015 – 3 Commencement orders made, 2 in 2016 + 1 in 2021
Date for full commencement early 2023
- Enabled Ireland to ratify:
 - UN Convention on Rights of People with Disabilities (UNCRPD)
 - Signed in 2007, Ratified in 2018
 - Hague Convention on International Protection of Adults
- Assisted Decision-Making (Capacity) (Amendment) Bill 2022)

Purpose of the 2015 Act

- To provide for the reform of the law relating to persons **who require or may require assistance in exercising their decision-making capacity**, whether immediately or in the future, having regard to the UN Convention for the Protection of Human Rights and Fundamental Freedoms (1950) and other national and international human rights instruments including the UN Convention on the Rights of Persons with Disabilities.
- To assist and support a person to maximise his or her decision-making capacity **before** assessing decision-making capacity

(The 2015 Act will repeal the Lunacy Regulation (Ireland) Act 1871)

Human Rights perspective to Decision-Making Capacity

Medical model > Human Rights model

- Move away from medical model of disability/impairment to a **rights based approach** under the social model that supports a person to maximise his or her ability (capacity) to make decisions
- Emphasis on the fact that a person with a disability has '**legal capacity**' - rights equal to others. Legal Capacity is the ability to hold rights and duties
- A person is entitled **to exercise his or her legal capacity** even if he or she may have or has difficulty making decisions personally. The legislation sets out a framework as to how a person in such circumstance is **enabled to exercise their legal rights**
- Emphasis in 2015 Act is to support and assist a person to exercise his or her rights

Who is the ADM(C)legislation for?

- A person whose **decision-making capacity is in question** or may shortly be in question in respect of one or more than one matter
- A person **who lacks capacity** in respect of one or more than one matter
- A person whose capacity is in question or may shortly be in question in respect of one or more than one matter and who lacks capacity in respect of one or more than one matter **at the same time** but in respect of **different matters**

Guiding Principles include:

- There is a presumption of Capacity
- Person shall not be considered as unable to make a decision unless all practicable steps have been taken, without success, to help him or her to do so
- A person shall not be considered as unable to make a decision by reason of making, having made or being likely to make an unwise decision
- **The rights of the person to dignity, bodily integrity, privacy, autonomy and control over his/her financial affairs and property must be respected**
- The intervener in making an intervention in respect of a person must:
 - Permit, encourage and facilitate the person to **participate** or to improve his or her ability to participate, as fully as possible in the intervention
 - Give effect, in so far as practicable, to the past and present **will and preferences**, in so far as are reasonably ascertainable
 - Take into account the **beliefs and values** of the relevant person
- **Act at all times in good faith and for the benefit of the person (no best interests)**

Assisting and Supporting Decision-Making

Appointment by person with Capacity to plan for the future – comes into effect when person lacks capacity

- Attorney: Enduring Power of Attorney
- Designated Healthcare Representative: Advance Healthcare Directive

Appointment by person when Capacity is in question/shortly in question

- Decision-Making Assistant: Decision-Making Assistance Agreement
- Co-Decision-Maker: Co-Decision-Making Agreement

Appointment by Court when person lacks capacity – EPA or AHD does not include decision to be made

- Court will make decision or
- Appoint a Decision-Making Representative: Decision-Making Representation Order

Deprivation of Liberty

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European Convention on Human Rights

Article 5

- Everyone has the right to liberty and security of person. No one shall be deprived of his liberty savein accordance with a **procedure prescribed by law** – exceptions (Article 5.1)
 - Crime, infectious disease, **persons of unsound mind**
- 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** ...(Article 5.4)
- 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 (Article 5.5)

Lawfulness of Detention – Article 5 ECHR cases

- The key purpose of Article 5 is to **prevent arbitrary or unjustified deprivations** of liberty
- In order to meet the requirement of lawfulness, detention must be **“in accordance with a procedure prescribed by law”** (Notion of ‘lawfulness’ requires a fair and proper procedure offering the person concerned sufficient protection against arbitrary deprivation of liberty ([V.K v Russia 2017](#)))
- The requirement of lawfulness is not satisfied merely by compliance with the relevant domestic law; **domestic law must itself be in conformity with the Convention**, including the general principles expressed or implied in it ([Pleso v Hungary 2012](#))
- Where deprivation of liberty is concerned it is **particularly important that the general principle of legal certainty be satisfied**. It is therefore essential that the conditions for **deprivation of liberty under domestic law be clearly defined** and that the law itself be foreseeable in its application, so that it **meets the standard of “lawfulness”** set by the Convention ([Khlaifia and Others v Italy ECHR 2016](#))

Deprivation of Liberty

(Council of Europe ECHR Guide on Article 5 – 31 August 2019)

