

# A New Model: Pathway to Implementation of the Decision Support Service NHI Annual Conference 15<sup>th</sup> November 2018

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# Overview

- ☐ Concepts of Capacity
- ☐ Key reforms under 2015 Act
- ☐ New Decision Support Structures
- ☐ Advance Planning
- ☐ Establishment of DSS / Director's Role
- ☐ Pathway to Implementation
- ☐ Deprivation of Liberty / Codes of Practice

# Assisted Decision-Making (Capacity) Act 2015

Signed into law *30<sup>th</sup> December 2015; largely not yet commenced*

*“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”*

☐ Abolishes Wards of Court system

# 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... 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”.*

**-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 - 'how not to':

## ❑ 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'.*

# Assisted Decision-Making Capacity Act 2015

- ☐ Section 3: Time-specific, Issue-specific test:
  - Understand
  - Retain
  - Weigh Information
  - Communicate decision
  
- ☐ Fitzpatrick & Anor –v- K. & Anor, [2008] IEHC 104 (2008)
  
- ☐ HSE: National Consent Policy: *“...cognitive deficits are only relevant if they impact on decision making.”*
  
- ☐ 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

Compare:

- ❑ 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*'



## Section 8: Guiding Principles for Interveners

- ☐ Presumption of Capacity
- ☐ Steps must be taken to maximise capacity
- ☐ 'Right to be unwise'
- ☐ Minimum intervention
- ☐ Will and preference
  
- ☐ Not 'Best Interests'

# Decisions: section 2

## ☐ Property and Affairs

- Management of property
- Carrying on of business
- Contracts and court proceedings
- Applications for housing or other benefits

## ☐ Personal Welfare

- Accommodation
- Education and training
- Social services
- Healthcare
- *“...other matters relating to the relevant person’s wellbeing”*

# Three Tiers of Decision Supporters

## ☐ 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.
- Section 18(5): 'duty of acquiescence'

## ☐ 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.
- Substituted decision-making

# Procedures and Standards for Decision Supporters

- ☐ Eligibility criteria: may not be owner or registered provider or employee etc. of designated centre or mental health facility where the RP resides
- ☐ Grounds for disqualification and nullity
- ☐ Procedures for notification/registration
- ☐ Performance of functions
- ☐ Reporting duties
- ☐ Complaints and Investigations

## Criminal sanction

- ☐ Offences of fraud, coercion, undue influence
- ☐ Section 80 (3)
  - *“...includes any case where a person’s access to, or continued stay in, a designated centre or mental health facility, is contingent (whether in whole or in part) on the person having to, or being led to believe that he or she has to, create, vary or revoke an enduring power of attorney.”*
- ☐ Section 145
  - *Offence of ill-treatment or wilful neglect by a decision supporter*
- ☐ Fines of up to €50,000 and/or 5 years’ imprisonment

# Advance Planning

## □ Council of Europe Recommendation on the Promotion of Human Rights of Older Persons

- *“Older persons have the right to respect for their inherent dignity. They 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, finances, place of residence, health, medical treatment or care”*
- *“Member States should provide for legislation which allows older persons to regulate their affairs in the event that they are unable to express their instructions at a later stage.”*

CM/REC(2014)2

# Advance Planning: Enduring Power 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 periodic reporting requirements
- ☐ Complaints and Investigations

# Advance Planning: Advance Healthcare Directive

❑ Part 8 of 2015 Act/ Minister for Health

## 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

## ☐ 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

## ☐ May not apply to withdrawal of basic care

## ☐ Designated Healthcare Representatives

## ☐ Role of the Courts to decide whether valid and applicable

## ☐ 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: Director's Functions include:
  - To promote public awareness of the Act and matters relating to the exercise of capacity, including UNCRPD
  - To promote public confidence around new processes
  - To provide information to relevant persons in relation to their options
  - To provide information to decision supporters
  - To supervise compliance by decision supporters
  - To provide information and guidance to organisations and bodies in relation to their interaction with relevant persons and decision supporters
  - To identify and recommend changes in practice to promote the exercise of capacity
  - Duties to report to Minister for Health and Minister for Justice and Equality

# Complaints and Investigations

❑ 96. (2) In response to complaint or on own initiative:

- (a) **summon witnesses** to attend before him or her,
- (b) **examine on oath** the witnesses attending before him or her,
- (c) **require** any such witness to **produce** to him or her **any document** in the power or control of the witness,
- (d) by notice in writing, **require any person** to provide him or her with such **written information** as the Director considers necessary to enable him or her to carry out his or her functions.

■ Non-compliance is a summary offence

❑ 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
- ☐ Director recruited and in office since October 2017
- ☐ Regulations to be drafted by DJE 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

# Deprivation of Liberty

- ❑ Safeguards/Prohibition of Chemical Restraint
  - Will become Part 13 of 2015 Act
  - DoH: Consultation process on Draft Heads of Bill
  - Deprivation of Liberty Advisory Group
  
- ❑ Compare position in England and Wales:

Cheshire West and Chester Council v P [2014] UKSC 19, [2014] MHLO 16

*(1) The 'acid test' for deprivation of liberty is whether the person is under continuous supervision and control and is not free to leave. (2) The following are not relevant: (a) the person's compliance or lack of objection; (b) the relative normality of the placement (whatever the comparison made); and (c) the reason or purpose behind a particular placement. (3) Because of the extreme vulnerability of ... P, decision-makers should err on the side of caution in deciding what constitutes a deprivation of liberty.*

- ❑ The quality of care or treatment is not relevant
  - "... a gilded cage is still a cage". - Lady Hale*

# Deprivation of Liberty

- A.C. -v- Cork University Hospital & Ors (Hogan J., Court of Appeal 2<sup>nd</sup> July 2018)
- Contrast with Mental Health Act 2001

*“.....the Oireachtas could never have contemplated that persons in the condition of Ms. A.C. could be detained by reference to some self-created power of detention, shorn of all the essential protections for independent review provided for by the 2001 Act.”*

# 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.”*

## ☐ Section 103 (3)

### ***Consultation Process to include the following:***

- (a) the Health Service Executive;*
- (b) the Health Information and Quality Authority*
- (c) the National Disability Authority;*
- (d) the Citizens Information Board;*
- (e) representatives of professional bodies in the healthcare, social care, legal and financial sectors;*
- (f) representatives of healthcare, social care, legal and financial professionals.*

## ☐ The Director will publish with consent of the Minister

## ☐ A code of practice will be admissible in any legal proceedings.

# Codes of Practice Continued

- ❑ 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)
- ❑ HSE Working Group also drafting composite code of practice under section 103:
  - General guidance for healthcare professionals on assessing capacity and supporting decision-making
  - Urgent treatment where consent cannot be obtained
  - Guidance for healthcare professionals in their dealing with relevant persons



# Concluding Comments

## Thank You