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# **Freedom to Negotiate: A Proposal Extricating ‘Capacity’ From ‘Consent’\***

## **Abstract**

In this paper we seek to radically reframe the legal construct of consent from a disability perspective. Drawing on feminist scholarship, and human rights standards around ‘free and informed consent’, we apply a concept of freedom to negotiate to laws regulating both consent to sex and medical treatment –key areas in which the legal agency of people with disabilities (especially people with cognitive disabilities) is routinely denied, restricted, or ignored.

We set out the essential ingredients for reframing consent: namely, legal personhood, freedom to negotiate, and understanding. We also outline conditions (i.e. coercion, undue influence and power imbalances) which impede valid consent. This represents a first attempt to move beyond labelling adults with certain disabilities as lacking the ‘mental capacity’ necessary to give valid consent – in order to explore in more depth particular expressions of consent or refusal and seek new validity criteria, beyond the label of ‘mental incapacity’.

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## Introduction

The concept of consent extends from civil law (including the laws of property, tort and marriage) to criminal law (including the law on sexual offences and assault). Consent has a wide range of legal consequences and effects. It can create or extinguish legal relationships (such as marriage). It can also bind the individual to complete certain acts (for example, within the law of contract) and enforce consequences for failure to carry out those acts. The absence of consent also carries with it legal consequences. In the context of sex, its absence typically renders what would otherwise be a lawful act an unlawful one. Its absence in the context of medical treatment has a similar consequence – with the potential to transform what would otherwise be a lawful procedure into an assault. As Hurd (1996, p.123) notes:

[C]onsent can function to transform the morality of another's conduct—to make an action right when it would otherwise be wrong. For example, consent turns a trespass into a dinner party; a battery into a handshake; a theft into a gift; an invasion of privacy into an intimate moment; a commercial appropriation of name and likeness into a biography.

However, consent is not a neutral or objective legal standard. Feminist and post modernist critiques of a masculine, embodied, rational, autonomous, consenting subject, endowed with freedoms to make choices that improve his well-being (DuToit, 2007), resonate deeply with perspectives from critical disability studies

and mad studies on consent (Costa 2013; Goodley and Lawthom 2005; Spandler, Anderson and Sapey 2015; Warme 2013). Therefore, at the outset of this work, we acknowledge the flaws in conceptualisations of consent from feminist, disability, sociological and human rights perspectives. Nevertheless, we propose to rely on feminist thinking on ‘freedom to negotiate’ consent to sex, to develop a proposal for ‘freedom to negotiate’ consent to medical treatment, which respects human rights obligations under the UN Convention on the Rights of Persons with Disabilities (CRPD).

We have selected these two aspects of the law on consent for further consideration because they represent some of the most significant ways in which the legal capacity of people with disabilities is routinely denied. While we acknowledge that there are important differences in the contexts in which legal theory on rape and medical treatment have evolved, we believe that there are sufficient similarities in their approaches to the issues of violence, coercion, voluntariness and communication that they can, to some extent, be examined in tandem to develop an approach that respects the human rights of persons with disabilities.

Many people, especially people with disabilities, experience systematic, systemic, state-sanctioned violence, including forced treatment in healthcare settings, especially in psychiatry. This experience may mean for some that the concept of consent is so debased that it is unredeemable and that psychiatry itself should be abolished (Burstow 2015). Nevertheless, this paper strives to rescue the concept of consent, as we believe that it is the only current workable construct available

to differentiate between morally acceptable and unacceptable interferences with the bodily integrity.

In so doing, we are conscious of the civil and criminal law implications of the presence or absence consent. We want to ensure that it is possible for a person who has experienced a non-consensual interference with her bodily integrity to sue for assault, regardless of whether or not the person has a disability and of whether the intervention was considered to be in her 'best interests'. We want to abolish discriminatory mental capacity assessments which are currently used to deny an individual the opportunity to consent to medical treatment. However, we also want to acknowledge the difficulty of determining whether free and informed consent was present in situations where no clear communication with the person can be established. Therefore, in certain situations we suggest that supporters can provide the 'best interpretation' of will and preferences as set out in General Comment 1 (2014), and further develop a framework of information and voluntariness to define the scope of freedom to negotiate in decisions relating to sex and medical treatment.

In summary, our proposal is that if the person is not giving free and informed consent, the Article 12-based response is not to remove their legal capacity so that a proxy can consent on their behalf, or force them to undergo treatment against their will. Rather, we argue that in the context of medical treatment, the person who proposes to administer treatment must provide all of the necessary information to the person about the treatment in a manner that is accessible to the person and respects her chosen form of communication. This may include

providing information to the person's appointed supporters, whose role may be legally recognised in a binding support agreement. Once the person has subsequently expressed will and preferences regarding the decision, if the person indicates a refusal of treatment (including where this refusal is communicated via supporters) this must be respected.

In order to develop the argument for this proposal, we consider in section one of this paper the relevant human rights standards which refer to the need for 'free and informed consent' in various legal contexts, with a particular focus on people with disabilities. In the second section we consider various feminist theories of consent and their impact on legal theory, in order to ensure that our proposal to apply a 'freedom to negotiate' standard to consent can avoid some of the pitfalls associated with definitions of consent in existing legal theory. The third section of our paper sets out the essential ingredients of our proposal for reframing consent: namely, legal capacity, freedom to negotiate, provision of accessible information, respect for will and preferences, and voluntariness. The fourth section of this paper considers the conditions which need to be eliminated (i.e. coercion and undue influence) or minimised (i.e. power imbalances) in order to ensure consent is valid. In so doing, this paper represents a first attempt to move beyond an approach that labels adults with certain disabilities as lacking the 'mental capacity' necessary to give valid consent – so that we can explore in more depth particular expressions of consent or refusal and seek new criteria, beyond the label of 'mental incapacity' for determining their validity.

