



Support & Advocacy Service
for Older People

'Laws Can Change Lives'

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28 February 2017

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Laws Can Change Lives

- Laws reflect the needs and values of society
- Laws can also strongly influence society and act as a catalyst for change

- *Lunacy Regulations (Ireland) Act 1871*
- *Marriage of Lunatics Act 1811*

- Culture
- Imbedded practices

UNCRPD

- Principles -
 - Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
 - Non discrimination
 - Full and effective participation and inclusion in society
 - Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
 - Equality of opportunity
 - Accessibility
 - Equality

Assisted Decision-Making (Capacity) Act 2016 (Capacity and Consent)

- Participation by the person in all decision-making
- Capacity to make a decision must be maximised
- Any intervention shall –
 - Be in a manner that minimises restriction of a person's rights and the restriction of a person's freedom of action
 - Have due regard to the need to respect the right of the person to dignity, bodily integrity, privacy, autonomy and control over his or her financial affairs and property
 - Be proportionate to the significance and urgency of the matter and
 - Be as limited in duration in so far as is practicable

Disability (Miscellaneous Provisions) Bill 2016

- Purpose - to address the remaining legislative barriers to Ireland's ratification of the UNCRPD includes -

Juries Act 1976

Electoral Act 1992

Garda Siochana Act 2005

Criminal Law (Insanity) Act 2006

Equal Status Acts 2000-2015

Employment Equality Acts 1998-2015

Taxes Consolidation Act 1997 ***

Social Welfare Consolidation Act 2005 ***

Companies Act 2014

Solicitors Acts

[Nursing Home Support Scheme Act 2009]***

Decision-Making Mechanisms (Most Advanced)

- Advance Healthcare Directive
- Enduring power of Attorney (to include healthcare)

- Decision-Making Assistance Agreement
- Co-Decision-Making Agreement

- Decision-Making Representation Order

- Guiding Principles apply to all

What Decisions?

- Treatment
 - In relation to a person, means an intervention that is or may be done for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person and includes life-sustaining treatment
- Decisions
 - Personal welfare
 - Property and Affairs

Personal Welfare

– means one or more of the following matters:

- (a) Accommodation including whether or not the relevant person should live in a designated centre
- (b) Participation in employment, education and training
- (c) Participation in social activities
- (d) Decisions on any social services provided or to be provided to the relevant person
- (e) Healthcare
- (f) Other matters relating to the relevant person's well-being

Property and Affairs

- Includes
 - The custody, control and management of some or all of the relevant person's property or property rights
 -
 -
 - Making an application for housing, social welfare or other benefits or otherwise protection or advancing the interests of the relevant person in relation to those matters

Applications to Court

- Art 13 of UNCRPD – effective access to justice for people with disabilities on an equal basis with others...in order to facilitate their effective role as direct and indirect participants....
- Hearings of applications shall –
 - Be conducted with the least amount of formality consistent with the proper administration of justice and
 - Be heard and determined otherwise than in public
- Court is an intervener – duty to empower relevant person to participate in decisions – whether realised in judicial practice
- Legal Aid and Assistance in court – promote interests and will and preferences

Deprivation of Liberty

European Convention on Human Rights

Article 3

- No one shall be subject to torture or to inhuman or degrading treatment or punishment (**absolute right**)

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

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

- State Parties shall ensure that persons with disabilities on and 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
- State Parties shall ensure that **if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of the Convention**

Disability (Miscellaneous Provisions) Bill

- General Scheme of the Equality/Disability (Miscellaneous Provisions) Bill (17 August 2016)
- **Head 3**
- **Deprivation of liberty**
- [To provide legislative clarity with regard to who has statutory responsibility for a decision that a patient in a nursing home or similar residential care facility should not leave for health and safety reasons.]
- Provide for an appeals process.]
- **Disability (Miscellaneous Provisions) Bill (21 Dec 2016)**
- **Second Stage 23 February 2017**
- **Committee Stage – Deprivation of Liberty**

Gaps in current Irish legislation

- Do not address deprivation of liberty/restraint and formal legal process required by ECHR or UNCRPD – (for those who lack capacity)
- No legislation on the use of chemical restraint
- Policies and Regulations
 - Philosophy and culture do not reflect requirements of human rights obligations
 - People living in nursing homes/residential centres are still subject to unnecessary restrictive procedures
 - Consent is not obtained
- Legislation must address these issues: Ireland due to ratify UNCRPD – must be Convention compliant

