

UCD Centre for Disability Studies

Discussions in Disability

Assisted Decision Making

A legislative framework for Capacity, Consent and
Safeguarding



'It is all about human rights'

Baroness Hale [2014]

Overview

- Human Rights Obligations
- Assisted Decision-Making (Capacity) Act 2015
 - Capacity
- Consent – different mechanisms
- Deprivation of Liberty
- Adult Safeguarding legislation
- Conclusion

Human Rights

- International Obligations
 - The European Convention on Human Rights
 - Hague Convention on the International Protection of Adults (2000)
 - *UN Universal Declaration on Bioethics and Human Rights 2005*
 - UN Convention on the Rights of Persons with Disabilities 2006
 - Council of Europe *Recommendation on Principles concerning Powers of Attorney and Advance Directives for Incapacity* September CMR/2009
 - Council of Europe *Recommendation on the Promotion of Human Rights of Older Persons* CMR/2014(2)

UN Convention on the Rights of Persons with Disabilities 2006 (Ratified by Ireland 2018)

- State parties undertake to ensure and promote the full realisation of all human rights and fundamental freedoms **for all persons with disabilities** without discrimination of any kind on the basis of disability (Art 4)
- 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 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)

Legislative Framework

- Assisted Decision-Making (Capacity) Act 2015
 - Enacted in December 2015 – 2 Commencement orders made
- Human Rights Conventions:
 - UNCRPD ratified in April 2018
 - Hague Convention on International Protection of Adults – still to be ratified
- [Equality]/Disability (Miscellaneous Provisions) Bill 2016
 - Amendment of other legislation to comply with UNCRPD
- Assisted Decision-Making (Capacity) Amendment Bill ?? 2018
- Protection of Liberty Safeguards (DoLs)
 - New Part 13 to ADM(C)Act 2015
- Adult Safeguarding Bill 2017

Assisted Decision-Making (Capacity) Act 2015

Who is the ADM(C)legislation for?

Relevant person

- 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**

Decision-making capacity = Not mental capacity (Legal test)

Cognitive ability/capacity = Medical assessment of mental state (Medical test)

- (Obligation to ensure that this is fully understood in practice. Direct communication with relevant person is necessary in order to fully comply with legislation)

Current policies not complied with:

- HSE National Consent Policy (2013)
- Medical Council Guide to Professional Conduct and Ethics (7th Ed 2009 and 8th Ed 2016)

Presumption of Capacity

- Applies to all regardless of physical or mental health/disability/age
- Common law principle now enshrined in legislation to state:
 - *It shall be presumed that a person (whose capacity is in question or may shortly be in question) has capacity in respect of the matter concerned unless the contrary is shown in accordance with the provisions of the Act*
(First principle)
- Onus/Burden of proof of lack of decision-making capacity lies with person who is alleging lack of capacity
- Burden of proof – balance of probabilities

Definition of Capacity/Functional Capacity

- A person's decision-making capacity is to be construed functionally
- **Capacity** - ability to understand **at a time** a decision has to be made, the nature and consequences of **the decision** to be made by a person **in the context of available choices at that time**
(No blank canvass KK case – onus on assessors)

Lack of Capacity

- **A person lacks of capacity to make a decision if he or she is unable to –**
 - Understand the information relevant to decision
 - Retain that information **long enough to make a voluntary choice**
 - Use or weigh that information as part of the process of making the decision or *(Not necessary for a person to demonstrate a capacity to understand and weigh up every detail of the respective options, but merely the salient factors KK case 2012)*
 - Communicate decision by any means (including sign language/assistive technology) or if the implementation of the decision requires the act of a third party

If a person cannot undertake **any one** of these four aspects of the decision-making process, then her or she is unable to make a decision.

How is capacity to be assessed?