## I. International Human Rights Law Standards

The human rights framework around informed consent to medical treatment grew from interpretations of Article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR): the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.<sup>1</sup> The Convention of the Elimination of Discrimination against Women (CEDAW) has been authoritatively interpreted to place duties on states to support informed consent.

The assertion of the right to be involved in decision-making and consent to treatment is greatly expanded by the CRPD.<sup>2</sup> Article 25 on health protects the rights of people with disabilities to the same, highest attainable standards of health without discrimination on the basis of disability. Art 25 (d) requires healthcare professionals to provide care 'on the basis of free and informed consent'. In addition, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) (2011: para 36) has called for measures to ensure that healthcare services, including all mental healthcare services: '... are based on the informed consent of the person concerned'.

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<sup>1</sup> Informed consent is enshrined as a core element of Art 12 in General Comment 14 (2000) by the UN Committee on Economic, Social and Cultural Rights. Paragraph 37(3) (iv) obliges states to support people to make 'informed choices' about their health.

<sup>2</sup> This paper is not seeking to explain the significance of the CRPD, which is ably done by many, including scholars such as Paul Harpur, Arlene Kanter, Amita Dhanda and others. Nor does it explain Article 12 CRPD in much depth or outline the consequences for people with disabilities denied legal capacity, as that is the focus of other papers in this special issue.

The concepts of respect for choice, and free, informed consent appear in a number of Articles throughout the CRPD. For example, 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons' is the first general principle of the Convention in Article 3. Article 14 prohibits deprivation of liberty on the basis of disability: which is often associated with forced treatment and other denials of the right to free and informed consent. Article 17 also requires respect for the physical and mental integrity of persons with disabilities on an equal basis with others, which can be interpreted to include a right to provide free and informed consent. In the specific context of community living, Article 19 obliges states to ensure that 'persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.'<sup>3</sup> However, arguably the key source of a right to free, informed consent for all decisions which attract legal consequences is Article 12 on equal recognition before the law. In its jurisprudence on this Article, the CRPD Committee has made it increasingly clear that people with disabilities can no longer be denied the opportunity to give free and informed consent, and that their consent or refusal, once given, must be respected, regardless of the level of decision-making ability which individuals might be perceived to have.

General Comment 1 states that 'legal capacity is the right to be a holder of rights and an actor under the law'; whereas 'mental capacity refers to the decision-making skills of a person' (CRPD Committee 2014, para 12). The Committee

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<sup>3</sup> For more in-depth discussion on how these rights are inter-related, see Kanter (2014).



further states that 'perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity' (2014, para 13). In laws which restrict an adult's ability to consent or refuse certain acts or interventions, mental capacity is often used as a criteria to override the person's autonomy and disregard their express consent or refusal. The jurisprudence of the CRPD Committee makes it increasingly clear that such an approach is no longer permissible in human rights law. If an adult with disabilities is found to 'lack the mental capacity to consent' and that individual's legal capacity for the relevant decision is removed, this potentially violates Article 12 as interpreted by the CRPD Committee. Currently, in these situations, a substitute decision-maker is typically appointed who can then make the decision on the person's behalf in her perceived 'best interests.' Such an approach clearly violates that person's right to legal capacity according to the CRPD Committee. The Committee has further reiterated this position in Guidelines on Article 14. They state: 'All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities.' (CRPD Committee 2015, para 11).

The Committee's position on the right to legal capacity as it relates to laws on consent will be further explored in the sections below as we explore the essential elements required for consent to be present in a possible post-CRPD legal framework. First, however, it is important to return to the ontology of consent and the extent to which this is reflected in various domestic laws.

## II. Feminist Theories of Consent and Their Impact on Legal Theory

Consent underpins the predominant understanding of the autonomous individual to be accorded equal rights especially with respect to legal capacity; yet feminist and critical scholars have pointed out grave concerns with an unproblematised, liberal understanding of consent (Hunter and Cowan 2004; Lord and Stein 2013; West 2010). In this section, we review some of the scholarship regarding ontological and epistemological considerations in order to clarify what we mean by consent, and the implications arising for deliberations about legal capacity. From our standpoint, as set out in the preceding articles of this special issue, (de Bhailís and Flynn 2017; Arstein-Kerslake and Flynn 2017) all adults are *de facto* legal agents competent to consent, and possess the necessary legal capacity to have their consent or refusal recognised in law.

We draw from feminist scholarship on consent to sex to inform our approach to consent to medical treatment for persons with disabilities for two important reasons. First, much of the feminist literature on consent to medical treatment is part of broader scholarship on the ethics of care, and relational autonomy. While these theories have potential from a disability rights perspective, to date, many of the scholars on this subject have either misunderstood or explicitly rejected the premise of the universal recognition of legal capacity in the CRPD (Fyson and Cromby 2013; Dunn, Clare and Holland 2008; Herring 2012). Second, much of the feminist literature on medical treatment has criticised where women's informed

consent was not sought, or where women's refusal to consent was overridden, without challenging the nature of the cognitive criteria imposed on women before their consent is recognised (Baker *et al* 2012; Holmes and Purdy 1992). As Stefan (1992) notes, feminist legal scholarship provides surprisingly little critique of the concept of competence to consent to medical treatment. Therefore, for the purpose of developing a disability-sensitive and human rights-compliant approach to consent to medical treatment, we find the feminist scholarship on consent to sex, particularly approaches premised on active communication and respect for refusals, to be the most relevant for our argument.

