

PSYCHOLOGY MISCELLANY

No.158 - 20th December 2021
Bioethics and Choice

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ISSN: 1754-2200

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An independent academic psychologist, based in England, who has written extensively on different areas of psychology with an emphasis on the critical stance towards traditional ideas.

A complete listing of his writings at <http://psychologywritings.synthasite.com/>. See also material at <https://archive.org/details/orsett-psych>.

CONTENTS

	Page Number
1. Organ Donation	4
1.1. Incentives	
1.2. Opt-out model	
1.3. References	
2. Treatment Refusal	9
2.1. Capacity to consent	
2.2. Advance decision-making	
2.2.1. Mental health ADM	
2.3. Mental capacity	
2.3.1. Disputes	
2.4. Right to live in community	
2.5. Human rights	
2.6. Appendix 2A - Mental Capacity Act (MCA) 2005	
2.7. Appendix 2B - Objectivity	
2.8. References	
3. Choice	27
4. Miscellaneous	30
4.1. Clinical practice guidelines	
4.2. Chimaeras	
4.3. NICE decision-making	
4.4. Human genome project	
4.4.1. Genetic data	
4.4.2. Genetic therapies	
4.5. References	

1. ORGAN DONATION

- 1.1. Incentives
- 1.2. Opt-out model
- 1.3. References

1.1. INCENTIVES

Individuals with kidney failure benefit from a successful transplant as compared to dialysis (or no treatment). "Significant improvement in transplant outcomes has led to expansion of candidacy criteria and a marked increase in the number of patients eligible for transplant" (Matas 2021 p807). This has worsened the problem of the demand for kidneys being greater than their supply from living or deceased donors. For example, in the USA in the last twenty years, 89 000 individuals have died while waiting for a kidney, and another 54 000 were removed from the waiting list due of becoming too sick to undergo the operation (Matas 2021).

How to increase the supply of kidneys, then? "A regulated system of incentives for donation could provide a sizable increase in the number of kidneys available for transplant" (Matas 2021 p807). But many countries, including the USA, make such systems illegal.

A regulated system run by the government or official health authority would provide oversight, protection, and transparency for all parties. This would overcome all the risks of the "underground" trade where individuals, often travel to another country, have poor quality medical services with no follow up.

The incentive for donation could include the provision of health care or tax benefits rather than cash (if that is seen as unacceptable). "Initially, the concept of incentives for living donation can be unsettling (some have said 'repugnant'). Yet ethicists worldwide have argued that there is no ethical reason to prohibit incentives. And studies show that the public is in favour of incentives. Additionally, dialysis is more expensive than transplant; a regulated system of incentives would be cost saving to the health care system" (Matas 2021 p807).

At the same time, many of the same countries allow incentives for donation of blood, sperm or eggs.

Veale et al (2021) reviewed one form of incentive system in the USA - the National Kidney Register (NKR) voucher programme: "Potential donors are able to donate a

Psychology Miscellany No. 158; 20th December 2021; ISSN: 1754-2200; Kevin Brewer

kidney and secure a voucher for their intended recipient, which can be redeemed, with the kidney of a different donor, if needed in the future" (p813). The vouchers have no cash value, and are not transferable.

The researchers analysed the NKR database from 2014 (the inception of the programme) to early 2021, and found 250 family voucher-based donations (which had facilitated 573 total transplants). Six vouchers had been redeemed subsequently.

Veale et al (2021) outlined some of the key findings:

i) Older donors leaving the voucher as a legacy for younger relatives if needed. The number of donors over 65 years old had tripled - 7.6% of all donors compared to 1.55 before 2014 (Veale et al 2021).

ii) "A family voucher donation may provide additional security for another transplant if needed in the future" (Veale et al 2021 p814). Occasionally transplants do not "take" and another one is required.

iii) "The voucher programme also has intangible social benefits, namely the increased access of minority populations to high-quality organs through transplant chains. Over the past decade, transplant chains have allowed greater inclusion of racial and ethnic minorities, with an increasing pattern of racial and ethnic crossover between donors and recipients over time" (Veale et al 2021 p815).

Veale et al (2021) summed up: "The initial 7 years of the NKR voucher programme have facilitated kidney donations that otherwise may not have occurred" (p816).

1.2. OPT-OUT MODEL

Deceased organ donation has traditionally been based on an "opt-in model of consent", where willing individuals sign up beforehand. But an "opt-out policy", where everybody is presumed to consent unless stated otherwise, would be a "revolution in donation" (Brennan 2015 quoted in Bea 2020). A "soft opt-out" (middle ground) would allow families to refuse donation after an individual's death ¹. The problem throughout is organ shortage.

¹ England, Wales and Scotland have recently moved to opt-out (or soft opt-out as families can provide evidence that the deceased would have not consented) (Bea 2021).

Bea (2020) argued that "the current debate, constrained within the legal polarity of informed or presumed consent, reduces the problem of organ shortage to negative individual behaviours, low level of registrations and high levels of family refusals, thus, unnecessarily framing organ donation as a matter of consent only and excluding the situated practicalities and relationalities of organ donation as a hospital practice" (p1935). She referred to her ethnographic work at a hospital in Barcelona. Here, "donation is enacted as a routinised and embedded healthcare activity, enabled by the existing hospital organisation and infrastructure, and also as a procurement practice that circulates organs across patients. For donors are enacted as hospital patients, as well as relational persons whose donation preference is to be transferred or inferred by their families, and corpses to be disposed of in short" (Bea 2020 pp1935-1936).

Organ donation as a "gift-of-life" presents "organ donation as a transformative experience that turns a 'senseless tragedy' into a heroic act of altruism, redemption and transcendence" (Bea 2020 p1936). Yet, in the USA, in particular, there is a growing "transplant industry", which has commodified body parts with a "chilling utilitarian ethos" (Sharp 2006), that is "seen to disregard the ambivalences of brain death diagnosis and the problem of 'living cadavers', objectify donors and intensify the commodifying practices" (Bea 2020 p1936).

The example of the hospital in Barcelona is, for Bea (2020), neither of these positions. Organ donation and transplantation is embedded in "routinised healthcare activities carried out in an ordinary manner" (Bea 2020 p1936).