- Deprivation of liberty is **not confined to the classic case of detention** following arrest or conviction, but may take numerous other forms (**i.e. the placement in social care institutions**) (P,PQ – living arrangements for a person who lacks decision making capacity)
- The right of liberty is too important in a democratic society for a person to lose the benefit of Convention protection....**especially when that person is legally incapable of consenting to, or disagreeing with the proposed action.** ([Medvedyev v France ECHR 2010](#))
- The fact that a person **lacks capacity does not necessarily mean** that he/she is unable to understand and consent to a proposed action
- **Even measures intended for protection** or taken in the interest of the person concerned may be regarded as a deprivation of liberty ([Khlaifia and Others v. Italy \(2016\)](#))

Deprivation of Liberty Principles

European Court of Human Rights

ECHR set down general principles:

- **Important not to confuse the question of the benevolent justification for the care arrangements with the concept of deprivation of liberty (AC case)**
- **Human rights have a universal character** and physical liberty is the same for everyone, regardless of their disabilities
- **What would be a deprivation of liberty for a non-disabled person is also a deprivation for a disabled person**
- The person's compliance or lack of objection, the relative normality of the placement and the purpose behind it are all irrelevant to this objective question

UN Convention on Rights of Persons with Disabilities (Deprivation of Liberty) (Art 14)

- State Parties shall ensure that persons with disabilities on an equal basis with others
 - (a) Enjoy the right to liberty and security of person
 - (b) **Are not deprived of their liberty unlawfully or arbitrarily**, and that any deprivation of liberty, **is in conformity with the law**, and that the existence of a disability shall in no case justify a deprivation of liberty

UN Committee on Article 14 (September 2015)

- Committee reaffirms that **liberty + security of person is one of the most precious rights** to which everyone is entitled
- States parties should refrain from the practice of denying legal capacity of persons with disabilities and **detaining them in institutions against their will, either without the free and informed consent of the persons concerned or with the consent of a substitute decision-maker, as this practice constitutes arbitrary deprivation of liberty** and violates articles 12 (equal recognition before the law) and 14 of the Convention.

UN General Assembly – Report January 2019

- Article 14 reaffirms the right to liberty and security of all persons with disabilities on an equal basis with others, stipulates that **person with disabilities cannot be deprived of their liberty unlawfully and arbitrarily and clarifies that disability shall in no case justify a deprivation of liberty**
- State Parties have an obligation **with immediate effect** –
 - To refrain from engaging in any action that unlawfully or arbitrarily interferes with the right to liberty and from authorising such practices
 - Protects this right against practices by private actors such as health professionals, and providers of housing and/or social services and
 - Take positive action to facilitate the exercise of the right of liberty
- States **have an obligation to immediately repeal all legislation** that allows for deprivation of liberty on the basis of actual or perceived impairment whether **in public or private settings**

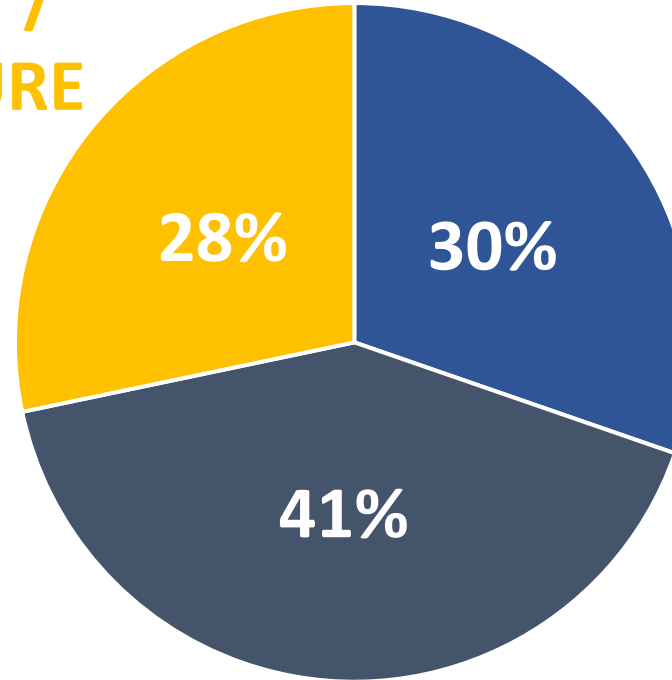
Consent for Place of Care

Base: All Adults Aged 18+; n=1,013

*Q.2 Do you agree or disagree with the following statement: A family member or friend has the authority to make decisions about Place of Care of another person who may be frail but does have decision-making capacity – **and this does not require the consent of that person.***

Clearly there is confusion over whether or not people have the authority to make decisions on behalf of another person, even if they do not have their consent.