We take as our starting point Monica Cowart's (2004, p.496) definition of consent. Consent, for Cowart, is a combination of the speaker's intention and the characteristics of exchange between the parties. The characteristics of the exchange include the minimum rules of communication, straightforward, unambiguous, mutually understood messages, so both parties know they agree to X and not Y. Thus situations where A told B he was conducting a medical or therapeutic treatment but went on to sexually assault her would constitute a miscommunication and therefore a lack of consent. For Cowart (2004) the intentions of both parties are taken into account in determining the communication of consent.

Most scholars deem communication of the presence of consent to be a necessary condition for acts which would otherwise constitute unlawful interferences with bodily integrity. Alexander (1996) and Malm (1996) contend that in agreeing to allow another to cross a particular boundary, such as bodily integrity -

communication of that state of willingness or acceptance to another is essential for consent to exist. There are significant divergences in the literature as to what might constitute 'willingness' – with some scholars suggesting that passive acceptance or acquiescence might be sufficient for legally binding consent (Dripps 1992;1996); and others arguing that a more active communicative approach should be required (Anderson 2004; Pineau 1989; 1996 cited in Beres 2007). Michelle Anderson (2004) is one of those who advocates a more active communicative approach in the context of consent to sex, which she terms the negotiation model. She argues:

“[T]he law should define “rape” as engaging in an act of sexual penetration with another person when the actor fails to negotiate the penetration with the partner before it occurs. The law should define “negotiation” as an open discussion in which partners come to a free and autonomous agreement about the act of penetration. Negotiations would have to be verbal unless the partners had established a context in which they could reliably read one another’s nonverbal behavior to indicate free and autonomous agreement. Force, coercion, or misrepresentations by the actor would be evidence of a failure to negotiate (Anderson 2004, p.1407).

This definition has some problematic elements, which have been critiqued by others, including its heteronormative focus on penetration as a requirement of rape (Burkett and Hamilton 2012), and its emphasis on the need for verbal communication (Arstein-Kerslake and Flynn, 2015). However, the priority it places on communication in determining consent, and its placing of the burden to

communicate on the person proposing to act upon another's body is a helpful starting point for our discussion about freedom to negotiate consent to medical treatment. In the same vein, simply signing a form to indicate consent to medical treatment should not be evidence of meaningful consent, and we hold that the freedom to negotiate model has an equal contribution when consent for treatment is being mooted. In this paper, we adopt the position that active, communicative agreement in an environment free of coercion, including the availability of meaningful choices, should be required by law for consent to be valid in the context of consent to medical treatment. In so doing, however, we must exercise caution to ensure that this approach does not fall into the traps associated with classic liberal conceptions of consent – i.e. reliance on the myth of the atomistic, disembodied, rational actor, as a basis for providing free and informed consent.

Developing the ontology of consent, Cowart (2004) insists a range of choices must exist. Therefore, as in the medico-legal context, consent is only meaningful if there is an accompanying right to refuse. Also, Cowart (2004) posits that the perspective of the individual needs to be considered: are the range of options consistent with the values and desires of the individuals? Considering the speaker's intention is important also to guard against undue influence and coercion, so for instance, if B says yes to sex with A in order to avoid threatened harm from A, then B has not given true consent. This is one of Cowart's minimum conditions for consent to exist, that it is freely given: 'the individual's will is in compliance with the action proposed by another' (2004, p.511). Communication of the person's will and preferences is core to our understanding of whether consent is present or not.

### III. Essential Elements of Consent

In this section we set out our proposal for reshaping existing standards of consent to medical treatment in light of the preceding feminist analysis of consent to sex. We contend that there are three essential elements of consent for this purpose: recognition of legal capacity, freedom to negotiate, information, respect for will and preferences and voluntariness; each of which we explore in further detail below.

#### A. Legal Capacity

The first element necessary for valid consent is for the consenting actor to be recognised as a person before the law. People with disabilities, like women, and people from other marginalized communities, have often been treated as lacking the legal capacity necessary to provide valid consent. This is evident in present day laws which preclude individuals under adult guardianship or other substitute decision-making regimes from making certain legally binding decisions without the consent of their guardian, including decisions to consent to or refuse medical treatment, to choose where and with whom to live, or to marry (Fundamental Rights Agency 2013).<sup>4</sup> Many of these current adult guardianship and substituted decision-making laws now focus on the cognitive functioning of an individual to determine if she can give valid consent. This functional approach prioritises cognition and rationality, and typically involves an assessment of the individual's

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<sup>4</sup> These include the Dutch curatele system and the tutelle system in France. For more information on the nature and impact of substituted decision making regimes such as adult guardianship in the member states of the EU, see Fundamental Rights Agency, *Legal Capacity of Persons with Intellectual Disabilities and Persons with Mental Health Problems* (Vienna: 2013).

‘mental capacity’ before determining whether she can give valid consent in a particular legal context.

Many people with disabilities (especially individuals with intellectual and psychosocial disabilities as well as acquired brain injuries and dementia) are disproportionately required to undergo functional mental capacity assessments to demonstrate their understanding of decisions which attract legal consequences; whereas other adults are not routinely required to undergo such assessments. In this way, ‘mental capacity’ is often conflated with, or viewed as a prerequisite for ‘consent.’ The functional assessment of mental capacity therefore operates as a preliminary hurdle which an individual has to pass before her consent or refusal will be considered valid. Where a functional assessment of mental capacity can result in an individual being denied the legal agency to consent or refuse a particular act, it should therefore be understood as a denial of the legal capacity of that individual in respect of the decision at hand.

