



The relevant person, human rights, and ethics

Drilling Deep into the Assisted Decision
Making (Capacity) Act 2015

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Dr. Joan McCarthy, j.mccarthy@ucc.ie

A TRADITION OF
INDEPENDENT
THINKING



UCC

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

I am going to talk about:

1. The 'relevant person' through a legal and ethical lens
2. Autonomy in healthcare
3. The limits on autonomy
4. The privilege of Health and Social Care Professionals (HSCPs)
5. The privilege of everyone else
6. Relational autonomy
7. Some implications

Relevant person is

- “(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”

ADM Act 2015 PT.1 S.2 [NO. 64.]

So,.... a relevant person is a person who may have difficulty making some decisions (but not others) without support, or, a person who lacks capacity to make some decisions (but not others)

What is relevant about the relevant person?

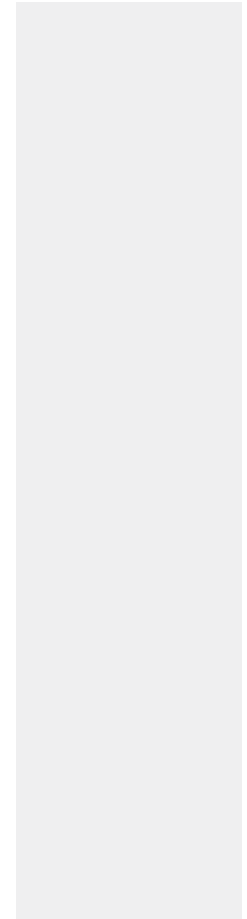
ADM Act 2015 provides for the legal recognition of the autonomy rights of relevant persons e.g. bodily integrity, self-determination, inclusion in decision-making

Legal and political heart of the matter:

is the idea that the unique values and preferences of the individual should be central to decisions pertaining to them

States have an obligation to protect, respect, and fulfill human rights (note HIQA Guidance on FREDA)

Human rights are a counterbalance to discriminatory, exclusionary, coercive practices – a mechanism by which the state is accountable on the domestic and international stage



What are the foundations of human rights?

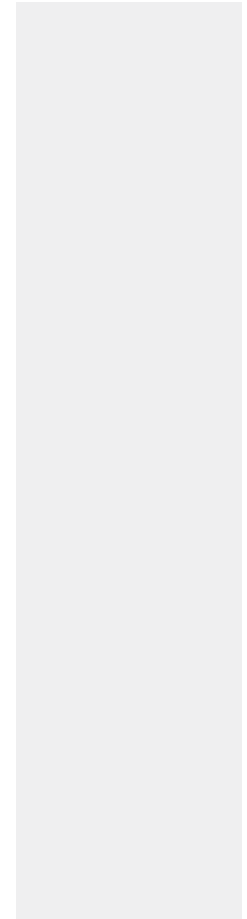
Many diverse accounts e.g. common humanity or dignity or natural law

Whatever their origins, greater agreement on the broad list of basic rights than there is on their foundations

The UN Declaration of Human Rights (1948) represents a consensus

“was much more a testament to the aspirations of the oppressed than it was a protection of the power of the wealthy.”

(Wolff 2012: 2-3)



Ethical heart of the matter:

- a person has moral authority over their own lives
- should be at the centre of decision-making concerning themselves – genuinely included

“I wish to be an instrument of my own, not other[s]’ acts of will. I wish to be a subject, not an object . . . deciding, not being decided for, self-directed and not acted upon by external nature or by other[s] as if I were a thing, or an animal, or a slave incapable of playing a human role, that is, of conceiving goals and policies of my own and realising them.”