- **Capacity** – Person is not to be regarded as unable to understand information relevant **to a decision** if they are able to understand an explanation of it given in a manner appropriate to his/her circumstances (clear language, visual aids or any other means)
- The fact that a person is able to retain information **relevant to a decision** for a short period only does not prevent him/her from being regarded as having capacity to make the decision

Assessing Capacity

- The fact that a person lacks capacity in respect of a decision on a particular matter **at a particular time** does not prevent him/her from being regarded as having capacity to make decisions on the same matter **at another time**

(Make sure correct environmental factors are suitable for the person – onus on assessor) **(Time specific)**

- The fact that a person lacks capacity of a decision **on a particular matter** does not prevent him/her from being regarded as having capacity to make decisions **on other matters (Issue specific)**

Guiding Principles

“Shall apply for the purposes of an intervention in respect of a relevant person, and the intervener shall give effect to those principles”

Guiding Principles

- All practicable steps must be taken to assist person to make decision
- Unwise decision is not indicative of a lack of decision-making capacity
- No intervention unless necessary – regard to individual circumstances
- Intervention – minimise restriction on rights, freedom of action and limited in duration
- Need to respect right to dignity, bodily integrity, privacy autonomy and control over financial affairs and property
- Permit and encourage participation, have regard to will and preferences and beliefs and values
- Act at all times in good faith for the benefit of the relevant person

Consent to Intervention

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**
 - Decision-Making Representative: Decision-Making Representation Order

Stages for appointment - Stage 1

A person with Capacity

- When a **person** has capacity **may appoint**:
 - Attorney under an Enduring Power of Attorney (**Notice + Registration**)
 - **Property and Affairs Decisions and Personal Welfare Decisions**
 - Designated Healthcare Representative in a AHD (or make an AHD with no appointed representative) (**Notice + Notice to Director DSS**)
 - **Medical Treatment Decisions**
- **Think Ahead/Plan Ahead**
 - **Enduring Power of Attorney**
 - **Advance Healthcare Directive**

Stages for appointment – Stage 2

A person whose capacity is in question

- **When a person considers his/her capacity to be in question or may shortly be in question may appoint a:**
 - **Decision-Making Assistant (to assist with decision/s)** (Notice Dir DSS)
 - Property and Affairs Decisions + Personal Welfare (Regulations)
 - **Co-Decision-Maker (to jointly make decision/s)** (Notice + Registration)
 - Property and Affairs Decisions + Personal Welfare (Regulations)
- Can be at different stages at same time for different decisions

Stages for appointment – Stage 3

A person who lacks decision-making capacity

- **When a person lacks capacity – application is made to the court and if the court makes a declaration that person lacks capacity, court will make an order (have regard to any AHD/EPA)**
 - **Make the decision on behalf of the person**
 - **Appoints a Decision-Making Representative to make specified decisions on behalf of person**

Capacity and Mental Illness



Review of Wards of Court

Deprivation of Liberty

No citizen shall be deprived of his personal liberty save in accordance with law

Constitution (Article 40.4.1)

Deprivation of Liberty

European Convention of 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 includes a person of ‘unsound mind’ (Article 5.1)
- Article 3
 - No one shall be subject to ...inhuman or degrading treatment ...
 - This is an absolute right – no exceptions
- Article 8
 - Everyone has the right to respect for his private and family life

Deprivation of Liberty

UN Convention on Rights of Persons with Disabilities

- Article 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
 - 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, including by provision of reasonable accommodation**

ICCPR: UN Human Rights Committee (Dec 2014)

- State parties should revise outdated laws and practices
- The existence of a disability shall not in itself justify a deprivation of liberty
- It must be applied only as a measure of last resort and for the shortest appropriate period of time, and must be accompanied by **adequate procedural and substantive safeguards established by law**
- The procedures should ensure **respect for the views of the individual** and ensure that any representative genuinely represents and defends the wishes and interests of the individual

Part 13 of Assisted Decision-Making (Capacity) Act

- Right of person to consent to 'place of care'
- If lack capacity to do so
- EPA or ?AHD

Legislative Framework required:

- Assessment of need for care in place other than home
- Supporting person to make decision (will and preference)
- If no arrangement in place, provide for procedures to be followed
- Review of any arrangement
- Scope
 - to capture de facto detention (what to include and exclude)
 - to include restrictive practices
 - to include chemical restraint

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 (ECHR)
 - 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**

Safeguarding Legislation

National Safeguarding Committee

- Multi-agency and inter-sectoral body
- Established by HSE but independent of the HSE - in recognition of the fact that safeguarding vulnerable persons from abuse is a matter that cannot be addressed by any one agency working in isolation but rather a number of agencies and individuals working collaboratively with a common goal
- Membership – key players in public services, legal and financial services, health and social care professions, regulatory authorities and NGOs representing older people and people with disabilities (32 organisations)

Strategic Plan 2017 - 2021

Actions (include)

- Raise public awareness
- Initiate conversations with Government and Oireachtas Committees on the development of legislation to include adult safeguarding, advocacy, the use of chemical restraint and deprivation of liberty

Why we need adult safeguarding legislation

- State, state agencies and organisations must have clear obligation to prevent abuse and to protect adults who are at risk and unable to protect themselves
- Prevalence of adult abuse and exploitation highlights the urgent requirement for adult safeguarding to be placed on a statutory footing
- HSE Policy is limited in its scope and has no statutory force
- UNCRPD requires that effective legislation and policies are put in place to ensure instances of exploitation, violence and abuse are identified, investigated and, where appropriate, prosecuted
- If safeguarding is everyone's responsibility, the legislation must be developed on a cross governmental, interagency and societal basis

Adult Safeguarding Bill 2017

April 2017

- Bill introduced in Seanad by Senator Colette Kelleher
- Received all party support (including Government)
- Passed to Committee Stage

December 2017

- Joint Health Oireachtas Committee Report
- Government Decision to develop a new National Adult Safeguarding Policy underpinned by legislation **for the health sector** - Unit in Department
- NSC collaborating but demanding an 'all of Government approach'

Adult Safeguarding Bill 2017

Main Provisions

- Definitions – ‘adult at risk’ - unable to protect him or herself from abuse or harm
- Establishment of National Safeguarding Authority
 - To promote standards in the safety and quality of services provided to adults at risk
 - To undertake investigations
 - To promote education, training and public awareness of adult safeguarding
 - To provide information to adults at risk in respect of abuse and harm
- Independent Advocate
- Right of entry and inspection by authorised person
 - To protect person
 - To obtain personal records
- Mandated person
 - To report

Policies and Standards

- HIQA and MHC – National Standards for safeguarding adults
 - To promote best practice in providing person-centred, safe and effective care and support **in health including mental health and social care services** across Ireland
 - Background Document published 9 May 2018
- HSE Review of 2014 *Safeguarding Vulnerable Persons at Risk of Abuse – National Policy and Procedures* - due for completion in 2018
 - McCoy Report (Aras Attracta) – need for legislative underpinning
- Department of Health
 - Will undertake an extensive exercise of research and policy development to assist in framing an appropriate policy and legislation **for the health sector**
 - Public consultation and engagement process in 2018

Some suggested Safeguarding Principles

- Each person has the right to be safe and live life free from harm
- Any intervention must respect the human rights of the person and promote the person's wellbeing
- Each adult at risk is entitled to access to an Independent Advocate to assist, support and empower them
- Safeguarding adults at risk requires a collaborative approach making sure that the person is the central focus for all

Conclusion

- Pending full commencement of 2015 Act – ethos of Act must be implemented
- Need to respect rights of each person as an individual human being, autonomy and self-determination – cultural shift required
- UN - liberty + security of person is one of the most precious rights to which everyone is entitled
- Pending enactment of Protection of Liberty safeguards the rights of each person to consent to care arrangements must be respected
- State, state agencies and organisations have clear obligation to prevent abuse
- Public awareness is key factor – every opportunity should be taken at all levels
- Adult safeguarding legislation and standards must be developed on a cross- governmental, interagency and societal basis

Thank You

Q and A