Our proposal aims to ensure that the functional test of mental capacity is no longer used as a determinant of legal capacity in the context of informed consent. Instead, we propose that all persons over the age of majority should be automatically recognised as persons before the law, and no further requirement to demonstrate ability to consent should be imposed.<sup>5</sup> This does not mean that in situations where

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<sup>5</sup> In this article and in most of our previous work, we have not considered how the concept of universal legal capacity might apply to children. We acknowledge that the age of majority is an arbitrary point at which legal capacity is fully recognised – however, our article seeks to demonstrate that at least for adults, with or without disabilities, a universal approach can be applied to seeking informed consent which does not directly or indirectly discriminate against persons with disabilities. Further work on the application of the concept of universal legal

the person was misled or misunderstood the information about the decision that she will be deemed to have provided informed consent. Rather, it simply means that a discriminatory hurdle will be removed, and questions about whether the person expressed clear agreement to a proposed course of action, with the required information about the action, will be considered as part of the evaluation of informed consent, discussed further below.

While the paradigm is shifting towards a recognition of the legal capacity of people with disabilities (including those with complex and significant disabilities) – the ramifications of this shift on existing laws which require free and informed consent from legal subjects have not been fully explored. If we begin with the premise that adults with disabilities are legal persons, capable of providing valid consent, then we can examine the kind of nuanced interpretations of will and preferences which can constitute consent; keeping in mind the environmental, socio-political and other factors which might impact on the validity of that consent.

#### B. Freedom to Negotiate: Communication and Agreement

An important prerequisite for valid consent to exist is the freedom of the individual to negotiate their consent or refusal to a particular action. This idea has primarily emerged from scholarship on consent to sex, and relies on Anderson's (2004) model of 'negotiating sex' which emphasises the communicative nature of

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capacity to the legal personhood of children is certainly needed, but is beyond the scope of this article.



consent to sex. One of the key elements of this approach is the requirement that the agreement must be an active one. This approach makes a break with previous rape laws which set out a passive and patriarchal notion of consent; in which submission or acquiescence (of a woman) to a (male) partner is sufficient grounds to infer consent. The negotiation model rejects the arguments of Schulhofer (1998) and others who say that consent can be inferred from behaviour – particularly because, as Anderson states: ‘study after study indicates that men consistently misinterpret women’s nonverbal behaviour. They impute erotic innuendo and sexual intent where there is none. Any theory that relies on a man’s ability to intuit a woman’s actual willingness allows him to construct consent out of stereotype and hopeful imagination.’ (2004 p.1409)

Anderson (2004) argues that the duty to negotiate agreement rests with the person who wants to penetrate his or her partner. While this focus on penetration is still problematic in the context of rape and sexual offences law, the notion of requiring the person who wants to act upon another’s body to commence a process of active communication and listening is a useful one for the context of medical treatment. If this model is extended beyond rape law into consent to treatment, it requires the person seeking to interfere with another’s bodily integrity to commence the negotiation. Communication is key to negotiating such an agreement. Anderson has a preference for verbal communication between partners who have not previously established a form of non-verbal communication. This preference is clearly grounded in the notion that verbal communication is easiest way for a person to understand whether their partner agrees to a particular action. This however, poses problems from a disability

perspective. Nevertheless, as Arstein-Kerslake (2015) has previously written, the requirement for verbal communication can be re-imagined from a disability perspective to consider the positions of those who use non-verbal methods as their primary or sole form of communication, while maintaining a preference for communicative methods that are objectively verifiable by others wherever possible.

The positive obligation to initiate negotiation and communication to reach an agreement helps to place the final ‘agreement’ in context. In the language of the CRPD, the communication process in this negotiation might be considered a means of exploring the individual’s ‘will and preferences’ which the CRPD Committee (2014) maintain must be at the heart of an exercise of legal capacity. A negotiation also implies that a range of options are open for discussion – and that both parties are considered legal equals in the encounter, meaning that refusals will be fully respected.<sup>6</sup> A full consideration of the context in which consent is sought is therefore needed.

In the context of rape law, Palmer (2013) suggests, that a framework of ‘freedom to negotiate’ would not simply consider whether the person ‘agreed’ to sex, but whether they were free to negotiate in the absence of a fear of violence, financial or other dependence, and power dynamics. A similar approach could be applied in the context of medical treatment to ensure that ‘mere agreement’ is not taken as evidence of free and informed consent. Agreement to a particular course of

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<sup>6</sup> For a discussion of the importance of the dialogue and the recognition of both professional and patient as legal actors see the Supreme Court decision of *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

medical treatment could be obtained in an environment that is fraught with coercion and this kind of agreement should not be considered valid consent. In light of the power dynamic which exists between doctor and patient and the pressure to choose a particular course of treatment, patients may not have freedom to negotiate consent or refusal. Therefore, in order to respect the right to bodily integrity, the individual must be the ultimate decision-maker on questions of medical treatment. Further, the concept of 'negotiation' reflects the centrality of an active communicative process between individuals – without which no negotiation can take place, and no agreement can be reached.

### C. Information, Expression of Will and Preferences and Voluntariness

Once the individual is recognised as possessing legal capacity, and we can establish that the consent or refusal is occurring in a context where the individual has 'freedom to negotiate' and is free from coercion or the threat of coercion; the next step is to establish that the individual has sufficient information about the action she is being asked to consent to or refuse. In the context of medical treatment, this would require the treating physician to disclose all possible side effects of treatment, which would require far greater disclosure (for instance, about the side-effects of proposed medications) in a mental health treatment context than that which currently occurs (Morrison et al 2012).

Once the relevant information has been provided, in a manner accessible to the person, and the person has been offered support to exercise legal capacity in this context if desired, then the person proposing the relevant course of action must

wait until the person has expressed her will and preferences on the matter before any further action can be taken. In keeping with General Comment 1 (UNCRPD Committee 2014), we consider that where the person's will and preferences are unknown, every effort to discover them must be made using all possible forms of support and communication. If a person's will and preferences remain unknown after all efforts to discover them have been made, a supporter may have to determine the 'best interpretation' of the person's will and preferences in that context to decide, for example, whether the person wishes to consent to, or refuse, medical treatment.

