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‘People Like That’: Realising The Social Model In Mental Capacity Jurisprudence 

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ABSTRACT

The Mental Capacity Act 2005, and the domestic law surrounding it, is currently in a state of instability, having undergone rigorous scrutiny by the House of Lords Select Committee. At an international level, the United Nations Convention on the Rights of Persons with Disabilities 2006 has cast substantial doubt over the very basis of this legal framework. The recommendations made by the Select Committee, and any resulting action by the government to address these, will be hoped to have an impact on the implementation of the legislation on those falling within its remit. On a deeper level, however, this thesis seeks to critically engage with the theoretical underpinnings which inform and guide this legislative framework. This entails a questioning of the ways in which those with disabilities and their carers are responded to under the statute.

Exploring the theoretical debates in this context leads to a conclusion that the Act promulgates an individualistic approach to the concept of mental capacity, and does not adequately reflect the reality and lived experiences of those deemed to lack capacity or their informal carers. The papers in this thesis interrogate these issues through a focus on three distinct areas- carers interests under the best interests test; the Deprivation of Liberty Safeguards though a social model lens; and capacity to consent to sex. In doing so, this thesis suggests that more relationally and contextually focused approaches can inform a legal framework which is attentive and responsive to the interwoven interests of those with cognitive impairments and their carers, and which facilitates the enjoyment of rights through a focus on the societal, structural and institutional barriers which have historically worked to exclude these individuals.
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_Beverley Clough_________________________________________ 2015
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Sheffield City Council v E [2004] EWHC 2808

Stanev v Bulgaria (2012) ECHR 46

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INTRODUCTION

Increasing attention is being paid in legal and theoretical discourse to the concept of mental capacity and the appropriate response to this. Domestically, the House of Lords Select Committee has undertaken its post-legislative scrutiny of the Mental Capacity Act 2005 (hereafter the MCA), and has made several recommendations to inform and improve compliance with the legislation. The Deprivation of Liberty Safeguards (DoLS) have been in the spotlight since their inception, and have faced heavy criticism by commentators and the House of Lords Select Committee. The Law Commission are currently reviewing the DoLS legislation as a result and are due to report on this in 2017. There has also been recourse to rely on the High Court’s inherent jurisdiction in order to plug cracks that have appeared in the legislative framework surrounding DoLS and the MCA. The Court of Protection is coming under increasing strain, dealing with progressively contentious issues and attracting media coverage.


2Ibid. Chapter 7. Also see the House of Commons Health Select Committee, Post Legislative Scrutiny of the Mental Health Act 2007, (London, TSO, 2013), particularly where they note: “The evidence the Committee heard regarding the application of DOLS revealed a profoundly depressing and complacent approach to the matter. There is extreme variation in their use and we are concerned that some of the most vulnerable members of society may be exposed to abuse because the legislation has failed to implement controls to properly protect them. An urgent review of the implementation of DOLS should be undertaken by the Department of Health and presented to Parliament, together with an action plan for improvement, within 12 months”, p4.


4An NHS Trust v Dr A[2013] EWCOP 2442. In the Government response to the Select Committee’s report on the Mental Capacity Act, it was stated in relation to this issue of an eligibility gap that: “Finally, regarding the recommendation from the House of Lords regarding what it calls “a new Bournewood Gap”. We do not consider there is a new "Bournewood Gap". If necessary, the inherent jurisdiction of the High Court could provide any further authorisation that may be required to deprive a patient detained under the Mental Health Act 1983 of their liberty for medical treatment unrelated to the patient’s mental disorder. Given the small number of cases in which this will arise, we do not propose to introduce legislative amendments”.


5See n1,Para 205-211.
attention in light of this. This has led to public disquiet seen in debates about the powers of the state over those deemed to lack mental capacity.

At the international level, the United Nations Convention on the Rights of Persons with Disabilities (2006) has reinvigorated discourse in this area, and has been seen as embodying a progressive and radical ‘paradigm shift’ in thinking about disabilities. In particular, the potential for the Convention to usher in a new way of thinking about, and responding to, cognitive and psychosocial impairment is broadly welcomed, and invites a challenge to accepted wisdom about defining concepts such as mental capacity and best interests.

These new ways of approaching and responding to cognitive impairments will form the foundations of the papers in this thesis. Exploration of more contextually-focused and relational conceptualisations of psychosocial impairment will uncover some of the issues that the current legal focus domestically may obscure- for example, the impact of our social relations upon our experience of impairment. Moreover, the legal responses to this will be critiqued with a view to arguing for a more substantive approach to equality and enjoyment of rights, based on an exploration of state obligations. Such a shift, it is argued, requires a move away from the individualistic underpinnings of much of our law in the context of mental capacity, and a reconsideration of the binary of capacity and autonomy that permeates this area.

These shifting discourses, and the impact of these on law and policy, will be explored across seemingly distinct contexts- moving from the interests of informal carers, to human rights more broadly, and finally looking at sexual vulnerability. However, at the core of these papers is a concern to frame more situated and contextual understandings of the lived experience of cognitive impairments, and to suggest the legal shifts necessary to reflect the scope of state obligations stemming from this. A more situated, relational approach is necessary, it is argued, as it is attentive to the multi-factorial barriers to the enjoyment of equality- barriers which an individualistic approach can work to obscure. The papers explore the nature of relationality at both micro and macro levels, and open up the space for questioning the entrenched boundaries that are currently drawn in law between autonomy and incapacity. As Nedelsky puts it, it is necessary to “understand what kinds of relationships foster- and which undermine- core values, such as autonomy, dignity or security. The next step is to examine what kinds of laws and norms help structure constructive relationships and which have helped generate the problems people are trying to solve”\(^7\).

Exploring the affinities between parallel conceptual and legal developments here will be central to the thesis, before moving on to consider the remaining tensions and broader implications of the approaches discussed. The opening chapter will introduce the theoretical approaches which inform the papers. Whilst they are nominally and theoretically distinct perspectives, they share at their core a concern for more substantive, relationally-focussed and situated conceptual approaches to law and policy. Through weaving these conceptual affinities together, an approach will be developed which is attentive to the concerns of care ethicists, vulnerability theorists and those writing on the social model, but which can integrate these within a broader theory of justice. Chapter 2 will contextualise the law surrounding mental capacity, in order to illustrate the increasing complexity of the legal

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landscape and highlight the core criticisms that this attracts at present. Chapter 3 provides brief outlines of the published papers, and these are replicated in the chapters which follow. The conclusion then draws on the arguments raised in the papers and reflects on the implications of these going forward for mental capacity law, and for other areas of the law impacting on disability and care more generally.
CHAPTER 1

1.1 Theoretical Context

Criticism of the individualistic philosophy of health care law and policy is not novel. There has been considerable rejection of what has been argued to be a reductionist and atomistic view of the person promulgated by liberal theories and its counter-part in legal principles. This chapter seeks to weave together and build on some of the theoretical discourse and perspectives which have stemmed from this rejection of individualism in order to provide a strong critical basis for exploring mental capacity law, which is more attentive and responsive to lived experience, relationality and socio-political reality.

The concept of the ‘self’ contained in traditional liberal theories has been criticised as being “individualistic, isolated, and ahistorical”\(^1\). According to some philosophers, liberal theorists have often assumed the existence of individuals in an “untenable vacuum”\(^2\) in which various societal aspects are overlooked. In his work, Sandel is heavily critical of exaggerated individualism\(^3\). He is disapproving of the atomistic individual presupposed by Rawlsian theories of justice, suggesting instead a holistic conception of the self which is both intersubjective and intrasubjective- one which sees community ties as morally relevant to the individual identity. He notes that often there will be “a plurality of selves within a single, individual human being”\(^4\) which exposes a more complex concept of the self than that residing in liberal theories. Similarly, MacIntyre has argued that this stark image of the individual unencumbered self results in the “unity of a human life”\(^5\) becoming invisible, and

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5 A. MacIntyre, ‘The Virtues, the Unity of a Human Life and the Concept of a Tradition’ in M. Sandel, Liberalism and its Critics. n3, p126.
that consequently life becomes “nothing but a series of unconnected episodes”\textsuperscript{6}. The image of the individual promulgated in liberal theories is in many ways unlike the individual in society. As a result, our dependencies, obligations, responsibilities and relationships with others in society become almost obsolete in moral and ethical thinking. Instead, the focus is on zones of non-interference, as opposed to interrogating the moral quality of inter-personal actions. More importantly for the purposes of this thesis, those who are not independent, atomistic, self-sufficient individuals are marginalised as attention is diverted away from the structural underpinnings of our web of relationships. Essentially, the charge against a liberal conception of the person entails a rejection of a restricted and impoverished view of our moral and social experiences\textsuperscript{7}. Relational theories of the self instead call for a more nuanced understanding which is attentive to the realities of interdependence, and the way in which our capacities can be enhanced or diminished by surrounding circumstances\textsuperscript{8}. Some of the early feminist thought seeking to capture and resist the more impoverished liberal understandings was developed through the ethics of care.

1.1.1 The Ethics of Care

The theory known as ‘the ethics of care’ was first explicitly articulated in the early 1980’s. It has roots in feminist thinking, and the early care ethicists certainly focused on the theory’s feminist underpinnings. At the centre of the theory is the privileging of networks of human interdependence, a challenging of the public/private divide, and a focus on the values arising from refocusing on interdependence\textsuperscript{9}. The work of Carol Gilligan, \textit{In a Different Voice}\textsuperscript{10}, provided the impetus for the development of ethics of care theory. Much writing developed in

\textsuperscript{6}Ibid.
\textsuperscript{10} C. Gilligan, \textit{In a Different Voice} (Harvard, Harvard University Press, 1982).
this area after Gilligan’s work. Initially, so called ‘first generation’ care ethicists, focused primarily on the distinctions between feminine and masculine morality, and furthermore on distinguishing care ethics from theories of justice. Nel Noddings, for example, in Caring focused on the idea that care should replace justice as the central concept of morality. Justice was perceived as a product of a masculine system, which was exacerbated by the public/private divide in relation to rights which was seen to propagate the relegation of women’s interests to the private sphere. As Spring discusses, the feminist critique of rights regards the traditional liberal understanding of rights as overly individualistic, as obfuscating the real political issues, and as isolating people from one another. Hankivsky, however, points out various limitations of this gender motivated approach which distanced care ethics from theories of justice. She notes, for example, that there is no empirical link between caring and females, and so there is nothing distinctly feminine about values gleaned from caring. Furthermore, she notes that “essentializing women and caregiving activities, maternal care theorists have been accused of contributing to race, class and ethnicity biases regarding women and not taking into account differences between women”. This is an important point which has been reiterated by other critics, including Joan Tronto, who will be discussed below.

As care ethics has moved on, there has been a renewed focus on care as a political theory which is free of ties to gender. Clement notes that “the most recent theoretical discussions of care include the assertion that care is not a superior form of morality and that there are

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11 To use a term coined by Hankivsky in ‘Social Policy and the Ethic of Care’, n9.
14 Hankivsky, n9, p12.
15 Ibid.
dangers in excluding justice considerations in deliberations about care”¹⁶. Hankivsky highlights this shared commitment to finding a meaningful relationship between care and justice¹⁷, which is the focus of the first paper in this thesis.

An early attempt at positing a relationship between care and justice was undertaken by Joan Tronto in her 1993 work Moral Boundaries. The focus of this was on care as a political ideal in the context of a democratic, liberal society. Tronto was critical of tying care ethics to feminist theory and instead focused on how care could fit within a liberal society. She discusses the ways in which “even conventional liberal thought will be transformed if we take care seriously”¹⁸, and introduces the values of attentiveness, responsiveness, responsibility and competence to inform care policy¹⁹. She distinguishes her approach from those preceding her by insisting that “we cannot understand an ethic of care until we place such an ethic in its full moral and political context”²⁰. She further argues that,

“In claiming that to care adequately is a quality of the morally good person or society, I am not asserting that a person or society that only provided for care would then be automatically adjudged moral. This injunction to care is not meant to serve as a total account of morality. It is not meant to overthrow such moral precepts as do not lie, do not break promises, avoid harm to others. Keeping to all of those other moral precepts, though, still leaves an account of morality that is incomplete because it ignores the central role of caring in human life.”²¹

This is an important development for care ethics as it highlights the incompleteness of theories of morality and justice which ignore the interdependence of people, and the care

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¹⁶ G. Clement, Care, Autonomy, and Justice: Feminism and the Ethic of Care (Boulder, Westview Press, 1996) p112
¹⁷ Hankivsky, n9, p14.
¹⁹ ibid. p127
²⁰ ibid. p125
²¹ ibid. p126
which is necessary in the development of human beings, thus affirming the need to reconceptualise or at least engage at the socio-political level. In a similar vein, Robinson argues that “the transformatory potential of an ethics focus extends beyond the personal to the political, and ultimately, to the global context of social life. More recent care theorists have attempted to provide accounts of the theory which sit alongside justice and rights in the political sphere” 22.

The recent work of Daniel Engster is testament to the renewed attention given to care theory as a valid and important contributor to legal and policy debates. In his work *The Heart of Justice: Care Ethics and Political Theory* Engster builds upon Joan Tronto’s work in providing a robust theory of care focused on moral and political principles of justice. Starting from the traditional ethic of care stance of human interdependency, he posits that there is a moral obligation to care when others cannot reasonably meet their needs on their own 23. In focusing on interdependency, Engster adopts the necessity of care as a means for all individuals to become autonomous as a central aspect of his theory. Indeed, this is where the ethics of care is seen to divert from liberalism, as under some liberal theories, individual autonomy is deemed to be pre-existing. John Rawls’ *A Theory of Justice* 24 is paradigmatic of such an approach, as those in his ‘original position’ are able bodied and capacitous individuals. Engster views care not just as a moral obligation, but moreover as a state obligation, thus positing his theory as primarily political in a similar way to Tronto. This is further developed by Jeffrey Spring in his thesis, which argues for a theory of justice which integrates concerns of care, vulnerability and power via a conceptually rich and substantive

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approach to rights and capabilities\textsuperscript{25}. Reconceptualising the distinctions between public and private thus allows more targeted scrutiny at a policy level of obstacles to caring practices. Rather than relegating issues arising in the ‘domestic sphere’ to the realms of private individuals, and outside of the scope of the state, reconceptualising this private/public divide presents such issues as a matter of societal and political importance. Presenting care as a political rather than a private issue differentiates first and second generation care ethicists. In doing so, it allows the needs of both carers and cared-for to be more seriously debated and presented in legal and policy discussions. Such developments are explored further in the first paper in this thesis, providing a critical exploration of the presentation and position of carers under the MCA, and questioning whether the reality of care relationships is adequately responded to in law.

1.1.2 Care Ethics and Disability Studies- A Fraught Relationship?

A parallel development to feminist care ethics was the disabled persons movement, and advocacy of the rights of disabled people. A central tenet of this initially was the social model of disability. This approach holds that much of the disadvantage experienced by those with disabilities or impairment is socially imposed rather than pertaining to their bodily or mental state\textsuperscript{26}. In its early form, the central ideas of the social model were presented in this statement in the UK of the Union of the Physically Impaired Against Segregation,


\textsuperscript{26} S Goering, ‘Revisiting the Relevance of the Social Model of Disability’ (2010) 10(1) \textit{American Journal of Bioethics}, p54.
“It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society”\textsuperscript{27}.

Such a view contrasts to the medical model that has been dominant in mental health and mental capacity law, which sees “diagnosis and classification functioning as ends”\textsuperscript{28}. Disability, viewed from this perspective, is simply an “unfortunate state of functioning and being”\textsuperscript{29} with a resultant focus on biological cure or management of the condition or person. In essence, the core of the social model, in its original formulation, is that societal structures and institutions, rather than impairments, cause disability\textsuperscript{30} and potentially lead to a “social and moral marginalisation of people with impairments and gives permission to debar them from full participation in society”\textsuperscript{31}. Like the ethic of care discussed above, this presents an approach which sees individuals as relationally situated and is attentive to the impact that society and relationships can have upon abilities. At the same time, however, there has been considerable discord between care ethics and the disabled peoples’ movement, as will be discussed below.

Whilst social models or approaches to disability have traditionally been concerned with physical disability, more nuanced approaches within the social model are exploring the inclusion of potentially incapacitating illness such as dementia and learning disabilities as similarly impacted upon by societal structures and institutions\textsuperscript{32}. Questions arise such as


\textsuperscript{28} K. Shogren, ‘Considering Context: An Integrative Concept for Promoting Outcomes in the Intellectual Disability Field’ (2013) 51(2) \textit{Intellectual and Developmental Disabilities}, p133.

\textsuperscript{29} S. Vehmas, ‘Ethical Analysis of the Concept of Disability’ (2004) 42(3) \textit{Mental Retardation}, p209.


\textsuperscript{31} Vehmas, n29 p210.

\textsuperscript{32} J. Gilliard \textit{et al}, ‘Dementia Care in England and the Social Model of Disability: Lessons and Issues’ (2005) 4 \textit{Dementia}, 571-586; P. Dorenlot, ‘Applying the Social Model of Disability to Dementia; Present day challenges’
whether the experiences of these illnesses similarly result from a complex interplay of biological and societal factors; or in this instance must we concede to the medical model and admit that the inherent consequences of the illness are responsible for limitations imposed upon the person affected? Until relatively recently, little consideration was given to such potentially incapacitating impairments. This may be because there seemed to be a lack of affinity between a social model of disability primarily concerned with societal structures and physical disabilities, and less visible mental disabilities. Furthermore, as Gilliard *et al* point out in the context of dementia, “it is hard (and probably impossible) to argue that their impairment does not have a significant impact upon their lives”\(^{33}\). This is reflected in a broadly medical model approach to dementia “together with the perception that little can be done for ‘patients’ and ‘sufferers’”\(^{34}\). When contrasted with a purely physical disability- for example, the paradigm case of needing to use a wheelchair- it is much easier to frame an argument that but for society’s use of stairs and steps as opposed to ramps, the impairment would not have a significant impact on their lives. In other words, in the case of physical disabilities, it is much easier to place the ‘blame’ for adverse experiences of disability at the door of society.

As noted above, writers who can still be classed under the umbrella of social model theorists are engaging more with the interplay between impairment and disability. As more nuanced approaches and understandings of the multiplicity of factors impacting upon the experience of illness have been framed, there is much more scope for an understanding of mental


\(^{33}\) J. Gilliard *et al*, *ibid*. p573.

\(^{34}\) *Ibid* 574.
disability which can encapsulate the varied experiences of such an illness. Strides are being made in this respect in the context of mental illness, learning disabilities and dementia and approaches are being framed which align the concerns of the social model with mental impairments.

Vehmas has written about the cultural aspects of mental illness, contending that those considered to “suffer from” mental illness are “disabled in that particular culture, but would not, perhaps, be disabled in some other culture”35. Writers such as Tremain36 and Kittay and Carlson37 similarly advance arguments for the need for sustained debates on non-medical factors, such as this, to be brought to the fore in discourse surrounding cognitive or psychosocial impairment. This shift in approach can potentially bring a variety of benefits for those deemed to lack capacity by virtue of the existence of a mental disorder or impairment.

With regard to learning disabilities, Shogren argues for the importance of a strong focus on context, defined as “the totality of circumstances that comprise the milieu of human life and human functioning”38 and the potential of this to help challenge the determinative nature currently ascribed to diagnosis and classification. Similar assertions have been made in the context of dementia. Dorenlot asserts that viewing dementia as a disability “encourages professionals to be aware of the role of the social environment and the persons experience of their condition”39. Marshall further outlines how regarding dementia as a disability under the social model enables a “focus on remaining abilities instead of losses; recognition of the ways in which people are discriminated against or marginalised; stresses the importance of

35 Vehmas, n29,p213.
37 E.F. Kittay and L. Carlson, n32.
38 Shogren, n32, p133.
listening to personal experience of dementia; and foregrounds the influence of the social and built environment in enabling or disabling people with dementia40.

However, the social model approach as it was initially conceived—denying a causal link between impairment and disability—has been subject to criticism, debate and refinement both from within the social model itself and also from external perspectives41. Writers such as Shakespeare and Watson42, Crow43 and Morris44 have emphasised the need to bring the body back in to social approaches to disability, and frame a more refined and inclusive approach which considers and builds responses to disability on a variety of levels such as physical, psychological, societal, political and cultural45. A bio-psycho-social model has been advocated for by commentators recently46. Such an approach thus seeks to carve a ‘third way’ between the extremes of the social and medical models47; one which recognises that “bodies are lived in, but in the social spaces that they inhabit”48. I suggest that this more inclusive and multi-factorial understanding of disability paves the way for a more thorough consideration of the role of society in creating or exacerbating the experience of cognitive disability. This requires a much more richly textured approach than one which places coercive responses as

40 Gilliard et al, n32, p576.
44 J. Morris, Pride Against Prejudice: Transforming Attitudes To Disability (University of California, New Society, 1991); J. Morris, Encounters with Strangers: Feminism and Disability (University of Michigan, Women’s Press, 1996).
45 Shakespeare and Watson, n42, p28.
46 Ibid.; S. McLean and L. Williamson, n41.
inherent or inevitable for certain illnesses or impairments. The focus shifts from looking at individual impairment and aspects of the condition, to asking how society and the surrounding environment altogether does and should regard people with impairments and respond do them. Whilst a model will not necessarily account for all the individuals and experiences it seeks to encompass, the utility of social model insights lies in the critical tools that it provides us with to question our assumptions and glean what can be socially changed.

This is central to the ideas in the second paper of the thesis, in which the dominance of the medical model in mental capacity jurisprudence is highlighted and presented as a barrier to critical legal engagement with the societal impact on the lived experience of impairment.

Whilst there are clear affinities between care ethics and the social model of disability, as both engage with experience in a relational way in contrast to the individualistic, social vacuum which has been the caricature of traditional approaches, at the same time there has been considerable debate between both camps as to the dangers of emphasising the needs and rights of one group in society over others. As Watson et al discuss, the concept of ‘care’ came to be viewed by many in the disabled people’s movement as a “byword for dependency” and instead there was a preference for the idea of ‘personal assistance’ to connote empowerment and liberation. In essence, the distinction between the theories was seen as one of a point of emphasis; where care ethics was seen as emphasising the needs of carers, the disabled people’s movement buoyed by the social model of disability was concerned with the needs of ‘care-recipients’. There is indeed a legitimate concern that a care


theory which emphasizes the burdens of care can present the disabled person as the source of this burden\textsuperscript{52}. However, the language of ‘personal assistance’ and ‘direct payments’ which permeates much of the disability rights debates has been criticised as simply reversing the concerns of the disabled people’s movement and reflecting it back onto carers- as entrenching the individualistic dichotomy that was the target of criticism. Carers can become seen simply as sources of assistance based on demand, carrying consumerist connotations. As Hughes \textit{et al} contend, this is a “wrong-headed strategy”\textsuperscript{53}. It “does not adequately observe the role of interpersonal relations between parties involved in the caring nexus”\textsuperscript{54}. Similarly, as Herring suggests, such an approach reinforces the idea of separation rather than interdependence and relationship\textsuperscript{55}. Instead, calls have been made for a bridging of such approaches, based on mutual recognition, need and embodiment. However, criticism has been levelled here that the idea of interdependence and reciprocity does not fully reflect the experiences of those needing care. As Shakespeare points out, “[t]here is a major difference in degree between interdependence of non-disabled people, and the forced dependence of some people with impairments”\textsuperscript{56}. This is quite right and illustrates the reality that whilst all those within society are in the main interdependent, those with long term impairments or disability are often \textit{more} dependent, or at least may have dependencies of a different nature. However, this is not an insurmountable criticism of care theory. In fact, the ethics of care is in a better position than less contextual theories to appreciate this. Whilst it is true that those in need of care may be more dependent than others within the caring relationship, this should not take away from the fact that carers rely on those that they care for too. Positions in the care relationship are not set in stone and the ability of care ethics to recognise and more

\begin{thebibliography}{99}
\bibitem{54} Watson \textit{et al}, n51, p339.
\bibitem{55} n52, p8.
\bibitem{56} n41, p146.
\end{thebibliography}
importantly to respond to this is notable. Furthermore, the fact of inequality should not be taken as argument against care ethics generally or recognition of interdependency more particularly. Instead, it creates an argument for care ethics either as or alongside a conception of justice so that those within the relationship are not exploited or negatively affected. The sense of difference highlighted in Shakespeare’s quote points to the necessity for a more context sensitive response. Recognition of the possibilities of inequality within caring relationships draws attention to the needs of policy to respond in a way which does not place too much of a burden on the care giver. The principles highlighted by Tronto, and later developed by Engster (responsibility, competence, responsiveness and attentiveness) apply to those within caring relationships, not just the carer or the cared-for. Rather than being a criticism of care theory, this is something which care theory can respond to in a much more nuanced way than other political theories. Simply employing an individualistic rights theory of justice, for example, which emphasizes the importance of the human rights of those requiring care vis. a vis. those who are carers, leaves the contextual issues pertaining to those within the relationship undetected, and can prevent a more nuanced approach to the interdependence and interconnectedness of those whose rights are presented as in conflict. An ethic of care instead allows recognition of the realities of caring, including the potential for significant burdens for care-givers, and responds to them.

A similar point has been argued by Williams, maintaining that a political ethics of care is required in order to reconsider interdependence as the basis of human interaction; at different times, in different places and in different ways we all need to be cared for. Similar understandings have been developed through those writing on ‘vulnerability’, and new ethical paradigms have been suggested which are attentive to the obligations flowing from need and interdependency and capture some of the concerns discussed above.

1.1.3 Vulnerability and the Responsive State

There is a growing body of literature seeking to reconceptualise ‘vulnerability’ and theorise the implications of this for law and social policy\(^{58}\). At the forefront of this is the work of Martha Fineman who has sought to re-imagine, at a political level, what we mean by vulnerability\(^{59}\). Central to Fineman’s thesis is the notion of ‘universal vulnerability’, advancing the idea that all human beings, by the very nature of being social beings, are vulnerable. This is in stark contrast to notions of vulnerability which have traditionally pervaded discourse, being based on subpopulations being vulnerable, and positing those standing outside of these “constructed vulnerability populations” as invulnerable\(^{60}\). Instead, a much broader understanding of vulnerability, divorced from ideas about a particular status, allows for more attentiveness to the multi-variant sources of this vulnerability. In essence, this is a more outward looking approach which seeks to identify sources of vulnerability which have otherwise been hidden in legal, social and cultural practices\(^{61}\), and to directly challenge the idea that vulnerability is inherent to certain individuals within a demarcated subpopulation. It is also a unifying approach which sees vulnerability as a common concern in humanity, rather than focusing ethical concern on a particular group as was seen in early debates between care ethicists and disability rights theorists.

In many ways, this theoretical starting point echoes the work of care ethicists and those writing on relational autonomy, as it highlights the networks of interdependence that pervade


society and the importance at a policy level of being attentive to and responding to these. Similarly, these understandings also chime with the social model of disability, which emphasises the societal impact on the experience of impairments, and shifts the focus outwardly onto disabling structural and institutional factors. However, contrary to the critiques of the social model discussed above, a vulnerability analysis requires much more attention to the embodied experience of individuals and responsiveness to this through an appreciation of the interplay of various sources of vulnerability in the particular individual.

Whilst an understanding of universal vulnerability may seem to gloss over the individual embodied experience of vulnerability, theorists emphasise that the particular experience of vulnerability must be understood at the individual level. Fineman refers to this as “embodied difference”, stressing that the “experience of vulnerability varies according to the quality and quantity of resources we possess or can command.”

Crucially, Fineman hones in on the need for a ‘responsive state’ as a key aspect of her vulnerability thesis, contending that an understanding of the various sources of vulnerability forms the basis of a claim that the state must be responsive to these. This signals an important recognition of the role that the state plays in the formation of systemic and institutional sources of vulnerability, and conversely that the state is in a position to ameliorate this and instead foster resilience. Building upon Fineman’s work, other theorists have sought to categorise sources of vulnerability to elucidate appropriate responses to these.

Mackenzie, Rogers and Dodds propose three broad, but not necessarily distinct, categorisations of sources of vulnerability; inherent; situational and pathogenic. Inherent

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64 Ibid.
65 Ibid. p13.
sources encompass intrinsic human characteristics, “arising from our corporeality...our dependence on others, and our affective social natures”. This is said to cover constant factors, such as our need for nourishment, hydration and sleep, but also factors that can vary depending on circumstance such as age, gender, illness and an individual’s resilience. Situational sources refer to context specific factors, which may be caused or exacerbated by the personal, social, political, economic and environmental situation. Notably, their category of ‘pathogenic vulnerability’ refers to the way in which abusive interpersonal or social relationships, and socio-political oppression or injustice can generate vulnerability. Moreover, they note that “pathogenic vulnerabilities may also arise when a response intended to ameliorate vulnerability has the paradoxical effect of exacerbating existing vulnerabilities or generating new ones”. The categorisation of sources of vulnerability is not clear-cut and there is significant overlap between them. An alternative categorisation is advanced by Dunn, Clare and Holland who draw on the concepts of etic and emic vulnerability which they suggest are more attentive to experiential aspects of vulnerability. Etic refers to external understandings equating vulnerability with perceived risk, and basing intervention upon this. Emic conversely refers to a more experiential and subjective understanding of vulnerability, based on the ‘lived-reality’ and resources a person can draw upon to withstand challenges. However, what both of these understandings and categorisations of the sources of vulnerability purport to do is to draw out the importance of a multi-factorial approach. This moving away from an individualistic focus is the key to unlocking the opportunities to transform societal and professional responses presented by the vulnerability approach. These

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67 Ibid.
68 Ibid.
69 Ibid. p9
70 Ibid.
understandings form the theoretical basis of the third paper in this thesis, which challenges conceptualisations of, and responses to, sexual capacity within a legal framework predicated on a dichotomy between autonomy and incapacity.

The development of these contextual relational theories has been instrumental in crafting a nuanced and attentive approach, aiding an understanding that relational interactions are not unidirectional and take place on both micro and macro levels in the development of individual capacities. As Dodd’s put it,

“Attention to vulnerability…changes citizens’ ethical relations from those of independent actors carving out realms of rights against each other and the state, to those of mutually-dependent and vulnerably-exposed beings whose capacities to develop as subjects are directly and indirectly mediated by the conditions around them” 72

Such an understanding will form the basis of the theoretical approach taken in this thesis, which will be developed in the next section. The importance of recognising and foregrounding interdependence and care in society is key to this, with relationships- personal and societal- being presented as largely overlooked in traditional ethical and political thought. Focusing on care relationships invites us to consider all of the parties in relationships and the reciprocal obligations of individuals and also of society to ensure that “caring obligations are not grounded in coercion and domination” 73. It will be suggested that care ethics, informed by contemporary understandings of disability and vulnerability, foregrounds the centrality of interdependence, inter-relatedness and universal vulnerability in society. Such recognition of interdependence and vulnerability invites a different set of ethical, legal and political

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73 S. Dodds, ‘Dependence and Vulnerability’ in Mackenzie, Rogers and Dodds, Vulnerability, n66, p194.
considerations - not just at an interpersonal level but on a wider societal level - and the papers in this thesis seek to consider what individual, social and institutional responses and obligations are generated when relationality is recognised.

1.2. Theoretical Approach

The critiques and rejection of individualistic models of autonomy discussed above will form the basis of the papers in this thesis. However, whilst relationality will be crucial to the approach here, this does not necessitate a wholesale rejection of the concept of autonomy. Instead, a reconceptualization of autonomy will be central - one which sees autonomy in a relational sense. As Nedelsky describes, “a relational approach does not stand in opposition to the importance of individuality; it is an account of what makes it possible”\(^\text{74}\). Stemming from the understanding of individuals as interconnected and interdependent, autonomy becomes something which can either be fostered or undermined by these relations. As theorists such as Meyers have maintained, we need to look at the ways an array of “autonomy competencies” are fostered, shaped and potentially thwarted\(^\text{75}\). An approach to justice which is cognisant of these relational concerns, and which can be used to underpin claims at a political level for a responsive state, is the capabilities approach.

1.2.1 Capabilities

The capabilities approach is essentially an international development approach first advocated by Amartya Sen and Martha Nussbaum\(^\text{76}\). The focus of the approach is on the prerequisites for achieving human potential and fulfilment. Crucially, the approach stresses the


importance of focusing on actual capabilities and the means of achieving them. Amartya Sen describes it thus:

“For example, utilitarianism, pioneered by Jeremy Bentham, concentrates on individual happiness or pleasure (or some other interpretation of individual utility) as the best way of assessing how advantaged a person is and how that compares with the advantages of others...In contrast with the utility based or resource based lines of thinking, individual advantage is judged in the capability approach by a person’s capability to do things he or she has reason to value...[it is]the freedom that a person actually has to do this or be that”\textsuperscript{77}.

According to Sen, what is missing from traditional liberal theories, “is the notion of ‘basic capabilities’- the person being able to do certain basic things”\textsuperscript{78}. This approach instead scrutinises “what people are actually able to do and be”,\textsuperscript{79} with a particular focus on just background conditions and the way in which societal structures and institutions can hinder access to certain purported rights or values. Sen’s critiques of traditional theories of justice highlight particularly how they tend to miss the “relevance of actual human lives and social behaviour in pursuit of justice, as well as the real consequences that different actions and decisions have on people’s lives”.\textsuperscript{80} The capabilities approach requires a focus on wider contextual aspects of a given situation, as opposed to a detached and abstract conception of justice. In common with the relational theories outlined above which underpin this thesis, the capabilities approach sees our lived-experience as the result of the “interlocking of individual

\textsuperscript{78} Ibid. p218.
\textsuperscript{79} Nussbaum, n76, p33.
and circumstantial features\textsuperscript{81} and relational interaction. Whilst much of the literature on the capabilities approach has been focused on international development, what this thesis seeks to do is to reflect on the potential of this approach to inform an approach to justice which is attentive, and responsive, at national, local and inter-personal levels.

The potential contributions of such an approach to debates in the context of mental capacity are explored through the papers in this thesis. In the remainder of this section, the conceptual affinities underpinning the capabilities approach and the macro and micro relational aspects noted above will be introduced.

\textbf{1.2.2 Care and Capabilities}

Many early ethics of care theorists were eager to distance care theory from liberal political institutions and products of them, such as justice and rights. The approach which will be taken here thus differs from such theories in instead emphasising the importance of background political structures of democracy and rights. It is submitted that to focus too much on the relational aspects of caring, rather than keeping in mind the individuals who constitute that relationship, creates a danger of subsuming the needs of individuals. Tronto similarly argues:

\begin{quote}
“I start from assumptions about the need for a liberal, democratic, pluralistic society in order for all humans to flourish. In this regard, I part company with feminist theorists who have turned away from traditional political analyses, who find the liberal democratic state corrupted, or who have moved towards romanticised commitments to community.”\textsuperscript{82}
\end{quote}


\textsuperscript{82} Tronto, Moral Boundaries, n 18. p x.
Tronto’s thesis provides the bedrock for a political ethic of care which stresses the responsibilities entailed in caring as a policy issue. She essentially took the issues faced by carers out of the realm of the private and thus demonstrated the public aspects and concerns of caring. Tronto emphasised the importance of focusing on the role of care ethics in the political realm, as opposed to limiting its scope to discussions of gender. Engster builds upon Tronto’s work substantially and provides a more detailed account of caring as not only a political but a moral obligation. For the purposes of this thesis, this approach will be used to promote attentiveness to the contextual issues facing carers and cared-for within a legal framework. The focus is thus on the inadequacies of the current approach to law and policy, and ways in which the care ethics could and should inform more responsive policy.

