



# National Patient & Service User Forum

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# Objectives of Forum

- ▶ To be an open inclusive combination of patients, service users, families and advocacy groups
- ▶ To be a national first point of reference for HSE directorates and clinical care programmes, for seeking opinions of, and consulting with, patients, service users, families and advocacy groups, on matters of national significance for the health service
- ▶ To provide input to the directorates and clinical care programmes on matters that have individual and national significance for patients, service users and their families
- ▶ To strengthen the voice of patients, service users and their families as partners in their own healthcare



Relevant person-  
a recalibration for the centrality of rights

....or just **some** antics?

RELEVANT - IRRELEVANT - PERSON

DECISION – INDECISION – SUPPORT SERVICE

DECISION SUPPORT SERVICE SUPPORTER OR INTERVENOR

# A welcome development

- ▶ Replacement of the long out-dated Lunacy Regulation (Ireland) Act of 1871
- ▶ Creation of a continuum of decision-making aids, ranging from informal support to more extensive decision-making arrangements
- ▶ Move from an all or nothing status approach to a flexible 'functional' view of capacity assessed on an issue-and-time specific basis
- ▶ Abolition of the Wards of Court system, the review of capacity of all existing wards and the establishment of the Decisions Support Service
- ▶ Modernisation of the law on Enduring Powers of Attorney.
- ▶ Advance Healthcare Directives

# Story of an 'irrelevant person'

- ▶ MB woman of 90+ in an acute hospital for long period of time
- ▶ Recovered well from initial illness
- ▶ Treating doctors believed she lacked capacity to decide where to live
- ▶ Nurses, who cared for her daily, believed she could decide for herself. No one asked her GP of decades.
- ▶ Wardship applied for by the HSE - papers landed on her bed
- ▶ Doctor then conceded she had capacity to decide where she lived
- ▶ Woman wanted her advocate involved but not a solicitor
- ▶ Judge 'preferred' the evidence of doctors about problems with capacity
- ▶ Woman wrote to President of the High Court to express her hurt at being made a Ward of Court. He didn't reply.

# Waiting for Godot



# ..in No Man's Land



- ▶ Advance Healthcare Directives
- ▶ Enduring Power of Attorney
- ▶ Assisted & Co-Decision Making
- ▶ Codes of practice

# Circles of support & decision making contain other relevant people

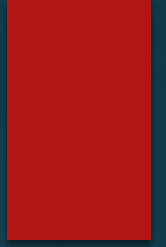




# Some Questions raised via Forum

- ▶ How will we know we have succeeded in developing the assisted decision maker role if they are not registered?
- ▶ How many people will want to act as co-decision maker or one of a number of co-decision makers if the decisions to be made are relatively complex and time consuming and not fully supported?
- ▶ When will we see a proper public awareness campaign organised through the Decision Support Service to promote the idea of supported decision making and the guiding principles?
- ▶ What sanctions will apply if the required annual report of a Decision Making Representative is not submitted or is inadequate?

The moon always has a dark side



# Relevant

Closely connected or appropriate to what is being done or considered

- ▶ Relevant person – if capacity is at issue
- ▶ Relevant organisation – if capacity is at issue
- ▶ Relevant systems – if capacity is at issue

# Scale of Relevance?



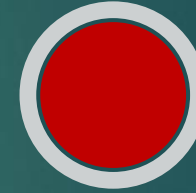
**Assistant  
Decision Maker**

Nothing about  
me without me



**Co Decision  
Maker**

Nothing about  
me without you



**Decision-Making  
Representative**

Nothing about  
me and all  
about you?

# The challenges of VOICE & RISK



# Supreme Court on AC – CUH Case

## October 17th



“It is essential that the voice of the individual be heard in the process, and if she cannot speak for herself then some person must be found, who is not otherwise involved in any dispute, who can speak for her”.

# From simplistic..... to subtle



Best Interests



Will & Preference (wishes)

# 'Culture eats strategy for breakfast'





# Public & Professional Awareness



The time wasted and the patients not cared for by divided relatives making 'decisions' without concern for a patient's wishes

# Relevant Organisations & Systems

- ▶ Who will be the relevant person accountable in Q4 2020 if the ADMCA is not fully commenced? MHC / DSS / DoH / DoJ ?
- ▶ How relevant are the corporate governance structures of the MHC – DSS given the substantial new responsibilities and challenges
- ▶ How relevant will my Advance Health Directives or Enduring Power of Attorney be if they cannot be quickly accessed in an emergency
- ▶ Monitoring / intervention (im)balance

# Relevant Legislation

## Supported Decision Making & Consent

Assisted Decision Making  
(Capacity) Act 2015  
Decision Support Service 2020  
Enduring Powers of Attorney  
Advance Healthcare Directives  
Repeal of 1871 Lunacy Act &  
Wards of Court  
HSE Consent Policy  
*Independent Advocacy*

## Protection of Liberties in Places of Care

UNCPRD  
Care & Custody  
Courts / HSE / DSS?  
*Independent Advocacy*

## Safeguarding

Adult Safeguarding Bill 2017  
Law Reform Commission  
framework due  
*Independent Advocacy*

# Relevant Structures



2015 - 2020

# Commencement - Credibility



Ministerial Champion - Adequate Budget – Effective Governance