It is particularly important that a supporter, trusted and chosen by the person, undertake this task, and that it is not undertaken by the healthcare professional who proposes to treat the person as this creates a clear conflict of interest. Further, we believe that there are limits on when a best interpretation approach can be used to determine will and preferences in the context of consent to medical treatment. This approach should only be used where all other options have been exhausted and where a decision about treatment urgently needs to be made. There are certain kinds of medical decisions which in our view should never be subject to best interpretation – especially where the decision is irreversible or has a significant detrimental impact in the long term on the person's life. These decisions include sterilisation and psychiatric treatment. Given the consequences of undergoing these treatments, we believe that they should not be administered without the person's clear expression of their will and preference to consent to such treatment. In the context of decisions to consent to sex, we also do not believe that a best interpretation approach would be appropriate – in these situations, a

clearly communicated agreement to engage in sexual activity must be present for valid consent to exist.

In life-threatening situations where no communication is possible with the person, for example, where a person is found unconscious by paramedics, we believe that medical intervention can be justified where it would be proportionate in the circumstances and is necessary to preserve the person's life, as set out by Flynn and Arstein-Kerslake (2017) in this issue. However, in this situation we presume that while the person has not provided consent for the intervention (due to unconsciousness), no desire to refuse medical treatment is indicated (for example, the person has not previously made a 'do not resuscitate' order which the paramedics have access to). If there is any indication that the person is refusing treatment – this must be respected. Once the immediate risk to the person's life is addressed (e.g. where resuscitation revives the person), consent must be sought for any further medical intervention. If, following the provision of support to exercise legal capacity, it remains impossible to establish communication with the person, and further medical treatment is offered (e.g. surgery on the person's wounds) then in accordance with General Comment 1, we suggest that a supporter may be needed to make a best interpretation of the individual's will and preferences which can be used to guide any further treatment decisions.

We acknowledge that a potential difficulty here is determining whether a particular medical emergency is 'life-threatening' and whether the treatment offered in that situation is a necessary and proportionate response to the

perceived risk to the person's life. It is important to reiterate here that we do not accept that a person perceived by medical practitioners to be in a state of extreme emotional distress should be forcibly sedated as this does not constitute a proportionate response to any perceived threat to the individual's life. This position is further explored and justified elsewhere in this volume (Flynn and Arstein-Kerslake 2017). For the purpose of this paper therefore, our position is that once the individual has expressed her will and preferences or where the person's will and preferences remain unknown, once a supporter has arrived at the best interpretation of that person's will and preferences, the role of the healthcare provider in the context of medical treatment is simply to either respect the individual's refusal, or if she thinks the individual is expressing a will and preference to undergo treatment, to take steps to verify that this agreement is a voluntary one.

Our focus on information, will and preferences and voluntariness for consent must be distinguished from the emphasis on rational decision-making from the liberal conception of autonomy described above. These liberal approaches often result in assessment of the person having, or not having, 'insight' into the decision to be made – for example, into the need for medical treatment. Medical practitioners' assumptions about lack of insight can inhibit meaningful dialogue, exaggerating inequalities between people's experiential knowledge and the scientific knowledge base of practitioners (Morant, Kaminskiy and Ramon 2015).

Diesfeld and Sjostrom (2007) illustrate how the construct of 'insight' is used to justify continued detention of people with psychosocial disabilities. Patients' factual accounts which contradict expert opinion are not treated as countervailing reports, but instead become evidence of symptoms. In the absence of concrete evidence, claims regarding lack of insight are a convenient blanket assertion to address credibility issues. Diesfeld and Sjostrom (2007) commented on the circular logic: (1) lack of insight causes non-compliance; (2) non-compliance is evidence of lack of insight. When clinicians claim the person lacks insight (and by implication will not comply with treatment) that assertion acquires medical certainty. Thus it undermines the person's credibility. Failure to comply with medication is taken as an indication of lack of insight while lack of insight substantiates the claims about non-compliance.

Morgan and Veitch (2004) further critique the notion that the purpose of mental capacity assessments is to verify the individual's actual understanding of the decision to be made. They argue that '...the real point of legal tests for mental capacity seems not to be to assess some projected future or, indeed, past ability to make a choice ... but to assess whether the person making that decision can construct a convincing case why he or she reaches the standard of the 'ability' that law expects in such circumstances' (Morgan and Veitch 2004, p.117). In support of this argument, Haidt (2001) and Iyengar and Lepper (2000) have demonstrated that individuals only conjure up reasons for their decisions when called upon to do so, and these reasons rarely correlate with their actual decision-making process at the time of the original decision, but rather reflect the most persuasive explanation the person can find for their decision. A disability perspective can

challenge this form of post-hoc rationalisation where judgments are based on socially intuitive moral reasoning – especially for people with disabilities who communicate differently or express reasons for their decisions which others find hard to understand or empathise with.

However, our approach, which would eliminate mental capacity assessments as a precursor to determining consent, would also eliminate the use of ‘insight’ as a basis on which to grant or deny the opportunity to consent or refuse treatment. In our view, the law has sufficient tools to determine whether free and informed consent was actually present at a particular moment, based on the discovery of will and preferences, without requiring people with disabilities to first demonstrate their decision-making ability before we consider the validity of their consent, as we will demonstrate in the following section.