Throughout this thesis, the values central to a political ethic of care, as posited by Tronto and Engster are important in forming my theoretical approach. Tronto emphasises that the “ethic of care is a practice, rather than a set of rules or principles”\textsuperscript{83}. In this sense then, essential considerations of this practice should be used to criticize and advance legal and policy arguments. From this, Tronto posits four essential ethical components of a political ethic of care. These are attentiveness, responsibility, competence and responsiveness\textsuperscript{84}. In the first paper, these values are central to the critical evaluation of the MCAand inform and advance arguments for reform. Whilst a purely ‘principled’ approach to ethics is rejected here, it is submitted that the values posited by Tronto, and later by Engster, provide important considerations which ought to form the heart of the ethic of care approach. As Tronto puts it, “[g]ood care requires that all four phases must fit together as a whole. This requires an assessment of needs in a social and political, as well as a personal, context”\textsuperscript{85}.

\textsuperscript{83}Ibid. p126.
\textsuperscript{84}Ibid. p127.
\textsuperscript{85}Ibid. p136.
In a similar regard, I argue that a theory of justice is essential to a strong and effective approach to care ethics. However, what is important is a theory which emphasises and complements the values and interdependencies inherent in relational care ethics. Martha Nussbaum in particular provides a useful theory of capabilities which is attentive to and enhances the efficacy of justice theories as a vehicle for relational approaches. She links the importance of facilitating capabilities to the idea of equal moral worth and dignity of persons, and further outlines a fundamental aspect of justice as care and compassion in a humane and decent society. In terms of care ethics, the capabilities approach can thus recognise the nature of interdependence and be attentive to the possibility of coercion or domination. It is a contextually-focused theory of justice, which is not concerned with rights in the abstract, but instead hones in on the lived reality and actual freedoms that people have, and the impact that their interaction within society has on this. This bears a similar focus to care ethics in that both theories call for attentiveness to context, and responses which are meaningful within that context. Central to the calls for attentiveness to context is the idea of breaking down the binary between the public and the private, and enabling a more nuanced understanding of the impact of law and policy beyond this imagined dividing line. The utility of this has not been ignored in the care literature. Tronto in particular noted that “by emphasizing that humans need the help of others in coming to develop their capacities, and in suggesting the fundamental importance of allowing all people to develop their capacities, Nussbaum’s notion of capabilities can be used to explicate the meaning of needs within the context of a theory of care.” Similarly, Spring has argued that “a relational, pluralistic, care oriented, capability-based conception of rights…highlights the transformative potential rights have to foster the kind of caring social relationships we correctly fault traditional rights theory for

87Tronto, n18, p140. Emphasis added.
ignoring or discouraging”\textsuperscript{88}. This will provide an interesting theoretical perspective upon which to explore critiques of the individualistic nature of the law— in particular, the MCA— in relation to carers, and to suggest more nuanced legal responses. It also provides a solid basis for human rights theory, as will be discussed in the ‘Legal Approach’ section below. As Nussbaum discusses in her article ‘Capabilities and Human Rights’\textsuperscript{89}, the approach “looks at people one by one, insisting on locating empowerment in \textit{this} life and \textit{that} life, rather than in the nation as a whole”\textsuperscript{90} and furthermore that “it is concerned with what is actually going on in the life in question; not how many resources are sitting around, but how they are actually going to work in enabling people to function in a fully human way”\textsuperscript{91}. This provides the basis of a relational theory of justice which emphasises a contextual approach, looking at capabilities rather than starting from the paradigm of rational individualism.

\textbf{1.2.3 Capabilities and the Social Model of Disability}

Attentiveness to the social situations of people with disabilities, as operationalised by the social model of disabilities, highlights the areas in which the state does have an impact on the experience of impairment and can shatter the illusion that autonomy is protected by the non-interference of the state. Aligned with a relational approach to autonomy, and a theory of justice which is premised on this such as the capabilities approach, such an understanding can give substance to state obligations which are responsive to this. Such a contextually focused approach calls for attentiveness to the actual experiences of individuals and the way in which their particular capabilities can be facilitated— or, conversely, negated— by social structures and institutions. Importantly, the capabilities approach can side-step distracting debates about the causes of disability, seen in the discussion of the social and medical models above, and instead focus on the multi-dimensional experience of disability.

\textsuperscript{88} \textit{Spring, n25 p121}
\textsuperscript{89} (1997) 66 (2) \textit{Fordham Law Review} 273-301.
\textsuperscript{90} \textit{Ibid.} p285.
\textsuperscript{91} \textit{Ibid.}
This shared affinity and complementarity between the social model of disability and capabilities approaches has been noted by authors such as Burchardt\textsuperscript{92} and Terzi\textsuperscript{93}. However, whilst both approaches can highlight background social, political, environmental or cultural obstacles to the achievement of capabilities, “concern for justice seems to require going beyond merely a critical approach to the hurdles society can place against the disabled, to a question of what further steps can be taken”\textsuperscript{94}. The capabilities approach requires a focus not just on the social, environmental, political and economic context, but importantly emphasises the need to situate such considerations within a particular individual. It is thus not concerned with group rights in the abstract,\textsuperscript{95} but entails a focus on the societal obstacles facing a particular individual. In some ways then, this speaks to the concerns discussed above as to the social model and its potential to disengage from the actual experiences of individuals. As Wendell notes in critiquing the social model in this way, whilst people with a certain disability may have many experiences in common, “their social experiences, their opportunities, their economic welfare, and their status in their communities will have profound effects on how disabling their [condition] is…and on how they experience their disability”\textsuperscript{96}. The capabilities approach is a more contextually focused approach which seeks to avoid broad brush assumptions about particular disabilities or other characteristics.

One of the crucial aspects of the capabilities approach here is that it can serve as a device “to justify the making of political claims”\textsuperscript{97}. From the informational focus on a person’s actual

\textsuperscript{95} A. Sen, The Idea of Justice, n77, p246.
\textsuperscript{97} C. Baylies, ‘Disability and the Notion of Human Development: questions of rights and capabilities’ (2002) 17(7) Disability and Society, p735.
ability to achieve certain basic capabilities, ethical assertions can be made about the required form of measures or policies aimed to facilitate such capabilities. Consideration of structural and institutional relations is central to this. Nussbaum argues that the capabilities approach acts as an ethical paradigm which serves to argue for “the greatest freedom of functioning of our basic capabilities, justifying expenditures that allow people with disabilities to have access to that which they require to have the freedom to function and develop their capabilities”99. As a corollary of this, states have a duty to provide the social basis for central human capabilities if they are to actually achieve social justice100. This may require different approaches to the achievement of a similar goal, depending on background conditions and context pertaining to different people. In accordance with this, in relation to disability, there is a political duty to ensure that, so far as possible, “impairments do not disable”101 based on an understanding that given appropriate and adequate enabling conditions, individuals with intellectual disabilities can become fully cooperating members of society102. This is a particularly salient point which is the central focus on the second paper in this thesis, which looks at the dominance of a medicalised approach to cognitive impairment in mental capacity jurisprudence. In advocating a shift towards a more contextualised and multi-dimensional understanding of disability in this area, the paper utilises the capabilities approach in order to suggest alternative societal and legal obligations in terms of conceptualising and responding to cognitive impairments.

1.2.4 The Responsive State

Building on this understanding of state obligations as entailed by the capabilities approach, the approach taken in this thesis will draw on Martha Fineman’s concept of the ‘responsive state’. As discussed above, the relational approach to vulnerability, both universal and particular, has the potential of drawing together the insights from care ethics and disability studies in focusing on interdependence as a unifying concept, and challenges the idea that dependence compromises autonomy.

One of the central ideas in the emerging vulnerability debates is the idea of ‘resilience’ as a counterpoint to the experience of vulnerability. Akin to the idea of fostering resilience, Mackenzie has argued that the focus of responses to mitigate vulnerability ought to be informed by an overall background aim of fostering autonomy wherever possible\(^\text{103}\). However, Mackenzie has expressed concern that Fineman’s conceptualisation of vulnerability dichotomises autonomy and vulnerability and sees the vulnerable subject model as in contrast to the ‘myth of autonomy’ contained in traditional liberal theories. Here, like Nedelsky, she reiterates that autonomy as a value should not be rejected by a relational analysis, and instead what is needed is a re-conceptualisation of autonomy as relational, rather than the individualistic conception residing in liberal approaches\(^\text{104}\). This understanding illuminates the way in which the development and sustained exercise of the capacity for self-determination requires ongoing interpersonal, social and institutional scaffolding which can be thwarted by social domination, oppression and disadvantage; and that state has obligations to develop social, political and legal institutions that foster the autonomy of citizens\(^\text{105}\). This is central to the third paper in this thesis, which looks at the


\(^{104}\) Ibid. p35; J. Nedelsky, ‘Laws Relations’ n74.

\(^{105}\) J. Nedelsky, ibid. “It is therefore not just when our physical capacities are diminished when we need others. We are dependent on others for the social world that enables us to develop all of our core capacities” p28.
societal role in creating or exacerbating sexual vulnerability - which tends to be hidden by a focus on individualistic concepts such as autonomy and incapacity in the sexual capacity case law. Uncovering the societal role in facilitating sexual autonomy here opens up consideration of the ways in which responses ought to be framed and the contours of state obligations in relation to this.

As Iris Marion Young has suggested - an idea that will be central to this thesis - equality is more than just requiring people to be treated in the same way\(^{106}\). This depends on attentiveness to the different specific sources of vulnerability impacting upon the particular individual, and targeted responses to these which are aimed at facilitating autonomy. The capabilities approach is recognised by Mackenzie as providing “the most promising theoretical framework for articulating this claim”\(^ {107}\) and this understanding will form the basis of the exploration of the questions posed in the papers in this thesis. It is presented as able to attend to the specificities of individual circumstances, and “enables a fine-grained analysis of the meaning of equality and so the different sources of social injustice, inequality and disadvantage”\(^ {108}\). In utilising this approach, it is important to consider what types of personal, institutional and structural relations best foster autonomy, and to examine law and policy in the context of psychosocial impairment in order to consider whether, and how, these can be augmented so as to achieve these values. Whilst the papers in this thesis span quite different areas of the law in the context of mental capacity, central to them all is an exploration of both the way in which the law currently characterises cognitive impairments, through a critical relational lens; but also the way in which more contextual understandings, through interaction of personal characteristics (also shaped by context) and through those contextually derived factors that make up the individuals total life situation.” \(^ {p42}\).


\(^ {107}\) Mackenzie, n103,p33.

\(^ {108}\) Ibid, p50.
built upon the centrality of interdependence, can uncover different state obligations and alternative legal responses. The legal and policy realm is crucial in terms of furthering the theoretical discourse outlined above, as it is this that has a deep influence on our choices, entitlements and protections.
CHAPTER 2

2.1. Legal Context

There are various legal and policy tools which potentially impact on people with cognitive or psychosocial disabilities. The main focus in this thesis will be on the Mental Capacity Act 2005 and the way in which this assesses mental capacity and responds to individuals deemed to lack mental capacity. As noted in the introduction, mental capacity law is increasingly facing theoretical and practical criticism, and its foundational premises are coming under conceptual scrutiny following the shifting discourses that have accompanied the UNCRPD. In particular, the thesis will consider whether the legislation is cognisant of the relational realities of caring for and living with psychosocial disabilities. The papers will harness the core theoretical critiques outlined in the previous chapter in order to critically analyse the conceptual and practical application of the MCA. The concern here is whether the legal framework reflects the embodied reality of disability and moreover whether it facilitates appropriate responses. It will be suggested throughout that the MCA takes a primarily individualistic approach, focusing on inherent and medicalised ‘deficits’, and obscures many of the complex social, relational and power dimensions. As will be seen, such debates are beginning to gain traction in this context as the UNCRPD has been seen as potentially ushering in a new paradigm for approaching disability (including cognitive disability); one which is attentive to the lived experience of disability and which places state parties under an obligation to respond to this in order to ensure the protection of the human rights of such individuals. As such, contemporary debates in the context of mental capacity and disability law are fast-paced and are increasingly drawing on the empowering language surrounding the UNCRPD, which is slowly starting to creep in to domestic jurisprudence. The legal contours

of these debates will be noted in this section, before moving on to outline how these will inform the questions addressed and the approach taken throughout the thesis.

2.1.1 The Mental Capacity Act 2005

The Mental Capacity Act 2005 governs decision making on behalf of a person who is deemed to lack capacity. The MCA came into force in 2007 after a long and contentious 11 year period of discussion and drafting. In the Law Commission 1995 Report on *Mental Incapacity* various reasons were given for the need for reform. They pointed to the way in which the law governing this area was “unsystematic and full of glaring gaps” and has “failed to keep up with developments in our understanding of the rights and needs of those with mental disability”. Furthermore, there was perceived to be a lack of an effective framework for resolving disputes about the care of people without capacity or for legitimating or regulating the substitute decision making that regularly took place in practice. The social context was also deemed to be an important factor in pushing for legal reform, with the Law Commission pointing to the moves to community care, the ageing population, medical advances and a rights-focused law and policy agenda as being key social and political drivers for change in this area.

In many ways, the resulting legislation consolidated and codified the existing law which had developed through various cases. It is also supported by a Code of Practice which provides additional guidance and case studies to illustrate principles and sections in practice. One of the central claims that heralded the MCA, and which regularly appears in discussions of the MCA in academic and policy literature, is the idea that the legislation is ‘empowering’ for

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4 Ibid. Para 1.1.
5 Ibid. Para 1.5.
6 Para 2.31.
those with disabilities. The Act sets out five statutory principles which underpin the statute. These are that

- A person must be assumed to have capacity unless it is established that he lacks capacity.
- 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.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- An act done, or decision made, under this act for or on behalf of a person who lacks capacity must be done or made in his best interests.
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the persons rights and freedom of action.

Section 2 outlines the diagnostic element of mental capacity, outlining how “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.” Section 3 of the Act goes on to define what is meant by ‘unable to make a decision’ and, if a finding of incapacity is made, the Act further lays out that decisions must be made on the basis of a ‘best interests’ test.

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9 See, for example, Lord Falconer’s statement in the foreword to the Code of Practice; “it will empower people to make decisions for themselves wherever possible.” Department for Constitutional Affairs, Mental Capacity Act Code of Practice (London, TSO, 2007).
10 Mental Capacity Act 2005, s1.
11 S2(1).
12 S3(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable (a) To understand the information relevant to the decision
This framework will form the basis of the arguments presented in this thesis through exploration of different contexts in which the relational reality may clash with the terms of the statute. Ostensibly, the MCA presents a simplistic framework for making decisions on behalf of those who are deemed to lack mental capacity, but as will be seen, this belies the complexity of issues which fall to be considered in this context, and the appropriateness of this framework is increasingly being questioned.

2.1.2 The Medical Model in the Mental Capacity Act

A key finding of the House of Lords Select Committee was that best interests decision making is not always done in accordance with the statute, and that the wishes, thoughts and feelings of the individual (P) are not always prioritised; instead, clinical judgements and resource-led decisions often predominate.\(^{14}\) Evidence provided by Headway, a charity for brain injury patients, stated that,

“Staff defined a ‘best interests’ decision as a ‘clinical decision’—and just saw it as a matter of clinical judgment. From the moment of my sister’s accident it was as if she belonged to them, they were not interested in what we knew about her and her wishes. I can understand this in the immediate emergency but this went on for months and months, it was a constant battle.”\(^{15}\)

This ties in with a long-held dissatisfaction with the medical model of disability which has arguably dominated mental health and mental capacity law. A discussed above, the medical model of disability situates problems stemming from disability within the individuals flawed

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(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).

\(^{13}\) s1(5) Guidance on best interests given in s4.


\(^{15}\) Para 92.
mind or body. Disability, viewed from this perspective, is simply an “unfortunate state of functioning and being” with a resultant focus on biological cure or management of the condition or person. The medical model thus sees “diagnosis and classification functioning as ends”. Consequences and limitations stemming from the disability are thus seen as regrettable but inherent to the condition.

Legally, commentators have contended that the MCA embodies this way of conceptualising mental disorders. The statute foregrounds the existence of an impairment of, or disturbance in, the functioning of the mind or brain. This places an emphasis on medical diagnostic criteria. However, medicalised conceptions are invited into the assessment of capacity which places a high value on rationality. Taylor draws attention to how assumptions of rationality, independence and normalcy can produce wrongful and harmful views of disability and humanity of disabled lives. Capacity can in turn be questioned on “flimsiest evidence”. This narrow understanding of capacity can lead to a sterile and unsophisticated assessment which does not take adequate account of the relational nature of capacity, in that people’s decision making abilities are highly context dependent and can be undermined or fostered by situational factors. In the context of sterilisation, there is a long recognised tendency for professionals and judges to defer to a medicalised understanding of learning disability and “ignore crucial questions about the importance of men and women with learning disabilities leading socially valued lives and produced a deeply problematic conception of sexed

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17 Vehmas, op. cit. 209
19 S(2)(1).
identity”. Furthermore, through this narrow lens, “patients become understood in terms of physical, mental or emotional frailty and dysfunction” thus situating risks within the person with a cognitive impairment and eschewing a broader consideration of the various sources of concerns and the means by which to support the person to meaningfully access their rights and participate fully in society.

2.1.3 Best Interests

A key aspect of this medical model is the way in which responses to those deemed to lack capacity are framed in terms of their ‘best interests’. This Act provides guidance on ascertaining an individual’s best interests in section 4. Part of this relates to ascertaining the individual’s wishes and feelings;

4(6) He must consider, so far as is reasonably ascertainable—

(a)the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b)the beliefs and values that would be likely to influence his decision if he had capacity, and

(c)the other factors that he would be likely to consider if he were able to do so.

However, it is clear from the case law surrounding the Act that the wishes and feelings of the individual are not necessarily determinative of the outcome of the best interests assessment. In reality, many decisions are taken without any legal oversight, and in cases that do go to

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25 Backed by the ‘general defence’ in s5 of the MCA. This states that;
(1)If a person (“D”) does an act in connection with the care or treatment of another person (“P”), the act is one to which this section applies if—
(a)before doing the act, D takes reasonable steps to establish whether P lacks capacity in relation to the matter in question, and
(b)when doing the act, D reasonably believes—
the Court of Protection, there is a ‘confusing incoherence’ in the way that courts obtain and evaluate the evidence required under s(4)(6)\(^{26}\). The ‘balance sheet’ approach developed by the courts following *Re A* (*Male Sterilisation*)\(^{27}\), which involves weighing up the benefits and negative outcomes of choosing a particular course of action, shows that the views of P will just be one factor in the overall assessment. In *Re M; ITW v Z and M*\(^{28}\) Munby LJ provided additional guidance on how to ascertain the importance of P’s wishes in the overall best interests calculation. He noted the following as relevant:

a) The degree of P’s incapacity; for the nearer to the borderline the more weight must in principle be attached to P’s wishes and feelings

b) The strength and consistency of the views being expressed by P

c) The possible impact on P of knowledge that her wishes and feelings are not being given effect to

d) The extent to which P’s wishes and feelings are, or are not, rational, sensible and responsible and pragmatically capable of sensible implementation in the particular circumstances and,

e) Crucially, the extent to which P’s wishes and feelings, if given effect to, can properly be accommodated within the court’s overall assessment of what is in her best interests.\(^ {29}\)


\(^{27}\) [2000] 1 FLR 549, Para 560.

\(^{28}\) [2009] EWHC 2525 (Fam).

\(^{29}\) Para 35.
This indicates that P’s wishes are as such not always determinative\(^{30}\). Further limitations on the extent to which P’s wishes will be given effect to can be seen in the decision of Lady Hale in *Aintree v James*\(^{31}\). This case, which centred on when it is legally permissible to withhold life-sustaining treatment, signalled a resounding recognition of the centrality of the views of the individual as being “a component in making the choice which is right for him as an individual human being”\(^{32}\). This recognition of the importance of focusing on P as an individual and being attentive to his views represents a crucial step towards seeing individuals with disabilities as “subjects, not objects”\(^{33}\) and can be viewed as an important antidote to the medical model. This intense focus on the centrality of P’s views was evident also in the case of *Nottinghamshire Healthcare NHS Trust v RC*\(^{34}\). This case involved a 23 year old man who had been in prison but was then admitted and detained in hospital under the Mental Health Act 1983. RC was suffering from a serious personality disorder which resulted in him self-harming regularly. He was also a Jehovah’s Witness and had made a purportedly valid advance decision refusing certain medical treatments, including blood transfusions. In essence, the legal issue arising in this case was whether it was lawful for the doctors to withhold treatment in accordance with the advance directive, despite the powers which existed under s63 of the Mental Health Act 1983 enabling treatment to be given for the mental disorder without the need for consent. Mostyn J concluded that

“...
disappear for any reason, the advance decision would be operative. To impose a blood transfusion would be a denial of a most basic freedom. I therefore declare that the decision of Dr S [not to compel treatment] is lawful and that it is lawful for those responsible for the medical care of RC to withhold all and any treatment which is transfusion into him of blood or primary blood components (red cells, white cells, plasma or platelets) notwithstanding the existence of powers under section 63 MHA35.

This demonstrates a clear focus on the views of the individual, and is a stark reminder that just because a treatment can be compelled, does not mean that it should be- even if such an option will be likely to result in death.

However, in Aintree v James, Lady Hale was also keen to stress that nothing in the judgement changed the law as previously understood36, and that the person’s wishes will not always prevail37. Indeed, an objective best interests test remains- it is just that the subjective wishes and preferences of the individual are seen as an increasingly important component of this decision. Concerns have been raised on numerous occasions as to whether prejudicial ideas about the preferences and abilities of disabled people may be masked by supposedly objective assessments of best interests and clinical prognosis or diagnosis38. P effectively remains a medicalised subject in the best interests assessment. As will be discussed in chapter 5, this also throws public law issues into sharp focus, as the powers of the Court of Protection to challenge the options that Local Authorities or Clinical Commissioning Groups put on the table are curtailed. For example, as will be discussed further in Chapter 5, King J in ACCG v

35 Para 42.
36 Para 47.
37 Para 45.
MN[^39] firmly stated the principle that the MCA is only concerned with “enabling the court to do for the patient what he could do for himself if of full capacity, but it goes no further”[^40]. Thus, there is no scope for demanding particular treatments or services, as this is not a right afforded generally in health and social care[^41]. King J outlined how, if the court were allowed to consider where MN’s best interests lay first, before deciding the issue of funding options, this would entail the Court of Protection potentially “using a best interests decision as a means of putting pressure upon the ACCG to allocate their resources in a particular way”[^42].

Here, there is an important power issue facing those deemed to lack capacity under the MCA and it may be difficult to challenge options which they are not satisfied with, except by judicial review. We can here query the obligations which are placed upon states to respond to disability, and whether these are being actualised through the application of the law in this context.

Furthermore, it is important to question the extent to which wishes and feelings are engaged with in more than a tokenistic manner in assessing best interests. This is particularly evident in complex cases such as those involving people with anorexia nervosa. Munro[^43] raises this issue in discussing the controversial case of *Re E*[^44] which involved the question of whether to forcibly feed a 32 year old woman with a long history of anorexia nervosa. The conflicting values of personal autonomy and protection of E’s life were placed as central to this case by Jackson J, and the outcome of the case was that E could be forcibly treated in a specialist hospital. The consideration of E’s wishes and feelings is interesting here, as Jackson J stated that E wishes for a treatment plan that would lead inevitably to her death[^45], whereas a closer

[^40]: *Ibid* Para 52 per King J.
[^41]: *R (Burke) v General Medical Council* [2005] EWCA Civ 1003.
[^42]: *Ibid*.
[^43]: N. Munro, n26, p66.
[^45]: Para 115.
reading of the case suggests that E’s views were much more subtle than this. As Munro points out, much of the criticism surrounding the case was based on the idea that Jackson J had overstepped his authority by failing to adhere to E’s wishes and thus to respect her autonomy. However, upon reading the case E does not state that she wants to die, but rather that she wishes to retain control over her body. Similarly, in the case of Re L, King J was faced with a 29 year old woman with a long history of anorexia nervosa who had spent around 90% of her life over the last 16 years as an inpatient in various units. At the time of the case, L weighed around 3 stone and had a very poor prognosis. The question arose as to whether it is in L’s best interests to forcibly re-feed her. The medical evidence was that the act of inserting a naso-gastric or PEG tube, and the sedation to do this, would lead to almost certain death due to her frail physical condition and severely impaired liver function. As such, it was held that force-feeding was not in L’s best interests, and that it was lawful to withhold such treatment. L was clear that she did not want to die and there is some brief discussion of L’s desire to move to a nursing home. It transpired that she had been due to move to one previously, but the home withdrew its offer of a bed, to which L reacted by reducing her food intake and becoming dangerously ill again. Later on in the case, mention is made of L’s desire to stay alive and her hope of becoming strong enough to move to a nursing home. Further written evidence stated that L felt that if a nursing home place was secured and funding put in place, she would have the motivation to move forward. With this in mind, it is somewhat disappointing that this is not closely engaged in by King J, and it can only be said with hesitation that L’s will and preferences were being addressed here.

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46 N. Munro, n26, p66.
47 Ibid.
48 (2012) EWHC 2741 (COP).
49 Para 44.
50 Para 31.
51 Ibid.
52 Para 23.
53 Para 31.
closely with wishes and feelings involves a much more complex and nuanced appreciation of the subtleties involved, and it is not clear that the legal framework created by the MCA allows for or facilitates a consistent engagement at a more than tokenistic level at present.

2.1.4 Carers under the Mental Capacity Act 2005

One of the further areas of criticism which has emerged in debates surrounding the Mental Capacity Act is the extent to which carers’ interests are reflected and respected through the legislation. In line with much of the writings of care theorists discussed above, the contention is that the Act perpetuates an individualistic approach to capacity and care, and is not attentive to the lived reality of interdependence.

The House of Lords Select Committee Report on the post-legislative scrutiny of the Act has recently highlighted the concern that professionals are not always getting the required input from families and carers when making best interests decisions, and recommends that professionals need to be made aware of their responsibilities under the Act.\(^{54}\) Cases such as *London Borough of Hillingdon v Neary*\(^{55}\) demonstrate the way in which the MCA can be used as a tool to exclude families from involvement with best interests decisions. Evidence made to the Select Committee reflected this:

“Moira Fraser of the Carers Trust reported that families had the impression that "professionals pick and choose when to involve them". Furthermore, families who disagreed with the decision being made found they were excluded on the grounds that “they are not acting in the best interests of the person whom they care for”.\(^{56}\)

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\(^{54}\) House of Lords Select Committee, n14. Para 107.

\(^{55}\) [2011] EWCOP 1377.

\(^{56}\) House of Lords Select Committee, n14,Para 93.
Quite aside from issues such as the extent to which section 4(7) is complied with by practitioners\textsuperscript{57}, the pressing issue here is whether the statutory framework itself overlooks the reality of the caring relationship. As Herring discusses;

“At first sight this may appear a welcome statutory acceptance of the importance of carers’ views about what should happen to those they care for. However, it is important to note the restrictions on this. Most significantly, the carer may speak as to what would be in the incapacitated person’s welfare. Their views as to what would assist them as carers is not a relevant consideration, unless it can be ‘dressed’ up as in the benefit of the individual. So, if the carer can say ‘if my views on this issue are not listened to I will cease to care for the individual and hence it is in their interests that my views are accorded weight’, then her views can be taken into account. But it would not be permissible to take into account the carer’s views if she is saying that something would make her caring role much easier, if that could not be said to benefit the individual directly’\textsuperscript{58}.

Ultimately, the legal focus is on the individual who lacks capacity. Whilst this may seem the correct focus, given the perceived vulnerability of someone who is deemed to lack mental capacity, it is argued that this may have a negative impact not just on the carer but also on the person being cared for.

There is arguably some scope for recognising family carers under the MCA. It has been noted that s4 of the Act introduces a level of subjectivity into an otherwise “‘objective’ assessment of best interests”\textsuperscript{59}. In \textit{G(TJ)}\textsuperscript{60}, the narrow view of best interests, which focused solely on an


\textsuperscript{58} J. Herring, ‘Where are the Carers in Healthcare Law and Ethics?’ (2007) 27(1) \textit{Legal Studies}. p59.


\textsuperscript{60} In the Matter of G(TJ) [2010] EWHC 3005 (COP).
individual’s self-regarding interests (as advocated for by Samanta\(^61\)) was firmly rejected. The dicta from this case does support consideration of “[t]he actual wishes of P, which are altruistic and not in any way directly or indirectly self-interested, can be a relevant factor. Further, the wishes which P would have formed, if P had capacity, which may be altruistic wishes, can be a relevant factor”\(^62\). Donnelly suggests this shows the MCA approach paying more attention to ‘the lived experience’ of people lacking capacity\(^63\), which, from the perspective of this thesis, ought to be explored in more detail.

The valuable work of ‘informal’ carers in the care of people with cognitive or psychosocial disabilities ought not to be understated. As Arksey contends, without this indispensable work, the NHS and social care system would rapidly collapse\(^64\). Yet, as Keywood discusses,

“There while much early research on caring focused considerable attention on the ‘burdens’ of care-giving, it is now commonly accepted that caring can be emotionally trying and also empowering for both the person cared for and the care-giver; it can be economically draining when carers are compelled to give up or reduce their employment responsibilities to look after a relative, yet at the same time carers represent a vital economic resource for the state, which is relieved of the considerable cost of providing formal care to all adults and children with support needs”\(^65\).

It is also important to consider the burden which can accompany care giving for a family member. In the context of dementia, for example, this is often compounded when taking into

\(^62\) Para 56, Per Morgan J.
\(^63\) Donnelly, n59, p313.
account the emotional factors associated with coming to terms with the gradual decline of a loved one. Law and policy in this context can have a marked impact on the care giving relationship, directly and indirectly.

Herring has written widely on this area\(^\text{66}\) and argues throughout that relationships should be the focus of law and policy in this dimension, as opposed to an individualistic approach as characterised currently. Keywood has also written critically about the position of informal carers in the law\(^\text{67}\) in which the differing and sometimes conflicting role of carers is analysed and highlights the multifarious role of the informal carer - as proxy, advocate and gate-keeper. Keywood argues ultimately that;

“Whilst the increased visibility of carers in law reform proposals provides timely acknowledgement of the central role that carers play in supporting the welfare needs of others, such visibility presents challenges for both carers and care recipients, for the varied and overlapping roles anticipated for carers highlight the tensions and conflicts inherent in the caring role as it is currently construed, yet offer no obvious solutions as to how these may be resolved”\(^\text{68}\).

Similar reflections are put forward by Donnelly and Murphy in the context of Irish health care law, where they make the important point that whilst the day to day realities may not always mirror the legal framework, the “legal provisions are important not least because of the attitude which they reflect”\(^\text{69}\).


\(^{67}\) Keywood, n65.

\(^{68}\) Ibid. p357

Thus, the role of the informal carer is unclear and seemingly unappreciated by current mental capacity law and in practice. The informal carer often takes on a variety of vital roles in the context of health care law and policy, only to be comparatively ignored in other contexts. Relations are often central to the lives of all individuals, and being deemed to lack capacity does not deprive people of these needs and feelings. These discrepancies will be more closely analysed and critiqued through the ethic of care lens in Chapter 4.

### 2.1.5 The Deprivation of Liberty Safeguards

The Deprivation of Liberty Safeguards were introduced into the Mental Capacity Act 2005, via an amendment to the Mental Health Act 2007, in response to the decision of the European Court of Human Rights in *HL v UK*. The DoLS, designed to close a lacuna in the law known as the ‘Bournewood Gap’, purport to provide a legal mechanism through which the deprivation of liberty of an adult lacking capacity can be authorised and subjected to safeguards in conformity with the European Convention on Human Rights. However, data and commentary on the use of the DoLS reveals that their implementation has been far from successful, and has been blighted by critical reports highlighting their complexity, bureaucracy, potential for conflicts of interests, lack of clarity, poor training, delays and expense.

An issue which has beleaguered the DoLS since their inception is the requirement that before the safeguards are triggered, there must be a ‘deprivation of liberty’, the meaning of which is determined in line with ECHR jurisprudence. Despite the guidance emerging from case law

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70 (2005) 40 EHRR 32.
and the Code of Practice, there remained a sense that it was still not sufficiently clear in many cases whether or not a deprivation of liberty was occurring. Whilst the starting point in earlier case law post-{\textit{HL v UK}} emphasised the need to focus on the concrete situation of the individual, and criteria such as the type, duration, effects and manner of implementation\(^{72}\), more creative analytical concepts emerged emphasising purpose, normality and objections\(^{73}\) - factors which turn the spotlight away from the material situation and towards the individual and the consequences of the impairment. Much confusion ensued as questions as to whether or not P is objectively being deprived of his or her liberty appear to be elided with considerations of whether or not this is justified\(^{74}\). Such concepts came to a head in the leading judgement of Munby LJ in \textit{Cheshire West and Chester v P}, which further muddied the murky waters of the meaning of deprivation of liberty\(^{75}\).

Munby LJ reasoned that a comparator is necessary in these types of cases, as simply focusing on the concrete situation “does little more than describe a forensic process”\(^{76}\), and that instead the task should be to “identify what it is that we are comparing X’s concrete situation with”\(^{77}\). He contended that whilst in most contexts, the relevant comparator is “the ordinary adult going about the kind of life which the able bodied man or woman on the Clapham omnibus


\(^{73}\) See, for example, the lack of clarity stemming from the reasoning used in \textit{MIG and MEG} (2010) EWHC 785 (Fam) and the Court of Appeal judgement in \textit{P and Q} (2011). Considerations such as the effect of objection/no-objection; purpose; and relative normality are covered in some detail in the \textit{P and Q} judgement, however the reasoning is not always evident nor conducive to clarity.

\(^{74}\) See, for example, the rather hair-splitting discussion of motive, purpose and intentions in \textit{Cheshire West and Chester Council v P} [2011] EWCA Civ 1257, per Munby LJ, paras 44-47. Note that Lloyd LJ, whilst agreeing with Munby LJ’s judgement, noted the potential for future debate on this issue, para 119.

\(^{75}\) Charles J, in \textit{A Local Authority v PB and P} [2011] EWHC 2675, implied that perhaps the emerging concepts in \textit{P and Q} and \textit{Cheshire West} are missing the wood for the trees, stating that the importance of DoLS lies not in the meaning of deprivation of liberty, but instead in the requirements stemming from them, namely that the placement be in P’s best interests and the least restrictive alternative; factors which he notes can be “applied without the assessor or court getting tied down in the difficult, time consuming and essentially unnecessary task of deciding whether or not the implementation of a care regime constitutes a DOL” (Para 64).