Environmental Restraint

Place of Residence/Deprivation of Liberty

- Issues
 - Consent of person is required for admission to a nursing home/designated centre
 - A person who lacks capacity enjoys
 - the same right to 'physical liberty' and security of person as everyone else and this can only be curtailed with proper safeguards
 - the right to privacy and family life
 - Right to decide on residence must be respected
 - Respite Care – tell the truth

Context for legislation – D of L

- Must be in the context of ADMC Act 2015
 - How capacity is to be construed – functional approach
 - Guiding principles must apply
 - Mechanisms for the support/assistance to make decisions
 - Pre Planning – Advance Healthcare Directives + Enduring Powers of Attorney
 - Contemporaneous – Decision-Making Assistant, Co-Decision-Maker and Decision Making Representative
 - Oversight of Decision Support Service
 - Court Jurisdiction
 - Independent Advocate

Deprivation of Liberty – Part 13 of ADMC Act??

- Every person to have the right to:
 - Consent to or refuse admission to designated centre
 - Consent to/refuse supervision and control while there
 - Leave at any time
- If person has capacity – can decide
- If person lacks capacity - procedure prescribed by law if intervention necessary.
- Person must be given information on the:
 - reason for the intervention
 - nature of the intervention
 - effect of the intervention

What procedures should the legislation provide for?

- Is admission necessary to provide care needs to the relevant person
- Assessment of care needs
- Review – is it necessary and proportionate
- Emergency process – where urgent intervention is necessary
- Access to an independent advocate
- Right of appeal to the court/process of appeal

Chemical Restraint

- Chemical restraint, is the intentional use of medication
 - to control or modify a person's behaviour or
 - to ensure a patient is compliant or not capable of resistance, when no medically identified condition is being treated, or
 - where the treatment is not necessary for the condition or the intended effect of the drug is to sedate the person for convenience or disciplinary purposes.
- Chemical restraint is inhuman and degrading treatment
 - Issue: [Is it Medical Treatment](#) or [Chemical Restraint?](#)
- The **appropriate use of drugs** to reduce symptoms in the treatment of medical conditions such as anxiety, depression, or psychosis, **does not constitute restraint**

Disability (Miscellaneous Provisions) Bill 2016

- Passed Second Stage – 23 February
- Referred to Committee Stage
- Deprivation of Liberty – to be introduced at Committee Stage
- Other amendments to Assisted Decision-Making (Capacity) Act 2015
- Potential for weakened approach due to lobbying of some professionals

Safeguarding

UN Convention on the Rights of Persons with Disabilities 2006 (Art 12.4)

- 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. **Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person**, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, **apply for the shortest time possible and are subject to regular review** by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

Safeguarding Legislation

Why we need it?

- NCPOP Prevalence study
- NSC Public opinion survey – worrying level of first and second hand experience of abuse – little awareness of what to do about it
 - publication April 2017
- HSE Safeguarding figures – biggest area of abuse is in the community

Safeguarding on a Statutory basis

- A definition of ‘person at risk’ / ‘vulnerable person’
- A definition of ‘abuse’ / ‘neglect’ – including a detailed code
- Reporting abuse or neglect – by whom and to whom
- Statutory obligation to determine if person needs support or assistance
 - Circumstance in which a person can refuse
- Investigative powers and duty to make enquires

Further Legislative Provisions

- Corresponding obligation of person to respond/offence if hinders or obstructs investigation
- Power to gain access to **any** premises to investigate
 - Current gap particularly where person is living at home
- Power to gain access to personal records
- Outcome of investigation – duty to report any offence
- Involvement of other agencies/also have safeguarding remit
 - Director of Decision Support Service
 - Mental Health Commission
- Court orders – to include orders against persons who are perpetrators

Structures

- An Independent Adult Safeguarding Board/Authority
 - Ring-fenced budget
 - Powers with regard to both public and private sectors
- Some existing structures can be basis for new legislation but must be independent of HSE
 - National Safeguarding Office
 - Safeguarding and Protection Committees

Independent Advocate

- Key component in safeguarding legislation
- *Assisted Decision-Making (Capacity) Act 2015*
 - Reference (code for advocates)
 - Application to court (person suitable, willing and able to assist)
 - Deprivation of Liberty
- Examples:
 - IMCAs under Mental Capacity Act 2005 (England and Wales)
 - Advocate under Care Act 2014 (England and Wales)
 - Adult Support and Protection (Scotland) Act 2007
 - Adult Guardianship Act (British Columbia)

Legislative Framework - Advocacy

- Development of robust concept of Independent Advocacy
- Development of National Advocacy Standards
- Education and Training standards
- Representation role in court applications

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Thank You

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