#### D. A Practical Example: The Case of Mr. B

Here, we will consider how our approach could be applied in practice, using the example of an existing case, *Wye Valley NHS Trust v Mr B*.<sup>7</sup> In this case, the man in question, Mr. B, was 73 years old and had type II diabetes. While he did not belong to any particular religion, he had strong spiritual beliefs, and told the judge that he heard the voice of angels, and that the Virgin Mary spoke to him in a vision and urged him to become a Catholic. He had been subject to forced psychiatric treatment on several occasions. He developed a foot ulcer as a result of diabetes

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<sup>7</sup> [2015] EWCOP 60.



that did not heal despite various interventions. In hospital, he refused medication and antibiotics for his foot and his condition rapidly deteriorated. His medical team explained to him that his foot now needed to be amputated, but he refused to consent to the procedure, although he did allow the wound to be cleaned and dressings changed. Various doctors reported that at different times, Mr. B had said that his spiritual beliefs informed his decision to refuse treatment.

The hospital sought a declaration that he lacked mental capacity to consent to an amputation and that an amputation should be authorised against his will, in his best interests. When Jackson J met with Mr. B, the patient told the judge that he believed his leg would get better with proper care and if he was allowed to use it. He also said 'I don't want my leg tampered with. I know the seriousness, I just want them to continue what they're doing ... I don't want it. I'm not afraid of death. I don't want interference. Even if I'm going to die, I don't want the operation.'<sup>8</sup> Jackson J determined that while Mr. B did not have the necessary mental capacity to consent to surgery, he did not think that forcing him to undergo surgery against his will was justified in his 'best interests.' While this decision represents a good example of an effort to promote autonomy within a discriminatory paradigm of mental capacity testing, under our proposal, the same outcome would have been reached without the need for a stigmatising and discriminatory labeling of Mr. B as lacking the mental capacity necessary to consent.

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<sup>8</sup> *ibid*, at para. 37.

Under our approach, the first task of medical team would be to make every effort to inform Mr. B of his treatment options, likely benefits and side effects, in a manner which was accessible to him and respectful of his preferred form of communication. It appears from the judgment that this was done – although no formal supports were offered to Mr. B to exercise his legal capacity in this respect – and it appears that he had no informal support network who could have provided assistance to him, if he desired it, in reaching his decision. Under our proposal, the state would have an obligation to provide such support if Mr. B required it to exercise his legal capacity. Mr. B made several unequivocal communications of his will and preferences in respect of the proposed surgery, as evident from his statements to the judge. Therefore, no further inquiry is needed into whether Mr. B truly understands the decision he is making – once all efforts to provide information about the decision and support to exercise legal capacity have been made.

The final step in this process is a confirmation that Mr. B's decision was a voluntary one – made in the absence of coercion. While Mr. B's spiritual beliefs may have influenced his decision, this is true of many treatment decisions that are made, and the reliance on a religious belief in making a medical decision should not be viewed as amounting to coercion which would vitiate his consent. It is clear from the facts that he was under pressure from the medical team to accept treatment, but he vigorously resisted this pressure, and was not subject to undue influence from any other source in reaching his decision. Under our proposal therefore, Mr. B's refusal of treatment would have been respected, and he would

not have had the humiliating experience of being brought to court, and declared to lack capacity, before his wishes would be respected.

This example demonstrates that Article 12 CRPD requires us to go deeper to discover, to the extent possible, the will and preferences of the individual, which can be used as a basis for determining if that person wishes to consent or refuse. If the person's will and preferences are clear, and the person is clearly consenting or refusing, using their chosen form of communication, then the legal position post-CRPD is relatively clear. All that is required in this scenario is due diligence by those seeking consent. For example, in a treatment context, medical professionals should ensure that the person has the necessary information in a format they can understand, and is given sufficient time and support to reach a decision. This case indicates the role that supported decision-making, for instance by trauma informed, intentional peer support (Mead and Hilton 2003; Mead 2007) can play in establishing the person's will and preference. Once a clear will and preference emerges, the law should simply require respect for the person's decision, even if the decision seems irrational, ill-informed, non-compliant, or unwise. However, where it is impossible to determine an individual's will and preferences at the moment where consent would usually be required – for example, where a person is found unconscious by paramedics – then treatment to preserve the person's life, health or safety can of course be provided; and practitioners in this instance would be protected from liability under the doctrine of necessity (Gooding and Flynn 2015). In this scenario, once the person returns to a position where she can once again express her will and preferences, consent must be sought for any further treatment.

As authors in this special issue have written previously, where a person's will and preferences are conflicting– for example, where a person experiencing anorexia expresses a will to live but a desire not to eat, then intensive support may be required to ascertain what treatment that person wishes to consent to or refuse (Flynn and Arstein-Kerslake 2014). Advance directives which include Ulysses clauses can also provide helpful support in these difficult treatment decisions, if they do not directly or indirectly discriminate in their application against people with psychosocial disabilities (Morrissey 2012). At the end of this process the person may still express a clear refusal of certain forms of treatment, which may even result in death, and in line with our previous argument, this refusal should be respected. We do not make this argument lightly, and acknowledge the challenge which respecting such refusals of treatment presents, but remain convinced that treatment without consent in these situations is not a solution which adequately respects the human rights of the individual.<sup>9</sup>

Our proposal is to integrate questions of information, will and preferences and voluntariness into a determination of the presence or absence of consent. This is an alternative to both the functional assessment of mental capacity undertaken on specific population groups prior to considering consent; and status approaches to those considered 'unable to consent' on the basis of a label of disability. This may seem to some a mere semantic or symbolic difference from the current legal framework. However, we view it as an important indicator of the paradigm shift

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<sup>9</sup> For a thoughtful exploration of this issue in a case involving a young woman with anorexia, see Series (2012).

(Kayess and French 2008) from viewing people with disabilities as objects to be manipulated to subjects and equal citizens, with equal rights and responsibilities. There is certainly a risk that within our proposed approach, which is prima facie non-discriminatory, people with disabilities and those with cognitive disabilities in particular, may continue to be disproportionately viewed as having will and preferences which are unclear or unknown.