\(^{76}\) Para 38.

\(^{77}\) Para 39.
would normally expect to lead” 78, such a comparison ought not to be made in the context of cases arising under the DoLS framework. He pointed out that the Court of Protection in such cases is dealing with adults with “significant physical and learning disabilities” whose lives are “inherently restricted” or “dictated” by their own “cognitive limitations” 79. As a result of this, he reasoned that the relevant comparator ought to be “an adult of similar age with the same capabilities as X, affected by the same condition or suffering the same inherent mental and physical disabilities and limitations as X”. The court must focus on “the kind of lives that people like X would normally expect to lead” 80. In essence, this approach seemed to require that rather than comparing the situation of P to that of a ‘normal’, ‘able-bodied’ adult, the judge instead must factor in the ‘inherent’ limitations that are ‘expected’ of people with a certain condition in determining whether they are objectively being deprived of their liberty. Much weight appeared to be placed upon the individual’s difficulties, as opposed to the wider limiting factors.

As will be discussed in Chapter 5, this reasoning echoed and cemented a medicalised approach to disability into the DoLS, and provides an opportunity to reflect on the medical model in mental capacity law as well as ways in which more nuanced and relational approaches can be crafted which are attentive to the structural barriers facing those with disabilities. Whilst the definition of deprivation of liberty has now been clarified to some extent by the Supreme Court 81, debates about the meaning of liberty are rumbling on, with the Millian concept of liberty being employed by Mostyn J to argue that a woman receiving care and support at home was not being deprived of her liberty 82. Furthermore, the DoLS are

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78 Para 102.
79 Ibid.
80 Ibid.
82 Rochdale MBC v KW [2014] EWCOP 45. Whilst the appeal of this case was allowed by consent by the Court of Appeal, Mostyn J has since argued that this was procedurally flawed and ultra vires, given that it was an appeal as to the merits of the decision and therefore a full hearing and judgement was required Rochdale MBC v KW
currently being reviewed in their entirety by the Law Commission and, as such, their future status is uncertain.

2.1.6 The MCA- An empowering legal framework?
This increasing ethical and legal complexity pervading the cases coming before the Court of Protection demonstrates that the MCA is struggling to capture many of the more nuanced theoretical aspects of disability that have been discussed in Chapter 1. The empowering focus which heralded the MCA is not being realised in many cases, and attention is not necessarily given to relational, structural and power issues underpinning the embodied experience of cognitive impairment. This criticism is not new, however, and similar points had been made by Carson in response to the initial Law Commission consultations in 1993. Carson highlighted various points which resonate with the core theoretical approach in this thesis. Importantly, he noted that

“Life is not so simple as mental disorder or no mental disorder, capacity or incapacity, although it is regularly portrayed by the law as being such. The Law Commission’s interim proposals, if implemented, would continue this dichotomous legal view of the world and avoid meeting the challenge or incorporating and rationalising legal developments such as misrepresentation, consent and undue influence into a more general law about when decisions made by anyone are validly made”.

Similarly, reflecting the power dimensions which permeate this context, Carson noted that there were “no proposals which will ensure that the implementation of the law will be actively monitored or enforced. It will, in practice, depend upon people with disorders and

[2015] EWCOP 13. The law here is now in a state of considerable uncertainty, particularly with regard to individuals receiving care and support in the community.


Ibid. p314.
disabilities, who will regularly be relatively powerless in comparison with their carers and service providers”⁸⁵. We are seeing vital recognition of this in recent cases such as AJ v A Local Authority⁸⁶. Similarly, the lack of procedural safeguards entailed in the MCA were highlighted in the evidence given to the Select Committee, with Fennell and Series stating that

“the informal and decision specific nature of the MCA should not blind us to the reality that a person may lose a tremendous amount of autonomy in their life without any formal court declaration”⁸⁷.

They also noted that the general defence in s5 provides professionals and family members “tremendous discretionary power to interfere with a person’s ECHR rights”⁸⁸. Again, this issue of discretionary powers for professionals and carers was something which Carson had highlighted in 1993, noting pithily that “the proposals will sort out the non-disordered peoples’ problems with disordered people, but that will not advance the cause of disordered people”⁸⁹. In essence, the concern is that the MCA has unduly focussed on providing a framework under which professional or carers decisions can get legal validation for proposed decisions, either through a declaration by the court, or by relying on the general defence in s5, which does little to address the undercurrents of power and inequality which pervade this area. The points expressed by Carson over 20 years ago are now more firmly on the academic and legal agenda. The scope for encompassing a less individualistic, and more socially and relationally situated view of P under the Mental Capacity Act 2005 is a matter that is gaining an increasing amount of attention following legal developments at an international level

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⁸⁵ ibid. p318.
⁸⁸ ibid. p633, para 10. Also see Fennell, n38.
⁸⁹ Carson, n 86.
which call into question many of the foundational underpinnings of the statutory framework. These developments and the debates which have stemmed from these will now be turned to, before outlining in more detail the way that this will inform the approach taken in this thesis.

2.1.7 The United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) can be seen as a key turning-point in the recognition of the rights of individuals with disabilities. It is significant in that it marks a recognition that “reliance on formal structures alone is not adequate to ensure full enactment of human rights…the convergence of formal and informal social forces is necessary for the roots of human rights to grow deep into social structures”\(^{90}\). The CRPD is an important milestone in this respect, as it demonstrates recognition at an international level of the centrality of law and policy in empowering people with disabilities. Indeed, the preamble and articles of the Convention are infused with the language of the social model and capabilities approaches\(^{91}\), echoing the need for equality and positive actions to achieve this. The Preamble, for example, stresses the importance of recognising that disability results from the interaction between persons with impairments and attitudinal and environmental barriers to equality, the need to promote and protect human rights for people with disabilities, including those who require more intensive support. The Convention is considered unique in that as well as setting out comprehensively the rights of those with disabilities, it focuses significant attention on the obligations of states to secure these. Obligations such as adopting measures to promote the human rights of those with disability; stopping practices which breach such rights; ensuring that the public and private sectors respect these rights; undertaking research and development of goods and services to promote and secure these rights; providing accessible information; and consulting with and involving


those with disabilities in the formation of law and policy. There is also a requirement of regular state monitoring of the implementation of the Convention at a national level, and to submit periodic reports detailing findings to the international Committee on the Rights of Persons with Disabilities.

For many commentators, the CRPD thus provides a timely and welcome catalyst to strengthen many of the claims emerging from the developing literature on the social model of disability. It reinforces and reaffirms the importance of enforceable rights and entitlements. More importantly, the ethos of the CRPD is very much about taking positive steps to enable rights to be protected. The UK, having ratified the CRPD in June 2009, is committed to taking concrete actions to comply with the Articles of the Convention, which span various aspects such as equality and discrimination, gender issues, children with disabilities, the right to life, access to justice, employment opportunities, privacy and liberty.

Article 12 is concerned with the right to equal recognition before the law for persons with disabilities and is seen as one of the pivotal articles in the Convention. The UN Committee on the Rights of Persons with Disabilities published a General Comment on Article 12 recently in which they affirmed its importance for those with cognitive and psychosocial disabilities and the need for states to holistically examine all areas of the law with a view to

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94 See UNCRPD Article 4, ‘General Obligations’.

95 We have seen the domestic courts gradually begin to grapple with the CRPD in judgements, see for example AH v West London MHT [2011] UKUT 74 (AAC) para 16.; A Local Authority v TZ (No2) [2014] EWCOP 973.

ensuring that people have opportunities to express or develop their will and preferences as well as having choice and control over their everyday lives. The Committee stated that Article 12 does not set out any additional rights but instead simply describes the specific elements that state parties are required to take into account to ensure equality before the law. However, this in itself is quite a radical step when considering the measures that the Committee foresees as necessary to ensure compliance with this. The General Comment outlines the importance of the concept of legal capacity for the exercise of civil, political, economic, social and cultural rights and also how, historically, the denial of legal capacity has led to people with disabilities being deprived of such rights through systems of guardianship and substitute decision-making. The Committee are keen to stress here that the conflation of legal capacity (comprised of legal standing and legal agency) with mental capacity (judgements about decision making skills) which has been used to justify systems of substitute-decision making or guardianship are to be abolished under the CRPD. In particular, and a clear reflection of the social model underpinning the CRPD, the Committee stress that

“Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.”

Instead of relying on such an approach, the Committee stress the need to provide support to exercise legal capacity, including supported decision making. As Bartlett and Sandland maintain, this approach “requires full and meaningful participation of persons with disability

98 Ibid. Para 1.
99 Ibid. Para 8.
101 Ibid. Para 14.
in decision-making...[and] thereby fundamentally alters the power dynamic that has prevailed in decision-making around the lives of persons with disabilities\textsuperscript{102}. This has provoked much debate at a domestic level about what this means in terms of the compatibility of the MCA with the CRPD\textsuperscript{103}.

Whilst these debates are undoubtedly important and of great significance in terms of compliance, this is not the central concern of this thesis. Instead, the approach taken here is to consider at a more conceptual level how the particular rights-model contained in the CRPD is cognisant of relational concerns and whether it can respond to these in a substantive way. This can also serve to flag up any areas where the domestic law is perhaps lacking, or where concepts within it can be re-configured to better respect the rights of persons with disabilities. The CRPD signals recognition of both the micro and macro levels of action needed to secure rights to people, and the need for states to be responsive in attending to background social conditions. As will be discussed in the next section, this conceptual shift can provide the legal vehicle for consideration of the relational aspects of the lived experience of disability and as such will inform much of the legal approach taken in this thesis. It is necessary to outline this in more detail and to elucidate how this can capture the theoretical concerns outlined in the previous sections.

2.2 Legal Approach

One of the innovative aspects of the CRPD is the shift in focus from state non-intervention and procedural rights to the need for states to address background conditions and obstacles to

\textsuperscript{102} Bartlett and Sandland, n30,p564.

facilitate and enable rights for those with disabilities. Indeed, many have commented on the fact that the value of the CRPD is not in creating new rights—many of the rights are already stated in other Conventions and human rights instruments—but instead resides in the shift in emphasis towards support and obligations. Quinn, probing the Convention a little deeper, suggests that the Convention represents “the latest iteration of a long extended essay at the international level about a theory of justice—a theory that is applied to disability to be sure, but one that is woven from a much deeper cloth and has universal reach.” He characterises the CRPD as an antidote to the “reductionist and essentialist picture in liberal theories of justice”– a concern shared by those writing from a relational ontology in the social model and capabilities contexts. Viewed from this perspective, the CRPD and discourse flowing from it opens up the space for broader consideration of state responsibility in relation to all citizens, not just those with disabilities. It may also provide the scope for more contextually situated and substantive approaches to justice which can recognise the realities of networks of interdependence, and consequences flowing from this in terms of rights discourse.

This shift in the conceptualisation of justice will be central to the approach taken in this thesis and will provide the foundations for critical examination of the way in which law currently recognises and responds to cognitive and psychosocial disabilities, and also the way in which the human rights framework can operationalise claims. Focusing on both interdependence and human rights is antithetical to the early work of many care ethicists who argued that the theories belong to different realms—rights being public, and ethics of care being private values. However, it is argued that when human rights are viewed in a relational or contextual manner, rather than merely as individualistic claims, the contrast with the ethic of care values

106 Ibid. p.57.
is not as stark as first presumed. As Nedelsky suggests, “Once rights are conceptualised in terms of the relationships they structure, the problem of individualism is at least radically transformed”\textsuperscript{107}. Similarly, rights will be seen as important “as a break on the dangers that might otherwise flow from a relational perspective”\textsuperscript{108}, particularly when there is a possibility that considerations of a ‘good’ caring relationship may overlook that needs of individuals within it. A related point is made by Nedelsky who notes that

“There will almost certainly still be people who want the kind of relationships of power and limited responsibility that the individualistic liberal rights tradition promotes and justifies. But at least the debate will take place in terms of why we think some patterns of human relationships are better than others and what sort of ‘rights’ will foster them”\textsuperscript{109}.

Such an understanding will underpin my legal approach. Human rights will be taken not just as narrow, procedural legalistic claims, but as fundamental capabilities to be actualised\textsuperscript{110}. The capabilities approach here will provide a starting point for suggesting that the human rights framework under the European Convention on Human Rights, and domestically under the Human Rights Act 1998, presents a primarily procedural approach to rights protection, and that instead a much more contextual and substantive approach is required. As Donnelly discusses, recognition of the way in which the state and the law has a role in facilitating individual autonomy and facilitating empowerment invites the development of a jurisprudence on positive rights\textsuperscript{111}.

\textsuperscript{109} Nedelsky, n108, p101.
\textsuperscript{110} See discussion of Capabilities in Theoretical Approach.
A major contribution of the CRPD will be in drawing attention to societal barriers to the
enjoyment of equal rights for people with disabilities, and so it is rightly seen as resonating
with the social model discussed above. One interpretation of the Convention, however, is to
see it as signifying a “radical social constructionist model” and as such, may be in danger
of glossing over the individual experience. However, the approach taken here is that the
CRPD provides a much needed focus on the individual and securing these rights to them
through attentiveness to their lived experience. One of the key concepts of the UNCRPD is
that of reasonable accommodation. This obligation is enshrined in the Convention in Articles
2 and 5, and strongly captures the practical requirements of substantive equality discussed
above. Reasonable accommodation requires that steps are taken “beyond embedding bald
discriminatory proscriptions in laws and policies” which will entail positive action to
ensure equality and the enjoyment of rights. As a concept, it operationalises the capabilities
insights by acknowledging the need to look not just to societal factors in the abstract, but to
focus on the particular individual and what steps ought to be taken to secure to them their
purported rights. Similarly, the General Comment highlights that “the type and intensity of
support to be provided will vary significantly from one person to another owing to the
diversity of persons with disabilities”, again suggesting that the Convention is not to be
interpreted as radically social constructionist, but reflects the concerns noted in the theoretical
sections above about the need to focus on the particular experience. Amartya Sen similarly
posits the importance of a capabilities approach which looks at individual, rather than group

113 Defined as “[N]ecessary and appropriate modification and adjustments not imposing a disproportionate or
undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment of
exercise on an equal basis with others of all human rights and fundamental freedoms”.
with Disabilities: The UN Convention on the Rights of Persons with Disabilities’ in M. Rioux, L. Basser and M.
115 Para 18.
capabilities. He argues that whilst the capabilities approach can have an influence on debates as to group rights, the crux of capabilities theory is to look at individual capabilities:

―Since groups do not think in the obvious sense in which individuals do, the importance of capabilities that groups have would tend to be understood, for reasons that are clear enough, in terms of the value that members of the group (or, for that matter, other people) place on the proficiency of that group. Ultimately, it is individual valuation on which we would have to draw, while recognizing the profound interdependence of the valuations of individuals who interact with each other‖116.

He goes on to state that ―to see them merely as a member of just one particular group would be a major denial of the freedom of each person to decide how exactly to see himself or herself.”117 These are important considerations that stress the importance of retaining a focus on the individual. Whilst those with cognitive impairments may face similar problems and obstacles to rights as capabilities, these admit of different degrees and people with disabilities are not homogenous. Whilst the law often applies to categories of human beings, such as the mental capacity or mental health legislation, the capabilities approach reminds us that we must also be alert to the actual effects of the legislation or policy on particular individuals within such categories. This is crucial to the approach taken in this thesis, as there is a danger that if a radical social model approach is taken to the CRPD, the differences in the experience of disability may be glossed over, and needs overlooked in the name of respecting choice.

Seeing the CRPD as a shift in approaches to justice invites reflection on the way in which laws and other institutions can similarly impact on the autonomy of individuals within society at a broader level- not just individuals with disabilities. Here, Fineman’s vulnerability thesis,

117 Ibid.
and in particular her work on the ‘responsive state’ is of particular importance. Fineman has developed her theory of vulnerability to call for states to develop structures to address inequality and disadvantage not on the basis of certain protected characteristics (as it common in many jurisdictions and rights documents, including the CRPD) but on the basis of the universal vulnerability that resides in all human beings in society. Universalism in this sense sees society as a “single group made of infinitely variable individuals”\textsuperscript{118} and calls for being attentive to, and responding directly to the actual needs of individuals as opposed to basing assumptions and actions on categorizations and dichotomies\textsuperscript{119}. In this way, vulnerability, from whatever source, potentially affects all of us in society and so is a universal concern. This calls for a questioning of the distinctions between capacity and incapacity which characterise mental capacity law, or categorisations stemming from a particular diagnosis\textsuperscript{120}. As Carson maintains, “life is not so simple as mental disorder or no mental disorder, capacity or incapacity, though it is regularly portrayed by the law as being such”\textsuperscript{121}. Bickenbach similarly states that “Eventually, the folly of this will dawn on people and we shall all joyously realize that we are all abnormal, disabled, impaired, deformed and functionally limited, because, truth be told, that is what it means to be a human being”\textsuperscript{122}. Instead, the state must recognise the variety of intersecting identities and societal factors at play and impacting on all citizens in society, and frame responses in a way which is attentive to situational vulnerabilities. This poses a significant challenge to the binary divide between

autonomy and capacity which permeates law and policy domestically at present, and calls into question the justifications for interference or non-interference that stem from this divide. How the state responds to these vulnerabilities is key to unlocking the potential residing in the CRPD. As Mackenzie has outlined

“A socially just state has an obligation to develop social, political and legal institutions that foster citizen autonomy. Of course, the state cannot (and ought not) require that citizens always exercise their autonomy well or wisely or that they make use of all the significant options available to them. Nor can the state guarantee that relations among citizens will always involve mutual recognition. A just state is, however, obliged to foster an autonomy supporting culture and to ensure that social institutions— including the family, educational institutions, businesses and social clubs— provide access to the resources and opportunities and support the kinds of social relationships that promote autonomy”123.

The law, and the judicial personnel in the legal system, are central to this potential social change through the implementation of the CRPD’s aims and embedding these into socio-legal debates. The tensions that legal implementation of these assertions will uncover will be discussed through the papers in this thesis and further elaborated upon in the conclusion with the aim of facilitating more focused debates in the future as to how a substantive approach to justice can be realised.

123 C. Mackenzie, in Mackenzie, Rogers and Dodds, ‘Vulnerability’, op. cit. p45.
CHAPTER 3

Outline of Papers

1. ‘What About Us? A Case for Legal Recognition of Interdependence in Informal Care Relationships’

As the number of people being cared for by relatives and friends rises, it is vitally important to examine whether legal frameworks surrounding care and treatment sufficiently account for the realities of informal caring. This paper undertakes such an analysis through the lens of care ethics, arguing that relational and contextual aspects of caring ought to be brought further to the fore. The Mental Capacity Act 2005 forms the central focus of criticism and it is suggested that the legislation and case law surrounding best interests decisions fails to heed the interdependence which permeates informal caring. In contrast to earlier care theories, however, the importance of retaining a focus on the rights and capabilities of individuals within the web of caring relationships is emphasised.

2. ‘People Like That’: Realising the Social Model in Mental Capacity Jurisprudence’

Through critical analysis of the law’s traditional response to mental disorders in mental health and mental capacity law, it will be argued that a medicalised model of disability has been predominant, and still permeates jurisprudence in this area. It will be suggested that insights from the social model and relational understandings of rights can highlight the ways in which wider contextual and structural relations can impact upon the lived experience of mental impairment. Moreover, an understanding of the various dimensions of mental illness can help elucidate how the law can respond effectively to structural, institutional, and contextual factors in order to facilitate the enjoyment of purported rights and values. In light of this, it will further be argued that the lingering precedence given to a narrow, medical view of cognitive impairment is outmoded given the more richly textured understanding of cognitive
impairments which has recently emerged. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has harnessed the insights from the social model of disability and the capabilities approach to justice, and will be presented as the legal articulation of such understandings. This article seeks to build upon these understandings of disability and social justice and argue for the need for a more responsive state and judiciary in addressing the concerns highlighted by the UNCRPD and embedding these into judicial discourse.

3. ‘Vulnerability and Capacity to Consent to Sex- Asking the Right Questions?’

The burgeoning body of literature seeking to conceptualise vulnerability has provoked new and interesting perspectives for legal and ethical debates. Commentators are beginning to explore the potential for vulnerability theories in various contexts and to challenge prevailing attitudes and accepted beliefs in doing so. This paper seeks to add to this growing body of discourse by examining the recent legal developments in the context of capacity to consent to sexual relations. It will be suggested that, viewed through the lens of vulnerability, the current judicial approach takes a narrow, individualised stance which obscures many of the situational and relational dynamics which interact and shape the landscape of consent to sexual relations. Moreover, and perhaps more importantly, it is argued that the current legal response here does not facilitate resilience and sexual autonomy, despite judicial statements to the contrary. Through uncovering the situational and pathogenic factors which are otherwise obscured by an approach hinging on the concept of mental capacity, the vulnerability approach opens up space for debates about the appropriate legal response to foster resilience and capabilities.
CHAPTER 4

What About Us? A Case for Legal Recognition of Interdependence in Informal Care Relationships

4.1 Introduction

Estimates place the number of informal carers in the UK at around 6.4 million\(^1\), saving the public purse around £119 billion per year\(^2\). The value of these informal carers, often family members, is not simply monetary\(^3\). Informal care allows the person needing care to continue living at home for longer, in turn enabling their community relationships to endure. Remaining in familiar surroundings, with family and friends, can also act as a buttress to identity for the person and help them to maintain independence for as long as possible\(^4\).

However, the growing body of literature on informal carers, conveys a sense of carers having unmet needs, being left to cope alone, and being viewed simply as a resource\(^5\).

In this paper, the “ambivalent way”\(^6\) in which the law views and utilises informal carers will be critically analysed in order to inform an argument in favour of a more nuanced relational approach. The theoretical basis of law and policy in this area will be explored, and it will be shown that, in the main, law and policy are underpinned by an individualistic approach. This

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\(^1\) NHS Information Centre, *Survey of Carers in Households 2009-10*, (December 2010).


\(^3\) I will use the phrases ‘family carer’ and ‘informal carer’ interchangeably within this paper. However, I do not use family in the closed sense of immediate relatives and recognise the myriad ways in which family can be constituted.


will be criticised for failing to reflect the realities of human relationships, and moreover caring relationships. Best interests’ decision making under the Mental Capacity Act 2005 will then be focused on more specifically, with a view to advocating an approach which reflects the relational actuality of informal caregiving within the family. The ethics of care will be presented as an approach which places contextual aspects of the caring relationship as a primary focus. At the same time, the imperative of keeping a watchful eye on the rights and capabilities of individuals within caring relationships to participate in and challenge decisions made will be acknowledged. The reality of care is that it is not experienced in isolation, and it is argued that an alternative discourse is needed, enabling room for inclusion of legitimate considerations which would otherwise fall outside the scope of an individualistic approach.

4.2 Concealing Interdependence

Criticism of the individualistic philosophy of health care law and policy is not novel. There has been considerable rejection by feminist and communitarian theorists alike of what has been argued to be a reductionist and atomistic view of the person promulgated by liberal theories and its counter-part in legal principles. The concept of the ‘self’ contained in traditional liberal theories has been criticised as being “individualistic, isolated, and ahistorical”⁷. According to some philosophers, liberal theorists have often assumed the existence of individuals in an “untenable vacuum”⁸ in which various societal aspects are overlooked. Sandel, for example, is heavily critical of exaggerated individualism⁹. He is disapproving of the atomistic individual presupposed by Rawlsian theories of justice, suggesting instead a holistic conception of the self which is both intersubjective and intrasubjective- one which sees community ties as morally relevant to the individual identity.

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He notes that often there will be “a plurality of selves within a single, individual human being”\(^10\) which exposes a more complex concept of the self than that residing in liberal theories\(^11\). The image of the individual promulgated in liberal theories is in many ways unlike the individual in society. As a result, our dependencies, obligations, responsibilities and relationships with others in society become almost obsolete in mainstream moral and ethical thinking. Instead, the focus is on zones of non-interference, as opposed to interrogating the moral quality of inter-personal actions. More importantly for the purposes of this paper, those who are not independent, atomistic, self-sufficient individuals are marginalised as attention is diverted away from the structural underpinnings of our relationships. Essentially, the charge against a liberal conception of the person entails a rejection of a restricted and impoverished view of our moral and social experiences\(^12\).

Many feminist theorists have been particularly strong in their rejection and criticisms of the liberal individualistic concept of the self. Naffine draws upon the image of the boundaried, atomistic self as akin to a “closed body bag”\(^13\) - situated in isolation as opposed to belonging within a community. This is problematic for some feminists as it effectively silences the voices of those who do not or cannot achieve the characteristics ascribed to the liberal ‘self’. But their critique points to a more general problem: a result of the liberal focus on the individual is that the less powerful are marginalised or ignored\(^14\). One focus of the feminist critique of liberal rights approaches is thus a “strategy of inclusion of those who might be

\(^{11}\) Similarly, MacIntyre has argued that this stark image of the individual unencumbered self results in the “unity of a human life becoming invisible”, and that consequently life becomes “nothing but a series of unconnected episodes” [A. MacIntyre, ‘The Virtues, the Unity of a Human Life and the Concept of a Tradition’ in M. Sandel, *Liberalism and its Critics.* n9, p126]
excluded from the liberal tradition”\textsuperscript{15}. This critique instead advocates a move away from ‘masculine’ accounts of the self and towards a relational approach which pays attention to “the ways that individuals exist within relations of social support and community”\textsuperscript{16}.

This dominance of the individualistic concept of the ‘self’ can be seen to be embedded in law\textsuperscript{17}. In health care law, the ethical principle of autonomy has been perceived as entailing many of the philosophical notions of the abstract, unencumbered individual\textsuperscript{18}. Legal principles regarding informed consent to medical interventions, for example, view family or other external involvement with suspicion\textsuperscript{19}. Ho perceives “a general concern that family involvement will muddle the patient’s decision-making process, such that a focused, individual decision is more valid and well-considered than a tainted one that involves the voices and considerations of others”\textsuperscript{20}. As Bridgeman contends,

“[t]he work of caring for dependents and emotional interdependency with our children, spouses, partners and families must remain concealed lest we appear not to be independent souls suited for the public world. Consequently, the nature of dependency, the responsibilities of those who care for dependents and

\begin{footnotes}
\item[19] See \textit{Re T (Adult: Refusal of Medical Treatment)} [1992] 4 All ER 645Per Lord Donaldson MR ‘A special problem arises if at the time the decision is made the patient has been subjected to the influence of some third party’, para 662.
\end{footnotes}
responsibilities of others, or the state, for those in need of care remains relatively unexamined"\textsuperscript{21}.

This is despite research by Gilbar suggesting that patients and relatives views reflect “a relational approach to patient autonomy”\textsuperscript{22}. He argues that the individualistic legal approach taken in English law does not correspond with experiences of patients and relatives, and as such the legal and bioethical reliance on such an approach should be reconsidered\textsuperscript{23}. Such research illustrates that individuals do often discuss their health issues with their family in order to obtain advice and guidance, and moreover that they may consider their family ties and responsibilities when making decisions. As Berger \textit{et al} found “many patients do not necessarily want their surrogates to adhere to specific treatment preferences … but instead wish them to respond dynamically to actual clinical situations in order to maximise their evolving, contemporaneous interests and to make judgements that integrate medical and non-medical considerations”\textsuperscript{24}. They further went on to describe how “some patients modify their preferences to accommodate their family members concerns and some give weight to the distress they anticipate their family will experience from unavoidable choices”\textsuperscript{25} and that “concerns held primary by patients may include minimizing emotional, financial or other burdens on a spouse or adult children, even if such a decision is not optimal in narrow health objectives”\textsuperscript{26}. In contrast to this, health care law appears to maintain a broadly individualistic approach to consent and autonomy. As Donnelly discusses, perhaps one of the reasons why the liberal conception of autonomy as non-interference - with its individualistic undertones -

\textsuperscript{23}ibid p233.
\textsuperscript{25}ibid, p48.
\textsuperscript{26}ibid, p50; See also R. Deber et al, ‘Do people want to be autonomous patients? Preferred roles in treatment decision making in several patient populations’ (2007) 10 Health Expectations, 248-258.
is so “enthusiastically received by the law is the ease with which this particular ethical concept can be converted into legal doctrine”\textsuperscript{27}. However, it is argued that this ease comes at the cost of nuance, and that the individualistic conception of the person fails to accord with the reality of human interdependence.

Whilst from a different conceptual and theoretical position than some more general critiques of liberalism, care ethics focuses more acutely on some of the gaps left in a purely individualistic approach to the law and policy, particularly in the context of care. Care ethics has gained significant and increasing attention in legal circles over the past couple of decades, with authors such as Herring\textsuperscript{28}, Bridgeman\textsuperscript{29} and Pettersen\textsuperscript{30} more recently advocating for legal recognition of the values underpinning this approach, with many others having been influenced by the insights from the literature. Stemming from the work of Carol Gilligan\textsuperscript{31}, the ethic of care has developed into a normative approach to law and policy which focuses on relationships and context as opposed to individualism and abstract reasoning\textsuperscript{32}. Noddings characterises, and criticises, the liberal concept of the individual as “the wrong start”\textsuperscript{33} and instead advocates a better start being built upon relation and encounter\textsuperscript{34}. At the heart of care theory is thus the inevitably and necessity of care and dependence at various stages of our lives- most clearly around birth but also to varying degrees throughout our

\begin{thebibliography}{9}
\bibitem{31} C. Gilligan, *In A Different Voice* (Cambridge Massachusetts, Harvard University Press 1982).
\bibitem{34} Ibid. p79.
\end{thebibliography}
lives- which traditional liberal theories cannot capture\textsuperscript{35}. Indeed, it has been suggested that “by excluding this dependency from social and political concerns, we have been able to fashion the pretence that we are independent”\textsuperscript{36}. As Yeates describes, “an analysis of the different facets of the legal status of carer…reveals that most of these roles are predicated on the capacity to exercise choice, a capacity that is often signally absent from carer’s actual experiences”\textsuperscript{37}. Care ethics, conversely, “has at its core a central mandate to care for the relationships that sustain life”\textsuperscript{38}. Building upon these insights in an attempt to explore care as a more general political theory, as opposed to a critique of liberal individualism, Tronto constructs care as a contextual theory requiring modification of an abstract approach to justice\textsuperscript{39}. At this more political level, care ethics “encapsulates a constructive critical perspective on the norm of independent citizenship”\textsuperscript{40} - one which perceives of actors as intertwined and interdependent and which structures policy and legal responses on the basis of this. Rather than being peripheral concerns, care and interdependence become central to societal responses. As Pettersen describes it, “the approach is to scrutinize real life

\textsuperscript{35} E. Feder Kittay and E K. Feder (Eds) The Subject of Care: Feminist Perspectives on Dependency(Maryland, Rowman & Littlefield, 2002).
\textsuperscript{37} Ibid. p438.
\textsuperscript{39} J. Tronto, ‘Beyond Gender Difference to a Theory of Care’ (1987) 12(4) Signs 644-663. Traditionally, care ethicists such as Noddings (1984) and Held (1993) have positioned themselves in opposition to a theory of justice which sits in contrast to care- namely, one which is abstract and built upon boundaried rights. See also H. Kuhse, P. singer and M. Rickard, ‘Reconciling Impartial Morality and a feminist Ethic of Care’ (1998) 32The Journal of Value Inquiry 452. “the caring ethic is best described in terms of how it differs from an ethic of justice”. However, as will be discussed later, this does not require a rejection of justice or rights per se, but instead invites a re-evaluation of how we conceptualise justice. See, for example, D. Engster, ‘Care Ethics and Natural Law Theory: Toward an Institutional Political Theory of Caring’ (2004) 66(1) Journal of Politics and J. Spring, ‘On the Rescuing of Rights in Feminist Ethics: A Critical Assessment of Virginia Held’s Transformative Strategy’ (2011) 3(1) Praxis 66-83. I take this view as the basis of my argument that care considerations can be aligned with considerations of social justice; an approach which allows for a much more responsive evaluation of current law and policy.
experience, and use this knowledge as a basis for developing analytical concepts and theories in order to better understand and handle what one empirically faces up to.\footnote{T. Pettersen, n30, p61.}

Whilst not exhaustive accounts, the above observations begin to give some understanding of the main recognised failures in a theoretical framework inspired by liberalism. These observations illustrate the need to broaden our scope of analysis if we want to ensure that the essential features of life and social interaction do not get “lost in translation”\footnote{R. Sandland, ‘Between “Trust” and “Difference”: Poststructuralism, Law and the Power of Feminism’ (1995) 1 Feminist Legal Studies p8.} into legal or ethical principles. As Shanley notes, “law shapes the way we conceptualise human relationships, we should make sure that the ‘tale told by law’ reflects an understanding of the importance of communal interdependence to both individuals and society”\footnote{M. Shanley, ‘Unencumbered Individuals and Embedded Selves: Reasons to Resist Dichotomous Thinking in Family Law’ in A. Allen and M. Regan, n7, p4.}. This can perhaps be most starkly illustrated in the context of caring relationships which are characterised by varying degrees of dependence and interdependence, reciprocal emotional needs and interwoven interests. In the following sections, policy and legal shortcomings of an individualistic approach to informal care will be explored in more depth.

4.3 Situating Carers

The very nature of informal family caring defies this caricature of the self-determining, self-sufficient individual. As a direct result of illness, age (young or old) and vulnerability, people are more likely to be dependent on others for care and welfare support; they are also often disempowered by virtue of this “in the sense that their ability to effect change on their own lives and environments may be more likely to be overruled or limited by the relationships of care and dependency that support them.”\footnote{R. Harding, ‘Legal Constructions of dementia: discourses of autonomy at the margins of capacity’ (2012) 34(4) Journal of Social Welfare and Family Law 425-442.} Dependence, viewed through the lens of liberal individualism, becomes a negative and undesired trait. Similarly, Dodds
contends that “human vulnerability and dependency have come to be viewed as evidence of a failing to attain or retain autonomous agency, rather than as conditions for agency and autonomy among humans”\(^{45}\). This obscures from dominant ethical debate those who are “legitimately dependent because of age, ill-health or other features of their lives”\(^{46}\). Whilst the intertwining of interests entailed in informal care remains antithetical to the norm characterised in legal and policy responses infused with the individual and autonomous self, the responses within these structures will remain impoverished and inappropriate.