Bea (2020) outlined three parts to the "process of assembling donations" at the studied hospital:

i) Detection and evaluation of potential donors - Each day transplant co-ordinators (TCs) visit the intensive care units (ICUs) in the hospital looking for deceased patients who could be potential donors. Collaboration with other staff is important, which included providing information about eligibility criteria for donation (eg: "safety of the organs").

ii) Request consent from families of eligible donors - The TCs learn when to approach the family to seek consent. Interviewee TC1 said: "You simply cannot arrive at a time that a family are initiating the grieving

process and ask about donation, no! You need to have enough respect to wait for the right moment which is when the family tells you 'we have nothing else left to do here' or 'and now what'?" (p1940).

TC4 explained their strategy: "I try to bring it up as something that is normal to the moment families are experiencing after losing someone, I mean that families aside from assimilating the death and starting grieving they also have to deal with funerary procedures that involve a great deal of paperwork and an elevated cost, what I propose to you, donation, is a possibility that you have to help other people that will not involve any effort or cost on your behalf" (p1940).

iii) Donor maintenance and organ extraction - Practically TCs had to arrange "the complex logistics for the ensuing organ extraction surgery and coordinating several evaluative procedures for each organ" (Bea 2020 p1941).

Bea (2020) emphasised the donation process as embedded in the hospital practices ie: "donors are to be attended to just like other patients" (p1941). But sometimes this is not achieved because healthcare staff do not collaborate. For example, TC9 reported an ICU nurse who refused to help the TC saying, "this is not a patient, this is a dead person, this is not my job" (p1943). Bea (2020) explained that there are "the inevitable frictions that emerge since donors are not like other patients at the hospital. Donation is not a therapeutic intervention on an individual who will benefit from it. It is a practice that involves dead patients in the hospital site where healthcare practices are always directed at treating living patients" (p1943).

Ending, Bea (2020) proposed that "organ donation should be understood as a collective accomplishment and situated both in and as a hospital practice" (p1945).

The opt-out policy is assumed to solve the organ shortage, but Bea (2021) questioned this. She considered three aspects that are important:

a) The employment of specialist donation professionals (eg: TCs), who are supported by other healthcare staff in hospitals.

b) The use of medical technology that helps in preserving organs.

c) The conversation about donation with bereaved families is still needed.

Bea (2021) pointed out: "Ultimately, there is no magic bullet to convince people to accept donation as the norm. It is a surgical intervention on a newly deceased patient who receives no direct therapeutic benefit. It is a thorny decision. Donation can be glorified morally, appealing to the heroics of the gift-of-life metaphor, or nudged as the current legal imperative, but donation cannot be expected to become normalized as the default choice. Instead of insisting on donation as an individual choice to be taken in life, public campaigns would be better served by reframing it as end-of-life choice and acknowledging the legitimate role of families as part of the decision-making process" (pp3-4).

1.3. REFERENCES

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2. TREATMENT REFUSAL

- 2.1. Capacity to consent
- 2.2. Advance decision-making
 - 2.2.1. Mental health ADM
- 2.3. Mental capacity
 - 2.3.1. Disputes
- 2.4. Right to live in community
- 2.5. Human rights
- 2.6. Appendix 2A - Mental Capacity Act (MCA) 2005
- 2.7. Appendix 2B - Objectivity
- 2.8. References

2.1. CAPACITY TO CONSENT

"The legal notion of mental capacity refers to an individual's ability to make autonomous decisions about their own welfare, often referred to as decision-making capacity (DMC)" (van der Plas et al 2019 p1).

In England and Wales, this is formalised in the Mental Capacity Act (MCA) (2005) (appendix 2A). The purpose is to outline the circumstances where individuals are viewed as lacking capacity to consent to care/treatment or make their own decisions, and so others (eg: doctors) will decide (appendix 2B).

The MCA assesses mental capacity via two criteria (van der Plas et al 2019):

a) Diagnostic - an impairment or disturbance to the mind or brain.

b) Functional - unable to understand, retain, and weigh relevant information, and communicate a decision.

A small number of capacity cases are contested/controversial, and the weighing of information is often the issue (van der Plas et al 2019). "The use or weigh requirement refers to the process of making a decision, rather than the outcome of a decision" (van der Plas et al 2019 p2).

All the time we are talking about decision-making, and psychology has studied this at length. It is sometimes assumed that individuals receive input and process it to give an output like a computer (ie: rational and objective).

A middle position is to distinguish between "perceptual decision-making" (PDM), which objectively

discriminates sensory information (eg: that an object is an apple), and "value-based decision-making" (VDM) (eg: the subjective preference for an apple over an orange) (van der Plas et al 2019).

While "cognitive biases" challenge any decision-making as objective. For example, "confidence (or overconfidence) bias", where individuals "who are more certain about an initial judgment are less likely to change their minds upon being presented with new sensory evidence or social advice" (van der Plas et al 2019 p4). Confidence can be further distorted in psychiatric disorders (van der Plas et al 2019).

This is important when advice is offered to help individuals making decisions. "For example, if you are completely convinced about the best course of action, you may be less likely to take someone's advice or consider another approach. On the other hand, if you are unsure about your decision, you may be more likely to look at what others are doing and follow their advice" (van der Plas et al 2019 p4).

This simple relationship can be mediated by metacognition and mentalising. The former (also called insight) is an awareness of one's own thinking (eg: aware of overconfidence), while mentalising (or theory of mind) is the ability to understand the advice-giver's point of view.

van der Plas et al (2019) added another layer to decision-making, namely private and public compliance. For example, a patient may agree to take a medicine while in hospital to hasten their discharge (public compliance), but what happens afterwards? If there is no private compliance (ie: a tactical public compliance), the individual will immediately stop the medication, whereas with a genuine appreciation of the need for the medication the individual will continue with it (private compliance) (table 2.1).

	Private compliance - yes	Private compliance - no
Public compliance - yes	Patient agrees with doctor's advice	Patient only agrees with advice to achieve an end (eg: release from hospital), and ignores subsequently
Public compliance - no	Refuses advice publicly but does agree with it privately (eg: "difficult patient")	No agreement with advice

Table 2.1 - Private and public compliance about following medical advice.