However, the difference with our proposal is that if the person is not giving free and informed consent, the response is not to remove their legal capacity so that a proxy can consent on their behalf, or force them to undergo treatment against their will. Rather, we argue that in the context of medical treatment, the person who proposes to administer treatment must provide all of the necessary information to the person about the treatment in a manner that is accessible to the person and respects her chosen form of communication. This may include providing information to the person's appointed supporters, whose role may be legally recognised in a binding support agreement. Once the person has subsequently expressed will and preferences regarding the decision, if the person indicates a refusal of treatment (including where this refusal is communicated via supporters) this must be respected. If the person indicates agreement with the proposed course of action, then, if the treating professional considers in good faith that the person is agreeing voluntarily and has all of the information required to give consent, then the agreement should be regarded as valid consent.

#### IV. Conditions to Eliminate or Minimise for Valid Consent

Once the elements described above are deemed to be present, it should be possible to determine whether someone is validly consenting to or refusing a particular action or intervention in the context of medical treatment. As noted above, in order to establish freedom to negotiate, it is crucial to eliminate the threat of coercion or force. The primary conditions which are obstacles to consent are: coercion; undue influence and power imbalances. While some of these cannot be eliminated entirely (especially power imbalances) they can be minimised in order to facilitate open communication to establish consent or refusal. An essential preliminary step is to acknowledge the existence of these obstacles to free and informed consent.

#### A. Coercion

The finding of the presence of coercion invalidates most legal agreements. Coercion can be evident in the overt form of practices such as: restraint (legal, mechanical or chemical) but more insidiously, coercion can be latent or unspoken, existing in threats of a range of measures including force, deprivation or encroachments on dignity and autonomy (McSherry and Freckelton 2013). Informal coercion (persuasion, inducements, threats, and force) has been widely observed operating in many in-patient mental health units (Lidz et al 1998). Sjostrom (2005) describes the 'coercive context' whereby coercion is invoked to control people and maintain order on hospital wards. A 'coercive invocation' may be the overtly locked doors or covert delaying tactics by nurses to distract and deter voluntary patients leaving a unit. An Australian study on the perspectives of people who have experienced seclusion and restraint, and of their family, friends

and supporters, describe the harms and chilling effect of these practices (Brophy et al 2016). They use the term 'emotional restraint' to describe the pressure to comply with behavioural expectations within mental health services. 'Emotional restraint' silences people and inhibits them expressing their views to staff for fear of the consequences. Therefore, it is unsurprising that people using mental health services frequently report care as coercive and controlling, without choices either to refuse care, about what is considered care, or over who provides this care (Newbigging et al 2015). Minkowitz (2007) goes further to describe the use of formal and informal coercion in psychiatry as an exercise of violence under the auspices of the state. Where informal coercion occurs within these contexts (often underpinned by formal legal coercion which supports forced treatment), this would, under our proposal, mean that no valid consent is given.

Likewise, coercive practices have been reported in residential care of older people, and of people with intellectual disabilities. Chemical and physical restraint are widespread practices to control challenging behaviour in under-resourced and oppressive institutional settings where people with intellectual disabilities and dementia live (Curkovic et al 2016; HSE 2006). In a study of Swedish care services for people with intellectual disabilities the authors found high levels of violence. Compulsory medication, along with force and seclusion, were used as means to restrain (physically or chemically) people who were not cooperative with staff (Strand, Benzein and Saveman 2004). In such situations, an atmosphere of fear is the antithesis of conditions necessary to foster real consent.

Increasingly community mental health services in the USA and UK are using coercion to ensure that people adhere to treatment (Burns et al 2011; Dawson 2005; Dunn et al 2012; Zigmond 2011). Rendering essential supports such as access to welfare income and accommodation services contingent on adherence to prescribed treatment removes any notion of free, informed consent. The unifying theme in this work, linking back to consent, is that all definitions of consent include the condition that valid consent cannot be said to exist in the presence of coercion.

## B. Undue Influence

Feminist jurisprudence asserts that consent to sex under undue influence is not true consent. In legal terms, undue influence is understood as any act of persuasion that over-comes the free will and judgment of another (Lehman and Phelps 2008). If undue influence is found by a court to have been present at the time instructions for a will were given (e.g. to an attorney) or when it was executed, it has the effect of rendering a will invalid.

Exhortations, importunings, insinuations, flattery, trickery and deception are all examples of undue influence. Talcott Parsons (1963) described four types of influence someone can exert over another: an appeal to shared values, inducement, persuasion and force. An appeal to shared values alone is not generally seen to be likely to constitute undue influence, but inducements (such as payments, early release from confinement, credits for courses or other favourable treatments) to participate in sex or medical treatment may constitute



undue influence. In general the greater the inducement, and the participants' need for what is offered them, the less voluntary the choice to participate is regarded. In the case of persuasion, the relationship and position of the persuader vis-à-vis the participant has a significant bearing.

If someone is not beholden they are more likely to be able to resist persuasion, but when there is an unequal power relationship, as in a child/parent, patient/doctor, or student/teacher relationship then certain kinds of persuasion have been determined to constitute undue influence. This is particularly the case for people dependent on care-givers who may not be in a position to refuse inappropriate demands made on them by their care-givers. For instance, literature on elder abuse is replete with instances of undue influence being brought to bear on isolated and vulnerable older people (following spousal bereavement or other losses) by people in positions of trust (Quinn 2000). Equally, decision-making by people with intellectual disabilities is frequently shaped by the undue influence their carers wield in mediating people's environments, and the choices made available to people (Jenkinson 1993).