However, it must be recognised that there has been a concerted effort in the past decade to enhance the rights of carers and draw attention to their interests in the political domain\(^{47}\). Dicta in *R (A and B, X and Y)*\(^{48}\) further stresses the importance of recognition of carers rights, namely to physical and psychological integrity in the context of carrying out physical care work based on Article 8 of the European Convention on Human Rights. The relevance of this in the wider context of informal caring is unclear and remains to be fully articulated, particularly with regard to the consideration of informal carers interests when making best


\(^{47}\) The British Institute for Human Rights (BIHR) published an accessible guide to carers on their human rights [British Institute of Human Rights, *Your Human Rights: A Pocket Guide for Carers* (2012) available at http://www.bihr.org.uk/sites/default/files/BIHR%20Pocket%20Guide%20for%20Carers.pdf [last accessed 8th Jan 2013]), and policy documents frequently express the need to see carers as partners in care and support carers’ interests in their own right. A key aspect of the National Dementia Strategy [Department of Health, *National Dementia Strategy: Living Well with Dementia* (2009)] and the Carers’ Strategy [Department of Health, *Caring About Carers: A National Strategy for Carers* (1999); Department of Health, *Recognised, Valued and Supported: Next Steps for the Carers Strategy* (2010); see also HM Government, *Carers at the Heart of 21st-Century Families and Communities* (The Stationery Office, 2008)] is the need for carers to be able to access support and information. To bolster such aims, the *Care and Support Bill* [Department of Health, *Draft Care and Support Bill* (July 2012) available at http://caringforourfuture.dh.gov.uk/] proposes a duty on local authorities to assess the carers’ needs separately to the care-recipient, and furthermore a duty to meet this need. Whilst this is laudable in principle, it is not clear that the provisions are sufficiently nuanced to appreciate the interpersonal, relational needs of the carer and cared-for. In effect, the proposed reforms perpetuate an individualistic division between carer and cared-for. The procedural division of services can obstruct the process of attending to individual and interdependent needs and choices and act as an obstacle to nuanced consideration of the needs of the care relationship as a whole and to the inclusive negotiation of interests in decisions being made.

interests decisions, which will be considered in more detail later. Despite this, insights from the social work literature depicts attitudes to informal carers as being centred on their utility as a resource, rather than as connected partners in care with a stake in decisions taken about care arrangements and medical decisions. Heavy burdens are placed upon informal carers without due regard to their competence to perform such tasks, and also the effects of such tasks upon them as individuals. Whilst there are positive aspects of caring for a relative, which are often given less attention in the literature, many disadvantages are apparent, such as the impact of exhaustion; physical and psychological and social problems and socio-economic implications. Hardwig argues that in this way, informal carers are treated unfairly— they are expected to provide support but their interests are often not acknowledged, let alone respected. There is also evidence that carers are reluctant to seek help as the focus is intensively on the person they are caring for. As such, the position of informal carers has been characterised as akin to “coworkers without employment rights”.

This lack of recognition of the carer as a rights-bearing entity is underscored further in the context of respite care. Here, the legal right to respite care attaches to the service user, rather than the carer. This is despite the fact that the ultimate beneficiary of the respite care is the carer. This has not gone unnoticed— as Mitting J stated in R (Hughes) v Liverpool City

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49 Such a view was reiterated in data collected by Barnes and Brannelly, leading them to conclude that “practitioners often viewed carers as a resource” [M. Barnes and T. Brannelly, ‘Achieving Care and Social Justice for People with Dementia’ (2008) 15(3) Nursing Ethics, p392].


51 N. Yannamani, A. Zia and N. Khalil, ‘Family Carers of People with Learning Disabilities: Common Themes Across Caring’ (2009) 8(11) Psychiatry, p441; Also Barnes and Brannelly, n49, p391. See also the findings from The Princess Royal Trust for Carers (2011) that:
- Two thirds of older carers have long term health problems or disability themselves
- Half of all older carers reported that their physical health had got worse in the last year.
- More than 4 out of 10 carers said that their mental health had deteriorated in the last year


53 Ibid.

Council⁵⁵‘the benefit to him [the service user] is indirect’ and ‘arises because his mother, upon whom the strains are otherwise intolerable, is given respite from having to look after him’⁵⁶. According to Yeates, ‘this legal nicety sidesteps the issue of articulating the opposition between carers and service users’ interests and hampers honest debate’⁵⁷.

A sense is now developing of legal and policy approaches that are one-dimensional and not sufficiently nuanced to appreciate or resolve the complex interplay of interests inherent in the caring relationship. The avoidance of sustained debate on the issue at a legal and policy level is unsatisfactory and betrays a sense of incompleteness in the rhetoric regarding carers’ ‘rights’. In the following section, the legal role of the family carer in ‘best interests’ decision making will be scrutinised in light of the deficiencies in theoretical and policy approaches discussed above, in the hope of moving the debate forward and away from the current “exclusionary attitude …towards the role of relatives”⁵⁸.

4.4 The Mental Capacity Act- ‘Us’ or ‘Them’?

Having seen the influence of individualism at a policy level, we now move to examine the more particular legal issue of the extent to which the ‘best interests’ decision making framework under the Mental Capacity Act 2005 compounds the problematic individualistic stance considered above. ‘Best interests’ is the gold standard to be attained in any decision made regarding a person found to lack capacity - yet one without any explicit normative moral guidance for consideration⁵⁹. As a conceptual and legal notion, ‘best interests’ has certainly not escaped criticism, having being described as “elusive and controversial”⁶⁰.

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⁵⁶ Ibid.
⁵⁷ V. Yeates, n54, p452.
⁵⁹ As Donnelly points out, it is difficult to identify a solid philosophical basis for health care decision making for those lacking capacity- M. Donnelly, n27, p176.
Interestingly, there is no definition of best interests in legislation or the attendant Code of Practice. The justification provided for this, contained in the Code of Practice itself, is that it is due to the sheer range and types of decisions which the Act potentially covers\(^{61}\), thus understandably making it difficult to legislate for all eventualities. Nevertheless, we can decipher shades of individualism underlying the best interests sections of the legislation.

Section 4 of the Mental Capacity Act outlines the approach to be taken in deciding on what is in the individual’s best interests. More importantly, s4(7) anticipates the consulting of others when making best interests decisions, with section 4(7)(b) indicating the requirement to consult anyone engaged in caring for or interested in the welfare of the person lacking capacity. It has been acknowledged that failure to involve significant others, with whom the cared-for person has a relationship, may be in breach of Article 8 ECHR\(^{62}\).

At first glance, section 4(7)(b) appears then to give some authority to the views of carers and relatives. Quigley, for example, suggests that this allows room for the interests of others around the person lacking capacity to be considered\(^{63}\). However, the section later goes on to emphasise that such views are only of importance in relation to finding out what is in the best interests of the person lacking capacity. The interests of the carer- contemporaneous or conflicting- or of the effect of the decision on the carer or the overall caring relationship are not relevant considerations. As Herring has argued,

“This is misguided - it is not possible to consider the incompetent person without considering the well-being of the incompetent person’s carer. The interests of the


\(^{62}\) *G v E, A Local Authority & F* [2010] EWHC 621 (Fam).

two are intertwined. No carer could possibly undertake the task of caring if every
decision which has to be made was solely on the basis of what is in the interests
of the cared-for. No one would want to be cared for in a relationship in which the
carer’s interests counted for nothing. The relationship of caring does and should
involve give and take”64.

Whilst it is suggested that the argument which Herring makes here - that nobody wanting to
be cared for in a relationship in which carer’s interests count for nothing – is not supported by
evidence and indeed may presume too much, it is an important point which ought to be
recognised and taken seriously by policy makers. Whilst it is not impossible to imagine an
individual who does not particularly care whether the carer’s interests are being considered,
the point is that a caring relationship cannot function well or justly if the care-giver is
overlooked and overburdened65.

Coggon, conversely, argues that “as a non-ideal construct, however, best interests’ is capable
of accommodating this. When we allow tacitly for ‘real world’ limitations we see that it is not
blind to the needs of others, despite its ostensible focus on the individual directly in question
at the time”66. One way in which the informal carer’s interests may legitimately be taken into
account, perhaps in the way which Coggon envisages, is if an argument is framed that the

64Op. Cit. Herring, Where are the Carers? n28,p70.
65See Pettersen, for example, who argues that “the normative value of care is related to the ideal of
contributing to the promotion of good, but it must be narrowed down in order to not entail self-sacrifice or the
sacrificing of the well-being of a third part. Care, the normative core of the ethics of care, can be portrayed as
a merging of the principle of non-maleficence when it is expanded to allow for certain types of interventions,
and the principle of beneficence when it is restricted to the prevention of systematic self-sacrifice and the
surrendering of the concrete others’ interests” T. Pettersen, ‘The Ethics of Care: Normative Structures and
Analysis, p221.
carer is unable to care for the individual then this might not be in the individual’s best interests. Such an argument was made in the case of *Re Y*\(^{67}\).

This case involved a 35 year old mentally and physically disabled woman who was incapable of understanding others’ needs but could express her own basic needs. Her older sister had the pre-leukemic bone marrow disorder Myelodisplastic Syndrome. She needed a bone marrow transplant, preferably from a sibling, to significantly prolong her life. The Court referred to evidence that *Y* benefited from her sisters visits and that it helped her maintain a link with the outside world. It was further submitted that if the application was unsuccessful then there was evidence that this would have an adverse effect on her mother’s health so that her relationship and contact with *Y* would be affected. Therefore it was of benefit to *Y* to act as donor. The Court also relied on the argument that disadvantages were very small and involved no real long term risks. As such, it was to *Y*’s emotional, psychological and social benefit to grant the declaration that she should be a bone marrow donor for her sister. The court emphasised that “the root question remains the same, namely, whether the procedures here envisaged will benefit the defendant and accordingly, benefits which may flow to the plaintiff are relevant only in so far as they have a positive effect on the best interests of the defendant”\(^{68}\). Such an approach was predicated upon the debates in *Re F*\(^{69}\) in which it was stressed by Lord Goff that whilst it may be good practice to consult relatives, the overriding consideration is the best interests of the individual patient.

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\(^{67}\) *Re Y* (Mental Incapacity: Bone Marrow Transplant) [1997] 2 FCR 172.

\(^{68}\) *Ibid.* Per Connell J.

\(^{69}\) *Re F* (Mental Patient: Sterilisation) [1989] 2 WLR 1025.
At worst, this approach can be seen as “tortuous”\textsuperscript{70}; at best, “inventive”\textsuperscript{71}. Instead of explicitly recognising the plurality of interests at stake, issues such as the interests of the sister in receiving the bone marrow, and gratitude from the mother and sister were viewed as aspects of the best interests of Y. Such an approach prevents the real reasons behind a decision from being openly reflected, which in turn denies an open basis for challenging the decision or more openly and transparently grappling with the undoubtedly complex issues at stake, such as relationality and obligations\textsuperscript{72}. Moreover, it is not clear if or when such reasoning will be applied by decision makers, leaving the carers in a position in which they rely on professional discretion to apply the capacity legislation in such a way\textsuperscript{73}. This is not to say that the outcome of the case is ‘wrong’ or that Y should not act as a bone marrow donor. The problem lies in the approach taken by the court, which sidestepped an opportunity to open up debate as to the more open appraisal of the various interests at stake.

In the more recent case of \textit{Re VW}\textsuperscript{74} the Court of Protection were faced with the issue of whether a lady with dementia could be moved to a care home closer to her son at his request. His aim, essentially, was to facilitate more frequent contact with fewer restrictions than were imposed at the time. In refusing this application, Macur J placed substantial weight on the importance of viewing benefit from the perspective of VW, rather than her son\textsuperscript{75}, and further on the evidence of Dr A, who is “unable to conceive that any living condition, no matter how physically superior to those in the present home occupied by VW will benefit her

\textit{Re VW; NK v VW} (2011) COP 27/10/10 11744555

Para 9. See also Para 13; “The sad fact of the matter is that NK lives at a considerable geographical distance from VW. His journeys to exercise contact with VW are difficult and costly. They are uncertain in that dependent upon VW’s moods, she may not be in a fit state to receive him. Those difficulties, unfortunately, are his, and I am not required to have regard to the benefits that would flow from the proposed order or directions to anyone other than VW”.

\begin{footnotesize}
\begin{enumerate}
\item A. Szerlectics, n60.
\item J. Coggon, n66, p224.
\item J. Herring and C. Foster ‘Welfare means relationally, virtue and altruism’ (2012) 32(3) \textit{Legal Studies}480-498.
\item The Code of Practice (2007) is not particularly helpful here as it similarly reflects the atomistic approach to best interests. See, for example, the discussion of Pedro at Para 5.7. The scenario, provided in order to assist those using and applying the legislation, presents the respective interests in such an unsophisticated way that an appreciation of the complex relational factors inherent in caring relationships is side-stepped.
\item \textit{Re VW; NK v VW} (2011) COP 27/10/10 11744555
\item Para 9. See also Para 13; “The sad fact of the matter is that NK lives at a considerable geographical distance from VW. His journeys to exercise contact with VW are difficult and costly. They are uncertain in that dependent upon VW’s moods, she may not be in a fit state to receive him. Those difficulties, unfortunately, are his, and I am not required to have regard to the benefits that would flow from the proposed order or directions to anyone other than VW”.
\end{enumerate}
\end{footnotesize}
emotional/welfare needs. In approaching the issue in such a unilateral manner, it is clear that arguments that family or carers interests are capable of being considered as part of the best interest’s analysis are not consistently substantiated.

Despite this, there are instances in the literature in which health care practitioners have considered and reflected the interests of carers and the enduring relationship in their decision making. Harding and Peel saw evidence of this in their study on carers, finding that 49% of carers felt that their needs were taken into account when considering the best interests of the person they cared for. Whilst this may be positive, there is no clear legal backing for such practices and, as such, no open basis for scrutiny of the resulting decisions. The lack of safeguards within the Act here denies the person deemed to lack capacity a clear route to challenge decisions made on a basis not envisaged or endorsed by the legislation, as well as leaving whose interests will be considered down to the discretion of the practitioner.

Interestingly, however, there is some appreciation of the interdependence entailed in caring relationships, as the Code of Practice states that;

“Para 5.47- S4(6)(c)of the act requires decision makers to consider any other factors the person who lacks capacity would consider if they were able to do so. This might include the effect of the decision on other people, obligations to dependants or the duties of a responsible citizen.

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76 Ibid
78 “In contrast [to the Mental Health Act 1983] [it might be thought surprisingly], there are no equivalent detailed procedures and safeguards stipulated anywhere for persons detained pursuant to orders made under the Mental Capacity Act 2005“ C v Blackburn and Darwen Borough Council (2011) EWHC 3321 (COP) Para 11 per Mostyn J; See also P. Bartlett, ‘The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law’ (2012) 75(5)Modern Law Review767.
Para 5.48 The act allows actions that benefit other people as long as they are in the best interests of the person who lacks capacity to make the decision. Best interests goes beyond the person’s medical interests.

For example, courts have previously ruled that possible wider benefits to a person who lacks capacity to consent, such as providing or gaining emotional support from close relationships, are important factors in working out the person’s own best interests. See Re A and Re Y.”79

Such recognition is indeed laudable. However, it is a matter of concern that no guidance is given as to what this means for decision making in practice, or how the balance of interests is to be achieved and resolved. It is noteworthy that Re A 80 and Re Y81 are mentioned, yet not discussed. This may of course be due to the great difficulty in elucidating any clear legal framework to guide decision makers from these cases- in which case, why mention them at all? These cases are complex and controversial and the principles arising from them are unclear. The Code of Practice is purportedly to advise and assist those acting under the remit of the legislation- thus including lay people such as relatives and carers. Indeed, in Re Y, it was emphasised that “this is rather an unusual case and that the family of the plaintiff and the defendant are a particularly close family”82. The inclusion of reference to this case in the Code of Practice, without explanation of its relevance, is thus a matter of concern and it is not envisaged that those relying upon the Code will be sufficiently clear about the reasons for alluding to these cases here. In essence, much is left to the discretion of the decision maker, which is of little assistance to both the person lacking capacity, and their carers.

79 Para 5.47-5.48.
80 Re A (Medical Treatment: Male Sterilisation) (2000) 1 FLR 549.
81 Re Y (Mental Incapacity: Bone Marrow Transplant) [1997] 2 FCR 172.
82 Per Connell J.
It is important to bear in mind the various individuals who will be making decisions for those lacking capacity—either knowingly or unwittingly. The legislation applies to family, friends and informal carers, not just health and social care professionals. Stanley and Manthorpe have highlighted the ease with which this is forgotten in debates about the application of the ‘best interests’ criteria, and the lack of “open dialogue” resulting from this. As a result, it is very difficult to discern how family carers themselves assess best interests, or the extent to which judicial offerings trickle down into practice. As they argue, “those receiving informal care in their own homes may be least accessible to such influences and much day-to-day care is shaped by interpersonal relationships between those providing and receiving care rather than by formal structures of care plans or Codes of Practice”. Dunn, Clare and Holland recently suggested the problematic nature of this, as “substitute decision making relating to day-to-day care and support will likely be more frequent and more pervasive (although less invasive and controversial) than substitute decision-making relating to medical treatment”. This is compounded by the lack of clear, tailored guidance available to informal carers. The Office of the Public Guardian has published a guide for informal carers and relatives on using the Mental Capacity Act. Whilst this is of undoubted utility to those in need of advice, it is simplistic and as such it does little to elucidate some of the areas of uncertainty highlighted here.

Interestingly, there is evidence elsewhere within the legislation of an at least implicit recognition of the social context of decision making. This is evident in the rather different

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84 Ibid, p45.
approach that is taken to research involving people who lack capacity— an approach which does not rely on a ‘best interests’ analysis. Case for example discusses how, in relation to research, interests of a third party- namely, society- are taken into account and explicitly balanced. The Mental Capacity Act states that the research must—

S31(5) (a) have the potential to benefit P without imposing on P a burden that is disproportionate to the potential benefit to P, or

(b) be intended to provide knowledge of the causes or treatment of, or of the care of persons affected by, the same or a similar condition.

This framework demonstrates an explicit balancing of the individual and society’s interest in research. This reflects the idea of person as a member of society and that society’s interests in research and advancement of knowledge may trump individualistic views of the person. Also, it implies recognition of the fact that individuals should not be prevented from being allowed to be involved in research just because they are deemed to lack capacity. Notably, the best interests test is absent from the framework, and an element of risk is permitted. Whilst not disputing the value of the approach taken here, it is questionable why there is recognition of the fact that the person is situated within a broader society, without recognising that often (although not always) the person is situated within a family and often being cared for by that family. Arguably, the ties between the individual and the family are much more direct and immediate than the ties between the individual and society, so the recognition of one relational aspect but not the other lacks clear justification. Moreover, the approach taken to


research does not entail an abandonment of the interests of the individual or a prioritising of society over the individual\textsuperscript{89}.

Why is this approach not taken ‘closer to home’? Clearly, the Mental Capacity Act does have the tools to give effect to relational values, albeit on a broad social scale, without losing sight of the vulnerability of those lacking capacity. If the law \textit{can} develop an approach which situates the individual in a broader context, and balances their needs (contemporaneous and competing) against the needs of the other without losing sight of the potential vulnerability of the person lacking capacity, why is this approach not taken in the informal care context? It is argued that in the family context, the ties are much clearer, much closer and much more direct.

4.5 An Alternative Approach?

These shortcomings apparent in the individualistic approach in the Mental Capacity Act reveal the need for a more sophisticated approach to decision making, one which recognises the complexities involved in the family context. The potential of care ethics, with its central concerns of context and relationship, can be explored as a viable alternative since an important part of this is recognising that interests within caring relationships are often entwined and decisions should not be taken without consideration of the impact that this will have upon those within the relationship\textsuperscript{90}. This then equips us with the analytical breadth to address the multi-faceted and admittedly complex nature of caring relationships and the interplay of interests within them\textsuperscript{91}. The focus becomes the preservation and protection of

\textsuperscript{89}Code of Practice Ch 11.
\textsuperscript{91}T. Pettersen, n30, p54.
good caring relationships\textsuperscript{92} albeit in ways which do not allow the carer to become ignored or over-burdened, that is “without care giving becoming a liability to one’s own well-being”\textsuperscript{93}.

Care ethicists such as Tronto, Sevenhuijsen and Engster have developed arguments for care as a social political concern and the values which should guide this\textsuperscript{94}. In terms of the values which Tronto advances as underpinning a political ethic of care, the current legal position in relation to carers of those deemed to lack capacity is unsatisfactory. The care ethics values of attentiveness and responsiveness require policy makers to be alert to such needs and respond to them accordingly. Attentiveness, according to Tronto requires that “caring becomes more prominent in social life” and involves making certain issues that are “currently obscured by their peripheral location” to be made central\textsuperscript{95}. Currently, the legal position and the Code of Practice have been shown to offer a simplistic view of informal family caring. Responsiveness requires more than simply inserting your own view of what you think person lacking capacity or their carer would want, but actually involving them and responding to their actual needs as opposed to perceived needs\textsuperscript{96}. Responsiveness, under Tronto’s model, also entails the recognition of vulnerability, and the moral consequences of it\textsuperscript{97}. This resonates with Fineman who similarly stresses the need to centralise vulnerability and dependency in responses to caring, and develops further the notion of ‘derivative

\textsuperscript{92}F. Kelly, n15,p390.
\textsuperscript{95}J. Tronto,ibid,p130.
\textsuperscript{96}ibid,p136.
\textsuperscript{97}“Vulnerability belies the myth that we are always autonomous, and potentially equal citizens...A political order that presumes only independence and autonomy as the nature of human life thereby misses a great deal of human experience, and must somehow hide this point elsewhere. For example, such an order must rigidly separate public and private life” ibid, p135.
dependency". Such dependency emphasises the idea that those who undertake caring become dependent on others, including the state, to provide the resources – material as well as structural - to enable them to carry out their role.

Competence is also a crucial value for analysing informal care provision through a care ethics lens. As Keywood discusses, many family carers are undertaking more and more complex medical tasks at home for their family member. Without support to do so, which comes from recognition of their interests and the realities of the informal care context, competence cannot be fully addressed. As Tronto argues “intending to provide care, even accepting responsibility for it, but then failing to provide good care, means that in the end the need for care is not met”100. The current approach to informal carers, viewing them as a resource rather than a partner in care, does not adequately equip them with the competence to care. Making decisions based upon the best interests of the person lacking capacity, without a thorough consideration of the impact of this upon the family carers abilities, and without their involvement or opportunity to balance the variety of interests prevents adequate scrutiny from the perspective of care ethics and good care.

The value of trust must also be acknowledged, since it “evolves around the willingness to establish and sustain connections, even when aversion, mistrust or fear for the unknown initially prevails. The establishment of trust demands moral effort”101. As a corollary of this, it is argued that transparency and openness should be regarded as central to a care ethics approach. A commitment to the value of trust entails transparency in the appreciation and awareness at judicial and professional levels of the inter-dependency and relational aspects of

100 J. Tronto, n94, p133.
informal caring. Explicit recognition of this in a visible way would enable discussions between the patient, family and healthcare professionals to take place in a more open and responsive way - and also, more importantly, allows decisions to be challenged on a more tangible basis.

The ethic of care can highlight the inadequacies of policies which fail to reflect the relational aspects of care. However, it is also salient to note that if we focus purely on relational interdependence, not only do we run the risk of essentialising those within the relationship in terms of pre-defined roles and obligations, we also run the risk of subjugating individual interests to the interests of the family as a whole. Relationships are not always benign. In addition to a strategy that asserts and values attentiveness, responsiveness, responsibility, competence and transparency, there must also be an explicit focus on the capabilities, or opportunities, of those within the relationships - to be involved in decisions which will affect them; to have their voice heard; to challenge and express disagreement; to have needs taken into account. Without a background conception of justice, care theory does not necessarily provide these opportunities.

I suggest that care ethics does not necessitate a rejection of rights per se, and that we can achieve a focus on care within a background conception of society informed by liberal frameworks, such as justice, democracy and equality. A vital addition to an ethics of care

102 Recognition of this, and advocating a justice dimension to care ethics, is antithetical to many early ethics of care theorists [See, for example, N. Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (Berkeley, University of California Press, 1984) 36-37; S. Ruddick, *Maternal Feminism: Toward a Politics of Peace* (Boston, Beacon Press, 1989) p131]. Early debates in the care ethics sphere were framed as viewing care and justice as dichotomous concepts, focusing in particular on rights as a masculine and atomistic concept. This unease with the place of rights within a care ethics framework still creeps into the literature [See Op. cit. Herring, *Where are The Carers*, n28].

103 M. Nussbaum, ‘Masking Dependency The Political Role of Family Rhetoric’ in E.F Kittay and E. K. Feder, *The Subject of Care*, n35. Spring has explored the potential of an integrated view of care and social justice in order to bridge the apparent gap between the concepts [J. Spring, ‘On the Rescuing of Rights in Feminist Ethics: A Critical Assessment of Virginia Held’s Transformative Strategy’ (2011) 3(1) Praxis, 66-83]. He builds upon Nedelsky’s contention that “once rights are conceptualised in terms of the relationships they structure, the problem of individualism is at least radically transformed”, [J. Nedelsky, ‘Reconceiving Rights as Relationship’]
response here is thus the placing of capabilities as a key legal and policy focus, rather than a more individualised concept of rights. By this, it is meant that that we should focus on the actual position that the individual is in and then consider whether they are capable of accessing their purported rights or furthering their interests, as a means to furthering social justice arguments. The focus on context and personal or societal obstacles to the achievement of rights as capabilities necessarily opens up the scope of analysis to include relational factors. Seeing rights in this way also allows us to reconsider how rights can foster caring relationships, bringing aspects to light which traditional rights theories can obscure. Whilst under a liberal rights paradigm, “it is up to citizens to accrue the material, social and emotional supports that make the exercise of those rights meaningful”\textsuperscript{104}, the capabilities focus instead entails scrutiny of societal, relational and material conditions affecting the actualisation of these rights. In moving away from viewing rights as “barriers that protect the individual from intrusion by other individuals or by the state”\textsuperscript{105} we can instead focus on the contextual and relational aspects of rights, such as how they structure relationships, in order to foster autonomy and capabilities\textsuperscript{106}. Rights retain their importance as means of protecting bodily integrity, bolstering claims to justice and in providing a wide scope of scrutiny of the opportunities to achieve goals\textsuperscript{107}. This is vitally important in the context discussed above, in which relational issues are left out of an exclusive focus on the interests of the person lacking

\textsuperscript{104}Dodds, n45, p502.
\textsuperscript{105}Nedelsky, n107, p98.
\textsuperscript{106}As Hankivsky describes, “uninformed by a care ethic, the conception of social justice will remain lacking- akin to an outline of a painting that has yet to be filled in. Care adds colour, dimension, texture, and perspective to the canvas”, O. Hankivsky, \textit{Social Policy and the Ethic of Care} (Vancouver, UBC Press, 2004) p31.
capacity in care and treatment decisions. More explicitly addressing and balancing the undoubtedly complex variety of interests at stake in decisions enables a much more reflexive and just approach in which background inequalities or obstacles to autonomy come under the spotlight. Whilst such considerations may factor in to decision making at present, the key to the approach advocated for here is the importance of bringing such factors to the forefront of jurisprudence in this context, in turn enabling a more inclusive and transparent interrogation of relevant interests. Here, care ethics and justice become mutually interdependent and each informs the response of the other.

4.6 Translating Theory into Practice

The contextual and relational nature of caring ought to be brought to the fore in our legal and policy responses, with an explicit acceptance of the fact that these factors may impact on how we make health care decisions. Compromise and inclusive negotiation are key characteristics in many decisions affecting families and the consideration of this is lacking in the current legal provisions. As demonstrated above, the current legal approach to decision making fails to fully appreciate such aspects of decision making or the fact that relationships endure beyond a finding of incapacity. A finding of incapacity should not act as an arbitrary boundary in this way. Suggestions as to how a legal approach could meet this body of criticism will follow.

It is perhaps problematic that the Mental Capacity Act 2005 and the Code of Practice potentially apply to such a broad range of people that more nuanced appreciation of contextual issues is difficult. However, this should not detract from the importance of providing usable guidance, tailored to the needs of informal carers, which anticipates and

\[\text{108} J. \text{Nedelsky, n107, J.Herring and C. Foster, n72; M. Minow, Making All the Difference: Inclusions, Exclusion and American Law (Ithica, Cornell University Press, 1990).}\]


\[\text{110 R. Gilbar, n22; J, Berger et al, n24.}\]
recognises the complexity of issues at stake and variety of situations in which best interests decisions will be required.

As discussed above, perhaps part of the problem relates to the outright privileging of ‘best interests’ of the person lacking capacity in s4(7), without concurrent recognition that such privileging can be at the expense of others with a stake in the decision. As Nedelsky puts it, “when the dominant metaphors turn our attention away from relationships, we cannot give either the relationships or the legal concepts that mask them the critical scrutiny they require”\(^\text{111}\). Recognition of this in the legislation and Code of Practice could be achieved through a clearer direction to consider and weigh the interests and abilities of those involved in caring for the individual lacking capacity and the impact of decisions upon the caring relationship. This would provide the space within which discussions of all of the relevant interests could take place, without the need to frame carers’ interests as parasitic on the best interests of the person lacking capacity. It would entail the plurality of interests being taken into account in an explicit way, which in turn provides a more open basis for discussion and challenge. Placing such a direction on a legislative footing would ensure that the level of considerations of wider interests was not left to professional discretion, and would further empower carers with a route to challenge professionals when they felt that such views were not being considered.

There has long been recognition of the “danger of giving legal force on the assumption that carers always make decisions that are best for the patient”\(^\text{112}\). It is agreed that it is incredibly difficult to expect a family member to divorce themselves from their own emotional ties and interests and view the interests of their relative in an objective and unbiased manner - an approach which the current approach in the Mental Capacity Act seems to require. Rather

\(^{111}\) J. Nedelsky, n15, p178.

than perpetuating this statutory fiction that the route of uncovering best interests can be achieved in this unilateral manner, and that carers can switch off other interests and focus solely on the ‘best’ interests of their family member, the legislation needs to grapple with the fact that a plurality of interests are at stake and balance these in a more open and transparent way. Carers should no longer be portrayed as a resource for helping to glean knowledge of the person lacking capacity, but should be seen as parties whose own interests and caring abilities will be affected by decisions.

Based on their research, Dunn, Clare and Holland advocate re-engaging with ‘best interests’ as a broad ethical principle, rather than as a procedural ‘check list’ style formality\textsuperscript{113}. This may provide the space needed for considerations which are lost in the procedural framework of decision making in the legislation, entailing an ‘all things considered’ approach to deciphering and balancing the relevant interests. The ‘balance sheet’ approach to best interests decisions may thus signify such a broad approach, as it is deemed to entail the consideration of “ethical, social moral, emotional and welfare considerations”\textsuperscript{114}. However, the guidance on best interests decisions and the balance sheet approach contained in the Practice Note and in case law still retains the focus on the benefits and disadvantages to the patient\textsuperscript{115}. It is suggested that instead we need a much more open and inclusive approach which is clear about what and whose interests are at stake, rather than defining others’

\textsuperscript{113} Dunn, Clare and Holland, n85.
\textsuperscript{114} Seen in Re MM (An Adult) [2007] EWHC 2003 (Fam) Para 99 Per Munby J.
\textsuperscript{115} Official Solicitor: Declaratory Proceedings: Medical And Welfare Decisions For Adults Who Lack Capacity Also see Thorpe LJ guidance in Re A [2000] 1 FLR 549 which directed a balance sheet approach to best interests. Whilst taking into account a range of factors, the approach is still solely focused on the best interests of the individual. However, see the dicta of Morgan J in In the Matter of G (TJ) [2010] EWHC 3005 (COP) in which he stated that the balance sheet approach has the effect of ‘considerably widening the matters which fall to be considered’. [Para 36]. He went on to state that “[T]he word ‘interest’ in the best interests test does not confine the court to considering the self-interest of P. The actual wishes of P, which are altruistic and not in any way, directly or indirectly self-interested, can be a relevant factor. Further, the wishes which P would have formed, if P had capacity, which may be altruistic wishes, can be a relevant factor” [Para 56] This is certainly encouraging, however the focus is still very much on P’s interests and attributing these in a way which includes others, rather than being open and explicit about the existence of other relevant considerations.
interests as simply an aspect of the individual’s best interests. Whilst doing so may reveal both contemporaneous and conflicting interests, it paves the way for a much more transparent debate which does not obscure the real reasons for the decision. Dunn et al suggest that on this approach, ‘best interests’ assessments “would be recognised as leading to a range of outcomes, many of which will be assessed as being sub-optimal and therefore requiring ongoing revision”\textsuperscript{116}. Indeed, such an approach is thus much more attentive and responsive to the interests of all concerned.

In a similar tenor to the discussions on interdependence, Hardwig has argued that when relatives are affected by a decision, justice and fairness require that they have a role in reaching this decision\textsuperscript{117}. However, he went further to contend that when a treatment decision dramatically affects the lives of the patients’ family, the interests of relatives might well prevail\textsuperscript{118}. In many ways, this approach which posits the family as the primary unit has echoes of the familist traditions of the China and Hong-Kong\textsuperscript{119}. In contrast to this, the approach advocated for here does not necessitate a commitment to the privileging of familial interests. Rather than placing duties and responsibilities by virtue of family membership, we need to focus instead on what is at stake in the decision- realising that ultimately the patient has a much greater stake in many respects than anyone else\textsuperscript{120}. A more appropriate response to the nature of interdependence in caring relations is thus to encourage a more open dialogue.

\textsuperscript{116} Dunn \textit{et al}, n85, p157.
\textsuperscript{117} J. Hardwig. ‘Is there a duty to die? (1997) 27Hastings Centre Report, p36.
\textsuperscript{118} Ibid. p35.
\textsuperscript{120} H. Lindemann Nelson and J. Lindemann Nelson, \textit{The Patient in the Family} (New York, Routledge, 1995). This similarly reflects the findings of Gilbar’s study (n22) which suggested that although individuals want involvement of family members, they also want to retain the final say over decisions. Like Coggon (n66) I agree that the injunction to focus on the person lacking capacity entailed in the direction to consider their ‘best interests’ reflects the fact that ultimately they will be most affected by the decision. So long as this does not prevent other considerations from being considered- and I don’t think it has to, provided some direction is given to consider other relevant interests- then this is an appropriate balance.
which recognises these elements, rather than continuing as though they do not exist, and which appreciates that other interests are at stake and ought to be recognised. In many ways we all compromise our individual ‘best interests’ in family or social situations. However, the threat may be greater for those who lack capacity, and the care and capabilities approach being advocated requires that we are alive to this risk and respond to it.

As has been highlighted above, the Act does have the tools within it to broaden the scope of analysis in such a way. The provisions governing research are not circumscribed by a ‘best interests’ analysis, but instead we see an approach infused by considerations of the individual as situated in society, and an explicit balancing of interests. Additionally, the research provisions are attentive to the vulnerability of those lacking capacity when wider interests are being brought into the balance, directing researchers to look for signs of objection.

Reform could thus be considered in light of the approach taken to research.