Overall, psychological research has shown that decision-making generally is a subjective and variable process, let alone difficult decisions related to capacity situations, and advice may or may not be taken.

2.2. ADVANCE DECISION-MAKING

The sovereignty (or autonomy) principle is the foundation of medical law - ie: an individual's right to refuse treatment. But "the historical development of the autonomy principle in healthcare has tended to bifurcate the right to refuse treatment into the adult of sound mind and the adult of unsound mind, conceptualising the former as the 'medical patient', the latter as the 'psychiatric patient'. For the latter, the right to refuse treatment is not recognised..." (Owen et al 2019 p163).

Time has subsequently been spent in specifying what is meant by "unsoundness of mind" in medical law. In recent years, the idea of "advance decision-making" (ADM) has emerged: "If a person had an absolute right to refuse medical treatment when they had mental capacity to decide it, why could that person not extend that right to a future time (eg: when in a coma) when they lacked mental capacity to decide" (Owen et al 2019 p163). However, ADM is weaker in relation to mental health.

Owen et al (2019) outlined similarities and differences between mental health and physical health ADM, including:

a) Similarities:

- Both involve a concept of DMC.
- Both require the forecasting of future illness and treatment.

b) Differences:

- Fluctuating DMC is more of an issue for mental health.
- The ability to predict future changes may be more difficult with mental health.

Owen et al (2019) argued for mental ADM:

i) A limited number of surveys, mostly in the USA, of individuals with serious mental illness find that positive views are expressed about the topic by the majority of respondents (Owen et al 2019).

ii) Where ADMs exist (eg: USA), psychiatric patients do not make unfeasible demands. For example, Swanson et al (2006) analysed the contents of 136 mental health ADM documents in North Carolina. None refused all treatment, and most refused some medications. Independent psychiatrists judged the majority of demands as "clinically feasible" (Owen et al 2019).

iii) Ethically, there is "precedent autonomy" (Dworkin 2011) - "this is the idea that autonomy can be reasonably extended to periods when one loses autonomy in order to maximise it overall, or give full expression to it" (Owen et al 2019 p172).

But the counter-argument relates to harm, both public and private (Owen et al 2019).

Here is a real-life example. "Kerrie Wooltorton" (David et al 2010) was a 26 year-old woman diagnosed with borderline personality disorder, who in 2007 deliberately swallowed anti-freeze for suicidal purposes. Despite calling an ambulance, she made it clear to hospital staff via a written statement (table 2.2) that she refused medical treatment that would save her life. "She was considered to have capacity to refuse treatment under the MCA [Mental Capacity Act 2005 in England and Wales] and died in hospital" (Owen et al 2019 p165).

- "To whom this may concern, if I come into hospital regarding taking an overdose or any attempt on my life, I would like for NO lifesaving treatment to be given. I would appreciate if you could continue to give medicines to help relieve my discomfort, painkillers, oxygen, etc. I would hope these wishes will be carried out without loads of questioning. Please be assured that I am 100% aware of the consequences of this and the probable outcome of drinking anti-freeze, eg: death in 95-99% of cases and if I survive then kidney failure, I understand and accept them and will take 100% responsibility for this decision. I am aware that you may think that because I call the ambulance I therefore want treatment. THIS IS NOT THE CASE! I do however want to be comfortable as nobody want to die alone and scared and without going into details there are loads of reasons I do not want to die at home which I will realise that you will not understand and I apologise for this. Please understand that I definitely don't want any form of ventilation, resuscitation or dialysis, these are my wishes, please respect and carry them out".

(Source: Owen et al 2019 p165)

Table 2.2 - Kerrie Wooltorton's written statement for hospital staff.

Owen et al (2019) accepted that there is not necessarily an easy answer here, and this case did, and would in similar future ones, create controversy.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) was created in 2006 to guarantee individuals with disabilities "equal recognition before the law". Guidance ("General Comment") is also given to help in understanding the Convention (Skowron 2019).

Individuals with learning, intellectual or mental disabilities are sometimes not able to express their wishes. General Comment No.1 to the UNCRPD stated: "Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the 'best interpretation of will and preferences' must replace the 'best interests' determinations. This respects the rights, will and preferences of the individual" (quoted in Skowron 2019).

Skowron (2019) reflected on the phrase, "the best interpretation of will and preferences", and noted its ambiguity: "The 'best interpretation' of a person's will and preferences could refer to two different things. It might refer to the best statement of a person's will and preferences, the outcome of a process of interpretation; but it might also refer to the best method of interpreting a person, the process of interpretation itself" (p126). Skowron (2019) favoured the latter, while accepting the difficulties involved.

2.2.1. Mental Health ADM

"Advance decision making (ADM) for mental health crises is widely approved, but under-used and under-resourced, particularly when compared to ADM in physical healthcare settings" (Stephenson et al 2020 p2). Stephenson et al (2020) explored the development of the mental health ADM using focus groups of service users, family members, and clinicians from a south London NHS Trust. In total, 94 individuals. The topic was ADM and bipolar disorder.

"Focus groups, a method considered useful for eliciting views from hard to reach groups, safe discussion of difficult topics, problem solving and generating new ideas... The aim was both to explore participants' experience and opinions on ADM and to help develop the ADM materials" (Stephenson et al 2020 p2).

Each group started with a video explaining ADM.