Undue influence (and indeed coercion) are aspects of the interpersonal power dynamics which shape and contribute to occasions of oppression in the realm of consent and decision-making for people with developmental and psychosocial disabilities. Work by Björnsdóttir and Traustadóttir (2010) illustrates how a complex web of intersecting oppressive structures: gender, class, religion and disability play a role in shaping and constricting the life choices available to people with intellectual disability in Iceland. In the same vein, many of the same macro

social structures limit occasions of respectful negotiation of consent. One of the most pervasive aspects of macro structures that indirectly impacts on free and informed consent are the power imbalances present between parties.

### C. Power Imbalances

Many feminist and other critical scholars move their focus beyond the interactions between individuals to consider the social factors that impinge on and shape individual instances of consent or refusal. For instance, Catherine MacKinnon (1991; 1996) argues that given the societal structures of patriarchy which give men so much power over women, women are not usually in a position to freely consent to sex with men at all. In this context, sex is a feature of men's expectations from women, part of what men feel is due them from women. Indeed early feminist work on rape asserts it is not motivated by sexuality so much as violence and hatred of women (Brownmiller 2013).

Susan Stefan (1992) highlights the power dynamics operating in the determination of competence, which is used to negate the individual's ability to consent. She argues that it is always the dominant professionals who determine the conditions under which the person is assessed and which define the outcome, and that 'questions of competence arise only as a function of a relationship between two or more people and that this relationship is necessarily a hierarchical one, characterized by dominance and subordination, by power and powerlessness' (Stefan 1992, p.766). Bridget Hamilton and Cath Roper also problematize the 'power relations between health professionals, who

predominantly define what is truth and good practice in mental health, and the people upon whom public psychiatric treatment is visited, commonly without their consent.' (Hamilton and Roper 2006).

Lukes and later, Gaventa, present a critical account of power in relation to decision-making forums: work which is applicable to consent to medical treatment (Gaventa 2006; Lukes 1974). Gaventa (2006) describes three forms of power: visible, hidden and invisible. Visible power determines the agenda for decision-making including the 'who, what and how' of decision-making. However, the other forms of power are often over-looked when considering how power influences relationships between professionals and lay people. Hidden power is held by the agents who can influence what is or is not allowed onto the agenda, what knowledge is valid for consideration, but more importantly who is not allowed to the decision-making table. The final form of power is the invisible 'shaping of the psychological and ideological boundaries of participation' (VeneKlasen and Miller 2002 cited in Gaventa 2006, p.29). Not only are issues kept off the table for discussion but people become to believe that the powerful are acting in their interests, and fail to see how things could be otherwise arranged. Lukes (1974) asserted that this third face of power is most successful when those subjected to it do not recognise its operation or indeed consider that the status quo is in their best interests.

Masterson and Owen (2006) apply Lukes' (1974) theory of power to the mental health field, and illustrate it using the example of decision-making around medication. The traditional Weberian understanding of power is apparent at the

first face of power: here the authority of a psychiatrist is very visible. In addition though, covert use of power controls the agenda of what can be discussed. If both the psychiatrist and the service-user were to discuss the relative merits of different drugs, with the final decision resting with the service-user, this can be considered an equal exercise of power at the level of covert (hidden) power. What is more common, however, is that the discussion precludes that the person could cope without medication. Another aspect of such hidden power is the omission of potential adverse effects of medications and an informed 'cost-benefit risk' discussion. These issues are not on the agenda for discussion, as the psychiatrist sets the agenda and uses covert power to pre-empt the decision-making process.<sup>10</sup> The fact that non-medical explanations of psychosocial distress are not considered, plus the legal power to force treatment, are examples of the third form of power: the latent or invisible power operating the hegemony of psychiatry (Brosnan 2012).

Health professionals are not the only sources of power imbalance in the context of determining valid consent in law. In all legal contexts in which consent is required there may be power dynamics at play – including the power dynamics between a patient and their family members and service providers in the context of medical treatment. We cannot expect the law on consent to require an elimination of all power imbalances in these contexts. For example, the person proposing a particular form of medical treatment will almost always have more power in these

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<sup>10</sup> Reformists of medication negotiations advocate a model of shared decision-making in considering treatment options. This practice model insists on shared negotiation, full disclosure and is linked to the ideal of partnership in obtaining informed consent (see Morant et al 2015; Kaminskiy 2015).

encounters. Nevertheless, laws on consent can require these actors to take steps to minimise the power imbalance, or at a minimum, be conscious of the power imbalance in determining whether undue influence or coercion might be present to the extent that it negates consent.

## Conclusion

Our proposal for a disability-neutral approach to laws requiring free and informed consent can, in our view, provide a better alternative to current laws while still providing protection from harm; albeit placing a greater priority on individual liberty and narrowing the scope for state intervention, as discussed in the previous article. In addition to these essential elements for consent, laws can require those who seek consent from another person to ensure this process occurs in an environment free of coercion and undue influence, while minimising the power imbalances that may override an individual's agreement to the extent that no valid consent is present. In considering all these factors, a consideration of the individual's wider context (including social, cultural and environmental contexts) is required. Communication remains vital to the entire consent process. Finally, refusals can be more confidently respected where the obligation to offer support to the person throughout the process of ascertaining consent or refusal is fulfilled.

Given the breadth of laws in which consent is required to make an action binding, and the diversity of legal systems and cultures in which these laws operate, it is probably unrealistic to attempt to develop a universal approach to consent in all disparate areas of law. However, the starting point in all reform processes which

seek to implement a human rights-based and feminist approach to consent, should be to ensure that the consenting parties have freedom to negotiate and freedom to refuse, with active communication between parties to ascertain will and preferences and to demonstrate consent or refusal.

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