**DON'T
KNOW /
NOT SURE**



AGREE

Higher for males aged 18-34 (36%)

DISAGREE

Higher for females aged 55+ (49%)



AC v Cork University Hospital and HSE [2018] IECA

- Application Article 40.4.1 and 40.4.2 of the Constitution
 - *Raises legal and constitutional issues of far reaching importance regarding the personal liberty...not least in so far as the care and welfare of the infirm and elderly are concerned*
 - *Right under the Constitution-cannot be swept away by Victorian wardship legislation*
 - **Legal issue not a medical one** – *(Art 40.4.1 provides that all detention must be in accordance with law. The reasons and motives of the detainer are not relevant to any consideration of this issue of law).*
- Whether detention lawful?
 - *The power [to detain] claimed by the hospital amounts to **a paternalistic entitlement to act in the best interests** of the patients whose capacity is impaired and, in effect, to restrain their personal liberty and freedom of movement and if necessary, to do at the expense of close family members. But ever, before the Constitution the common law has always rejected the claim that personal liberty could be compromised on such a basis.*

AC v Cork UH and HSE [2018] IECA

□ Whether detention lawful?

- *While one can, certainly sympathise with the position of CUH, **their self-created power of detention might, if unchecked, lead to widespread abuse.** For if the power of detention claimed by CUH was to be judicially accepted, the logical consequences would be that tens of thousands of the infirm elderly who are suffering from dementia (or whose capacity is otherwise impaired) and who are presently residing in nursing homes and other similar institutions could equally be restrained from leaving. **In many cases this would doubtless be for good clinical reasons. In other instance, however, this decision could be simply for reasons of convenience and, perhaps in a small minority of cases, for even less noble motives***

AC & others v Cork UH and HSE [2019] IESC 73

- *I consider that the constitutional guarantee of the **right to liberty protects mentally impaired persons to the same extent as everyone else – deprivation of liberty must in all cases be in accordance with law.***
- *To hold that persons cannot be found to be ‘detained’ if they are not capable of making a valid decision to leave for themselves, or if they are not aware of or able to object to their situation, would not simply permit restrictions on their freedom of movement for their own protection. **It would also have far-reaching consequences of denying to vulnerable persons...the benefit of the constitutional guarantee that they will not be deprived of their liberty otherwise in accordance with law.** It is possible for a person of full capacity to be detained without necessarily being conscious of that situation, and, equally, it is possible in the case of a person with impaired capacity. Both are entitled to legal protection. (Para 334)*

AC & others v Cork UH and HSE [2019] IESC 73

- *For the same reason, a benevolent or protective motivation or purpose for whatever measures have been taken cannot be considered to alter the legal fact of detention....If benevolent intentions meant that there was no deprivation of liberty, and therefore no grounds for inquiry into the legality of deprivation of liberty, there would be no legal basis upon which the courts could ask whether the measures taken were justified and were in fact in the individual's best interests.*
- *This would, in fact, leave vulnerable people without legal protection against arbitrary or unnecessary detention. The persons or institution that takes charge of them would there appoint themselves as a substitute decision-maker without legal process. Neither the Convention nor the Constitution permit of this result.*
(Para 335)

AC & others v Cork UH and HSE [2019] IESC 73

- *The most striking feature of all of the litigation and all of the court-mandated procedures to date – that it proceeded to this point on the basis of arguments between third parties, and decisions of courts, as to what Mrs C wants and what is in her best interests, **without her voice being heard.***
- The Supreme Court also pointed out that - ‘...at not stage has it been claimed by any party that Mrs C suffers from a mental illness of a nature that would warrant her confinement under the provisions of the Mental Health Acts’.

Deprivation of Liberty – Legal Framework?

- Constitution, ECHR and UNCRPD requirements – Ireland has no process prescribed by law
- Heads of Bill and Consultation published in 2017
- Since AC case a large increase of cases proceeding to High Court – have been dealt with under wide jurisdiction of wardship
- Not included in the *Assisted Decision-Making(Capacity)(Amendment) Bill 2022*
- Work recommenced in 2022 – now to be separate piece of legislation
- High Court to continue to exercise its inherent jurisdiction pending the introduction of a legislative framework
- Slow process
- Continuing demand/need for Independent Advocacy to protect right of person to decide where they wish to live/receive care

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Financial Abuse

- Most common type of abuse of older persons is financial abuse (University College Dublin, 2010 Irish Prevalence Study, National Centre for the Protection of Older Persons)
- HSE Reports – Financial abuse alleged incidents were reported to a greater extent in adults over the age of 80 years
- Law Reform Commission’s Issue Paper (2019) on *A Regulatory Framework for Adult Safeguarding* highlighted issues that contributed to financial abuse, a lack of understanding of financial decisions including a lack of public awareness of the abuse of adults at risk, financial abuse related to joint accounts, financial abuse related to social welfare payments and increasing rates of financial abuse linked to advancements in technology.