Key to the acceptability of moves away from a focus on procedural assessment of interests is the need to consider the capabilities of the individuals in these caring relationships when making decisions. In adopting more collaborative models of appreciation, negotiation and compromise it is essential that both carers and cared-for are given a voice. However, it is also important to ensure that views of the person lacking capacity are not readily dismissed, and that efforts are made to facilitate decision making. Collaborative decision making is being

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121 Donnelly similarly points out that “there is undeniable potential for conflicts of interest and for abuse in such decisions. However, it is also important to remember that people lacking capacity are not necessarily less ‘embedded’ in their families than people with capacity. Recognition of this may, in some situations, justify respecting the altruistic wishes of a person lacking capacity albeit that this must take place within the context of a broader ‘best interests’ assessment which takes all relevant factors into account” M. Donnelly, n109.
122 Mental Capacity Act 2005, s33(4).
123 Ibid. s33.
124 Ibid. s33(2)(a).
125 Donnelly discusses this in relation to G(TJ) “the speed with which Morgan J dismissed the possibility of Mrs G’s participation draws attention to the risks of a dismissive approach to section 4(4) based on what is ‘reasonably practicable’. This risk is that decision-makers will too easily dismiss on grounds of practicality the potential contribution of the person lacking capacity, especially where imaginative efforts are required to assist the person lacking capacity to participate.” M. Donnelly, n109, p313.
advocated for, as a means by which to allow open and accessible discussions on decisions and caring practices and the contemporaneous and conflicting interests inherent in this\textsuperscript{126}. As Benhabib has written, integration of values may not be achievable, but ethical practice is more likely to emerge from participation in environments which recognize and debate difference\textsuperscript{127}. Thus, the relational approach being advocated may possibly attract a similar decision in a case that a best interest analysis would, but would necessitate a much more open appreciation of the family dynamics and the nature of balancing and compromise which occurs within families\textsuperscript{128}. This would require, as a first step, judicial explicitness as to the plurality of interests when making declaratory statements as to best interests. As I have argued above, such openness and transparency is vitally important for enabling decisions to be challenged. The convoluted reasoning and mental gymnastics which permeated \textit{Re Y} detracts from this and prevents an open appraisal of interests and resolution of conflicts\textsuperscript{129}. Indeed, as it is clear that carer’s interests do figure in judicial and health care decisions, it is better to do so in a candid and transparent way\textsuperscript{130}.

\textsuperscript{126}The concepts of relational autonomy and supported decision making have gained prominence in legal commentary recently with regard to the literature on the United Nations Convention on the Rights of Persons with Disabilities 2006. This is a positive development in this context for emphasising the voice of the person lacking capacity and enhancing their capabilities in decision making. As Richardson discusses, “[a] relational approach tends to a supported decision-making model: autonomy, or its legal counterpart mental capacity, is not to be assessed in the individual in isolation, rather she is to be supported and helped” G. Richardson, ‘Mental Disabilities and the Law: from Substitute to Supported Decision-Making?’ (2012) \textit{Current Legal Problems} 1-22, p10.

\textsuperscript{127}S. Benhabib, \textit{Situating the Self: Gender, Community and Postmodernism in Contemporary Ethics} (Routledge 1992).

\textsuperscript{128}Koehn similarly outlines how “the care ethic contends that we will not be able to identify the conditions under which individuals can co-exist satisfyingly within a community if we fail to create a space in which we can hear from individuals in their own voices. If we simply impute positions to them; or if our methodology leads us to dismiss certain kinds of concern as morally irrelevant, impermissible or immature, then whatever ethical scheme we devise will fail to be satisfactory”, D. Koehn, \textit{Rethinking Feminist Ethics: Care, Trust and Empathy} (New York, Routledge, 1998) p27.

\textsuperscript{129}J. Herring and C. Foster ‘Welfare means relationally, virtue and altruism’ (2012) 32(3) \textit{Legal Studies} 480-498.

\textsuperscript{130}Talking Mats are perhaps one means by which such collaborative discourse can be facilitated in the context of dementia. “Talking Mats provides a framework whereby the needs and views of the person with dementia and their carer can be articulated and shared [enabling them to] jointly discuss and make decisions”, J. Murphy and T. Oliver, ‘The use of Talking Mats to support people with dementia and their carers to make decisions together’ (2012) \textit{Health and Social Care in the Community} p8.
Moreover, we need considerations of whether carers are being provided with support to enable them to carry out their caring activities competently. Looking at complex safeguarding cases such as *HBCC v LG, JG and SG*[^131^], there can be a tendency to emphasize the unsuitability of the family carer, without a corresponding focus being placed upon support (existing or future) to facilitate good care in the home[^132^]. Similarly, in *FP v HM and A Health Board*[^133^] we see a laudable effort in the Court of Protection to recognise the importance of family ties, but without any clear regard for the welfare of the wife and son and risks associated with the return to the family home of a man with dementia associated with alcoholism. Inclusion of such considerations is necessary in order to reflect the impact that caring has on those around the individual needing care. An approach is needed which acknowledges that caring relationships cannot function or thrive without background conditions enabling them[^134^].

Aside from legal procedural aspects, attention needs to be given to helping carers to consider their own interests and the contextual obstacles to this, which the research suggests is difficult for them to do in a relationship in which the interest of the cared for is repeatedly given precedence[^135^]. With the ageing population meaning that increasing numbers of older people will rely on care it is salient to note the impact that this will have on spousal carers. Attention should also be drawn to obstacles that older people more generally face in accessing justice and their conceptions of ‘rights’, as this will undoubtedly impact on how

[^131^]: *HBCC v LG, JG and SG* [2010] EWHC 1527 (Fam).
[^132^]: In the case of *CC v KK and STCC* [2012] EWHC 2136 (COP), Baker J similarly emphasised the importance of providing full information of support and care packages which would be made available depending on which choice the person made. The choice which KK should be asked to weigh up is not between the nursing home and a return to the bungalow with no or limited support, but rather between staying in the nursing home and a return home with all practicable support.” Para 68.
[^134^]: Holstein, Parks, Waymack, n4,p139.
[^135^]: As Dodds suggests, “The expectations of due care and competent exercise of skills presuppose that the social and institutional context for care and the resources required will permit the competent execution of the caring role” n45,p502.
older carers perceive and react to care and support needs\textsuperscript{136}. Traditional justice based models do not always capture these factors\textsuperscript{137}. It is vitally important then to provide assistance to enable carers to recognise, and to have the opportunities to communicate, their interests.

In practical terms, this would entail a supportive and collaborative approach, involving carers early on in decision making processes alongside those they care for\textsuperscript{138} and throughout, but also explicitly considering their interests and needs in an open and transparent way. This would guard against an approach which would place undue burdens or expectations on the caregiver without a clear appraisal of the consequences of this for the caring relationship\textsuperscript{139}. The care ethics values discussed ought to apply on micro and macro levels, necessitating that law and policy consider them in relation to how they affect carers at a policy level, but furthermore how this affects caring relationships on the ground. As Rummery points out, “carers are in a much stronger position to be able to be attentive, competent, responsive and take responsibility for people if they entered into caring relationships on a basis which enables them to exercise choice over which elements of care they provide and how”\textsuperscript{140}. The focus of reforms here should thus be on “empowerment rather than non-interference”\textsuperscript{141}—both for carers and for the person being cared for.

4.7 Conclusion


\textsuperscript{138}Yannamani et al. n51, p442.

\textsuperscript{139}Hankivsky, n106, p120.


This paper has considered the shortcomings of the current individualistic approach taken in law and policy as it affects family carers. It has been suggested that the current approach fails to regard the interests of carers and the relationship as a whole as a legitimate considerations in decision making. The relational approach advocated for ought not to be framed as a move towards giving precedence to third party interests. The real issue is that the current legal and policy approach, focusing on procedure and ‘best interests’, is not sufficiently nuanced enough to appreciate the realities of caring. The decision making criteria “oversimplifies a process that is complex, dynamic, personal and even idiosyncratic and tends to de-emphasize other ethically valid considerations, including morally relevant emotions and virtues such as mutual responsibility”\(^{142}\). The problem is thus with unsophisticated decision making frameworks- whether they place decision making discretion in the hands of the family, or in the hands of health care professionals.

Challenging legal individualism will be an important starting point for progress here. Yet relational approaches may be difficult to translate into legal doctrine. As Skaerbaek contends, “not one ethical approach can cover the complexity of the challenging dilemmas of health and social arenas. It is, however, necessary that ethical theory and practice takes into account that all of us are embodied and gendered human beings, dependent and independent, constructing and being constructed by various factors in our personal and public lives”\(^{143}\). Combining complex ideas of individual and interdependent interests in a context infused with valid safeguarding concerns will undoubtedly be difficult for policy makers to grapple

\(^{142}\) Bergeret et al, n24,p51.
However, the law should not ignore the realities of informal caring and perpetuate an unsophisticated approach to decision making in this context.

An approach is needed which allows all parties with a relevant interest to have a voice, and crucially to have the impact of a decision being made upon them to be acknowledged as a relevant consideration. To do otherwise ignores the realities of the caring relationship, and renders the carer simply as a resource. Legal recognition or reforms which emphasise the need to consider wider interests will undoubtedly be an important step to achieve this. In essence, the changes would require a change in process, not necessarily outcome. However, this will not do all of the work. The matter is much more complex than simply being a ‘legal’ problem and more research is needed into the extent to which different factors impede open and inclusive decision making. Moreover, legal tests do not always operate on the ground in the way envisaged by policy makers\textsuperscript{145}, and so reform of the capacity legislation or Code of Practice would not necessarily effect the required changes. Wider professional and societal attitudes, and an overarching fear of diverging interests creating irreconcilable conflict, need to be challenged\textsuperscript{146}. What the law can do, however, is provide much needed safeguards for the open scrutiny of decisions. At present, the lack of explicit judicial and professional acknowledgement that wider interests are being considered - perhaps due to the need to fit decisions into the procedural framework entailed in the legislation- prevents this transparency. To quote a family carer “it’s all about transparency; we need to be true and honest with each other. We’re all in this together, aren’t we?"\textsuperscript{147}

\textsuperscript{144} See, for example, M. Donnelly, ‘Best Interests, Patient Participation and the Mental Capacity Act 2005’\textit{Medical Law Review} 17 (2009) 1-29 for an analysis of the problems entailed in participatory decision making.
\textsuperscript{145} Dunn et al, n85.
\textsuperscript{146} Ho, n7, p132.
\textsuperscript{147} J. Watson, ‘Supported decision making for people with severe to profound intellectual disability: We’re all in this together aren’t we?’ In C. Bigby & C. Fyffe (Eds.) \textit{Services and families working together to support adults with intellectual disability} (6th Annual Roundtable on Intellectual Disability Policy 2011). Victoria: Living and Disability Group, La Trobe University, p45.
CHAPTER 5

‘People Like That’: Realising The Social Model In Mental Capacity Jurisprudence

5.1 Introduction

The United Nations Convention on the Rights of Persons with Disabilities (2006) (UNCRPD) has been heralded as signalling a ‘paradigm shift’ in thinking about disability rights. Many commentators have lauded the potential success of this instrument in securing rights to people with disabilities by providing a renewed focus on the positive obligations of states to facilitate the enjoyment of rights. In the context of mental disability, this could have a profound impact on the lives of many with mental health problems or who are deemed to lack mental capacity.

Despite these grand claims, an analysis of the domestic case law in this context tells a different story. This paper will consider the entrenchment of a narrow, medical understanding of mental disability which permeates judicial discourse in many cases. A particularly stark illustration of this, namely the ‘relevant comparator’ test propounded by the Court of Appeal in Cheshire West and Chester Council v P, will be explored in more detail. This is presented as a strong manifestation of a medicalised understanding of the experience of mental disability, which situates the problematic aspects of disability firmly within the individual, and perpetuates the illusion that the state or society has no role in this. This is an attitude that the aforementioned UNCRPD has been praised for shifting away from - yet it clearly still resides in this context and is proving stubborn to move. As will be discussed, the ‘relevant comparator’ test has now been rejected by the Supreme Court; however, it serves as a

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particularly stark illustration of the pervasive role of the medical model in judicial reasoning and the ease with which it can be endorsed despite the changing rhetoric which has accompanied the UNCRPD. The recent Supreme Court judgements in *Cheshire West* and *Aintree v James* ostensibly signal a desire to shift away from the medical model, yet still present some ambiguities which suggest that the social model is yet to be legally embedded.

By focusing on the way in which the law has framed and responded to mental disorders, through the lens of the social model of disability and relational theories such as the capabilities theory of justice, this paper seeks to argue that despite the gains in political discourse surrounding disability, and mental impairments more specifically, these will not become a reality for many people without judicial awareness of the social situation from which claims are being made, and the need to facilitate the enjoyment of rights and access to justice. In light of this, it will be argued that the lingering precedence given to a narrow, medical view of mental disorder is outmoded given the more richly textured understanding which has emerged through theoretical insights focusing on the social and relational nature of the experience of impairment. Consideration of the broader dimensions intersecting in the experience of mental illness casts the spotlight on structural and systemic relations which can either facilitate or undermine the enjoyment of rights and fostering of core values such as equality and liberty. At the same time, critical developments in our theorising of the social model and capabilities theory highlight the importance of a focus on the particular and the contextual barriers for particular individuals. The law is in a position to impact upon the structural relations between people with mental disabilities and the state and, moreover, to positively enable access to rights in this vein. This is particularly evident in the context of mental health and capacity law, which manifestly structures the relationship between the state

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151 Ibid.
and the person with a mental disorder. Unsworth pointedly recognised this when arguing that “law actually constitutes the mental health system, in the sense that it authoritatively constructs, empowers and regulates the relationship between the agents who perform mental health functions”\textsuperscript{154}. The UNCRPD serves as a crucial vehicle for a facilitative approach to rights by harnessing the understandings gleaned from the social model of disability and the capabilities approach to justice within a legal instrument. This paper seeks to advance these understandings of disability and social justice and argue that there is still work to be done to firmly embed these understandings into legal responses. The need for a more responsive state\textsuperscript{155} and judiciary will be central to addressing the concerns highlighted by the UNCRPD and entrenching these into judicial discourse in the context of mental disabilities. Without judicial responsiveness in this regard, the hard-won gains envisaged by the UNCRPD will remain an ideal.

5.2 Legal Responses to Disability and Cognitive Impairments

It has been said that the dominance of the medical model has been one of the greatest barriers to the enjoyment of human rights by persons with disabilities\textsuperscript{156}. This is certainly borne out in a cursory analysis of the law’s traditional response to mental illness and capacity. The medical model of disability situates problems stemming from disability within the individuals flawed mind or body\textsuperscript{157}. Disability, viewed from this perspective, is simply an “unfortunate state of functioning and being”\textsuperscript{158} with a resultant focus on biological cure or management of the condition or person. The medical model thus sees “diagnosis and classification
functioning as ends”⁵¹⁵. Consequences and limitations stemming from the disability are thus seen as regrettable but inherent to the condition. This is perhaps an understandable stance, given that the very notion of disability evokes the idea of being ‘less’ than others at least in a biological sense. However, this is a rather one-dimensional view which ought to be scrutinised, particularly when it can have serious and far-reaching implications in terms of the enjoyment of particular rights.

In the context of mental health law there has been a long held dissatisfaction with the medical model’s grip⁶¹⁶. Due in part to the foregrounding of a medical diagnosis and a reliance on medical experts, it is not surprising, and perhaps understandable, that there is a high level of recourse in law to a medical model⁶¹⁷. A medical diagnosis of a mental disorder is the gateway to the provisions of the Mental Health Act 1983 (as amended), and legitimisation of detention for assessment or treatment is largely in the hands of medical professionals⁶¹⁸. Burns has argued that the “institutionalised medical language of mental disability…situates mental conditions squarely within an individual disease framework. Terms such as ‘mental disease’ and ‘mental disorder’ construct psychological, emotional, and behavioural conditions as innate, biological, pathological states independent of socioeconomic, cultural, and political context”⁶¹⁹. The narrow lens of the medical model focuses attention on control, care and treatment as a consequence of the mental disorder and defines these responses in a medicalised way. The focus of detention under the legislation is treatment, often by

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⁵¹⁷ The Mental Health Act 1983 (Amended 2007) ss2 and 3.


pharmacological means combined with psychotherapy, with the Mental Health Act circumscribing and legitimising the provision of such treatments\(^{164}\). Non-compliance with such responses is “perceived as an unacceptable act of deviance”\(^{165}\). The broad definition of treatment residing in the Mental Health Act 1983 and case law stemming from it widens the remit of the medicalised response to mental illness in this context, marginalising more nuanced understandings of the situational factors impacting on the experience of the impairment\(^{166}\). Service users report the negative impact that this has on professional understandings of their illness, noting that “it’s a deficit deviant model…they don’t see it as a social issue, it’s a biological thing full stop”\(^{167}\).

The Mental Capacity Act 2005 similarly foregrounds the existence of an impairment of, or disturbance in, the functioning of the mind or brain\(^{168}\) - without such an impairment or disturbance, the individual is unable to be deemed to lack capacity for the purpose of the Act. This again places an emphasis on medical diagnostic criteria. In various cases involving people deemed to lack capacity, we see that the judges often accept the professional’s view that the person lacks capacity without necessarily scrutinising the particular requirements outlined in the Act\(^{169}\). A recent worrying example of this can be seen in \textit{Re AA},\(^ {170}\) a case

\begin{itemize}
  \item[164] Mental Health Act 1983, Part IV.
  \item[166] See cases such as \textit{B v Croydon Health Authority} [1995] 1 ALL ER 683 (CA) and \textit{Reid v Secretary of State for Scotland} [1999] 2 AC 512 which demonstrate the broad definition of ‘treatment’ which will satisfy the requirements under Part IV of the Act. For example, in \textit{B v Croydon} we see that medical treatment for the mental disorder includes treatment of the symptoms of the disorder (as well as the disorder itself) and includes a range of acts ancillary to the core treatment. In this case, force-feeding was deemed to be medical treatment under s145 (1) of the Mental Health Act 1983. Similarly in \textit{Reid}, a broad definition of medical treatment was endorsed which was said to include things done under medical supervision to alleviate or prevent a deterioration of the mental disorder, or the symptoms of it.
  \item[168] Mental Capacity Act 2005 s2(1).
  \item[169] The Mental Capacity Act 2005, s3(1). See, for example, \textit{DH NHS Foundation Trust v PS} [2010] EWHC 1217 (Fam) Para 3, ‘PS is 55. As the Official Solicitor accepts she has “a significant impairment in intellectual functioning as a consequence of a learning disability” and thus lacks the capacity to make decisions about her healthcare and treatment. She also lacks the capacity to conduct or defend proceedings.’
  \item[170] [2012] EWHC 4378 (COP) (In Private).
\end{itemize}
involving the decision to undertake a Caesarean on a woman detained under the Mental Health Act 1983. The question of her capacity was briefly touched upon, but Mostyn J seemingly accepted that she lacked capacity based on her mental illness without scrutinising the requirements in s3. A rather interesting exchange is recorded in the transcript between Mostyn J and Counsel for the Official Solicitor which implicitly places a strong emphasis on medical understandings of mental illness:

MR. LOCK: … We invite your Lordship to approach it in this way. First of all the question is: does she have capacity? She plainly does not, because there is evidence of delusional beliefs. We have thought carefully as to whether we ought to ask your Lordship to adjourn this so that we can get further into capacity, but given that this is the treating psychiatrist and she has been in his care since at least June of this year, there appears to be evidence, therefore, based on a fair amount of background information; not like a psychiatrist who has seen a patient on one occasion and just gives a view where there is always a concern that there may be some background that the psychiatrist was not fully aware of. This appears to be a reasoned report based on a good knowledge of the patient. Therefore we do not propose to ask your Lordship to adjourn.

MR. JUSTICE MOSTYN: No, I agree with that. I am struggling to envisage a circumstance where a patient detained under section 3 as an inpatient with a diagnosed mental illness has got capacity. It is possible, but I am struggling to imagine how it could happen\textsuperscript{171}

As will be returned to in due course, it is imperative the judiciary grapple with and closely scrutinise assessments of capacity which rely heavily on clinical judgement, particularly

\textsuperscript{171}\textit{Ibid. Transcript of Proceedings}, p11.
when core rights are at stake. Cases such as this are not only an affront to the principles of the Mental Capacity Act 2005, but employ a dangerous misunderstanding that a diagnosis of mental disorder is sufficient for establishing mental incapacity. Whilst there is a presumption of capacity in the Act, the demands of impartiality may be difficult to achieve in practice for medical professionals. Taylor draws attention to how assumptions of rationality, independence and normalcy can produce wrongful and harmful views of disability and humanity of disabled lives. Capacity can in turn be questioned on the "flimsiest evidence". Preconceptions about the impact that a cognitive impairment can have on competence and functional ability can colour professional assessments. Conversely, Secker has argued that, "once the value laden, socially constructed nature of competence is recognised, the potential for biases in competence assessment becomes more readily apparent". This narrow understanding of capacity can lead to a sterile and unsophisticated assessment which does not take adequate account of the relational nature of capacity, in that people’s decision making abilities are highly context dependent and can be undermined or fostered by situational factors.

Such a response to cognitive impairment has similarly permeated understandings of best interests for people deemed to lack capacity. In recent evidence to the House of Lords Select Committee on the Mental Capacity Act, a concern was raised that best interests can seem to

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175 Bartlett, n13, p461.
be reduced to clinical interests.\textsuperscript{178} This was reflected in the Select Committee’s conclusions, where it was highlighted that clinical judgements or resource-led decision-making predominate.\textsuperscript{179} In the context of sterilisation, there is a long recognised tendency for professionals and judges to defer to a medicalised understanding of learning disability and ‘ignore crucial questions about the importance of men and women with learning disabilities leading socially valued lives and produce a deeply problematic conception of sexed identity.’\textsuperscript{180} Furthermore, through this narrow lens, “patients become understood in terms of physical, mental or emotional frailty and dysfunction”\textsuperscript{181} thus situating risks within the person with a cognitive impairment and eschewing a broader consideration of the various sources of concerns and the means by which to support the person to meaningfully access their rights and participate fully in society.\textsuperscript{182}

As will be discussed in turn, progress is being made as more nuanced theoretical understandings of disability and cognitive impairment have emerged in professional and legal discourse. However, a recent example of the narrow conception of cognitive impairment warrants closer scrutiny as it serves to highlight how the medical model is still active in judicial dicta, and further illustrates the consequences of this in terms of the protection of the

\textsuperscript{178} The Select Committee on the Mental Capacity Act, Revised transcript of evidence, 15\textsuperscript{th} October 2013, per Baroness Barker Q164, p26 [available at http://www.parliament.uk/documents/Mental-Capacity-Act-2005/cMCA151013ev8%20-%20Final.pdf].


\textsuperscript{180} K. Keywood, ‘Sterilising the Woman with Learning Difficulties - In Her Best Interests?’ in J. Bridgeman and S. Millns (eds.) \textit{Law and Body Politics: Regulating the Female Body} (Aldershot,Dartmouth, 1995).


\textsuperscript{182} This medicalised understanding outlined above is not limited to the context of mental health and capacity law, but can further be seen in other contexts such as best interests decisions relating to children born with disabilities. See J. Bridgeman, ‘Caring for Children with Severe Disabilities: Boundary and Relational Rights’ (2005) \textit{13 International Journal of Children’s Rights}, p110, where it is argued that in cases such as \textit{A NHS Service Trust v D} [2000] FLR 677, parents feel that doctors are not looking at quality of life in a holistic sense, but instead drawing on a medical perspective, from their own non-disabled experience. This is reiterated by McLean and Williamson who highlight that best interests decisions risk not being made from the perspective of the impaired infant but a third party- usually an able-bodied adult- who may all readily assume that all disabled experience is bad experience (S. McLean and L. Williamson, Ch7 ‘Countering Discrimination Against the ‘Disabled’: What good are ethics and law?’ \textit{Impairment and Disability: Law and Ethics at the Beginning and End of Life} (Oxon: Routledge, 2007) 183, p189).
rights of persons with cognitive disabilities. The case of *Cheshire West and Chester Council v P*\(^{183}\) in the context of the Deprivation of Liberty Safeguards (DoLS) is a stark example of judicial endorsement of a narrow, medical conceptualisation of mental disability. As noted in the introduction, this is of particular concern given the supposed ‘paradigm shift’ in political discourse in this context.

5.3 ‘The Kind of Lives That People like X Would Normally Expect to Lead’\(^{184}\)

*Cheshire West* centred around whether P, an adult with cerebral palsy and Down’s Syndrome, is being deprived of his liberty in a residential home known as ‘Z House’. Details about his care reveals that P frequently presented with challenging behaviours, such as refusing to move or comply, and stripping off his clothes and throwing objects. Furthermore, he has a history of continence problems and has developed a habit of tearing his continence pads and putting them in his mouth. In response to these behaviours, staff attempted various techniques, including a ‘finger sweep’ of his mouth to check for the pads, and also the wearing of an all in one body suit which prevents P’s hands from touching his groin area and so preventing him from touching the pads. The question arose as to whether some of the mechanisms used by staff, such as physical interventions and restraint, amounted to a deprivation of P’s liberty. If they did, then the DoLS\(^{185}\) would be triggered in order to provide a legal mechanism through which the deprivation of liberty can be authorised and subjected to safeguards, in conformity with the European Convention on Human Rights\(^{186}\).

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\(^{183}\) *Cheshire West and Chester Council v P* [2011] 9 November 2011 EWCA.

\(^{184}\) *ibid.* para 102.

\(^{185}\) Mental Capacity Act 2005, s4A, Schedules A1 and 1A.

The Court of Appeal, with the leading judgement delivered by Munby LJ, concluded that P was not being deprived of his liberty. The reasoning applied to this question by Munby LJ is certainly detailed and complex. Whilst aspects of the judgement such as the objective purpose, and the concept of relative normality he employed have attracted significant criticism, of greatest interest here is the attempt to carve out the ‘relevant comparator’ test. Whilst the central approach in the case has since been overruled by the Supreme Court, it is important here for our purposes as it serves to illustrate how a medicalised understanding of cognitive impairment has been drawn into judicial reasoning in this context at appellate level, despite the rhetoric that has accompanied the UNCRPD. It is argued that the approach taken is symptomatic of a medical model of disability and portrays a narrow view of the lived experience of cognitive impairment and the various factors which impact upon this.

Munby LJ reasoned that a comparator is necessary in these types of cases, as simply focusing on the concrete situation of the individual when considering whether they have been deprived of their liberty “does little more than describe a forensic process”, and that instead the task should be to “identify what it is that we are comparing X’s concrete situation with”. Munby LJ contended that whilst in most contexts, the relevant comparator is “the ordinary adult going about the kind of life which the able bodied man or woman on the Clapham omnibus would normally expect to lead”, such a comparison ought not to be made in the context of cases arising under the DoLS framework. He pointed out that the Court of Protection in such cases is dealing with adults with “significant physical and learning disabilities” whose lives


188 Para 38.
189 Para 39.
190 Para 102.
are ‘inherently restricted’ or ‘dictated’ by their own ‘cognitive limitations’. As a result of this, he reasoned that the relevant comparator ought to be “an adult of similar age with the same capabilities as X, affected by the same condition or suffering the same inherent mental and physical disabilities and limitations as X”. The court must focus on “the kind of lives that people like X would normally expect to lead”. In essence, this approach seems to require that rather than comparing the situation of P to that of a ‘normal’, ‘able-bodied’ adult, and focusing on whether the situation of P is a deprivation of liberty in light of this, the judge instead must factor in the ‘inherent’ limitations that are ‘expected’ of people with a certain condition in determining whether they are objectively being deprived of their liberty. This is of key importance in terms of triggering the DoLS-if the comparator is someone ‘like’ P, and it is deemed that their circumstances are therefore ‘normal’, then it is less likely that the situation will be deemed to be a deprivation of liberty, and thus the procedural safeguards necessary to oversee and challenge the circumstances are not triggered. This ignores the institutional and situational factors which can hinder or undermine liberty, and further perpetuates the illusion that the state and society play no role in the lived experience of those with cognitive impairment.

The ‘relevant comparator’ test is infused with comments situating the problematic consequences of illness or disability firmly within the person lacking capacity. Perhaps the most telling example of this is where Munby LJ states that:

Some adults are inherently restricted by their circumstances. The Court of Protection is dealing with adults with disabilities...adults with significant physical

\(^{191}\text{ibid.}\)

\(^{192}\text{ibid.}\)
and learning disabilities, whose lives are dictated by their own cognitive and other limitations.\textsuperscript{193}

Whether or not intended by Munby LJ, such comments resonate strongly with the central principles of the medical model of disability, which similarly situates problems stemming from disability within the individual’s flawed mind or body,\textsuperscript{194} and chimes with Munby LJ’s characterisation of disability and impairment as inherently restrictive. This narrow characterisation precludes sustained consideration of wider factors which may exacerbate the disabbling aspects of the impairment, such as cultural assumptions, resources, environmental and psychological factors. Instead, people with cognitive impairments who are deemed to lack mental capacity are “judged according to their peers”\textsuperscript{195} based upon a diagnostic classification and ‘inherent’ impairing consequences of this. Munby LJ’s casting of cognitive and other limitations as inherently restrictive presents an unsophisticated and one dimensional account of the totality of the lives of those who are deemed to lack mental capacity. Obfuscating the structural and institutional relations which impact upon the lived experience of people with mental health problems impedes a clear understanding of what is needed to actually secure the enjoyment of values, such as liberty in this context, to a person with disabilities. Attentiveness to such difference and to the background conditions external to a diagnosis that impact upon experiences is being called for by the social model. The social model demands a broader focus on the barriers preventing persons with disabilities from exercising legal capacity and living in the community\textsuperscript{196} and the framing of individual responses based on this. An approach predicated on “false universalising”\textsuperscript{197} prevents such

\textsuperscript{193} Para 120 (emphasis added).
\textsuperscript{194} Barnes and Mercer, n10, p2.
\textsuperscript{195} Hewitt, n40, p284.
\textsuperscript{197} Ibid; As Shakespeare and Watson contend, ‘[d]isability cannot be reduced to a singular entity: it is a multiplicity, a plurality’, and moreover that, ‘many people are simultaneously situated in a range of subject
scrutiny. In the case itself, this would have required the judges to focus not on the supposed inherent restrictions posed by a cognitive disability, but instead on the ways in which the societal and environmental factors impacting upon the individual are causing or exacerbating the disability- and more importantly, how these can be augmented so as to avoid or ameliorate this.

Furthermore, the judgement in *Cheshire West* raised worrying implications for human rights protections of people who lack capacity due to cognitive impairments. Disability is increasingly a human rights issue and in particular the right to liberty in the context of institutional care has been repeatedly asserted in Strasbourg. The ‘relevant comparator’ test in *Cheshire West*, however, could be seen to “abandon the idea that there are common standards, common liberties…or common protections that are available to everyone; and it implies that the mentally ill or the mentally incapable are entitled to fewer protections, to lower grade liberty”.

5.4 Mental Capacity in the Supreme Court

It is on this understanding of the universal nature of human rights that the Supreme Court allowed the appeal in the case and found that P was in fact being deprived of his liberty. Lady Hale delivered a resounding statement of the “universal character of human rights, founded on the inherent dignity of all human beings” and stated that this serves as a
starting point for decisions as to whether a person is being deprived of their liberty. Adding to this, important recognition was given to the fact that:

“Far from disability entitling the state to deny such people human rights, rather it places upon the state (and upon others) the duty to make reasonable accommodations to cater for the special needs of those with disabilities”203.

This clearly resonates with the underlying principles of the social model which emphasise the importance of recognising the social and environmental constraints upon rights such as liberty, but also the responsibilities that this generates to ameliorate these effects. Furthermore, the relevant comparator approach was rejected on the basis that it elided the question of deprivation of liberty with the issue of whether this was justified. As Lady Hale stated, “a gilded cage is still a cage”204. However, whilst the rejection of the relevant comparator test is to be welcomed, the Supreme Court decision does not necessarily reflect a wholesale shift towards judicial appreciation of the social model. The statement above about the universal nature of human rights is entangled with the assertion that:

“It may be that those rights have sometimes to be limited or restricted because of their disabilities, but the starting point should be the same as that for everyone else”205.

This perpetuates the idea that rights can be restricted on the basis of the inherent characteristics of an individual i.e. their disability, and focuses attention on such characteristics and the management of them, rather than externally on the social environment. Similarly, the recognition of the concept of ‘reasonable accommodation’ is laudable. However, the interpretation of this alongside the limited role of the Court of

203 Ibid.
204 Para 46.
205 Para 45.
Protection in best interests decisions (a point which will be returned to later) may delimit the potential for the legal recognition of, and response to, the external context in individual cases.

The potential for a shift towards an approach informed by the social model is even less clear when we look at the other recent Supreme Court case involving the Mental Capacity Act 2005: *Aintree v James*. This case, which centred on when it is legally permissible to withhold life-sustaining treatment, signalled a resounding recognition of the centrality of the views of the individual as being “a component in making the choice which is right for him as an individual human being”\(^{207}\). This recognition of the importance of focusing on P as an individual and being attentive to his views represents a crucial step towards seeing individuals with disabilities as “subjects, not objects”\(^{208}\) and can be viewed as an important antidote to the medical model. Yet it is unclear, following *Aintree v James*, to what extent the status quo has been affected. Lady Hale was keen to stress that nothing in the judgment changed the law as previously understood\(^{209}\) and that the person’s wishes will not always prevail\(^{210}\). Indeed, an objective best interests test remains; it is just that the subjective wishes and preferences of the individual are seen as an important component of this decision. Concerns have been raised on numerous occasions as to whether prejudicial ideas about the preferences and abilities of disabled people may be masked by supposedly objective assessments of best interests and clinical prognosis or diagnosis.\(^{211}\) P effectively remains a medicalised subject in the best interests assessment, as concepts of ‘futility’ and ‘prospect of recovery’ remain as signposts for decision makers, albeit ones that are meant to be viewed

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\(^{206}\) *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

\(^{207}\) Para 45, per Lady Hale.

\(^{208}\) Quinn and Degener, n9.

\(^{209}\) Para 47.

\(^{210}\) Para 45.

from P’s perspective. The ‘touchstone of intolerability’, itself a medicalised concept residing in much of the case law involving children, is noted by Lady Hale but not clearly endorsed or disapproved, leaving its legitimacy unclear. Concepts such as ‘intolerability’, ‘quality of life’ and ‘futility’ have been heavily criticised in the past by those challenging the medical model.

The case of RB v Brighton and Hove CC, following the other Supreme Court decisions, indicates that the medical model is still very much alive in the jurisprudence. The judgement in the case, which involved the deprivation of liberty of an alcoholic man following severe brain injury, is peppered with the language of the medical model, some of which is reminiscent of Munby LJ’s ‘relevant comparator’ test. It was asserted by Jackson LJ that “RB’s physical and mental disabilities are such that he is not currently capable of independent living outside an institutional setting.” Whilst regard is had to the requirement to take into account RB’s wishes, these are perfunctorily dismissed with little explanation.

The control and cure response, associated with the medical model, prevailed in this case without any exploration of the ostensibly more human rights orientated dicta from the Supreme Court in Cheshire West. The law is still presenting the relevant starting point as seeing coercive responses to mental disabilities as being appropriate in some circumstances, with the role of the law being to delineate when and how this is appropriate. Thus, whilst the Supreme Court decision in Cheshire West is to be welcomed for providing an important reminder as to the human rights of people with mental disabilities, it will not necessarily facilitate the legal shifts required to realise the social model.