Analysis of the discussions produced the following themes:

i) ADM documents - The language and format of materials, and what to included were discussed. For example, changing "nearest relative" to "nominated person" was popular. One service user said: "I would like lots and lots of different questions to help tease out the... the appropriate and relevant stuff to you" (p6).

ii) Creation of ADM documents - One participant said: "has to be validity and ownership around it, not just the person writing it taking ownership, but collectively within the environment and the culture that you're working in... that these are actually valid, and people's views are actually heard, rather than it just being an exercise of making you feel better, that 'When you become unwell we might do this'" (p5).

iii) Accessibility - "A major universal concern was ensuring clinician awareness of existing documents and accessibility, particularly for someone presenting out of area or lacking social support" (Stephenson et al 2020 p8).

iv) Harnessing the expertise of "lived experience" - eg: A family member said: "We as a family have to try.. and like probe out the psychosis talk, just so they see that he's unwell, otherwise he can easily mask it... otherwise he will go for months where... not quite being sectionable but not being himself, which is very draining and hard" (p7).

v) Personalising the documents - eg: One mental health professional told of a service user who wrote: "'I will say and do anything to avoid admission, so just ignore me, and crack on and do your job'. He actually wrote that... So that works fantastically well" (p10).

vi) The outcome of making and using ADM documents - "Participants' experience led them to believe the process of creating these documents could offer a space for service users to reflect on their experience of living with their illness leading to enhanced self-management. In addition, it was felt that a collaborative process of making ADM documents could increase understanding of the service user's experience and foster a stronger therapeutic alliance with family members and health professionals" (Stephenson et al 2020 p10).

Stephenson et al (2020) ended: "Desired aims for ADM catering for fluctuating capacity within a mental health context may range from avoidance to facilitation of admission and include both requests and refusals" (p12). A prototype document template called PACT (Preferences and Advance decisions for Crisis and Treatment) was co-produced.

2.3. MENTAL CAPACITY

Mental incapacity or lack of mental capacity allows for others to make decisions for the individual. "For centuries, people with mental disabilities have been presumed to be incompetent, thereby justifying laws and policies that have deprived them of their rights to legal capacity and freedom - rights that people without disabilities take for granted. Today in most countries in the world, a person's diagnosis provides the state with legal authority to appoint a guardian to make decisions for the person, without even consulting the person and without regard to the person's preferences. A label of disability also provides the legal justification for involuntary confinement and treatment" (Craigie et al 2019 p161).

Craigie et al (2019) continued later: "People with intellectual disabilities or psycho-social disabilities (mental health issues) have been stripped of their autonomy, segregated in far-away institutions, where their lives were cut short often by terrible conditions. They had no right to refuse psychiatric and other unwanted interventions, they had no equitable access to healthcare that they wanted and needed. If no family member was able to provide care, there was no access to independent living or the skills needed to give effect to it. People were stripped of the right to love, their children were removed arbitrarily. They were not allowed to vote or participate in public life. If they had any complaints about the above, they were denied access to justice. Lives were cut short. 'Civil death' describes how people were stripped not just of their autonomy, but of their rights. That may be history in some countries, but in too many others that describes the current situation" (p165).

Craigie et al (2019) outlined a number of issues that arise in relation to capacity, including:

- i) If individuals are given the ability to choose

their behaviour, what happens if they make bad choices? This may include endangering themselves (or others), when should the State step in?

ii) What is the relationship between mental capacity and legal capacity? Or part another way, can mental incapacity be the basis for imposing restrictions on legal capacity?

Craigie et al (2019) stated: "The best reason (and the only reason) why we sometimes need to make decisions for others – why we cannot jettison the concept of mental capacity altogether – is that it is just a basic fact that some people cannot make decisions for themselves in any commonly accepted sense of the word 'decision'. For example, it seems incontrovertible that a person lacks the capacity to make a treatment decision if her delirium leads her to believe that the doctors are in fact not doctors but impostors, and for this reason does not believe that what is being offered is a truly life-saving treatment" (p164).

iii) Persons with disabilities may "require" support in exercising their legal capacity. "But what does 'require' mean in this context? Who determines what supports may be required in a specific decision-making context and on what basis?" (Craigie et al 2019 p162).

One answer relates to autonomy, which Beauchamp and Childress (2009) defined as "'self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice'... Autonomous action, they argue, takes place when a person acts: '(1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action'" (Craigie et al 2019 p163).

iv) Compulsory treatment and capacity.

Craigie et al (2019) quoted this experience of one individual: "A few weeks ago my compulsory community treatment order was renewed for the ninth year in a row, I have a diagnosis of paranoid schizophrenia; it means that I believe that I am a devil who is bringing about the end of the world. I have the most wonderful life with my partner; but, given the choice, I would stop taking my medication because I think it stops me realising just how evil I am. I feel that I need to face what I am and rid the world of someone like me. My friends, family and the professionals around me believe that without medication I will become very ill very quickly and very likely attempt

to kill myself. Intellectually I can understand that I have an illness, can understand that it is schizophrenia. My mind understands that it is probably the medication and the support that helps me have the wonderful life I do, but my heart does not accept this. It says you have all made a mistake and that my every action is polluting the world and that I should be stopped destroying the people and places that I love. I even sort of understand that I may lack medical capacity. I understand the basis for this assessment, and am in some ways grateful for the fact that I do not have to take the decision to stop my medication and lose the vibrant life that I have now. I am able to exercise my legal capacity in almost all aspects of my life: while under compulsory treatment in the community, I have bought a house, got divorced, I have entered into a contract to have a book about my life published. And yet in one aspect of my life, my judgment is seen as profoundly impaired and in that aspect the state has removed my legal capacity. Is that right and proper? I think so; when I see friends who are in similar situations, I can see the need to intervene" (p163).

v) Involuntary detention and treatment may be experienced by some individuals as "relief at a diffusion of responsibility, a feeling of safety and a sense of these interventions as a means of receiving treatment they would otherwise be unable to accept" (Craigie et al 2019 p166).

vi) The narrow focus on legal capacity may mean that wider issues are overlooked, like resources, services, support and care.

2.3.1. Disputes

In England and Wales in recent years, the "functional model of capacity" has come to dominate. This is "the idea that mental capacity is time- and decision-specific, in other words (1) that anyone, at any time, may lack mental capacity to make a decision (for instance in the immediate aftermath of an accident); and (2) those with permanent impairments of their mind or brain may well be capable of making decisions in relation to one area of their life even if they are not capable of doing so in relation to others" (Keene et al 2019 pp56-57).

The UNCRPD challenged this approach because "it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not

pass the assessment, it then denies him or her a core human right - the right to equal recognition before the law" (quoted in Keene et al 2019). This highlights "the difficulty of applying the legally 'neat' concepts of the functional model of mental capacity across the full complex spectrum of human life" (Keene et al 2019 p57).