Red C Poll 2019 – BPFi + Safeguarding Ireland

(Banking & Payments Federation Ireland)

Defined financial abuse as including –

- theft, fraud, exploitation;
- pressure in connection with wills, property, inheritance or financial transactions; or
- the misuse or misappropriation of property, possessions or benefits

Key Findings of a 2019 Red C poll –

- One in five (20%) adults aged 18+ in Ireland either were currently experiencing or have in the past experienced financial abuse
- The most common type of financial abuse reported included accessing or using someone's property or possession without permission and people living with others that are not paying their way to cover household costs and bills

Financial Abuse – Covid 19

- Government encouraged those who were compelled to ‘cocoon’ to give ‘agency’ to a third part to collect State benefit and manage their money.
- Banks and stakeholders worked together to make people aware of the potential risks and encouraged people to try and keep in contact directly with Banks
- According to a Red C poll commissioned by Safeguarding Ireland and the Banking and Payments Federation in October 2020 – **two thirds of people** who needed help from others to manage their money during the Covid 19 lockdown (11% of those polled) **had not taken back control of their own finances.**

The Poll also showed that:

- 5% stated that they experienced financial abuse during the lockdown
- 13% were concerned about someone taking advantage of them financially
- 12% experienced less control of their finances since the pandemic began

Financial Abuse: Some progress but limited

- S.I. No. 375/2012 Solicitors (Professional Practice, Conduct and Discipline - Conveyancing Conflict of Interest) Regulation 2012 (Law Society)
 - Limited to conveyancing transactions
- Department of Social Protection
 - Vulnerable customer unit established
 - Agency form updated, agency arrangement noted on account – follow-up?
- Central Bank of Ireland Consumer Protection Code 2012. Review of Code commenced 2022
 - Definition of Vulnerable Consumer
 - Reasonable arrangements and/or assistance -**more specific requirements and duties owed to vulnerable customers**
- Banking & Payments Federation – vulnerable customer units in retail banks
- Safeguarding provisions in the Assisted Decision-Making (Capacity) Act 2015 for Decision Supporters and Enduring Powers of Attorney created under the 2015 Act
 - Suitable person, Schedule of assets and liabilities, income and expenditure, periodic reports required
 - 1996 Attorneys – no reporting requirements
 - Complaints to Director of Decision Support Service
 - Investigations by Director of Decision Support Service

Nursing Home Support Scheme (NHSS) (Fair Deal)

- The Nursing Home Support Scheme provides financial support for people in long term nursing home care. Those who use the scheme contributing 80% of their income. It is a means tested scheme.
- For those who have assets the value of a person's home is included in the financial assessment for the first 3 years of their time in care. Recent legislation has also provided that farmers and business owners will also qualify for the limitation of a 3 year charge on family farms and family business in order to 'better safeguard' these assets for future generations.
- **The charge on a person's assets may be deferred in their lifetime and not be collected until after their death.**
- The NHSS scheme may not be the 'fair deal' that it is purported to be in that people can and do put assets beyond the reach of the scheme through legally transferring assets and/or not fully declaring assets.

Rules on rent or sale of family home now more relaxed under Fair Deal Scheme (Irish Times 15 November 2022)

With effect from 1 November 2022 - under Part 9 of the *Regulation of Providers of Building Works and Miscellaneous Provisions Act 2022*

- may now have rental income assessed at 40% rather than 80%
- Nursing home residents now keeps 60%

Important to ensure that this money is spent on the care needs of the older person.

Funding of Long Term Support and Care

- Human rights include access to care
- Entitlement to the right to care tends to increase with age
- Access to care must be in a setting appropriate to a person's need
- The quality of life and well being is important – access to therapies, availability of suitable chairs, aids and appliances impacts on that quality.
- Safeguarding of these rights need to be robust

People have a right to use their own assets to support their care needs without individual, cultural or societal pressure or expectation to use these assets to fund other people's expectations and aspirations.

Conflict in Irish Society — Funding Long Term Care and Support for Older People

There is a basic conflict in Irish Society between:

- People as citizens who typically want the best possible care and quality of life for vulnerable older people;
- People as taxpayers who do not wish to pay their equitable share to ensure that such care is available to all who require it; and
- People as family members who want to pass on or inherit family wealth and who may privilege inheritance over paying for care in later years.

At the core, inter-generational solidarity assumes a consensus between the generations on how the resources of society, both financial and non-financial, are shared for the benefit of all – however, there is a real danger, as may have happened during the pandemic, that the economic prospects of the young are perceived as being damaged by the need to protect the most vulnerable.

Conclusion

Positive:

- Move from 1871 – medical model to a human rights framework
 - UNCRPD compliant
 - Principles of the ADMC Act 2015 becoming embedded in policies and legislation
 - Model for others

Still a lot of work to do:

- To achieve – *Safeguarding older persons' legal and human rights through active citizenship and inter-generational approach*

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