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212 See, for example, Para 41.
214 See literature in n35 for discussion about the medical model in decision making at the beginning of life.
216 Para 80.
217 Para 81.
5.5 Situating the Social Model

In light of this, the need for a new perspective which captures the various dimensions of mental disability is clear. The critical importance of insights from the social model taking hold in judicial consciousness lies in the need for judges to challenge and question assumptions being made through a narrow medical lens. The social model of disability holds that much of the disadvantage experienced by those with disabilities or impairments is socially imposed rather than pertaining to their bodily or mental state\(^{218}\). In essence, the core of the social model, in its original formulation, is that societal structures and institutions, rather than impairments, cause disability\(^{219}\). Such an approach, denying a causal link between impairment and disability, has been subject to criticism, debate and refinement both from within the social model itself and also from external perspectives\(^{220}\). Commentators have emphasised the need to bring individual experiences back into social approaches to disability\(^{221}\) and frame a more refined and inclusive approach which considers and builds responses to disability on the basis of a variety of levels such as physical, psychological, societal, political and cultural\(^{222}\). As Shakespeare and Watson contend, “[d]isability cannot be reduced to a singular entity: it is a multiplicity, a plurality”, and moreover they note that, “many people are simultaneously situated in a range of subject positions. To assume that disability will always be the key to their identity is to recapitulate the error made by those


\(^{222}\) Shakespeare and Watson, ibid. 28.
from the medical model perspective who define people by their impairment.”

In essence, there is a need to situate the social model within the particular experiences and context of the individual.

This is particularly pertinent in the realm of cognitive impairments. Until relatively recently, little consideration was given in the social model discourse to potentially incapacitating cognitive impairments such as dementia and learning disabilities. This may be because there seemed to be a lack of affinity between a social model of disability primarily concerned with societal structures and physical disabilities, and less visible mental disabilities. Furthermore, as Gilliard et al point out in the context of dementia, “it is hard (and probably impossible) to argue that their impairment does not have a significant impact upon their lives.” However, commentators are engaging more with the interplay between cognitive impairment and disability. Certainly, there is a higher degree of complexity involved in aligning the concerns of the social model and cognitive impairments, which is a concern that has been relayed by mental health service users themselves. There is a more general concern that the social model of disability can inhibit an understanding of the lived experience of an impairment and marginalise other relevant factors affecting the individual in different contexts and circumstances. Thus, a polarised distinction between the social and medical perspectives is less tenable.

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226 Beresford et al, n13.
models is perhaps unhelpful and inappropriate. A bio-psychosocial model has been advocated for by commentators recently. Such an approach seeks to carve a ‘third way’ between the extremes of the social and medical models; one which recognises that “bodies are lived in, but in the social spaces that they inhabit.” Indeed, the need for a more nuanced understanding is particularly pertinent in the legal context.

Moreover, whilst the insights from a broad social model of disability can provide a way of conceptualising social, economic and environmental disadvantages and barriers faced by people with impairments, the practical implications or obligations stemming from this require further elucidation. As Barnes et al have suggested, “there is generally a much changed political rhetoric responding to disabled people’s claims…but promised improvements all too often fail to materialise.” Central to the claims in this paper is the notion that insights from the social model alone are necessary but not sufficient to effect real legal progress in this context. What the social model does do is provide the critical tools to scrutinise previously entrenched assumptions about the experience of cognitive impairment, and has the potential to shatter illusions that society and its structures and institutions have no role to play in this. However, the responsibilities stemming from these more nuanced understandings require further elucidation. The focus should thus be on whether the way the law is applied to the particular individual, considering the contextual situation from which the


claim is being made, fosters or undermines the achievement of such goals. In exploring this further, it is important to scrutinise concepts of justice and equality and the law’s characterisation of these through rights discourse in the context of cognitive disability. Through doing this, it will be suggested that capabilities theory, as an approach to justice, can provide the basis for more particular and contextual responses to previously obscured sources of disadvantage and inequality in this context.

5.6 Building on the Social Model - From Legalism to Capabilities

Attention was drawn to the need to create justiciable rights for people with mental illness through the work of Larry Gostin, then legal officer for MIND in the 1980s. The focus of his work was on the need for procedural safeguards in mental health law to off-set the power of the medical professions, and it was prominent in the debates leading up to the Mental Health Act 1983. Whilst this work was and is still highly valuable and instructive, there is a sense in which the ‘legalism’ which developed as a result of it has failed to produce the changes anticipated. As Fennell suggests, the focus has remained on procedural issues, with little scope to use the rights to challenge coercive treatment or secure support. The sense is that the resulting legal framework has simply created “medical freedom with the appearance of legal control,” with the ethos informing Gostin’s original work being “lost in translation into domestic law.” Viewed through the relational lens being advocated for here, which focuses on the external structures and institutions which can impact upon rights enjoyment, it is clear that this procedural approach has not provided an adequate conceptual framework.

233 Nedelsky, n6.
236 Bartlett and Sandland, n18, p347.
within which broader understandings have been able to be accommodated or responded to. Procedural safeguards do not necessarily invite the decision maker to consider whether or not wider structural and societal factors impacting upon the person foster the achievement of the right or value in question.

Such failings of legalism in the context of mental health law are echoed on a wider scale in general rights discourse. There is dissatisfaction with the procedural focus of rights instruments such as the European Convention on Human Rights, which Richardson claims is mainly concerned with the protection of individuals from unjustified interference.\textsuperscript{238} The Convention essentially contains public law, due process rights, to ensure that limitations imposed on protected individual rights are imposed only if they are “prescribed by law, intended to achieve a legitimate objective, and necessary in a democratic society”\textsuperscript{239}. However, such rights are of doubtful utility for those who are not in a position in society to meaningfully access or enjoy them. There is a widespread dissatisfaction with the limitations of the procedural face of rights-based legalism to address broader questions of social justice, or recognise and facilitate claims to access supports to enable rights to be valuable\textsuperscript{240}. Focusing on procedural aspects of rights tends to ignore the background conditions in which the rights instrument is being employed and so is questionable as a means for bringing discriminatory powers to attention, or “reversing the differential impact of pathogenic social forces”\textsuperscript{241}. Thus, as Kanter claims, “even when laws, policies and programs value equality, the valuing of people subjected to those rules, laws and programs cannot be assumed”\textsuperscript{242}.

\begin{itemize}
\item G. Richardson, ‘Rights-Based Legalism: Some Thoughts from the Research’ in McSherry and Weller, n88, p182.
\item This has recently been recognised in MH v UK [2013] ECHR 1008, see in particular Para 82. The ramifications of this across mental health and mental capacity law are as is as yet unclear.
\end{itemize}
This is particularly concerning in the context of mental health and cognitive impairments, where it has been suggested that the government has taken an essentially ‘Convention proof’ approach. Fennell outlines how, in the process of the reform of the Mental Health Act 1983, the government aimed for “the minimum restraint on compulsory powers consonant with Convention compliance”.

Similarly, the DoLS discussed above are deliberately tied to the Strasbourg Article 5 jurisprudence, effectively ensuring that the government need only comply with the Convention in their obligations in this context. Indeed, we saw above Lady Hale’s recognition of the need to recognise deprivations of liberty separately from their justification, as “a gilded cage is still a cage”. However, it is to be questioned whether a procedural check on this- ensuring that it is in compliance with the requirements of Article 5- makes the experience for the individual any less of a cage, or is able to adequately scrutinise or address the way in which the right to liberty may be facilitated. Whilst procedural protection entails an assessment of the individual’s best interests, it is not necessarily clear that this will be undertaken in a way which adequately scrutinises the way in which the social environment may be augmented to enable liberty, or that best interests assessments can give effect to the changes necessary to enable this. Indeed, acting in a person’s ‘best interests’ in this regard may serve to further gild their cage by “locking them into cycles of dependency and despondency” rather than focusing on the barriers to the achievement of particular rights for the individual. This is a point that will be returned to subsequently, however it is important here to highlight this given the concerns about the limited utility of essentially

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243 Fennell, n88, p20-22.
244 ibid.
245 Endorsed in House of Lords Select Committee Report, n32, Chapter 7.
246 P v Cheshire West and Chester Council and P and Q v Surrey County Council, above n 3, para 46.
247 G. Quinn and T. Degener, ‘Expanding the System: The Debate about a Disability-Specific Convention’ in Quinn and Degener, n9.
procedural Convention rights in contexts in which wider issues of social justice have a bearing on the actual enjoyment of such rights.

Such problems with the procedural face of rights have long been recognised and are tied to a wider concern about law’s ‘liberal legalist’ orientation which focuses on the denial of civil or political rights, without sustained recognition on a deeper level that such rights can also be “eroded or rendered meaningless if the bare necessities of life are missing”\(^{249}\). A broader understanding of the context in which rights are operating calls for a more substantive appreciation of the social, cultural and economic obstacles to rights enjoyment- in essence, a bridging of the gap between substantive and procedural rights. This resonates with the burgeoning literature on the capabilities theory and the obligations stemming from such understandings of justice, rooted in the work of Amartya Sen\(^{250}\) and Martha Nussbaum.\(^{251}\)

According to Sen, what is missing from traditional liberal theories, “is the notion of ‘basic capabilities’- the person being able to do certain basic things”\(^{252}\). This approach instead scrutinises “what people are actually able to do and be”,\(^{253}\) with a particular focus on just background conditions and the way in which societal structures and institutions can hinder access to certain purported rights or values.

In this way, the capabilities approach shares a relational starting point with social understandings of disability. The focus is on the way in which the environmental, cultural, political and economic context can hinder or facilitate an individual’s enjoyment of certain

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\(^{252}\) Sen, n103,p218.

\(^{253}\) Nussbaum, n104, p33.
capabilities. Without paying attention to these factors, claims about particular individuals’ enjoyment of certain rights and freedoms are incomplete. Sen’s critiques of traditional theories of justice highlight particularly how they tend to miss the “relevance of actual human lives and social behaviour in pursuit of justice, as well as the real consequences that different actions and decisions have on people’s lives”254. The capabilities approach requires a focus on wider contextual aspects of a given situation, as opposed to a detached and abstract conception of justice, further echoing insights from the social model of disability, in which intersecting factors impacting upon the person with disability are considered255. This shared affinity and complementarity between the social model of disability and capabilities approaches has been noted by authors such as Burchardt256 and Terzi257. However, whilst both approaches can highlight background social, political, environmental or cultural obstacles to the achievement of capabilities, “concern for justice seems to require going beyond merely a critical approach to the hurdles society can place against the disabled, to a question of what further steps can be taken”258. The capabilities approach requires a focus not just on the social, environmental, political and economic context, but importantly emphasises the need to situate such considerations within a particular individual. It is thus not concerned with group rights in the abstract,259 but entails a focus on the societal obstacles facing a particular individual. In some ways then, this speaks to the concerns discussed above as to the social model and its potential to disengage from the actual experiences of individuals. As

255 Vehmas, n78,p216: ‘the well-being or ill-being of all individuals depends primarily on their relation to other people...Humanity and human well-being are, thus, mainly granted to us by other people; the humanity of all individuals ... depends on other peoples’ recognition’.
Wendell noted in critiquing the social model in this way, whilst people with a certain disability may have many experiences in common, “their social experiences, their opportunities, their economic welfare, and their status in their communities will have profound effects on how disabling their [condition] is…and on how they experience their disability”\(^\text{260}\). The capabilities approach is a more contextually focused approach which seeks to avoid broad brush assumptions about particular disabilities or other characteristics.

Such an understanding has particular resonance in examining approaches to human rights\(^\text{261}\). Thus, as noted above, whilst traditional liberal rights theories focus on non-interference and zones of inviolability, the capabilities approach requires that we ask whether the right is substantively capable of being achieved, and whether unjust background conditions or other barriers are inhibiting the actual opportunities for the particular individual to enjoy or secure the right. As Nussbaum asserts, securing a right “involves affirmative material and institutional support, not simply a failure to impede”\(^\text{262}\). This enjoins those who are in a position to secure rights to citizens - such as the government and the judiciary - to consider the way in which structural relations can facilitate the enjoyment of such rights and to respond to claims on this basis. The social model as outlined above can illuminate areas in which this could generate such commitments in the realm of cognitive impairment, whilst the capabilities approach calls for responses to this which are attentive to the particular individual. This involves a more intense scrutiny of the contextual aspects of rights enjoyment than an approach which concerns itself with whether procedural requirements have been adhered to.


\(^{261}\) Ibid. p37.

One of the crucial aspects of the capabilities approach is that it can serve as a device “to justify the making of political claims.” From the informational focus on a person’s actual ability to achieve certain basic capabilities, ethical assertions can be made about the required form of measures or policies aimed to facilitate such capabilities. Consideration of structural and institutional relations is central to this. Nussbaum argues that the capabilities approach acts as an ethical paradigm which serves to argue for “the greatest freedom of functioning of our basic capabilities, justifying expenditures that allow people with disabilities to have access to that which they require to have the freedom to function and develop their capabilities.” As a corollary of this, states have a duty to provide the social basis for central human capabilities if they are to actually achieve social justice. This may require different approaches to the achievement of a similar goal, depending on background conditions and context pertaining to different people. In accordance with this, in relation to disability, there is a political duty to ensure that, so far as possible, “impairments do not disable” based on an understanding that given appropriate and adequate enabling conditions, individuals with intellectual disabilities can become fully cooperating members of society.

These critical theoretical insights help to develop a more textured understanding of cognitive impairments and the wider societal obligations stemming from these in order to facilitate social justice. This involves moving beyond an approach to rights based on procedural

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263 Baylies, n 51, p735.
264 Sen, n 112, p232.
elements and focusing instead on more substantive aspects of justice. Indeed, I suggest that
the UNCRPD in many ways provides a vehicle for this shift in approach by harnessing the
critical insights from the social model and enjoining states to respond accordingly in order to
facilitate the achievements of the rights contained within it.

5.7 Bridging the Gap
The UNCRPD marks a recognition that ‘reliance on formal structures alone is not adequate
to ensure full enactment of human rights…the convergence of formal and informal social
forces is necessary for the roots of human rights to grow deep into social structures’269. The
UNCRPD is an important milestone in this respect, as it demonstrates recognition at an
international level of the centrality of law and policy in empowering people with disabilities
Indeed, the Preamble and Articles of the Convention are infused with the language of the
social model and capabilities approaches,270 echoing the need for equality and positive
actions to achieve this. The Preamble, for example, stresses the importance of recognising
that disability results from the interaction between persons with impairments and attitudinal
and environmental barriers to equality, and the need to promote and protect human rights for
people with disabilities, including those who require more intensive support271.

One of the key concepts of the UNCRPD is that of reasonable accommodation. This
obligation is enshrined in the Convention in Articles 2272 and 5, and strongly captures the
practical requirements of substantive equality discussed above. Reasonable accommodation
requires that steps are taken “beyond embedding bald discriminatory proscriptions in laws

269 F. Owens and D. Griffiths, Challenges to the Human Rights of People with Intellectual Disabilities (London,
270 O’Mahony, n49; Samaha, n73.
272 Defined as ‘[N]ecessary and appropriate modification and adjustments not imposing a disproportionate or
undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment of
exercise on an equal basis with others of all human rights and fundamental freedoms’.

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and policies”  which will entail positive action to ensure equality and the enjoyment of rights. As a concept, it operationalises the capabilities insights by acknowledging the need to look not just to societal factors in the abstract, but to focus on the particular individual and what steps ought to be taken to secure to them their purported rights. Further, it echoes the idea that impairment and disability are experienced differently by different individuals, and so different responses are needed to enable reasonable accommodation to occur. Denial of reasonable accommodation under the Convention forms a basis upon which a claim for discrimination can be made, which explicitly provides an enriched and robust understanding of positive obligations to facilitate rights. Despite the concept being part of existing legal frameworks prior to the UNCRPD, its use was diffuse and thin, and the renewed and more robust emphasis on it in this context is to be welcomed as a mechanism to address underlying factors creating or exacerbating inequality and discrimination.

Another innovative aspect of the UNCRPD in relation to cognitive impairments is the emphasis in Article 12 on equal legal capacity, and the obligation upon states to provide supports to achieve this. Supported decision making is a key aspect of this obligation and is seen as one of the more innovative requirements of the Convention. This demonstrates vital recognition of the relational and situational impacts upon an individual’s abilities and the ways in which these can be enhanced through appropriate and attentive responses. This emphasis on measures to empower and support people with cognitive impairments strongly

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274 Bartlett (2012), n 13, p761.

275 Art 2: Disability discrimination defined as ‘[a]ny distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including the denial of reasonable accommodation’.

resonates with the theoretical insights presented above in calling for the facilitation of abilities to realise capabilities.\textsuperscript{277} For many commentators, the UNCRPD thus provides a timely and welcome catalyst to strengthen many of the claims emerging from the developing literature on the social model of disability.\textsuperscript{278} However, it should be seen as providing more than simply a ‘radical social constructionist’ approach to disability rights.\textsuperscript{279} It reinforces and reaffirms the importance of enforceable rights and entitlements,\textsuperscript{280} but it goes beyond this, with a much needed focus on the individual and securing these rights to them through attentiveness to their lived experience. More importantly, in line with the capabilities approach, the ethos of the UNCRPD is very much about taking positive steps to enable an individual’s enjoyment of rights to be secured.\textsuperscript{281} The UK, having ratified the UNCRPD in June 2009, is committed to taking concrete actions to comply with the Articles of the Convention, which span various aspects such as equality and discrimination, gender issues, children with disabilities, the right to life, access to justice, employment opportunities, privacy and liberty.\textsuperscript{282} The UN Committee on the Rights of Persons with Disabilities has published a General Comment on Article 12 recently in which it affirmed the importance of Article 12 for those with cognitive and psychosocial disabilities and the need for states to holistically examine all areas of the law with a view to ensuring that people have opportunities to express or develop their will and

\textsuperscript{277} T. Carney, ‘Involuntary Mental Health Treatment Laws: The ‘Rights’ and Wrongs of Competing Models?’ in in McSherry and Weller, n88, p263.


\textsuperscript{281} UNCRPD Article 4, ‘General Obligations’.

\textsuperscript{282} We have seen the domestic courts gradually begin to mention the UNCRPD in judgements, see for example AH v West London MHT [2011] UKUT 74 (AAC) Para 16.
preferences as well as having choice and control over their everyday lives\(^\text{283}\). The UNCRPD signals recognition of both the micro and macro levels of action needed to substantively secure rights to people with disabilities. The notion of a responsive state is thus central to this and the law - and judicial personnel within the legal system - have a key role to play in effecting this shift through the implementation of the UNCRPD’s aims and embedding these into socio-legal debates.

5.8 The Need for a Responsive Legal System

As we have seen, whilst the insights gained from a relational understanding of the social context of cognitive impairment are vital, the commitments and responses stemming from such understandings require further elucidation. When seen as the means to operationalise core societal values, facilitating and securing rights involves scrutiny of the ways in which the law structures relations with a view to evaluating whether the right is in fact capable of being actualised. The UNCRPD has been shown to be an important political recognition of this in the context of disabilities. However, for the gains envisaged by this to firmly take root in the everyday lives of people with disabilities, there is a need for both micro and macro level change. The impact of the UNCRPD for many people with disabilities depends heavily on the extent to which it influences decision making on the ground\(^\text{284}\). Once these decisions have been made however, there are further barriers facing disabled people, particularly those with cognitive impairments, if they want to challenge them. Access to justice is multidimensional and involves the interplay of environmental factors, governmental

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transparency, accountability and responsiveness\(^{285}\). Without concerted action at all these levels, the gains envisaged by the UNCRPD will have little impact in reality.

Evidence is emerging which suggests that knowing where to seek advice and being able to access legal services is a serious obstacle for access to justice for people with disabilities\(^{286}\). Concerns have been raised about the level of advice being offered when services are sought out\(^{287}\) alongside recommendations for training for those in the legal professions on good practice\(^{288}\). The fact remains that those most at risk of abuse, neglect or exploitation, remain the least likely to access advice or representation\(^{289}\) and this is particularly true for those with cognitive impairments. Without such concerns being adequately addressed, there will be little challenge to the status quo for many with disabilities.

When disputes are taken further, it is crucially important that the voice of the person is heard in proceedings. It is vital that in framing responses, we are attentive to their actual views rather than what we perceive them to be, or indeed what we think they should be\(^{290}\). Here, supported decision making and the centrality of the individual is key. Whilst a relatively simple concept, it is crucial, as such views can become overlooked in complex multidisciplinary discussions. The courts are beginning to recognise this in the mental capacity context, and it is here that we can see the impact that this can have on decision making. In \(KK v STCC\)^{291} for example, Baker J was faced with the issue of KK’s capacity and best interests in relation to residence. Attention was drawn to KK’s over-use of the


\(^{286}\) P. Swift et al, ‘What Happens When People with Disabilities Need Advice about the Law?’ (University of Bristol: Norah Fry Research Centre, 2013).


\(^{288}\) See n126.

\(^{289}\) H. Brown, ‘Safeguarding Adults and Children with Disabilities Against Abuse’ (Council of Europe: Strasbourg, 2003).

\(^{290}\) See J. Tronto, Moral Boundaries: A Political Argument for an Ethic of Care, (New York, Routledge, 1993) for an outline of central principles to a political ethic of care.

\(^{291}\) (2012) EWHC 2136 (COP).
emergency lifeline service, and the impact that this has had on professionals’ assessment of her capacity to make a decision about where to live. He clearly notes the obligation on the local authority to assist KK in this matter, stating that:

“To my mind, however, the local authority has not demonstrated that it has fully considered ways in which this issue could be addressed, for example by written notes or reminders, or even by employing night sitters in the initial stage of a return home…Ultimately, however, I am not persuaded that calling an emergency service because one feels the need to speak to someone in the middle of the night, without fully understanding that one has that need or the full implications of making the call, is indicative of a lack of capacity to decide where one lives”

Whilst in many cases, much more will need to be done than simply posting notes and reminders around a person’s house, the dicta here demonstrate at least some piecemeal recognition of the need to emphasise support and to be attentive to ways in which capacity can be facilitated for the individual by changes to the social and relational environment. There is at least implicit recognition in this case of the way that institutional relations between KK and the various professionals can be structured differently in order to facilitate her capacity and decision making.

Of further importance in this case is that the experts’ view of KK’s capacity was overturned as a stronger focus was had on KK as an individual and the steps that could be taken to facilitate her in living at home. The presence of the person can thus be crucial in offsetting a narrow medicalised approach to their capacity, but also for making them feel connected to

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292 *Ibid. Para 71.*

293 Similarly in *Re SB* [2013] EWHC 1417 (COP) we see that the involvement of P in proceedings can result in professional views being challenged (see Para 63).
the proceedings. It is envisaged that if this trend continues, a much more holistic assessment of capacity and best interests will permeate the jurisprudence in line with the UNCRPD.

However, both the capabilities approach and the UNCRPD emphasise the non-coercive nature of supports and the importance of the choice to refuse to engage with these. At the same time as emphasising supports to facilitate autonomy then, it is imperative not to lose sight of the individual and their subjective experience in this process. It is all too easy to replace the medical model with a social model which then enables interventions which may ignore the wishes of the individual, on the basis that societal or cultural relations or attitudes have shaped that individual’s refusal. Looking at the case of *ReWMA* we see judicial recognition of wider relational factors impacting upon a person’s capabilities. This case involved a 25 year old man with atypical autism and a pervasive development disorder. He had lived at home with his mother, however there was a history of local authority and police involvement due to concerns about WMA’s care at home. In this judgement, there is consistent reference to the way in which MA (WMA’s mother) has hindered WMA’s development. The professionals and the judge in this case were in agreement that WMA’s abilities were limited not by his impairment, but by his mother. The evidence of the care manager neatly encapsulates this attitude:

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294 *Re M [2013] EWHC 3456 (COP) Para 42, per Jackson J.*
148 See for example Bartlett and Sandland, n18, p169, who note in relation to reasonable accommodation that it ‘does not follow that people with disabilities can be required to use the services provided by way of reasonable accommodation’. See also Sen, n112, p238, who notes that, in relation the capabilities approach ‘...claims of individuals on society may be best seen in terms of freedom to achieve (given by the set of real opportunities) rather than actual achievements...If a person has the opportunity for socially supported healthcare but still decides, with full knowledge, not to make use of that opportunity, then it could be argued it is not as much of a burning social concern as would be the failure to provide the person with the opportunity to healthcare’.
149 [2013] EWHC 2580 (COP).
150 Para 15.
“She felt that WMA needed to be moved, to be ‘encouraged to push the boundaries’ in B [the care home]. He would be ‘empowered’, she thought.”²⁹⁸

Ostensibly the case illustrates recognition of a wider, relational impact on the experience of cognitive impairment and an appetite for removing such obstacles in order to enable ‘a more fulfilling life’²⁹⁹. However, at a deeper level, questions can be raised about the lack of engagement with WMA’s own clearly expressed wishes. We see his views briefly noted but equally briefly dismissed in the case:

“WMA unequivocally told me he wanted to be “permanently” with his mother. The work done by Delos, he said, was too much and he thought three hours of support four days a week was just not acceptable. He wanted one hour two days a week. Delos did not leave the home when he asked them to go. They would not listen to him. He wanted proper appointments and did not want extra people turning up on visits. As to spending his time, he liked to watch DVDs and watch the TV. He likes to take his dog, Joe, for a walk in the park. He does not like mixing with people. “That's my choice,” he said. But, of course, he really has not experienced a life that is other than isolated hitherto”³⁰⁰

The legitimacy of WMA’s views here were questioned because of the focus on the external constraints on his development, and so the social model and capabilities approaches here seem to clash. In incorporating social model and capabilities understandings here, the judiciary will be faced with the task of grappling with issues of a complex interdisciplinary nature which may be beyond their expertise. Disentangling these issues in individual cases, against a backdrop of theorising of disability which can seem to be pulling in different

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¹⁵¹ Para 88.
¹⁵² Para 67.
³⁰⁰ Para 45. See also Para 47.
directions, is a task which currently is beyond the judiciary. Indeed, such factors undoubtedly need to be addressed at a macro level and encompass broader questions of service provision and policy goals. Yet whilst it is difficult for judges to get to the root causes of injustice in this sense in individual cases, it is crucially important that they seek to question assumptions about the effects of particular impairments, and the impact of this on capacity, as well as scrutinising the supports made available to facilitate their capabilities.

However, legal practices or accepted rules of law can “stultify or nullify” any anticipated gains in terms of substantive equality here\(^{301}\). As we saw above, the concept of reasonable accommodation may provide an inroad into capturing the concerns of social model and capabilities theorists legally. Yet, much of the success of this depends on the readiness of the judiciary to apply the concept in a robust way and to closely scrutinise the obligations of the state and others in this regard. The UNCRPD obliges reasonable accommodation via ‘necessary and reasonable adjustments not imposing a disproportionate or undue burden’\(^{302}\) but if judicial unwillingness to closely scrutinise resource-led decisions continues then the substantive justice envisaged here will not be achieved at a domestic level. As Kayess and French point out, given the potential downward pressure on the extent of the obligation, the anticipated gains of the concept of reasonable accommodation may fall victim to the problems we have seen with traditional, procedural rights approaches\(^{303}\).

A similar problem with the traditional legal framework being applied in individual cases in the mental capacity context is the concept of best interests\(^{304}\). There is a sense, at a general level, that best interests decision making- and in particular the emphasis on objective

\(^{302}\) Art 2. (emphasis added).
\(^{303}\) Kayess and French, n 132, p9.
\(^{304}\) See Bartlett (2012), n13 and also Bartlett and Sandland, n18, p199, for further discussion of the extent to which best interests decision-making is, or can be, compliant with the UNCRPD.
assessments of best interests, can stifle the overall empowering aims of the UNCRPD, by enforcing choices upon people rather than enabling their autonomy. Further, the Select Committee Report highlighted the way in which best interests decisions are often driven by clinical judgements and resource-led considerations. This is an area in which the judiciary need to challenge medicalised or individualistic assumptions underlying best interests assessments and the options presented by care providers in light of these. There needs to be a shift away from framing options in line with the aims of the medical model and focusing on the opportunity to provide ‘more than medical or physical rehabilitation directed at individuals’. However, scope for doing so may be limited. Cases such as Aintree v James and ACCG v MN have firmly stated the principle that the Mental Capacity Act 2005 is only concerned with ‘enabling the court to do for the patient what he could do for himself if of full capacity, but it goes no further’. Thus, there is no scope for demanding particular treatments or services, as this is not a right afforded generally in health and social care. King J outlined how, if the court were allowed to consider where MN’s best interests lay first, before deciding the issue of funding options, this would entail the Court of Protection potentially “using a best interests decision as a means of putting pressure upon the ACCG to allocate their resources in a particular way”. It is through judicial review that challenges to the irrational or unreasonable allocation of resources ought to be challenged, not through best interests decisions. However, it is questionable whether this approach furthers the goals of the social model or capabilities insights argued for here, as discriminatory practices or attitudes- demonstrated in the options available in a person’s best

305 Above, n32. See also paras 90-91.
309 Ibid Para 52 per King J.
310 R (Burke) v General Medical Council [2005] EWCA Civ 1003.
311 Ibid.
interests—may be allowed to continue unchallenged. King J did note that there may be exceptional cases in which a court may choose to hear a best interests argument showing that a provider, in failing to agree to fund a particular package of care, has breached or may breach the human rights of the individual. Quite when these exceptional cases will arise is as yet unclear, but, if the courts are ready to engage with such arguments, it is necessary that this is undertaken in a way which is attentive to the social context of the claim, and which will move beyond the procedural face of rights claims in responding to this.

It might be suggested that if indeed the Court of Protection were to begin to press these human rights issues further and consider public law questions in best interests decisions, this would put people with mental impairments in a more advantageous position than those without such disabilities. It is clear from cases such as *Burke* that a patient cannot demand a particular treatment or service and that the courts are not willing to order this on their behalf. Yet this is precisely what is entailed by a focus on the societal and institutional barriers to the achievement of rights in a positive manner and the cognisance of the social basis for central human capabilities if they are to actually achieve social justice. This may require different approaches to the achievement of a similar goal, depending on background conditions and context pertaining to different people. Sen employs the simple example of a wheelchair-user to illustrate this, outlining how such a person will require more resources than a person with ‘normal’ mobility if the two are to attain a similar level of ability to get around. Thus, recognition needs to be had of the barriers facing the individual—particularly the lack of meaningful choices and options available to facilitate certain rights and freedoms—and the judiciary in given cases are in a position to recognise and respond to this.

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312 Para 73.
313 n152.
315 Sen, n103.
Moreover, the capabilities approach is not limited to focusing on group rights, or the rights of people with disabilities. This calls into question the dichotomy created by arguments positing the rights of persons with disabilities as in competition with the rights of people without disabilities. Moreover, it calls into question at a general level the reluctance of the judiciary to probe further substantive questions of rights and justice when there are potential resource issues at stake. The capabilities approach can thus reinvigorate claims for substantive equality in all cases, not exclusively those involving people with disabilities. This is precisely the shift in approach that Quinn was referring to in his assertion that the UNCRPD is not simply a Convention concerned with the rights of persons with disabilities, but instead represents a shift in theoretical debates about justice on a broader level. He sees the Convention as “the latest iteration of a long extended essay at the international level about a theory of justice- a theory that is applied to disability to be sure, but one that is woven from a much deeper cloth and has universal reach”316.

It is clear then that a significant obstacle to be overcome in achieving the paradigm shift envisaged by the UNCRPD is the level of judicial appetite to challenge accepted wisdom in this area. To embed the transformatory ideas into decisions affecting people with cognitive disabilities, we need the judiciary to ensure that they are eschewing the traditional narrow focus which we have seen in mental health and capacity law. The trend of focusing attention on definitional or technical considerations in contentious areas is not unique to the mental health context. In the community care context, we see a long held dissatisfaction with the judicial method of attending to more technical procedural aspects of decisions, and avoiding broader notions of substantive justice317. The majority judgements in the case of McDonald are testament to this tradition of confining the scope of analysis when tricky issues of social

justice are engaged. This is the very thing that the UNCRPD seeks to address through its conception of substantive equality and justice. Without a shift in the judicial approaches in this regard, it is difficult to see how the aims of the UNCRPD can be actualised in individual cases. The successful and meaningful implementation of the Convention requires close scrutiny and the challenging of assumptions and narrow understandings regarding disabilities. These will continue to dominate unless there is a sustained effort to move beyond these at a judicial level. Whilst the ability of the judiciary in individual cases to address issues of deeply ingrained inequalities may be rather limited, and the vessel for such macro considerations ought to be the state, it is clear that a more sustained and responsive approach to substantive questions of equality and rights is required here to uncover and illuminate these, rather than allow them to continue and become more ingrained.

There are undoubtedly public law concerns to be raised when calls are made for more judicial intervention in such decisions. This is particularly the case when resources are at stake such as in community care funding assessments, and - less visibly - in the DoLS context. In the current climate of cuts to public services and an austerity agenda, this is all the more salient. Syrett has argued that judges lack the democratic legitimacy to determine who should receive resources and that, instead, the utility of their role lies in open and transparent reasoning to enable political debate. However, like Herring, I argue that in this context, where there is a lack of sustained political attention or challenge combined with a lack of political

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319 See Carr, ibid.
320 Palmer, n102.
321 This was noted in P and Q, above n 40, where Wilson J pointed to the ‘vast, unquantifiable’ number of cases that would be before the courts if an appeal were to be allowed (Para 4). However, he goes on to state that this resource implication is an irrelevant factor. Similarly, Ruck-Keene argues, that we should not ‘allow the tail of resources to wag the dog of statutory interpretation’ when it comes to DoLS. A. Ruck-Keene, Tying Ourselves into (Gordian) Knots? Deprivation of Liberty and the MCA 2005 (2012) available at http://www.39essex.com/docs/articles/ark_deprivation_of_liberty_paper_december_2012.pdf, 42.
voice for many with mental impairments, the judiciary play a vital role in providing recourse\textsuperscript{323}. If judges do not engage with such issues then there is no real and effective route for remedial action. Furthermore, as O’Cinneide has argued, “it is one thing to be wary about extending the reach of legal controls to cover the whole terrain of resource allocation; it is another thing to insulate public authorities from any form of legal accountability for how they address issues of social justice”\textsuperscript{324}. This is particularly important in the context of the UNCRPD as this is an area which, through ratification, the state has indicated support for a broader concept of justice. Without this permeating judicial discourse, the UNCRPD will simply be another re-statement of rights, which history has shown have done little to affect the actual lived experience of people with mental disabilities.

