

A New Model: Towards Implementation of the Assisted Decision-Making (Capacity) Act 2015

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**Decision
Support
Service**

Overview

- Concepts of Capacity
- Functional Assessment
- Guiding Principles
- New Decision Support Structures
- Advance Planning
- Pathway to Implementation

Assisted Decision-Making (Capacity) Act 2015

“An Act to provide for the reform of the law relating to persons who require or may require assistance in exercising their decision-making, whether immediately or in the future”

Signed into law 30th December 2015; largely not yet commenced

Legal Capacity / Decision-Making Capacity

“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, 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”.

-Hamilton C.J.

In Re a Ward of Court (No.2) 1996 2 IR

Convention on the Rights of Persons with Disabilities (UNCRPD)

- ❑ 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);
 - reaffirm that persons with disabilities **have the right to recognition everywhere as persons before the law** (Art 12.1);
 - shall recognise that persons with disabilities **enjoy legal capacity on an equal basis with others in all aspects of life** (Art 12.2);
 - 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)

Assessing Capacity

☐ Status Approach

- ❖ *‘You are someone with an intellectual disability or dementia or a brain injury and therefore, you cannot have capacity’.*

☐ Outcome Approach

- ❖ *‘What you want to do is so unwise, so contrary to prudent advice, that you must lack the capacity to decide to do it’.*

Functional Assessment

Time-specific, Issue-specific test:

- Section 3. (1) *“a person’s capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time.”*

- Understand
- Retain
- Weigh Information
- Communicate decision

Contrast ‘all or nothing’ status approach of Wardship

Section 2 Lunacy Regulation (Ireland) Act 1871

*“a person of **unsound mind** and incapable of managing himself or her affairs”.*

Incapacity need not have a medical cause

Contrast:

- ❑ Mental Capacity Act of 2005 (England and Wales)
 - Section 2.(1) defines incapacity as deriving from *‘an impairment or disturbance in the functioning of the mind or the brain’*

Functional Assessment at Common Law and Policy

☐ Common Law:

- **Fitzpatrick & Anor -v- K. & Anor, [2008] IEHC 104 (2008)**

- Rebuttable presumption that an adult has the capacity to refuse treatment
- Importance of communication and duty to provide comprehensive information

- **Governor of X Prison -v- P McD [2015] IEHC 259**

“PMcD’s right to self-determination may prevail over the duty of the State to preserve life”.

☐ Healthcare Policy and Guidelines:

- *“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 QPSD-D-026-1.2.V.1.12

- Irish Medical Council: Guide to Professional Conduct & Ethics (8th edition)

Guiding Principles for Interveners

❑ Section 8

- Presumption of Capacity
- Steps must be taken to maximise capacity
- ‘Right to be unwise’

“A relevant person ... shall not be considered as unable to make a decision in respect of the matter concerned merely by reason of making, having made, or being likely to make, an unwise decision.”

- Minimum restriction of rights and freedom of action
- Due regard to dignity, bodily integrity, privacy, autonomy
- *“The intervener shall give effect, in so far as is practicable, to the past and present will and preferences of the relevant person ...”*

❑ Not ‘Best Interests’

The ‘Relevant Person’

☐ Section 2 (1)

“relevant person” means—

- (a) a person whose capacity is in question or may shortly be in question in respect of one or more than one matter,
- (b) a person who lacks capacity in respect of one or more than one matter, or
- (c) a person who falls within *paragraphs (a) and (b)* at the same time but in respect of different matters

Decisions: Property and Affairs

- Property (Custody, Control, Management, Sale, Acquisition)
- Business
- Contracts
- Financial obligations
- Providing for the needs of others
- Conduct of proceedings

Decisions: Personal Welfare

- Accommodation
- Education and Training
- Participation in Social Activities
- Social Services
- Healthcare
- “...other matters relating to the relevant person’s wellbeing”

Informal Decision-making

Mental Capacity Act of 2005 (England and Wales)

1. If a person (“D”) does an act in connection with the care or treatment of another person (“P”), the act is one to which this section applies if—
 - a) before doing the act, D takes reasonable steps to establish whether P lacks capacity in relation to the matter in question, and
 - b) when doing the act, D reasonably believes—
 - i. that P lacks capacity in relation to the matter, and
 - ii. that it will be in P’s best interests for the act to be done.
2. D does not incur any liability in relation to the act that he would not have incurred if P—
 - a) had had capacity to consent in relation to the matter, and
 - b) had consented to D’s doing the act.

Defence of necessity in Ireland?

Types of Decision Makers

Decision-Making Assistant

- Lowest and least formal of the three levels
- **Appointed by Person** when they consider capacity is or may shortly be called into question
- **Decision** is still **by the appointer**

Co-Decision Maker

- **Appointed by Person** when they consider capacity is or may shortly be called into question
- Make specified **decisions jointly with the appointer.**

Decision-Making Representative

- **Appointed by the Circuit Court** following an **application under Part 5**
- Appointment follows on a declaration of incapacity by the Court, **only if** the Court considers that a **Co-Decision Maker will not suffice.**

Decision-making Assistance Agreement

Duties of DMA

- Assist the appointer to obtain relevant information
- Advise the appointer by explaining relevant information
- Ascertain the will and preferences of the appointer and assist the appointer to communicate them
- Assist the appointer to make and express a decision
- Endeavour to ensure that the appointer's decisions are implemented

Decision remains that of the Appointer

Co-Decision-Making

- Relative or friend in personal contact and in a relationship of trust
- Performance of functions:
 - Advise the appointer by explaining relevant information
 - Ascertain Will and Preferences
 - Assist in obtaining information
 - Discuss alternatives and outcomes
 - Make decision jointly
 - Ensure implementation as far as possible
- Section 19 (5): *“... a co-decision-maker... shall acquiesce with the wishes of the appointer in respect of the relevant decision ... unless it is reasonably foreseeable that such acquiescence or signature, as the case may be, will result in serious harm to the appointer or to another person.”*