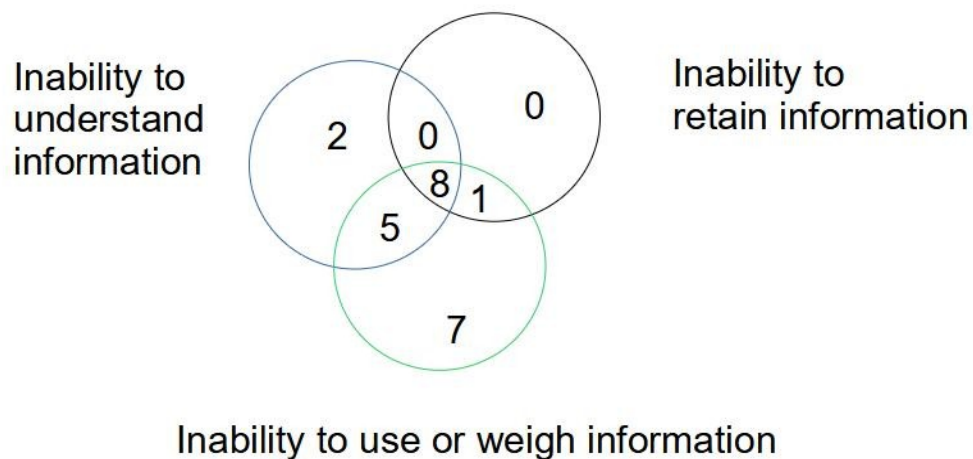
When mental capacity is contested, it is resolved by the Court of Protection in England and Wales (created by the MCA 2005 and founded in 2007). The purpose of the Court includes:

- "to determine whether a person has mental capacity to make specific decisions,
- where the person does lack capacity, to make the decision on their behalf and in their best interests or to appoint a deputy to do so,
- to make declarations as to the lawfulness of acts done or to be done in relation to a person,
- to determine questions in respect of Lasting and Enduring Powers of Attorney and Advance Decisions to refuse medical treatment;
- (since 1 April 2009), to hear challenges against so-called deprivation of liberty safeguards ('DOLS') authorisations" (Keene et al 2019 pp59-60).

Keene et al (2019) reviewed disputed capacity cases in the first ten years of the Court's existence. Nearly three-quarters of the forty published cases studied involved individuals with learning disabilities or dementia. The most common type of dispute overall was between the patient (P) (or family and friends) and the health and/or social care professionals (HSCP) involved in P's care. Most cases were brought by the body responsible for P's care.

Of 40 cases about P's capacity, in 22 judges determined lack of capacity, thirteen capacity, and five were "mixed" (ie: capacity in relation to certain issues but not others). In 23 of these cases, functional inability was cited by the judges as determining lack of capacity, and in particular, the inability to use or weigh information. Inability to communicate was not mentioned in any case (figure 2.1).

Keene et al (2019) noted that P spoke directly to the judge in only thirteen cases, and "overall [this] is disappointing and suggests an area for development" (p69).



(After Keene et al 2019 figure 2 p67)

(In some cases judges cited more than one reason, thus the overlapping circles)

Figure 2.1 - Number of cases and functional disabilities cited by judges.

2.4. RIGHT TO LIVE IN COMMUNITY

The "capability to live in the community as an equal member" (CLCE) is key for individuals living with disabilities. In fact, it is viewed as a human right, and it is enshrined in the UNCRPD (Wynne Bannister and Venkatapuram 2020).

But "what is so important about living in the community that it is seen to be a human right and one which should be enshrined in international law" (Wynne Bannister and Venkatapuram 2020 p1)?

Wynne Bannister and Venkatapuram (2020) grounded the CLCE in the "capabilities approach" (CA) (eg: Nussbaum 2011), and in freedom and dignity.

The CA evaluates "a person's well-being or quality of life in terms of her practically possible opportunities ('capabilities') to achieve various outcomes - 'beings and doings' ('functionings') that make up a good or flourishing life" (Wynne Bannister and Venkatapuram 2020 p2). There are ten central capabilities that make up "a life with human dignity" (Wynne Bannister and Venkatapuram 2020 p2) (table 2.3).

1. Life
2. Bodily health
3. Bodily integrity
4. Senses, imagination and thought
5. Emotions
6. Practical reason
7. Affiliation
8. Other species
9. Play
10. Control over one's environment

Table 2.3 - The ten central capabilities.

Wynne Bannister and Venkatapuram (2020) emphasised that "capabilities are not just internal characteristics of a person and they are not individual capacities; capabilities are formed through the combination of internal and external conditions. The internal factors encompass individual, often biological characteristics. These can include factors such as impairments, illness, gender or age. All of which result in diverse biological needs. Whereas external conditions encompass both the physical and social environments. These cover environmental diversities such as climatic circumstances; institutional variations such as the different public services available in different contexts; varied relational perspectives which relate to commodity requirements established by social norms, conventions and customs; and distributional factors, such as how goods are distributed among groups including families" (p2).

So, the CA "provides a way of conceptualising the disadvantage experienced by individuals in society, which emphasises the social, economic and environmental barriers to equality" (Burchardt 2004 quoted in Wynne Bannister and Venkatapuram 2020). For individuals with disabilities, leaving aside biological limitations, common to the "social model of disability, is the focus on environmental restrictions. "The distinction between disability, which involves the social, economic and environmental or external conditions, and impairment, which refers to the biological or internal condition, is the seminal contribution of the social model of disability" (Wynne Bannister and Venkatapuram 2020 p3).

The CLCE can be linked to the capability of affiliation. Nussbaum (2011) drew out two freedoms here: "(A) being able to live with and toward others, to recognise and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another... (B) Having the

social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin" (quoted in Wynne Bannister and Venkatapuram 2020).

But, at the same time, CLCE is "not meant to achieve deinstitutionalisation with the result of persons being left to fend for themselves" (Wynne Bannister and Venkatapuram 2020 p6). It requires the provision of appropriate services and support from the state and others.

2.5. HUMAN RIGHTS

Is coercive care intervention a violation of UN human rights standards? Or put another way, "can coercive treatment ever comply with UN human rights standards?" (Martin and Gurbai 2019 p118).