(Berlin 1992: 131)

Autonomy in healthcare

Negative rights: the right to demand that a health professional desist from doing something to you e.g. right to refuse medication, refuse a transfusion, refuse life prolonging treatment

Positive rights: the right to some personal, social or institutional benefit or provision e.g. adequate information, pain relief, good care

A **relevant person** is someone who may need different kinds of support to exercise these rights of autonomy

Personal autonomy is limited

by the legitimate autonomy and welfare claims of others

- Harm
- Scarce resources
- Duties to others
- Professional and personal integrity of HSCPs

Privilege of HSCPs

In the past, patients' choices were subordinated to the deciding power and paternalism of doctors or other HSCPs

deemed best qualified to know what served their “best interests”

assumption was that because health professionals have clinical authority and expertise, they also have moral authority and ethical expertise

Mrs Heinrich, patient representative

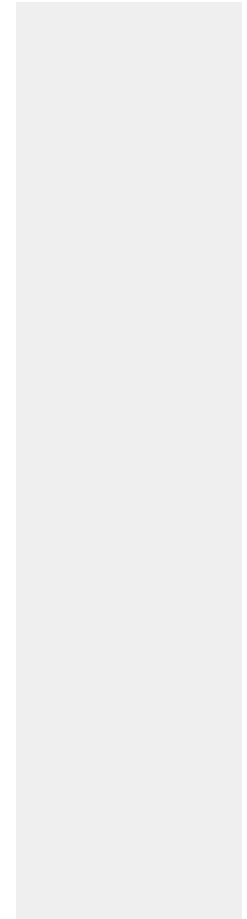
“What about people who have no one to stand up for them, who are impressed by white coats and other symbols of power, who take everything told them at face value, who are helplessly at the mercy of every arbitrary action and highhanded decision made on their behalf? [...]

It is not right that one has to fight for the simplest decencies.[...]

Last but not least, the opportunity to speak with the responsible and attendant physicians is not a privilege and not a generous offer, but should be a matter of course.[...] and not be the occasion for **extraordinary gratitude.**”

[case 465]

(Inken et al 2014)



Today (or tomorrow?) policy, professional codes, ADM 2015:

- focus on respect for a patient's choices
- the patient's own view of what is best for her is central
- all codes confirm that defending patients' rights and interests is an inherent part of the professional role and should be core to all decisions and interactions.

In short, increased value is placed on **patient autonomy** as an antidote to paternalism of the past

But how is this autonomy ensured in the case of relevant persons?

Privilege of everyone else

Power asymmetries between patients and HSCPs,
but also power asymmetries between patients, family members, advocates, assistant-decision makers, co-decision makers, decision-making representatives, designated healthcare representatives

Does a representative have a clear insight into the needs and interests of the patient as the patient perceives them and can they **represent** them authentically to HSCPs?

In any case,

The abstract view of person as absolute center of decision making associated with standard view of autonomy

- does not fit the reality of the vulnerable and seriously ill person
- turns health care into consumer/commodity relationship
- pits the patient and the professional against one another
- leaves out human connectedness, basic sympathy or concern and quality of care

Solution might be relational autonomy

“We are not isolated atoms, or islands, or self-contained entities [...] The existence of any person is dependent on the existence and social arrangements of many others. Our interests are discovered by and pursued within social environments that help to shape our identities, characters, and opportunities.”

(Sherwin 2008)

Not about limiting autonomy but viewing autonomy as achievement through recognizing what enables/disables it e.g. poverty, socialization, marginalization

Implications of the relational view

1. A person's values, desires, decisions and actions are influenced by social context

Social norms and oppressive patterns may be internalised by the person making the choice

The ability to imagine and pursue a course of action depends on the options available

2. Human beings are “motivationally social” – motivated to act, not by rational self-interest or by a striving for self sufficiency

– but informed by a sense of solidarity and by deep attachments to other people

(Barclay 2000)

Some features of support, advocacy, allyship

- Familiarity, proximity, continuity, transparency
- Attending to effects of oppressive socialization; building self-trust, self-understanding, self-direction
- Concerns may relate to social, not medical, world
- Disagreements may be about treatment goals not treatment working
- Acceptance of uncertainty, complexity, and moral progress, not Truth
- Communication and dialogue are part of the solution – it's not worked out in advance
- Positive organizational culture e.g. patient representatives on clinical ethics committee; early referral to advocacy organisations
- Democratizing healthcare organisations

So, I am saying ...

Any legislation is limited and imperfect

The ADM Act 2015 is underpinned by a commitment to human rights and it holds great promise

Focus on the unique values, beliefs – autonomy – of patients/clients departs from traditional paternalistic and outdated practices and attitudes

This is great but it brings its own problems

Whose job is it to meet these challenges?

Ours

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