5.9 Conclusion

Much progress has been made at a theoretical level to off-set the predominance of the medical model in discourse surrounding mental impairment and disorder. The extent to which this has trickled down into mental health and capacity jurisprudence has currently been rather limited, and progress has been piecemeal and isolated to particular cases. The UNCRPD has been much lauded, and serves as a vital vehicle for more textured relational understandings of mental disorder to take hold in the legal and policy arena. The Convention moves beyond the “artificial boundaries of the health care context”\textsuperscript{325} and turns much needed attention to the wider socio-political aspects impacting upon the lived experience of mental illness. However, for this ‘paradigm shift’ to take root and impact upon the lives of those with disabilities, more needs to be done than simply paying lip-service to the transformative potential of the Convention. We saw in the Supreme Court in \textit{Cheshire West} welcome recognition of the universal nature of human rights, and the obligations stemming from reasonable

\textsuperscript{323} Herring, n170, p147.
\textsuperscript{324} O’Cinneide, n102.
\textsuperscript{325} Secker, n29, p304.
accommodation in this context. Rights discourse is but one aspect of progress here, and “cannot be the total sum of any strategy of empowerment”\(^{326}\). The limitations of traditional rights discourse to translate into effective rights protection has been well-documented, and whilst the UNCRPD serves as a timely reminder that positive and negative rights are tightly intertwined and interdependent, it is imperative that this translates into legal and policy understandings. Without such understandings taking hold in day-to-day decisions affecting people with disabilities, or providing an impetus to provide meaningful access to justice to question such decisions, the gains envisaged by the UNCRPD will not materialise. At the same time, questions about the costs of such gains in an economic climate that has seen cuts to public services impact heavily upon those with disabilities\(^{327}\) need to be debated and brought to the fore.

We have seen that we are not yet there in achieving the anticipated shift entailed by the Convention. In the same breath that lauded the importance of universal rights, Lady Hale noted that:

> “It may be that those rights have sometimes to be limited or restricted because of their disabilities, but the starting point should be the same as that for everyone else”\(^{328}\)

Not only is this contrary to Article 14 of the UNCRPD,\(^ {329}\) such a statement also suggests that the paradigm shift in attitudes away from narrow, medicalised understandings of disability and cognitive impairments is not yet realised. If the judiciary do not become fluent in the

\(^{326}\) Bartlett and Sandland, n18, p350.


\(^{328}\) n58.

\(^{329}\) Article 14.1 requires State Parties to ‘ensure that persons with disabilities, on an equal basis with others, enjoy the right to liberty and security of persons...and the existence of a disability shall in no case justify a deprivation of liberty’.
language of the Convention or question the current narrow understandings residing in mental health and capacity law, recourse for those able to challenge decisions will be non-existent.

As Carson has previously stated:

“The law can, and should, incorporate a dynamic which keeps the pressure on all involved to minimise disability, to maximise habilitation and rehabilitation. That it may lead to unorthodox or non-traditional forms of legislation is no excuse: legislation must be a tool and a servant of social policy, not its master”\footnote{Carson, n121,p309.}

Whilst strides are being made in this respect, a ‘responsive state’ is key to the success of the emerging ideas in this context. The various mechanisms within the legal system need to work together in order to ensure that meaningful recognition is given to appropriate responses which facilitate enjoyment of the rights of those with mental disabilities.
CHAPTER 6

Vulnerability and Capacity to Consent to Sex - Asking the Right Questions?

6.1 Introduction

Emerging theories on vulnerability have the potential to reinvigorate legal and ethical discourse in various contexts, inviting a shift in thinking away from vulnerability as a characteristic inherent in certain individuals, towards seeing it as a universal concern which impacts on all human beings. As Susan Dodds puts it,

“All attention to vulnerability…changes citizen’s ethical relations from those of independent actors carving out realms of rights against each other and the state, to those of mutually-dependent and vulnerable-exposed beings whose capacities to develop as subjects are directly and indirectly mediated by the conditions around them.”

This renewed focus on the universal nature of vulnerability provides the basis for arguments against traditional liberal and individualistic understandings of autonomy as non-interference, and instead pays heed to the fundamental role of relational and situational dynamics in facilitating autonomy and resilience.

Whilst the normative impact of this burgeoning area of discourse on law and policy is still being explored, commentators have begun to debate its significance in various areas of public and private law. This paper seeks to add to this growing literature in considering the potential for vulnerability theories to elucidate the concerns at the heart of debates about capacity to consent to sexual relations. Whilst the issue of capacity to consent to sex was

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3 See J Wallbank and J Herring, Vulnerabilities, Care and Family Law (London, Routledge, 2014), and M Fineman and A Grear, n1, for recent developments in the legal literature.
previously hidden from the medico-legal arena, as it was not seen as an activity that those with disabilities were- or ought to be- engaging in, there has been a steadily increasing legal awareness of such intimate relationships as the judiciary, mainly through first instance decisions, has had to grapple with the thorny question of the appropriate test for capacity to consent to sexual relations. The vulnerability perspective calls into question the current state of the law in this context, which has adopted a low-threshold, act-specific approach to capacity. This focuses on the mechanistic aspects of sexual relations, primarily on whether the individual has a basic understanding of what is involved in sexual activity and the risks of pregnancy and sexually transmitted infections. In adopting such an approach, the judiciary have repeatedly asserted that they are upholding private rights and sexual autonomy, and that a balance is to be struck between the conflicting values of empowerment and protection for those with cognitive disabilities. In a recent significant case, the issues was framed as- “When is it appropriate for society to intervene paternalistically in a decision or decisions that individuals make as to their sexual relations?”

The emerging literature on vulnerability emphasises the contextual and situational factors impacting on all individuals, in a disability-neutral sense, as well as the way in which legal, policy and societal responses can either entrench vulnerability, or foster resilience. In contrast, the capacity framework can be characterised as having a much narrower focus- primarily on the intrinsic or inherent vulnerability accompanying a disability, and a person’s inabilities, often in terms of understanding the relevant information. From this perspective a capacity approach may obscure from the legal gaze the power dynamics and situational

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5 See X City Council v MB, NB and MAB [2006] EWHC 168 (Fam) and Re MM (an adult) [2007] EWHC 2003 (Fam).
7 A Local Authority v TZ [2013] EWHC 2322 (COP).
8 IM v LM and Others [2014] EWCA Civ 37.
factors which will impact on the individual. As such, responses to incapacity will be centred on the individual, rather than addressing on a broader level what can be done to facilitate sexual autonomy. Conversely, for those deemed to be capacitous and thus capable of making an autonomous decision, these sources of vulnerability will remain uncovered as they will be seen as ‘invulnerable’. The literature on vulnerability casts a much wider gaze than the mental capacity approach, looking not at assumed inherent characteristics but instead at the interaction between multi-variant sources which impact on all individuals universally, and in doing so exposes previously ‘hidden’ vulnerabilities- such as access to supports, power dynamics and cultural and societal attitudes- which have fallen outside of traditional capacity/autonomy binaries.

It will be suggested that the pivotal role that mental capacity plays here results in an abstract and artificial understanding of the experience of sexual vulnerability, and hinders an effective response to facilitating resilience. It is contended that the current legal approach, as seen in *IM v LM*,\(^9\) instead simply respects liberty, in terms of non-interference, rather than sexual autonomy as is claimed. If instead the state seeks to be responsive to the sources of vulnerability- as is incumbent in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) - a much more nuanced understanding is needed of what is required to secure sexual autonomy. As will be seen, the UNCRPD ushers in new ways of conceptualising and responding to disabilities- including cognitive impairments- which may call into question the very basis of the MCA\(^10\). As Keywood has argued, a “more robust conception of sexual empowerment will help us to understand that empowerment and protection are not mutually exclusive goals”\(^11\). Insights from the vulnerability literature allow

\(^9\)Ibid.


us to break the empowerment/protection dichotomy down and focus in on more nuanced understandings of, and responses to, vulnerability in a sexual sense.

6.2 Re-Conceptualising Vulnerability and Sexual Capacity

There is a growing body of literature seeking to conceptualise ‘vulnerability’ and theorise the implications of this for law and social policy. At the forefront of this is the work of Martha Fineman who has sought to re-imagine, at a political level, what we mean by vulnerability. Central to Fineman’s thesis is the notion of ‘universal vulnerability’, advancing the idea that all human beings, by the very nature of being social beings, are vulnerable. This is in stark contrast to notions of vulnerability which have traditionally pervaded discourse, being based on subpopulations being vulnerable, and positing those standing outside of these “constructed vulnerability populations” as invulnerable. Such an understanding has been embedded in adult safeguarding policy, and provided the basis for potentially disempowering interference in the lives of those falling within the definitional remit. For example, the No Secrets guidance on adult protection provided a definition of a vulnerable adult as:

‘A person aged 18 or over who is or who may be in need of community care services by reason of a mental or other disability, age or illness; and who is or who may be unable to protect himself or herself against significant harm or exploitation’.

Similarly, in Setting the Boundaries, a report on the reform of sexual offences, we see a focus on the individual characteristics of the disability as constitutive of their ‘vulnerability’,

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“Mentally impaired people are a particularly vulnerable group— they are obedient and suggestible, and once adult they may well have sexual feelings and not be able to resist inappropriate behaviour”\(^{16}\)

This starkly locates the source of the vulnerability as inherent to the individual and as causally connected with their disability, age or ill health\(^{17}\). Instead, a much broader conceptualisation of vulnerability, divorced from ideas about a particular status, allows for more attentiveness to the multi-variant sources of this vulnerability. In essence, this is a more outward-looking understanding which seeks to identify sources of vulnerability which have otherwise been hidden in legal, social and cultural practices\(^{18}\), and to directly challenge the idea that vulnerability is inherent to certain individuals within a demarcated subpopulation. As social and relational beings, we are all vulnerable to natural disasters, ill-health, loss, economic hardship, and constraints on social institutions such as welfare, health care and education.

In many ways, this theoretical starting point echoes the work of some care ethicists\(^{19}\) and those writing on relational autonomy, as it highlights the networks of interdependence that permeate society and the importance at a policy level of being attentive to and responding to these\(^{20}\). At the heart of this is the argument that the traditional liberal individualistic conception, which is central to many of our policies and laws, misrepresents the relational nature of human beings and hides much of the messy reality of relationships, dependency and

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\(^{16}\) Home Office, Setting the Boundaries: Reforming the law on sexual offences (London, TSO, 2000) para 4.1.2

\(^{17}\) For more detailed discussion of the impact of the Care Act 2014 on discourses of vulnerability see A. Brammer, ‘Safeguarding and the elusive, inclusive vulnerable adult’ in Wallbank and Herring, n3, 216-234.


vulnerability. Whilst an understanding of universal vulnerability may seem to gloss over the individual embodied experience of vulnerability, theorists emphasise that the particular experience of vulnerability must be understood at the individual level. It is important to focus on the particular experience of vulnerability here, as a theory premised solely on the universal nature of vulnerability runs the risk of down-playing the experience of it and negating its conceptual and normative importance. Fineman refers to this as “embodied difference”, stressing that the “experience of vulnerability varies according to the quality and quantity of resources we possess or can command”. An inherent condition may seem to place an individual at risk of harm or exploitation; however they may not subjectively experience themselves as vulnerable, perhaps due to access to material and social supports promoting resilience. Thus the vulnerability thesis draws attention to the experience of vulnerability, rather than the presence of a particular condition and in this way can conceptually “bridge the gap between the legal subject as currently conceived of and real human beings”.

Other theorists have built upon Fineman’s work to elucidate more clearly the multi-variant sources of vulnerability. Mackenzie, Rogers and Dodds propose three broad – but not necessarily distinct- categorisations of sources of vulnerability; - inherent; situational and pathogenic. Inherent sources are characterised as intrinsic to the human condition and inevitable need and dependence, although this can vary depending on age, gender, disability

22 M Fineman and A Grear, n1, p21.
23 Ibid.
26 C Mackenzie, W Rogers and S Dodds, n24,p7.
and health status, whilst situational refers to context specific sources, which may be caused or exacerbated by the personal, social, political, economic and environmental situation. Notably, their category of ‘pathogenic vulnerability’ refers to the way in which abusive interpersonal or social relationships, and socio-political oppression or injustice can generate vulnerability. Moreover, they note that “pathogenic vulnerabilities may also arise when a response intended to ameliorate vulnerability has the paradoxical effect of exacerbating existing vulnerabilities or generating new ones.” This is particularly salient as it invites a deeper analysis of the impact of laws and policies - their ability to achieve their stated aims and, more importantly, to foster resilience in those rendered vulnerable - which is a point which will be turned to now in evaluating the legal responses in the context of sexual capacity.

Until recently, the question of mental capacity to consent to sexual relationships was grappled with in the lower courts, and there was a lack of authoritative guidance from appellate level. Similarly, the criminal law has struggled to define a workable test in relation to capacity for the purposes of section 30 of the Sexual Offences Act 2003. However, with the Court of Appeal judgement in IM v LM and Others we have a clear statement of the assessment to be undertaken in considering whether an individual has the mental capacity to consent to sex. This was accompanied by a resounding endorsement of pragmatism in this context, and the importance of the right to engage in sexual relationships. The development of the law in this area provides a backdrop to explore whether in fact sexual rights and autonomy are being prioritised by the capacity framework, and what a vulnerability analysis can contribute.

27 C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, n24, p38.
28 C Mackenzie, W Rogers and S Dodds, n24, p7.
29 Ibid, p9
30 Ibid.
The struggle in the courts can best be viewed as one between an act-specific approach to capacity, and a person- or situation- specific approach. The roots of the judicial approach in the civil law lie in *Sheffield City Council v E*[^32^] which was primarily concerned with capacity for marriage. The case involved a 37 year old woman with physical and intellectual disabilities who had moved in with, and was intending to marry, a man with a significant record for crimes of sexual violence. Munby J outlined how a contract of marriage was a simple one, and that accordingly the test for capacity to enter into this contract has a low threshold. In particular, the test was to be focused on the particular nature of the act, and not on the person with whom the contract of marriage was to be entered into. This was followed subsequently in *Re MAB*[^33^] and *Re MM*[^34^], where Munby J again asserted that in relation to sex, the level of understanding required “need not be complete or sophisticated” and that “rudimentary knowledge of what the act comprises and its sexual character”[^35^] is sufficient. He saw the issue of capacity as either/or, noting that “it is difficult to see how it can sensibly be said that she had capacity to consent to a particular sexual act with Y whilst at the same time lacking capacity to consent to precisely the same act with Z”[^36^].

This provides a valuable lens through which to scrutinise certain assumptions about the sexual vulnerability of people with cognitive impairments, and in doing so it will be argued that it is perhaps not quite so difficult to see how this could be the case once attention is paid to the situational aspects of the decision elucidated by a focus on sexual vulnerability. This has been a relatively under-explored area, despite increased debates around the social model of disability and growing appreciation of the situated nature of autonomy[^37^]. We saw above

[^32^]: [2004] EWHC 2808 (Fam).
[^33^]: *Re MAB, X City Council v MB* [2006] EWHC 168 (Fam).
[^34^]: *Re MM* [2007] EWHC 2003 (Fam).
[^35^]: Para 74.
[^36^]: Para 87.
the way in which information and understanding of basic information are central to the act-specific capacity approach. However, the empirical literature is rich with examples of the way in which this lack of information provided to people with disabilities can in turn render them more vulnerable to sexual abuse. A study by Hollomotz revealed that a participant, Tyler, had been sexually violated by a fellow pupil at his school, but that as he did not understand that sex between men was possible, he did not immediately identify this as abuse\(^{38}\). This in effect meant that Tyler was in a vulnerable position, not due to his learning disability, but in a large part due to his inability to adequately recognise what happened as sexual abuse because of a lack of knowledge and information about this. This is a recurring theme in the mental capacity cases\(^{39}\) - not necessarily because of an inability in their mental functioning, but because the information simply has not been provided, or has not been communicated in an appropriate way. It is well-documented that people with intellectual disabilities are reliant on care-givers and support workers for sex education, and that attitudes of such gatekeepers can be a barrier to information and proactive support\(^{40}\). Furthermore, it is widely acknowledged that for many people, most sex education is gained through informal channels such as discussions with peers, as well as experience and experimentation in intimate relationships. However, many people with intellectual disabilities have fewer friends and spend a large proportion of time with adults under supervision, and so are not exposed to this\(^{41}\). Such examples directly challenge the charge that sexual vulnerability is inherent to people with disabilities and thus renders them in need of protection. We see how social and situational factors can impede knowledge and understanding about sex and abuse. If


\(^{41}\) A Jahoda and J Pownall, ‘Sexual understanding, sources of information and social networks; the reports of young people with intellectual disabilities and their non-disabled peers’ (2014) 58(5) Journal of Intellectual Disability Research p430; Rushbrooke et al, Ibid.
information is withheld in the name of protection, a pathogenic source of vulnerability is in fact created, as a response intended to ameliorate vulnerability had a paradoxical effect of increasing it.

6.3 Situating Vulnerability
Aside from informational aspects, the situational factors may have a further impact on the sexual autonomy of people with cognitive impairments. Power and relational dynamics do not just stem from individual interaction, and structural phenomena can shape choices and opportunities. In a residential care setting, for example, rights to sexual expression and choices in this regard are often curtailed. Owen and Griffiths outline how opportunities for healthy sexuality are often lacking and are routinely restricted as people are denied privacy or choice about sexual expression, due in large part to accommodation arrangements. This in turn can create pathogenic vulnerability as a result of the lack of safe and private spaces to explore sexual relationships - both in residential and group settings - often people need to resort to rushed activity in isolated public spaces or semi-isolated private spaces, which provides little real opportunity to consider personal boundaries. This can lead to a high risk of abuse, pregnancies and sexually transmitted infections. In relation to aged and dementia care facilities, similar findings are prevalent, and the lack of lockable doors or private spaces and also staff attitudes are highlighted as standing in the way of safe opportunities for sexual expression. In Hollomotz’s study, a participant named Rachel, living in a residential group setting, has access to her own vibrator. However, she needs to give this back to staff to lock

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43 F Owen and D Griffiths, Challenges to the Human Rights of People with Intellectual Disabilities (Jessica Kingsley, 2009) p187
in a cupboard each morning and has to request it to be signed out whenever she wants it. This means that staff are inevitably aware of her sexual life, diminishing her control over private matters, with little clear justification. Further examples of situational constraints on sexual autonomy and control are found in the CHANGE Report on the views of young people with learning disabilities, which highlighted how many young people want to be in relationships but don’t have the opportunity to develop these. This lack of opportunity to embark upon or develop intimate relationships demonstrates an aspect of the situational impact upon sexual vulnerability. Linked to this is the concern that the lack of opportunity to effect any real choice and control over more mundane daily choices, such as how to spend the day and who with, will impact upon the assertiveness of the individual when it comes to intimate relationships. Thompson points to a “learned helplessness” which is manifested when individuals have to ‘fit’ into existing services. Here, attention is drawn to the way in which individuals may be too afraid to challenge their violator; may feel helpless and powerless; or may not think that they have a choice about participation in sexual activity. Without the opportunity to experience intimate relationships, and to exercise choice and control in these (and in other aspects of life), sexual autonomy is impeded. Similarly, the power dynamics within a relationship can impede upon the individual’s ability to express their choice, making it entirely conceivable that consent to a sexual act can be given to Y but

47 A Hollomotz, n38, p61.
50 M McCarthy, n48, p128.
52 Mencap Behind Closed Doors (London, Mencap, 2001)
54 Centre for Disability Law and Policy NUI Galway, Submission on Legal Capacity- The Oireachtas Committee on Justice, Defence and Equality available at http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality_.pdf [last accessed 1st July 2014] p7- “development of capacity requires experience of living independently and being included in the community and forming relationships”.

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not to the same sexual act with Z. This undoubtedly leaves the individual at risk of having their will over-borne in a way that the capacity framework seems not to be cognisant of, and which directly challenges Munby J’s statement above.

Such criticisms were touched upon to a certain extent in the criminal law context in the case of R v Cooper. This case involved a 28 year old woman with a diagnosis of schizo-affective disorder, an emotionally unstable personality disorder, and an IQ of less than 75. She had a history of admissions under the Mental Health Act 1983, and had recently been discharged from hospital to a hostel. There was evidence that she was struggling to cope, and on the day of the incident she had been seen by a consultant psychiatrist who recommended her compulsory admission to hospital. Later that day she met the defendant and told him she wanted to leave Croydon as people were after her. The defendant offered to help her so she went with him to his friend’s house. In this time, he sold her mobile phone and bicycle and gave her crack. When she went to the bathroom, the defendant followed her and asked her for a ‘blow job’. She stated in her evidence that she was very afraid and panicky and wanted to leave, but as she did not want to die she stayed and was subjected to a number of sexual acts by the defendant and his friend. She was later found by the police wandering the streets in great distress.

The case was brought under s30 of the Sexual Offences Act 2003. Unlike the non-consensual sexual offences, the focus of s30 is on proving that the complainant was unable to refuse the sexual activity because of or for a reason related to the mental disorder; that the defendant knew or could reasonably be expected to know that the complainant had a mental disorder, and that because of it, or for reasons related to it, was likely to be unable to refuse. With regard to the inability to refuse, this centres on the lack of capacity to choose, or being unable

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55 [2009] UKHL 42.
56 s30(1)[c].
57 s30(1)[d].
to communicate such a choice. At first instance, the defendant was convicted, but this was set aside on appeal. The Court of Appeal relied heavily on the dicta of Munby J in the civil cases outlined above, noting that an “irrational fear that prevents the exercise of choice cannot be equated with lack of capacity to choose. We agree with Munby J’s conclusion that a lack of capacity to choose to agree to sexual activity cannot be ‘person specific’ or, we would add, ‘situation specific’”. On appeal, a unanimous House of Lords overturned the Court of Appeal decision. Baroness Hale delivered the leading judgement, which advocates a situation specific appraisal of capacity in relation to sex. She highlighted how the case law on capacity has “for some time recognised that, to be able to make a decision, the person concerned must not only be able to understand the information relevant to making it, but also be able to ‘weigh that information in the balance to arrive at a choice’”. This put a renewed focus on the ability to use and weigh the information given, given the situation that the individual is in. In this regard, Baroness Hale noted that the approach encompasses a wide range of circumstances in which the mental disorder may rob them of the ability to make an autonomous choice, despite having sufficient understanding of the information relevant to making it. This is a significant step away from viewing the question of capacity as a matter of setting the level of information required. In a resounding dismissal of a narrow, act-specific approach, Baroness Hale stated that,

“It is difficult to think of an activity which is more person and situation specific than sexual relations. One does not consent to sex in general. One consents to this

58 s30(2)(a) and (b).
59 R v Cooper [2008] EWCA Crim 1155, para 53.
61 Ibid. para 25.
act of sex with this person at this time and in this place. Autonomy entails the freedom and the capacity to make a choice of whether or not to do so.\footnote{62}

This signals a clear endorsement of a situational analysis noting the power dynamics which can impede choice and consent. Attention is here paid to the “vulnerable, terrifying position”\footnote{63} in which the complainant was in, noting the impact that this must have had on her ability to exercise a choice. Viewed from the vulnerability perspective, this offers a much richer appraisal of capacity and the reality of consent. Yet it is still problematic in that s30 relies on proving that the mental disorder, rather than external factors, was the cause of vulnerability. As Saunders has put it, “attributing the complainant’s non-communication to her mental disorder, rather than to the defendant’s behaviour, is questionable to say the least. This complainant was not momentarily mad to consent or communicate. Rather she was repeatedly raped.”\footnote{64}

There may be pragmatic issues of evidence here which prevent or discourage prosecutors from relying on non-consensual offences in these circumstances, yet it is lamentable that proceeding under s30 involves a primary focus on the effects of the complainant’s mental disorder.

Following R v Cooper, there was a lack of clarity about whether the situation specific approach taken by Baroness Hale would be followed in the civil cases. However, it is clear in the subsequent cases that it would not be, and that the low threshold, ‘act-specific’ approach would be retained\footnote{65}. These cases, however, are all first instance decisions, and there was a need for an authoritative appellate level statement on the correct legal approach. This opportunity came in IM v LM and Others\footnote{66}. The case concerned a 41 year old woman, LM, 

\begin{itemize}
\item \footnote{62}{Ibid. para 27.}
\item \footnote{63}{Ibid. para 26.}
\item \footnote{64}{C. Saunders, ‘Making it count: sexual offences, evidential sufficiency, and the mentally disordered complainant’ (2010) 31(2) Liverpool Law Review,p189.}
\item \footnote{65}{D County Council v LS [2010] EWHC 1544 (Fam) D Borough Council v AB [2011] EWHC 101 (CoP).}
\item \footnote{66}{IM v LM and Others [2014] EWCA Civ 37.}
\end{itemize}
who had a history of drug and alcohol abuse and convictions for prostitution. She had 3 children already from a former abusive partner, and these were raised either by her mother, IM, or her sibling. Whilst in hospital in 2010 for surgery related to liver disease, she suffered a cardiac arrest which led to hypoxic brain injury. As a result, she suffered significant distressing memory loss and amnesia. Questions arose as to LM’s capacity in relation to contact with her current partner AB, who had been barred from visiting her in hospital for ‘inappropriate behaviour’, and who also had a significant criminal record. During the course of discussions in relation to this, the issue arose as to her capacity to consent to sex with AB after LM suggested that she would like to re-establish a sexual relationship with him.

In the eagerly anticipated Court of Appeal decision, Sir Brian Leveson pointed to Munby J’s statement that there is a distinction to be drawn between “complex decisions such as medical treatment” and “marriage or sex decisions” and that whilst a refined analysis of the ability to use and weigh the information may be necessary in complex decisions, this is not the case in simple decisions. He went on to state that “I do not say that these analyses are irrelevant; they are not. I merely say that in this particular context it is unlikely to be either necessary or even particularly helpful to refer to them.” Sir Brian Leveson here sought to suggest that the extent of the judicial investigation is what is key and confirmed that in cases about sex and marriage a low threshold is to be set. Moreover, the situation specific approach which Baroness Hale endorsed in Cooper was distinguished by Sir Brian Leveson, noting that,

“the fact that a person either does or does not consent to sexual activity with a particular person at a fixed point in time, or does or does not have capacity to give such consent, does not mean that it is impossible, or legally impermissible,

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68 Ibid.
for a court assessing capacity to make a general evaluation which is not tied down
to a particular partner, time and place.”\textsuperscript{69}

The notion of person-specificity, as the situation-specific test is sometimes presented as, has been dismissed by judges as conflating capacity with best interests, and in effect amounting to social-engineering through vetting particular partners\textsuperscript{70}. Furthermore, as Mostyn J noted in \textit{D Borough Council v AB}, a person-specific test would conflate “capacity to consent to sex with the exercise of this capacity.”\textsuperscript{71} However, the situation specific approach advanced by Baroness Hale does not necessitate an evaluative focus on the suitability of a partner, or social engineering in the way feared. Baroness Hale is drawing attention to the situational factors which can impact upon a decision, echoing many of the concerns of vulnerability theorists. The particular characteristics or identity of the partner is not the issue— it is whether the individual can make a choice if another individual in the particular circumstances, or the situation itself, is overbearing this. Here, the concern is about the ability to freely exercise a choice, regardless of how high or low the level of information required is pitched at.

Embedded in the judgements above are allusions to pragmatic concerns and the limitations of the Mental Capacity Act 2005 as a mechanism in these cases. As is well-established, the Mental Capacity Act 2005 takes a functional approach, focusing on the particular decision to be made and assessing capacity in relation to this— “a person is not capable or incapable in an abstract or general way.”\textsuperscript{72} Yet, what is clear from these sexual capacity cases is that the judges are keen to assess capacity in relation to sex in a more global manner. As Sir Brian Leveson pointed out in \textit{IM v LM}, “it would be totally unworkable for a local authority or the Court of Protection to conduct an assessment every time an individual over whom there was

\textsuperscript{69} IM v LM and Others [2014] EWCA Civ 37, para 76.
\textsuperscript{70} Noted by Wood J in \textit{D County Council v LS} (2010), para 42.
\textsuperscript{71} D Borough Council v AB [2011] EWHC 101 (Fam), paras 34-35.
doubt about his or her capacity to consent to sexual relations showed signs of immediate interest in experiencing a sexual encounter with another person\textsuperscript{73} as such, it is seemingly impossible to apply this functional, decision specific approach which is entailed in the statute\textsuperscript{74}.

6.4 The Responsive State

A further concern ought to be raised about the ability of the Mental Capacity Act to provide an appropriate legal response here. Section 27 precludes a best interests decision from being made if the person is deemed to lack mental capacity under the Act\textsuperscript{75}. In effect, if a person is deemed to lack capacity to consent to sexual relations, then their freedom to engage in sexual relations will be curtailed by supervision and control to prevent it. On the other hand, if someone is deemed to have capacity, then the scope for judicial intervention ends, as the person is deemed to be capacitous and so autonomous. It is perhaps then understandable that given this all-or-nothing approach, the judges are somewhat constrained by pragmatic concerns- and the empowerment/protection binary that accompanies the dichotomy between capacity and autonomy- and a low-threshold may be seen as the optimal way to protect sexual rights. Indeed, this is clear in Baker J’s assertion in \textit{A Local Authority v TZ} that “with respect to Baroness Hale, it seems to me that the approach favoured by Munby J and Mostyn J is more consistent with respect for autonomy in matters of private life”\textsuperscript{76}. However, this statement with regard to respecting autonomy needs to be unpacked further. It will be considered below whether this emphasis on non-interference does indeed respect autonomy in the way that is being suggested, or adequately address the issues illuminated by vulnerability theorists.

\textsuperscript{73} IM v LM, para 77.
\textsuperscript{74} See J Herring and J Wall, ‘Capacity to Consent to Sex’ (2014) 22 Medical Law Review260 for a more in depth legal critique of IM v LM.
\textsuperscript{75} Mental Capacity Act 2005, s 27.
\textsuperscript{76} A Local Authority v TZ [2013] EWHC 2322 (COP), para 23.
Crucially, Fineman hones in on the need for a ‘responsive state’ as a central aspect of her vulnerability thesis, contending that an understanding of the various sources of vulnerability forms the basis of a claim that the state must be responsive to these. This signals an important recognition of the role that the state and societal institutions play in the formation of sources of vulnerability, and conversely that the state is in a position to ameliorate this and instead foster resilience. Once the interplay of various sources in the creation of vulnerability is revealed, responses can be framed with the purpose of fostering resilience in the individual. As suggested by the particular nature of vulnerability, responses cannot be framed on a one-size-fits-all approach, and must be tailored in light of the individual experience. Akin to the idea of facilitating resilience, Mackenzie has argued that the focus of responses to mitigate vulnerability ought to be informed by an overall background aim of fostering autonomy wherever possible. Here, she reiterates that autonomy as a value should not be rejected by a vulnerability analysis, and instead what is needed is a re-conceptualisation of autonomy as relational, rather than the individualistic conception residing in liberal approaches. This understanding illuminates the way in which the development and sustained exercise of the capacity for self-determination requires ongoing interpersonal, social and institutional scaffolding which can be thwarted by social domination, oppression and disadvantage; and that the state has obligations to develop social, political and legal institutions that foster the autonomy of citizens. This attentiveness to the role of societal institutions in the development and sustainment of autonomy brings into question the idea that autonomy and rights are best protected by non-interference, and thus poses new questions about the role of the state in facilitating the enjoyment of autonomy and rights. Viewing rights in this way.

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77 M Fineman and A Grear, n1, p.13.
78 C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, n24, p.33.
80 Ibid. p.42. “It is therefore not just when our physical capacities are diminished when we need others. We are dependent on others for the social world that enables us to develop all of our core capacities” (28).
resonates with the capabilities approach to justice, which entails a focus on the contextual situation of justice claims and a more substantive exploration of equality and opportunities. In terms of rights discourse, the capabilities approach instead requires that we ask whether the right is capable of being achieved, and whether unjust background conditions or other barriers are inhibiting the actual opportunities to secure the right. As Nussbaum asserts, securing a right ‘involves affirmative material and institutional support, not simply a failure to impede’. This enjoins those who are in a position to secure rights to citizens—such as the government and the judiciary—to consider the way in which structural relations can facilitate the enjoyment of such rights and to respond to claims on this basis.

In this regard, the UNCRPD can be seen as a turning-point in conceptualising and responding to disability. It is significant in that it marks a recognition that “reliance on formal structures alone is not adequate to ensure full enactment of human rights…the convergence of formal and informal social forces is necessary for the roots of human rights to grow deep into social structures”. The preamble, for example, stresses the importance of recognising that disability results from the interaction between persons with impairments and attitudinal and environmental barriers to equality, the need to promote and protect human rights for people with disabilities, including those who require more intensive support. It reinforces and reaffirms the importance of enforceable rights and entitlements. More importantly, the ethos of the UNCRPD is very much about taking positive steps to enable rights to be protected.

The UK, having ratified the UNCRPD in June 2009, is committed to taking concrete actions to comply with the Articles of the Convention, which span various aspects such as equality.

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81 C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, p34.
85 See Article 4 UNCRPD, ‘General Obligations’. 
and discrimination, gender issues, children with disabilities, the right to life, access to justice, employment opportunities, privacy and liberty.  

Article 12 is concerned with the right to equal recognition before the law for persons with disabilities and is seen as one of the pivotal- and most controversial- articles in the Convention. The UN Committee on the Rights of Persons with Disabilities published a General Comment on Article 12 recently in which they affirmed its importance for those with cognitive and psychosocial disabilities and the need for states to holistically examine all areas of the law with a view to ensuring that people have opportunities to express or develop their will and preferences as well as having choice and control over their everyday lives. The Committee stated that Article 12 does not set out any additional rights but instead simply describes the specific elements that state parties are required to take into account to ensure equality before the law. However, this in itself is quite a radical step when considering the measures that the Committee foresees as necessary to ensure compliance with this. The General Comment outlines the importance of the concept of legal capacity for the exercise of civil, political, economic, social and cultural rights and also how, historically, the denial of legal capacity has led to people with disabilities being deprived of such rights through systems of guardianship and substitute decision-making. The Committee are keen to stress here that the conflation of legal capacity (comprised of legal standing and legal agency) with mental capacity (judgements about decision making skills) which has been used to justify systems of substitute-decision making or guardianship are to be abolished under the

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86 We have seen the domestic courts gradually begin to grapple with the CRPD in judgements, see for example AH v West London MHT [2011] UKUT 74 (AAC), para 16.
88 Ibid. para 1.
89 Ibid. para 8.
UNCRPD\textsuperscript{90}. In particular, and a clear reflection of the social model underpinning the UNCRPD, the Committee stress that,

“Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity”\textsuperscript{91}

Instead of relying on such an approach, the Committee stress the need to provide support to exercise legal capacity, including supported decision making. This has provoked much debate at a domestic level about what this means in terms of the compatibility of the MCA with the UNCRPD\textsuperscript{92}- in particular, the way in which the legislative framework hinges on the concept of mental capacity, and endorses responses based on the ‘best interests’ of the individual.