Martin and Gurbai (2019) offered this preliminary response to this "watershed question". The question is "a clear example of what grammarians call a 'closed question'. That is, the only possible answers are YES or NO. In considering one's answer, it is crucial to pause over the word 'ever'. If we think that there are any circumstances where coercive care is justified, then our answer to the watershed question must be YES; the challenge is then to articulate a legal standard that defines and delimits those circumstances. To answer NO is to conclude that coercive care is never justified" (Martin and Gurbai 2019 p118).

Taking the "no" side (or "abolitionist" position), which Martin and Gurbai (2019) represented as having three versions:

- A1 (extreme position) - "No hospital admission or medical intervention shall be undertaken without prior valid consent" (p118).

Martin and Gurbai (2019) gave this example: "Suppose that you are a paramedic, arriving at the scene of an accident involving a wheelchair-user and a bus. A disabled accident victim is unconscious. Given the circumstances, it is clearly not possible to obtain valid consent for medical treatment. Under A1 Abolition you would have to refrain even from basic first aid, much less admission to hospital" (p118).

- A2 - "No hospital admission or medical intervention

shall be undertaken in the face of valid refusal" (p118).

In the above example, the "unconscious accident victim can't consent, but neither is he refusing. So A2 Abolition leaves room for a paramedic to do her job: stabilise, transport, admit if appropriate" (Martin and Gurbai 2019 p118).

- A3 - "No hospital admission or medical intervention shall be undertaken in the face of any dissent, resistance or objection" (p119).

It is important to define terms, like "non-consensual treatment", which is "any treatment that is undertaken in the absence of valid consent (Non-Consensual = Without Consent). But it is important to appreciate that not all non-consensual treatment is coercive or forced. Suppose for example that the paramedic in our example had proceeded to provide emergency medical treatment to the unconscious accident victim... That treatment would be non-consensual, since no valid consent was obtained, but it does not seem right to describe it as coercive or forced. After all, the accident victim is not resisting, and (at least in the absence of contrary evidence) it is entirely reasonable for the paramedic to assume that the victim would indeed have consented to necessary and appropriate medical treatment had he been able to do so" (Martin and Gurbai 2019 p119).

Take this example: "Think about a person with bipolar disorder, entering an acute manic state. She knows (and the family knows and the care team knows) that her acute manias can lead to very severe harm to herself or to others; they can even threaten loss of life. Moreover, her ability to assess risks is profoundly impaired during her manic episodes. Yet she insists that she is not unwell, denies that she is entering a manic episode, and does not consent to treatment" (Martin and Gurbai 2019 p120). Coercive treatment is faced by a conflict of rights here, including the right to life and the liberty for the individual, and the rights of others who may suffer without the treatment. One form of resolution of this conflict is "proportionality". The limits of the right to liberty may be, in certain circumstances, a proportionate response to the threat to life and others.

There are many points of all sides of these issues

and the watershed question, but Martin and Gurbai (2019) offered three possible solutions:

i) Rule out A1 abolition.

ii) Emphasis discrimination/non-discrimination as in an A4 abolitionist position: "No hospital admission or medical intervention shall be undertaken on the basis of a policy that discriminates on the basis of a disability" (p125).

Applying this to the paramedic example above, the provision of non-consensual treatment is acceptable. "The paramedic is providing non-consensual treatment to an unconscious disabled accident victim. But she is doing so because he is an unconscious accident victim. The fact of the victim's disability is not a determinant of her decision to act without free and informed consent, and she would have done the same if (for example) she had been uninformed about his disability, or if he had not had a disability at all" (Martin and Gurbai 2019 p125).

iii) Seek greater clarity about difficult and contested issues - eg: clarifying what psychiatric care is a violation of rights.

2.6. APPENDIX 2A - MENTAL CAPACITY ACT (MCA) 2005

Three principles of the MCA 2005 relating to mental capacity are that "(1) a person must be assumed to have capacity unless it is established that he lacks capacity; (2) a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success...; and (3) a person is not to be treated as unable to make a decision merely because he makes an unwise decision" (Keene et al 2019 pp58-59).

In the MCA 2005, "a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain" (quoted in Keene et al 2019).

A person is unable to make a decision, according to MCA 2005, if he or she is unable:

"(a) to understand the information relevant to the decision, (b) to retain that information, (c) to use or weigh that information as part of the

process of making the decision, or (d) to communicate his decision (whether by talking, using sign language or any other means)" (quoted in Keene et al 2019).

2.7. APPENDIX 2B - OBJECTIVITY

A number of "disability rights advocates argue that mental health law fails to be objective in that it reflects blatant bias against persons with intellectual and psycho-social disabilities..., arguing that the law takes cover behind the rhetoric of objectivity, while it stigmatises and imposes 'ableist' norms on persons with intellectual and psycho-social disabilities" (Burch and Furman 2019 p60). This is important because decisions about mental capacity, and deprivation of a person's liberty are presented as objective.

Whether objectivity is possible at all is a philosophical issue, so as a practical solution, the "risk account of objectivity" (eg: Koskinen 2020) has been developed. This means that measures are used to mitigate "our frailties" (eg: cognitive biases; community biases; idiosyncrasies) (Burch and Furman 2019).

In relation to science, Douglas (2004) identified three types of objectivity:

- i) Convergent - Researchers reach the same results by using different means.
- ii) Procedural - The methodology used allows the changing of the researchers without altering the results.
- iii) Interactive - Diverse views within the research community.

"This doesn't mean that objective science is infallible, just that best efforts have been made to avert certain factors that are likely to take us further away from the truth" (Burch and Furman 2019 pp61-62).

Applying this idea to law, Burch and Furman (2019) saw objectivity as "self-responsible stance" to identify and mitigate our imperfections. Put another way, it is a form of risk management.