Decision Making Representative (DMR)

- ❑ On application by anyone with bona fide interest,
- ❑ Circuit Court may make a declaration that the relevant person:
 - (a) lacks capacity in respect of the decision unless a CDM is available
 - (b) lacks capacity even if a CDM is available or
 - may make declaration as to the lawfulness of a proposed intervention

Where (b) applies, the Court may move to

- make an order making the decision on behalf of the relevant person if the matter is urgent
- appoint a suitable decision-making representative (DMR)

DMRO: Periodic Review, Reports, Accounts

- Declarations of capacity
 - Reviewed periodically at intervals of 12 months, or
 - 3 years if the Court believes that there is no prospect of the relevant person recovering capacity.

- DMR Reports to Director:
 - Submit a report to the Director in relation to the performance of the DMR's functions every 12 months
 - Include details of all transactions within the scope of the DMRO
 - All costs expenses and remuneration received by the DMR.
 - Schedule of the Relevant Person's assets and liabilities and projected income and expenditure within 3 months of appointment
 - The DMR must keep proper accounts and financial records and submit these to the Director or to a **general visitor**.

- Non-compliance with these reporting duties,
 - Director can apply to the Court - determine if DMR should be removed.

Procedure and Standards for Interveners

- Eligibility criteria
- Grounds for disqualification
- Procedures for notification/registration (where applicable)
- Reporting duties
- Complaints and Investigations:
 - Acting outside the scope of the agreement or order
 - Unsuitable or unable to perform functions
 - Fraud, coercion, undue influence
 - Not acting in accordance with will and preferences
 - Higher level of support required.

Criminal Sanctions

- Offences of fraud, coercion, undue influence to force a person to make vary or revoke and agreement
- Includes any case where a person is led to believe that access to a residential facility is dependant on making or varying a CDM or EPA
- Making false statements on registration
- Ill-treatment or wilful neglect
- Fines of up to €50,000 and/or 5 years' imprisonment

Advance Planning: Enduring Powers of Attorney

- EPAs created under Powers of Attorney Act 1996 remain valid
- EPAs extended: authority to make decisions of a medical nature (previously not included in 'personal care' under 1996 Act)
- Shall not include refusal of life-sustaining treatment
- Restrictions on restraint
- New reporting requirements
- Complaints and Investigations
- Offences of fraud, coercion and undue influence

Advance Planning: Advance Healthcare Directive

❑ Section 83

(1) *The purpose of this Part is to—*

- (a) *enable persons to be treated according to their will and preferences, and*
- (b) *provide healthcare professionals with information about persons in relation to their treatment choices.*

(2) *A relevant person who has attained the age of 18 years and who has capacity is entitled to refuse treatment for any reason (including a reason based on his or her religious beliefs) notwithstanding that the refusal—*

- (a) *appears to be an unwise decision,*
- (b) *appears not to be based on sound medical principles, or*
- (c) *may result in his or her death.*

Advance Planning: Advance Healthcare Directive

- Validity and notification requirements

- Section 86 (1)

“A specific refusal of treatment... as effective as if made contemporaneously by the directive-maker when he or she had capacity”

- Distinguish refusal of treatment and request for treatment

- May apply to life sustaining treatment (AHD must be explicit)

- May not apply to withdrawal of basic care

- Designated Healthcare Representatives

- Role of the Courts in interpreting validity and applicability

- Section 85 (7)(a) AHD shall be complied with unless treatment is regulated by Part 4 of the Mental Health Act 2001

Decision Support Service

- ❑ Integrated office within the Mental Health Commission
- ❑ Part 9 relating to appointment of Director has been commenced
- ❑ Director's Duties include:
 - To promote public awareness of the Act
 - To promote public confidence around dealing with people who require assistance in exercising their capacity
 - To provide information to relevant persons in relation to their options for exercising capacity
 - To provide information and guidance to organisations and bodies in relation to their interaction with relevant persons and decision supporters
 - To identify and make reference for change of practices in organisations which may prevent a relevant person from exercising capacity
- ❑ Section 95 (2): *"The Director shall have all such powers as are necessary or expedient for, or incidental to, the performance of his or her functions."*

□ Pathway to Implementation

- Inter-departmental Steering Group established 2016
- Regulations to be drafted by DoJE and DoH
- Panels to be established:
 - Decision Making Representatives
 - Special Visitors
 - General Visitors
 - Court Friends
- Amendments to the 2015 Act
- Disability (Miscellaneous Provisions) Bill to amend other legislation
- Part 13: Deprivation of Liberty Safeguards/Prohibition of Chemical Restraint

“the administration of medication not necessary for a medically identified condition with the intention of controlling or modifying the relevant person’s behaviour or ensuring that he or she is compliant or not capable of resistance”

Codes of Practice

Section 103 (13)

“A person concerned shall have regard to a code of practice ... when performing any function under this Act in respect of which the code provides guidance.”

National Disability Authority drafting Non-Healthcare Codes

AHD Multidisciplinary Working Group, appointed by Minister for Health

- Draft Code on how to make an AHD
- Draft Code of Practice for DHRs
- Draft Code of Practice for Health and Social Care Professionals on AHDS

HSE National Assisted Decision-Making Steering Group

- Education and Training Implementation Plan
- Information and Communications Plan
- Advance Healthcare Directives Implementation Plan

HSE Guide for Health and Social Care Professionals (March 2017)

Concluding Comments

Thank You