Burch and Furman (2019) outlined some risks that need managing in legal decisions:

- a) Interpreting the data.

b) The lack of procedures to limit idiosyncrasies.

c) Independence of decision-makers from self- or group-interests.

d) The exclusion of certain views. For example, "the voices of outsiders remain our best hope for catching sight of the blind spots that lie hidden in consensus views. This captures some of the impetus behind the well-known slogan and principle of disability rights activism, 'Nothing About Us Without Us'; many activists believe, rightly we think, that conversations about disability rights will be inflected with collective biases that persons with disabilities are uniquely positioned to identify, challenge, and correct" (Burch and Furman 2019 p66).

e) Structural biases.

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3. CHOICE

Irvine et al (2021) began: "Over the past two decades, the concept of patient choice has become enshrined in UK health policy. Greener (2009) provides an historical analysis of the use of the term 'choice' in UK Government publications, charting its conceptual transformation within an overarching framework of 'health consumerism'. Today, the principle of patient choice in healthcare provision involves both a concept of market level choice between providers of a service, and choice at the level of what specific treatments (medications, therapies etc) will be taken up" (p4). This fits with ideas of patient involvement/engagement, empowerment and autonomy in care, satisfaction, shared decision-making, and personalised care (Irvine et al 2021).

What is the reality for patients? Fotaki (eg: Fotaki et al 2008), for example, has questioned the issue of choice. "Aspects of choice that are prioritised by a market/consumer rationale may not be those that are important to patients, and there is evidence that choice is exercised differently by patients with different socio-demographic characteristics, which can unwittingly contribute to inequality of access and outcomes... Furthermore, the evidence of clinical benefits arising from shared decision-making is variable" (Irvine et al 2021 p4).

"Improving Access to Psychological Therapies" (IAPT) in the UK was developed to treat mild-to-moderate depression and anxiety-related mental health problems. Choice is part of IAPT, and Irvine et al (2021) investigated choice of guided self-help interventions via group, one-to-one, telephone, or digital means.

The interactions in 123 telephone-delivered IAPT sessions from the North and East of England in 2018-19 were recorded and analysed. They included initial assessments, first and second treatment sessions of sixty-six patients with nine Psychological Well-Being Practitioners (PWPs).

The initial session included the choice of future modes of delivery. Three patterns of presentation of the options emerged from analysis of the transcripts:

i) "Presenting a single delivery mode" - The PWP proffered one mode only (eg: "I think you may benefit from..." or "we do a really, really good..."; extracts 1 and 2; p7). The patient accepted the option.

ii) "Incrementally presenting alternative delivery modes, in response to patient resistance" - Here "PWPs again began by suggesting a particular (single) mode offer, which patients resisted. Their resistance was variously manifested as hesitancy, delayed response, or explicitly problematising or rejecting the mode that was presented. In response to this lack of take-up from the patient, PWPs revealed that there were alternative mode options available..." (Irvine et al 2021 p8).

iii) "Parallel presentation of multiple delivery mode options" - All options presented by the PWP in parallel. But it was "observed that PWPs' language and explanations sometimes suggested or implied that one option might be preferable to another, in such a way as to steer a patient towards one of the available options" (Irvine et al 2021 p12).

Five techniques were distinguished in how the PWPs "steered" the patients' choice, whatever option(s) offered:

- a) Recommending one option.
- b) Highlighting one option as "standard practice" or popular.
- c) Strongly endorsing one of the options.
- d) Emphasising how one option fitted with the patient's circumstances.
- e) Providing extensive information to support one option.

"Without being given choices, patients cannot share a role in making decisions; in which case the interactions out of which decisions are made are led by the professional, relegating the patient to confirming whatever is recommended by the professional" (Irvine et al 2021 p14). The PWP may believe that they are offering the patient choices, but Irvine et al (2021) observed that the actual interactions may not be doing so. They stated that "where a single delivery mode was offered, this tended to be a group course - arguably the least resource-intensive mode. Correspondingly, in incremental presentations, group courses again tended to be offered first, with the more resource-intensive option of individual, face-to-face treatment tending to be revealed

in second or final position. These observations support qualitative evidence that PWPs' choice-offering practices may be driven by institutional concerns of resource management and efficiency, themselves a response to government-level monitoring of service performance..." (Irvine et al 2021 pp14-15).

Irvine et al (2021) favoured the parallel presentation of all options as the closest to "real" choice, and along with the PWPs' clinical expertise, this would be shared decision-making.

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4. MISCELLANEOUS

- 4.1. Clinical practice guidelines
- 4.2. Chimaeras
- 4.3. NICE decision-making
- 4.4. Human genome project
 - 4.4.1. Genetic data
 - 4.4.2. Genetic therapies
- 4.5. References

4.1. CLINICAL PRACTICE GUIDELINES

Clinical practice guidelines (CPGs) are "statements that include recommendations intended to optimise patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options" (Institute of Medicine 2011 quoted in Dahlen et al 2021). They are assumed to underlie healthcare delivery, but their quality depends on the evidence selected. Grading of Recommendations, Assessment, Development and Evaluation (GRADE) was developed as a tool to help here (Dahlen et al 2021).

But, as Dahlen et al (2021) observed: "Strength of evidence is only one component of what makes a 'good' CPG; factors such as transparency, rigour, independence, multi-disciplinary input, patient and public involvement, avoidance of commercial influences and rapidity should also be considered" (p2). The Appraisal of Guidelines for Research and Evaluation (AGREE II) tool includes many of these factors (Dahlen et al 2021). Overall, the issue is the quality of guidelines for healthcare professionals.

Dahlen et al (2021) focused on trans/gender minority, using this definition: "'Trans' is an umbrella term for individuals whose inner sense of self (gender identity) or how they present themselves using visual or behavioural cues (gender expression) differs from the expected stereotypes (gender) culturally assigned to their biological sex. 'Gender minority' is an often-used alternative population description. Some gender minority/trans people may seek medical transition, which involves interventions such as hormones or surgery that alter physical characteristics and align appearance with gender identity" (p2).

Guidelines should cover specific needs related to medical transition and health consequences, and associated mental health issues, as well as general

health needs. There is the World Professional Association for Transgender Health (WPATH) Standards of Care Version 7 (SOCv7) (Dahlen et al 2021).

Dahlen et al (2021) performed a review of CPGs relevant to trans/gender minority healthcare. Twelve CPGs were included as relevant. Four of them covered HIV prevention, transmission and care, one blood-borne viruses, three related to overall transition care, three to aspects of transition, and one oncology communication guidelines. "No international guidelines were found that addressed primary care, psychological support/mental health interventions, or general medical/chronic disease care (such as cardiovascular, cancer or elderly care)" (Dahlen et al 2021 p6).

Dahlen et al (2021) summed up their findings thus: "Variable quality international CPGs regarding gender minority/trans people's healthcare contain little, conflicting information on mortality and QoL [quality of life], no patient facing messages and inconsistent use of systematic reviews in generating recommendations" (p8). The CPGs related to HIV, however, were higher quality.

4.2. CHIMAERAS

Tan et al (2021) reported the development of monkey embryos injected with human stem cells and survival for nineteen days. Six days after fertilisation, 132 embryos were injected with the human cells, and three embryos survived to Day 19 after fertilisation (Subbaraman 2021). Such human-animal hybrids ("chimaeras") are interesting as potential models to test drugs, or to grow human organs for transplants (Subbaraman 2021). Other chimaeras previously tried include rat embryos grown with mouse cells, and pig embryos grown with human cells (Subbaraman 2021).

Such research receives two lines of criticism (Subbaraman 2021):

- i) Practical - the ability of the cells to thrive.
- ii) Ethical - eg: the status and identity of such a hybrid.

This debate takes place in the context of the use of "human embryo-like entities" (Green et al 2021), which is limited to 14 days, though there is an argument to increase this (eg: International Society for Stem Cell Research). Green et al (2021) argued for maintaining the

14-day limit. They summarised four "compelling reasons": "Its clarity leaves little room for misinterpretation. It corresponds to important biological events, including the beginning of ectoderm/neural progenitors. In marking the end of the possibilities of twinning or chimaerism, it is the start of a unique biological identity. There is no later relevant nexus of events" (Green et al 2021 p333).

4.3. NICE DECISION-MAKING

"In most healthcare systems, the availability of potentially beneficial interventions surpasses the available resources, necessitating decisions about which interventions to adopt and which to reject. In the UK, these are largely the responsibility of the National Institute for Health and Care Excellence (NICE), whose advice plays a major role in determining which technologies users of the National Health Service (NHS) in England can access" (Charlton 2021 p1).

NICE's advice, however, involves value judgments, and these are based on two ethical frameworks - "accountability for reasonableness", and the "ethics of opportunity costs" (Charlton 2021).

The former implies transparency in decisions, while the latter emphasises the importance of evidence. Daniels (2000) noted: "There must be no secrets where justice is involved, for people should not be expected to accept decisions that affect their well-being unless they are aware of the grounds for those decisions" (quoted in Charlton 2021).

Charlton (2021) argued that NICE has failed to be transparent in its procedures for making decisions.

4.4. HUMAN GENOME PROJECT

It is twenty years since the first draft sequence of the Human Genome Project (HGP) ². It has had "a profound effect on biomedical research - at the bench, on the computer, and across the scientific community. Large datasets and reference maps are now valued resources to guide scientific and clinical research, drug development, and medical practice" (Rood and Regev

² The complete human genome was not fully sequenced until 2021. "Because the genome had to be read in small chunks and then reassembled, some highly repetitive parts proved impossible to place, a bit like a jigsaw where all the pieces look alike" (Marshall 2021 p14). Technical development has allowed the full sequencing now. Two hundred million base pairs of DNA have been added (out of a total of 3 billion base pairs), and over 2000 genes (Marshall 2021).

2021 p1442). But, at the same time, there is still a need "to understand how genomic information leads to the development, function, and malfunction of cells and organisms and to fully leverage this knowledge to promote human health and treat disease" (Rood and Regev 2021 p1442).

There is also concern that the HGP is benefiting the richer countries rather than the whole world, particularly as "the vast under-representation of people of non-European ancestry in existing genomics datasets limits our understanding of human genetic variation, health, and disease. It also undermines health equity because it could lead to diagnostic models or therapies targeted to disease variants that do not occur in most of the world" (Rood and Regev 2021 p1443).

4.4.1. Genetic Data

The Y-chromosome Haplotype Reference Database (YHRD) was set up online in 2000. It includes over 300 000 anonymous Y-chromosome profiles, which can show the male lineage of over 1300 distinct global populations (Schiermeier 2021).

But there is concern that many of the profiles were obtained from men who did not freely give their informed consent (eg: Uyghurs in China; Roma in eastern Europe). Data came from police authorities in many cases (Schiermeier 2021).

Forensic geneticist Peter Schneider pointed out that "because the YHRD and other databases hold information only on particular genetic markers, and not full DNA sequences, individual donors can't be uniquely identified... [] keeping data accessible is more beneficial to society than harmful to an individual" (quoted in Schiermeier 2021).

Forzano et al (2021), writing on behalf of the European Society of Human Genetics, called for an end to academics collaborating with groups, like the Chinese police, where there are ethical concerns.

Forensic geneticist Walter Parson, however, worried that removal of non-consensual data, usually from minority groups, "could bias statistical evaluations in forensic reports - to their disadvantage" (quoted in Schiermeier 2021).

4.4.2. Genetic Therapies

The ability to read the human genome has now been supplemented by the possibility of writing it (eg: editing genomes of disease-relevant somatic cells), and so the US National Institutes of Health (NIH) has set up the "Somatic Cell Genome Editing (SCGE) Consortium" to develop safer and more effective methods (Saha et al 2021).

Genome editing could help with genetically inherited diseases, as well as disabling the genomes of invading pathogens, or helping the immune system (Saha et al 2021).

Antisense oligonucleotides (ASOs) are an experimental kind of drug that involve short strings of DNA or RNA letters that cling to particular sequences of RNA, and so are applicable with genetic conditions, like Huntington's (Kwon 2021).

ASOs were first noticed in the 1970s, but toxicity was an issue. Interest in their use peaked again in the 21st century with developments, and clinical trials began (eg: nusinersen) (Kwon 2021).

But there are problems like the delivery of the drugs via lumbar puncture in order to reach the central nervous system, and the lack of knowledge about long-term effects (Kwon 2021).

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