The contextual understanding of sources of vulnerability, and emphasis on the obligations of the state in responding to these, is reflected in the ethos of the UNCRPD - “both aim at societal measures to empower individuals regardless of their own abilities”\textsuperscript{93}. Crucially, both approaches aim at augmenting capabilities, rather than particular functionings or outcomes, and so prioritise autonomy through supports, rather than substituted decisions. One of the innovative legal aspects of the UNCRPD is the shift in focus from state non-intervention and procedural rights to the need for states to address background conditions and obstacles to facilitate and enable rights for those with disabilities. This is a direct challenge to the idea that autonomy is engendered through non-interference and recognises that background social and political contexts are central to facilitating autonomy. Indeed, many have commented on

\begin{flushleft}
\textsuperscript{90}Ibid. paras 13-15.
\textsuperscript{91}Ibid. para 14.
\end{flushleft}
the fact that the value of the UNCRPD is not in creating new rights- many of the rights are already stated in other Conventions and human rights instruments- but instead resides in the shift in emphasis towards support and obligations\textsuperscript{94}. Quinn, for example, suggests that the Convention represents “the latest iteration of a long extended essay at the international level about a theory of justice- a theory that is applied to disability to be sure, but one that is woven from a much deeper cloth and has universal reach”\textsuperscript{95}, and is an antidote to the ‘reductionist and essentialist picture in liberal theories of justice’\textsuperscript{96}. Viewed from this perspective, the UNCRPD and discourse flowing from it opens up the space for broader consideration of state responsibility in relation to all citizens, not just those with disabilities. An understanding of, and focus on, vulnerability directs states to develop structures to address inequality and disadvantage not on the basis of certain protected characteristics (as it common in many jurisdictions and rights documents, including the UNCRPD) but on the basis of the universal vulnerability that resides in all human beings in society. This focus on the universality of vulnerability avoids the ‘othering’ which can result from a legal approach predicated on a dichotomy between capacity and autonomy, and is reflected in some of the writing on the UNCRPD which sees this new paradigm of ‘universalism’ as uncovering the limitations of traditional approaches to equality and non-discrimination\textsuperscript{97}. As Bickenbach maintains, this is based on a concept of impairment as “an infinitely various but universal feature of the human condition”\textsuperscript{98}. This approach has the potential to open up more expansive ways of framing responses to vulnerability within society, being based on broad understandings of the sources of vulnerability rather than distinct categorisations of particular group membership and


\textsuperscript{96} Ibid. p57.


capacity. Might this approach guide us in understanding and responding to sexual vulnerability in a way which fosters resilience and autonomy?

Focusing on the interplay between situational factors and the embodied experience of the individual, and noting the caveat that responses can potentially aggravate vulnerability in the pathogenic sense, can help to elucidate more appropriate responses if the overall aim is to facilitate sexual autonomy. It is important not to lose sight of the disquieting high incidence of sexual abuse against people with cognitive impairments\textsuperscript{99}. However, the narrow approach to sexual vulnerability which can be seen at present, situating the source of vulnerability within the person and framing protective responses to the perceived risk are directly called into question by the insights highlighted above. Without a full understanding of the variety of sources involved, the focus of intervention becomes risk management and protection\textsuperscript{100}. As Leach Scully has noted,

“It is true that cognitive impairments more than physical ones expose a person to the significantly different vulnerabilities of exploitation by others, lack of self-care or self-protection, and simple failure to be offered a place of security and comfort in complex societies. But it is also true that some of those vulnerabilities could be reduced by social and attitudinal change”\textsuperscript{101}

As seen above, a contextual, situational analysis reveals the nature of power imbalances that permeate relationships, particularly abusive ones. A vulnerability analysis can centralise such concerns and necessitate responses to these which facilitate autonomy through various means, providing a theoretical model which accounts for power dynamics, sexual knowledge, situational concerns and the diverse levels of capacity - and the ability to exercise this, not just

\textsuperscript{99} Mencap Behind Closed Doors (London, Mencap, 2001)
\textsuperscript{100} A Hollomotz, \textit{Learning Difficulties and Sexual Vulnerability: A Social Approach} (Jessica Kingsley, 2011), 34.
\textsuperscript{101} J Leach Scully, ‘Disability and Vulnerability: On Bodies, Dependency and Power’ in C Mackenzie, W Rogers and S Dodds, n24, p209.
within the population of people with cognitive impairments and mental disorders, but also as a universal concern. Account can also be taken of the way in which abilities can be diminished due to inadequate support and resources. Little has been done to address such issues in the context of mental capacity and consent and to how these intersect with sexual vulnerability and autonomy. With this in mind, the paper now turns to the current legal response to capacity to consent to sexual relations in order to question whether it has the potential to secure sexual rights and autonomy.

6.5 Facilitating Sexual Autonomy

The provision of information, and education about sexual relationships, is undoubtedly important and emphasis is rightly placed on it. However, focusing only on information ignores the importance of choice and control—“in order to successfully self-defend against sexual violence an individual must be able to utilise their self-determination skills.” Adopting a low informational threshold signals to those charged with facilitating sexual capacity that we are only concerned with providing a limited amount of information, rather than a more holistic and reflective understanding which empowers that person to exercise choice. A similar point was raised by Keywood in the context of contraceptive decision making, who noted that whilst there may be good reasons for adopting a low informational threshold for capacity, we need to question whether we can isolate all of the broader dimensions of decision making. She went on to note that “to exclude an appraisal of some of the broader consequences as they are perceived as being relevant to the person does not necessarily ensure respect for autonomy.” In focusing on the informational aspect, the

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103 Ibid.
104 A Hollomotz, n38, p41.
106 Ibid.
courts are effectively asking in an abstract vacuum about a person’s ability to make a
decision. Here, the commitment may be to “ostensible, rather than substantive protection of
autonomy”\textsuperscript{107}.

This may be seen as part of a wider problem with the binary nature of autonomy and capacity
which is seen in medical law more generally. The assumption is that once a person is deemed
to have capacity, they are capable of acting autonomously and thus their decisions ought not
be interfered with\textsuperscript{108}. Tied to this liberal understanding of autonomy is the corollary idea that
autonomy increases with the reduction of state interference or restrictions\textsuperscript{109}. Capacity
assessments under the MCA thus may obscure from view the power dynamics and situational
impacts upon a person’s autonomy, in the name of freedom from interference\textsuperscript{110}.
Furthermore, this understanding of autonomy promotes a “questionable equation of non-
intervention with respect for human rights in circumstances where individuals are
disempowered relative to their abusers and by their abuse”\textsuperscript{111}. The vulnerability lens, and the
UNCRPD, show that a respect for autonomy and rights does not hinge on non-interference.
On the contrary, without adequate background conditions which foster resilience and choice,
autonomy and capabilities are an illusion. Vulnerability requires us to “rethink, rather than
discard, the concept of autonomy”\textsuperscript{112}. The MCA, however, is not in a position to facilitate this
here as it struggles to fit the reality into a workable framework.

\textsuperscript{112} C Mackenzie, W Rogers and S Dodds, n24, p16.
The capacity framework also has the potential to leave people in vulnerable and abusive situations, as it only ‘protects’ those who are ‘incapable’; those deemed to be capacituous and thereby autonomous, are left outside of its remit, even if they are vulnerable. It does not engage with the crux of the problem. We also see in this sense the way in which the response of the MCA can leave people in a vulnerable position both when they are deemed to have capacity and when they are deemed not to. In *A Local Authority v H*, for example, we see how a focus on individual disability or impairment can ignore many of the situational factors which have affected her decision making abilities. H was a 29 year old woman with mild learning difficulties, atypical autism and an IQ of 64. The evidence in the case suggested an “early and deep degree of sexualisation”, and Hedley J noted that whilst H may have consented to such sexual encounters, these may have been exploitative or unconventional as they involved multiple sexual encounters at a time, much older men, bisexual oral and anal sex and attempted sex with a dog. H was deemed to lack capacity for sexual relations because she realised about sexual health but not how to protect herself; she struggled to say no and she did not fully understand the relevant issues. The response of the MCA, in holding her to lack capacity, is to deprive her of her liberty and to control and manage aspects of her life to prevent sexual relationships from occurring. She was subject to ‘1:1 supervision at all times whether in or out of the property and not free to leave the property on any other basis’. Viewed through the lens of vulnerability and capabilities, this does not foster autonomous decision making, as decisions are taken out of her hands, actively entrenching her vulnerability.

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115 *ibid.* para 6.
116 *ibid.* para 9.
On the other hand, if a person is deemed to have capacity to consent to sex under the MCA, they may equally be left in a vulnerable situation, as opportunities to facilitate autonomous decision making are precluded by a focus on non-interference. If situational sources of vulnerability have been obscured by a narrow capacity focus, these cannot be responded to and so will endure. Moreover, the need to frame the capacity questions carefully in light of the pragmatic limitations of the statute has resulted in artificial and arbitrary distinctions being drawn between capacity to consent to sex, and capacity to consent to contact. We see this starkly in the line of TZ cases\textsuperscript{117} - after declaring that TZ had capacity to consent to sexual relations, there was a concern that TZ, in exercising this in particular instances, may lack capacity. Whilst this may reflect some of the situational vulnerability concerns that have been explored in this paper, the way that these become framed in the capacity framework are troubling. To avoid the pragmatic pitfall that a best interests decision cannot be made with regard to sexual consent, the question in TZ (2) was posed as to,

“whether TZ has the capacity to make a decision whether or not an individual with whom he may wish to have sexual relations is safe”\textsuperscript{118}

According to Baker J, this focuses in on the ‘specific factual context’\textsuperscript{119}; however it is contended that this is no less abstract or artificial than a general declaration of either capacity or incapacity in relation to sex. It is clear, however, that in framing the question this way, the court is entitled to then make best interests decisions on behalf of TZ in relation to particular relationships, as it becomes not a question of sexual capacity, but a point of emphasis on contact. In doing so in this case, the court were able to purportedly make declarations to support, in a positive way, that individual to have contact and sexual relations with another individual. Interestingly, it was also raised that if TZ lacked capacity in relation to this first case

\begin{flushleft}\textsuperscript{117}A Local Authority v TZ [2013] EWHC 2322 (COP); A Local Authority v TZ (No.2) [2014] EWHC 973 (COP)\end{flushleft}

\begin{flushleft}\textsuperscript{118}Ibid (No.2), para 18.\end{flushleft}

\begin{flushleft}\textsuperscript{119}Ibid. para 17.\end{flushleft}
point, then it also had to be asked whether he has the capacity to make a decision as to the support that he requires when having contact with an individual with whom he may wish to have sexual relations. Thus, whilst the notion of support ostensibly chimes with the UNCRPD and vulnerability arguments, the approach here inverts the logic of these and hinges the type of support on what is deemed to be in their best interests in relation to contact. This allows ‘support’ to then be imposed against TZ’s own will and preferences in his best interests. This approach allows for the control and management of that individual, rather than supporting him to make the decision for himself, and seems to perpetuate the legal interference with the validity of his actions. If vulnerability can be created through a lack of choice and control over one’s life, then such an approach simply perpetuates this and creates a pathogenic source of vulnerability.

6.6 Responding to Vulnerability- Resilience and Capabilities

As seen in the previous section, the vulnerability critique can highlight the pitfalls of a binary approach to capacity and autonomy, tied to the traditional liberal concept of autonomy as non-interference. The focus on setting a low threshold for capacity in this context can be shown to create pathogenic vulnerability through either necessitating non-interference and ‘hoping for the best’ when a person is deemed to be autonomous, or, conversely, control and management of a person deemed to lack capacity. A vulnerability analysis instead shifts the focus away from tests for capacity, and instead on responding to multiple sources of vulnerability in a way which promotes resilience and autonomy. It is cognisant of the way in

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120 Ibid. para 18.
121 In this case, seemingly in perpetuity as the declaration of incapacity was global and not dependent on who the other party was, and was also accompanied by evidence from an expert that it may take 4-5 years for TZ to acquire capacity with regard to such decisions. Para 59.
122 Also see Re MM [2007] EWHC 2003 (Fam)- contact with partner highly regulated despite being found to have capacity in relation to sex.
which “state attempts to protect the vulnerable can simply exacerbate powerlessness”124. In this way, vulnerability is disability-neutral and can highlight how a mental capacity framework can be both under and over inclusive.

However, focusing on vulnerability rather than capacity may seem problematic. As the discussion of vulnerability at the outset of this paper demonstrates, vulnerability and the sources of it are very difficult to pin down125, and responding to these requires more than can be delivered by the courts alone. Capacity, on the other hand, has been seen as providing an objective legal standard126. Despite this, it is an illusion to think of capacity as objective in this sense. It is itself a socially determined concept127- albeit one which draws a bright line distinction in a way which may be attractive to some seeking at least pretence of clarity. A vulnerability perspective enables a much more explicit focus on the identification of situations or contexts which justify a social response, and moves us to think about what responses are appropriate to address vulnerability, with a subjective focus on the “particular and embodied problem identified”128.

Crucially, the approach called for here advocates the need to link embodied experience to embodied resilience. Structural and institutional responsiveness ought to be accompanied by micro level, individually focused supports. Thus whilst emphasising the universal nature of vulnerability, and the way in which all humans, as social beings, are impacted upon by institutions and societal structures, the approach also strongly prioritises attention to the particular and the need to frame responses which are appropriate and tailored to the

124 J Wallbank and J Herring, n3,p1.
125 Ibid.
individual to achieve the same goal. As Mackenzie suggests, inherent and situational dimensions of vulnerability don’t always need to correlate exactly.

“An inherent condition may seem to place an individual at risk of harm or exploitation but they may not subjectively experience themselves as vulnerable, perhaps because of access to material resources or social supports that promote resilience”\(^{129}\).

Insights from the empirical literature can illustrate the ways in which a much more nuanced approach to sexual vulnerability is required than one which focuses on the provision of information. Looking at the everyday ability to make ‘mundane choices’ of adults with learning disabilities, Hollomotz has highlighted how there is a distinct lack of control over daily decisions- there is often a choice to be made from a pre-arranged menu of activities at a day centre, but no choice about whether to attend in the first place\(^ {130}\). This is disempowering and can lead to passivity, which in turn will impact upon the ability to make choice in other areas of life. Hingsburger echoes this by asserting that sending people on sex education training about the right to make choice and say ‘no’ is not sufficient when they do not have such options in everyday life\(^ {131}\). External and environmental factors can have an impact on choices far beyond the impact of the impairment or disability\(^ {132}\). A focus on vulnerability can centralise attention to these factors, and prioritise the need for responses which address choices more generally, rather than being focused on a particular abstract decision in a vacuum.

\(^{129}\) C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, n24, p46.


\(^{131}\) D. Hingsburger, ‘Just Say Know! - Understanding and Reducing the Risk of Sexual Victimisation of People with Developmental Disabilities’ (Diverse City Press, 1995).

In promoting resilience through experience and choice, such an approach is in stark contrast to the control and management paradigm that is often seen when people are deemed to lack capacity. This is informed by an understanding that interventions which are guided by an assumption of vulnerability and carried out by practitioners on behalf of a passive individual “do little to equip him or her with the skills necessary to manage risk themselves”\(^{133}\). This resonates with statements as to the need to view people with disabilities as subjects, not objects\(^{134}\). Hollomotz and the Speak Up Committee, a group of self-advocates, stated that

“We want our partners to be allowed into our bedroom. We want to be private and safe. Then we could call for help if we need to. We would be comfortable. We would be able to take time and enjoy each other”\(^{135}\)

Thus, promoting autonomy and resilience through responsive and appropriate support can be contrasted from an approach which sees non-interference as preferable. The background need is for the availability of support - the challenge is to ensure that this support in itself does not become coercive. The threat to autonomy in this way can be seen not as the existence of potential ‘interference’ by others, but instead in the way in which this support needs to be responsive in a way which does not become controlling. This is further illustrated by Hollomotz’s study in which she discussed relationships with people with learning disabilities. She discussed one of the participants, Rachel, who had lived with her boyfriend and had initially been happy but after a year this partner had become abusive. As she had a support agency, she sought help from them who enabled her to move out\(^{136}\). Similarly, Emma discussed how she had a long term partner who became controlling and sometimes locked her

\(^{133}\) A Hollomotz, n38, p47.
\(^{135}\) A Hollomotz and the Speak Up Committee, ‘May we please have sex tonight?: People with learning difficulties pursuing privacy in residential group settings’ (2008) (37) British Journal of Learning Disabilities 94
\(^{136}\) A Hollomotz, n38, p135.
in a room. Her father eventually enabled her to move out. These illustrate the way in which a supportive response from an agency or relative may be needed to enable people to escape an abusive situation. Without these, it is difficult to see how their autonomy could be respected by leaving them in vulnerable situations. Yet it is important to also note that both women discussed how such negative experience have enabled them to learn and develop their relationship skills and are now happier in other relationships. This focus on fostering autonomy and resilience through experience and support echo to a certain extent the ‘dignity in risk’ argument that has been in the literature and also judicially advocated for by Munby J. In Re MM, he stated,

“The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as to the price appropriately to be paid in order to achieve some other good- in particular to achieve the vital good of the elderly or vulnerable persons happiness. What good is it making someone safer, if it merely makes them miserable?”

It similarly reflects the UNCRPD focus on taking measures to prevent exploitation, violence and abuse of people with disability, but ensuring that this is done in keeping with the other Articles of the Convention. A submission by NUI Galway on legal capacity highlights how a high standard or rigorous test for capacity is not the most effective form of protection from abuse, as control and management does not foster autonomy. It could similarly be added to this that, on the other hand, setting a low threshold which ignores the situational vulnerability

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137 Ibid. p137.
138 [2007] EWHC 2003 (Fam) para 120.
139 Art 16.
of an individual and thus does not respond to this can equally be seen as contrary to autonomy.

There are certainly barriers to such an approach taking hold at present. Dunn et al highlight how care workers report that they can face negative responses from their agencies when they try to support people to take risks\textsuperscript{141}. Similarly, the culture of risk aversion which permeates much of social care may struggle at present to accept such risks. Yet, the vulnerability thesis can highlight the ways in which responding to sources of vulnerability to risk, rather than simply focusing on the management of the individual, can pose different questions and elicit different responses. As we have seen, the current approach necessitated through the use of the MCA takes as a starting point a concern about the apparent conflict between protection and autonomy or rights to sexual expression, and is constrained by the individual and disability focused mechanisms of the statute. Instead, focusing on vulnerability and capabilities invites us to “focus on the importance of choice or freedom with attention to the social conditions of choice”\textsuperscript{142}. If the MCA cannot reflect these nuances, might other areas of the law be better equipped to do so?

6.7 ‘The Great Safety Net’
Deflecting attention from the individual and onto the situational constraints on autonomy invites a more nuanced response than is available through the MCA. The inherent jurisdiction may provide a more appropriate vehicle within which to respond to the situational impacts on individual decision making. Such an argument has been raised by Wall and Herring, in relation to the case of \textit{PC v York}\textsuperscript{143} which involved the question of capacity for contact. They characterised the non-interference stance taken by the Court of Appeal here as “hoping for

\textsuperscript{141} M Dunn, I Clare, and A Holland 'Living a life like ours': Support workers' accounts of substitute decision-making in residential care homes for people with intellectual disabilities' (2010) 54(2) Journal of Intellectual Disabilities Research, p144.

\textsuperscript{142} C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, n24, p51.

\textsuperscript{143}PC and NC v City of York Council [2013] EWCA Civ 478.
the best”, and noted with incredulity that given the obligations on the state to protect vulnerable adults, it is “extraordinary that that the Court of Appeal limited itself to the analysis of the MCA and did not consider the use of the inherent jurisdiction”\textsuperscript{144}. Indeed, in \textit{PC}, MacFarlane LJ highlighted the importance of the ‘causal nexus’ in the MCA between the mental disorder and the lack of capacity. It is not enough that there is a coincidence between having a mental disorder and lacking capacity- the former much cause the latter. This is an important point to note, and one which has not been routinely emphasised in the case law. Being mindful of this invites more scrutiny of the situational factors which may equally impact upon decision-making, and whilst it is clearly difficult to pin-point precisely the source of incapacity\textsuperscript{145}, it enables much more rigorous consideration of appropriate responses. The alternative- to view the coincidence of a mental disorder and an inability to make decisions as enough to necessitate making a decision on behalf of the person- clearly perpetuates a medical approach to disabilities, which I have argued against elsewhere\textsuperscript{146}. Such considerations may thus point to the inherent jurisdiction as being a more appropriate forum within which to respond to facilitating decision-making, being focused not on the individual but on external impacts upon them.

The scope of the inherent jurisdiction is notoriously wide, and its parameters are unclear. Case law does however seek to elicit the overarching purpose of this “great safety net”\textsuperscript{147} and it is often reiterated that the focus is on the need to enable people to regain and maximise autonomy\textsuperscript{148}, particularly when this is threatened by others. In a similar vein, it is also stated

\textsuperscript{145} Ibid.
\textsuperscript{146} B. Clough, ‘People Like That': Realising the Social Model in Mental Capacity Jurisprudence’ (2015) 23(1) Medical Law Review 53-80.
\textsuperscript{147} A term coined by Lord Donaldson in \textit{Re F (Mental Patient: Sterilisation)} [1990] 2 AC 1.
\textsuperscript{148} \textit{A Local Authority v DL and Others} [2012] EWCA Civ 253.
that the exercise of the inherent jurisdiction is “facilitative rather than dictatorial”\textsuperscript{149}. This reflects in many ways the ethos of the vulnerability critique, and the UNCRPD, by focusing on responding to the particular individual and the ways in which their autonomous decision making can be facilitated\textsuperscript{150}. Parker J in \textit{XCC v AA and Others}\textsuperscript{151} sought to clarify the relationship of the inherent jurisdiction with the MCA, noting that,

“The protection or intervention of the inherent jurisdiction of the High Court is available to those lacking capacity within the meaning of the MCA as it is to capacitous but vulnerable adults who have had their will overborne, and on the same basis, where the remedy sought does not fall within the repertoire of remedies provided for in the MCA 2005. It would be unjustifiable and discriminatory not to grant the same relief to incapacitated adults who cannot consent as to capacitous adults whose will has been overborne.”\textsuperscript{152}

However she went on to note how the principles entailed in the MCA are not exported into the inherent jurisdiction, which is a point which will be returned to later. In essence, it is clear that the inherent jurisdiction endorses a flexible approach, seeking to facilitate decision-making by using a range of responses tailored to the individual situation.

We see this at work in the case of \textit{A Local Authority v A}\textsuperscript{153} which involved a woman with severe learning difficulties, and the question before the court was whether she had capacity in relation to contraceptive decisions. Bodey J, as we saw above, noted that the scope of what needed to be understood was limited and did not require consideration of a woman’s ability to foresee the realities of parenthood or the demands of caring for a child not yet

\textsuperscript{150} Echoing, for example, the impetus in the UNCRPD to provide support for decision making (Art 12(3)); respect for will and preferences (Art12(4)) and promoting autonomy (Art 4).
\textsuperscript{151} XCC v AA and Others [2012] EWHC 2183 (CoP).
\textsuperscript{152} Ibid, para 54.
\textsuperscript{153} A \textit{Local Authority v A} [2010] EWHC 1549 (Fam)
conceived\textsuperscript{154}. However, he then went on to consider that in relation to the need to be able to use or weigh this information, she was unable to do so not because of her impairment, but because of the overpowering control that her husband, Mr A, exercised over her. Bodey J, however, did not make a decision based on Mrs A’s best interests to order the use of contraception—instead, invoking the inherent jurisdiction, he favoured an approached aimed at achieving a capacitous decision, through support and a discussion without undue pressure from her husband\textsuperscript{155}. Thus we see that the focus becomes on situational factors, rather than the disability itself, and responses are framed in light of this, rather than “controlling people of marginal capacity”\textsuperscript{156}. This perhaps leaves more scope for engaging with the embodied individual, and to take into account the multi-faceted nature of vulnerability in the particular situation and how resilience can be fostered in light of this. Highlighting the need to facilitate autonomous decision-making accords with Mackenzie’s emphasis on the capabilities framework, as she argues that without it, “discourses of vulnerability and protection may open the door to objectionably paternalistic and coercive forms of intervention”\textsuperscript{157}. Approaching sexual vulnerability in this way may pave the way for a more nuanced understanding of the way in which responses can be augmented towards facilitating sexual autonomy, in a way which is obscured when using the mechanism of the MCA.

Having said this, the inherent jurisdiction will not solve all of the problems in this context. As Keywood has pointed out, it is a piecemeal and incremental mechanism\textsuperscript{158}- being focused on particular cases coming before the court- and so it is unable to feed into practice on the ground, or into wider policy change to give effect to facilitating autonomy and capabilities at

\textsuperscript{154}Ibid. paras 63–64.
\textsuperscript{155}Ibid. para 79.
\textsuperscript{157}C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, n24, p33.
a macro level\textsuperscript{159}. In addition to this, we have seen that the inherent jurisdiction is of imprecise scope, and the principles underpinning it are even less clear\textsuperscript{160}. The statements by Parker J that the principles guiding the MCA- which have been lauded by commentators and by the recent House of Lords Select Committee report on the MCA\textsuperscript{161}- are not exported to the inherent jurisdiction, may be a cause for concern for some. There is a legitimate concern that if principles such as a presumption of capacity, the least restrictive alternative, and the protection of unwise decisions, are ignored, then there is a possibility of purportedly supported decisions becoming coercive, rather than empowering. In the context of debates surrounding the UNCRPD, the idea that supported decision-making may become coercive is similarly agonised over, although Quinn suggests that when we view autonomy as relational, this is a reality for us all when we make decisions, and a threat we must all navigate\textsuperscript{162}. Dunn similarly suggests that the mere fact that there was external pressure involved in a decision is not sufficient to attract the claim that it is an invalid decision\textsuperscript{163}. We cannot be blind to this, or assume it is unique to people with mental disabilities (or any other protected characteristic). Instead, we need to be attentive to this reality. When looking at vulnerability in the universal sense, we can expose this fact and question what, precisely, are we seeking to respond to. It is not decision-making in the abstract- divorced from the reality of social situatedness - which is aimed for. It is decision-making which is cognisant of the situational constraint and impact, but which seeks to ensure that these situational factors are responded to where possible, to facilitate autonomous decision making.

\textsuperscript{159} However, the fact that it is exercised by the courts, rather than non-judicially like the MCA, may support an argument that the inherent jurisdiction is more compliant with Art 12(4) of the UNCRPD in providing more robust safeguards than the informal mechanisms contained in the MCA

\textsuperscript{160} J. Collins, ‘The Contours of Vulnerability’ in J Wallbank and J Herring, n4.


\textsuperscript{163} M Dunn, ‘When are adult safeguarding interventions justified?’ in J Wallbank and J Herring, n4.
6.8 Conclusion

It is clear, based on the state of the domestic law and international legal developments in this area, that debates as to whether capacity to consent to sex should be approached in a situation or act specific way will persist. The vulnerability critique provides an alternative perspective from which to consider sexual autonomy, and to highlight the ways in which the current approach obscures many relevant considerations from view. It is clear that the MCA, and the criminal law, by maintaining the focus on the existence of a mental disorder, are too blunt mechanisms for attending to the nuances entailed in a vulnerability analysis. Furthermore, both the MCA and the criminal law are reactive mechanisms, and only tend to arise when a concern is raised, or sexual activity has taken place. This does little to address the commitments entailed by both the UNCRPD, and the vulnerability analysis, to promote autonomy and resilience in a more broad sense as an ongoing concern. The vulnerability approach is, as such, not necessarily so concerned with the content of a particular, isolated decision, but the resources available to individuals in navigating choices and opportunities throughout their lives. As Verkerk suggests, we need to think about how coercive interventions can be prevented and how a situation in which only two strategies remain (non-interference or coercion) can be avoided\textsuperscript{164}. This more nuanced response is not enabled by debates which are framed as a conflict between state intervention and autonomy and in which legal responses hinge upon the concept of mental capacity.

Such an analysis can also highlight the way in which facilitating autonomy is not just a question for law- laws and their institutions cannot eradicate vulnerability. As Williams has put it “laws do not solve social problems, but they can promote resilience and mediate or lessen vulnerability”\textsuperscript{165}. Focusing through the lens of vulnerability emphasises the need for a


range of responses. In the context of sexual vulnerability, this points to the need for education, training, access to justice, as well as services being augmented towards choice and control through positive risk taking. Central to this is a responsive state providing supportive background conditions. This is not currently provided by the MCA in the context of sexual capacity, as it is evident that the legal approach is erroneously premised on non-interference as a means to promoting sexual rights. The focus needs to be not on whether state interference is appropriate- as relational beings, we all navigate various sources of state and social interference- but rather on the appropriate response, and whether this seeks to secure autonomy and capabilities. Until relational vulnerabilities, such as those at play in the context of sexual relationships, are recognised, then we cannot question what, if any, should be the appropriate legal response.\textsuperscript{166}

Taking the next step and thinking through the overarching legal repercussions of these conceptual considerations is a difficult task which warrants sustained consideration in another paper. However, it is clear that it requires a significant rethinking of the boundaries used to determine when support is to be offered and on what basis, and the justification, if any, for intervention in a decision against a person’s apparent wishes.\textsuperscript{167} As Richardson has pointed out, the process of defining these boundaries “would at least generate express consideration of the underlying moral dilemmas” which the law can currently avoid confronting “by flexible interpretation of established concepts”.\textsuperscript{168}

\textsuperscript{166} J Bridgeman, ‘Relational Vulnerability, Care and Dependency’, in J Wallbank and J Herring, n4, p202; R. West, Caring for Justice (New York University Press, 1997) p176.
\textsuperscript{168}Ibid. p104.
CONCLUSION

“...the illusion of independence rests on a denial of interdependence”\(^1\).

The theories and ideas driving the preceding papers offer a novel and nuanced foundation for rethinking the legal approach to mental capacity and cognitive impairment. The application of feminist and relational approaches in critiquing quite different areas of the law in this context has revealed the pitfalls of the legal framework, which is built-in the main-on an individualistic liberal philosophy. The contribution of care ethics and vulnerability theories here has enabled scrutiny of the stubborn and pervasive boundary between ‘private’ and ‘public’ issues, which has long served to ensure that many of the issues explored in the papers were hidden or seen as outside of the scope of state interest. Breaking down this boundary, and highlighting the state and societal impact upon the lived experience of care and disability, brings such issues to the centre of legal and political debate and enables us to question state approaches and responses in this context. As Knight suggests

“our political pursuits are largely shaped by power relations that precede and exceed us. The political contexts – the ‘spheres’ we inhabit- influence which values are politically salient and the kinds of claims we should be making on the state and on each other”\(^2\).

Moving these issues into the centre of our political thinking can recast the way we conceptualise them and challenge long-held assumptions that permeate discourse in this context.

The combination of these critical approaches, alongside a theory of justice such as the capabilities approach, allows us to advance social justice arguments for change and more responsive laws and policy. Whilst the capabilities approach has been subject to criticism, contradictory interpretation and controversy, the core elements of it as a contextual approach to justice and rights helps to advance the theoretical aims here. Understood consistently with the relational theories employed, the capabilities approach can crucially highlight power relations and oppression within a social context, as well as being attentive to the subjective experience of care and disability. It can highlight the way in which purported rights, in reality, are not being secured for certain individuals, and the way in which the structural, institutional and systemic make-up of the state and society can adversely impact on this. It is the interaction between the particular individual and the social context in which they exist that ought to be the focus of the inquiry here, if the capabilities approach is to further the aims of the relational approach.

Going beyond the evaluative and critical element of the theories used in these papers, an important contribution is made to the literature here by stressing the obligations that arise to respond to the issues when they become public, rather than private or personal matters. The traditional liberal approach which has been discussed in the papers has allowed the family, and individual needs for assistance, to be seen as private and personal issues, outside the realm of state involvement or responsibility. As Lacey explains, the traditional dichotomy “allows government to clean its hands of any responsibility for the state of the ‘private’ world

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and depoliticizes the disadvantages which inevitably spill over the alleged divide"⁵. By moving the issues into the realm of the public, and blurring this dividing line, we can no longer pretend that the state structures and institutions have no role in these areas. The capabilities approach here feeds into the human rights discourse by emphasising positive, as opposed to negative rights approaches. The UNCRPD has been highlighted in these papers as potentially furthering these aims to facilitate capabilities and the enjoyment of rights of people with disabilities on an equal basis with others in society, and for having the potential to usher in an alternative conception of justice not just for those with disabilities, but for all in society⁶. Whilst by no means a perfect model, the UNCRPD allows us to see to a certain extent how these theoretical approaches may look in a legal framework. The implementation of the UNCRPD is still at a fairly abstract level in English law, so it is important to be cognisant of the pitfalls of the legal and theoretical approaches in trying to build legal responses based on the Convention.

Despite this, there remain some further tensions that ought to be explored and clarified as well as key areas for further research if the contribution of this thesis is to be advanced. These will be dealt with by examining the contribution and future implications of each paper in turn, before highlighting the key future questions provoked by them.

7.1 A Relational Approach to Caring

The first paper highlighted the lack of legal recognition given to carers’ interests under the Mental Capacity Act 2005, and the way in which the legal framework fails to adequately reflect the realities of caring. Under the current legal framework in the Mental Capacity Act 2005 it is an individualistic approach which is instead promulgated- one which presents


carers as essentially a means to elucidating the interests of the person lacking capacity. This in effect denies the interdependence of those within caring relationships—interdependence which permeates not just the caring relationship, but also their relationship with society and the state. The relational approach developed in this paper, and in the subsequent papers, is built upon Tronto’s work toward a politically focused ethic of care. Whilst the care relationship is of importance, it is argued that without attention being paid to the individuals within it, and their needs and interests being responded to, individual interests can become subordinate to the overall relationship. To enable this responsive approach, it is crucial that a contextual focus is fostered which looks at the dynamics of the care relationship, but also the interaction of individuals with their socio-political environment. As Donnelly has suggested, “this requires legal engagement not just with individuals but with surrounding practices, asking whether these enhance or erode autonomy capabilities”. An important aspect of this, however, is recognition that responsibilities (falling on all parties) are a central feature in relationships—permeated as they are by interdependence and interwoven interests. It is not always possible to maximise the interests of one party without acting to the detriment of another. Compromise and balance are therefore central to any legal attempt to implement a relational approach. The political context, and service providers, must be mindful of this when tailoring responses and ensure that the needs of one are not overlooked in order to maximise the interests of another. A key part of this is ensuring that the voice of both carers and cared-for is heard.

As noted in the introduction, an important contribution of care ethics in the political sense is to centralise caring relationships as a societal concern, and to ensure that legal and policy responses are crafted in such a way as to facilitate good caring relationships through recognition and provision of services, and to ensure that the interests of those within caring

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relationships are recognised. As a point of emphasis, it is important in this regard to avoid the dichotomising of carer and care-receiver which had pervaded much of the debate between care ethicists and disability rights advocates in the past. However as discussed in the paper, it is important not to overlook the needs and interests of those individuals within the relationship. It is a complex and nuanced response which is required; one which is attentive to the way in which the capabilities of all those within the relationship ought to be responded to, in order to facilitate a good caring relationship. As discussed in the paper, best interests assessments ought not to see the carer or family members as disinterested parties whose role is to simply communicate what the persons best interests will be. It is important to consider individual interests as well, and to consider the impact which certain treatment or residence decisions may have on the caring relationship. As Back has argued, it is important to emphasize the political significance and civic membership of both carers and those receiving care, in contrast to the ‘nested obligations’ approach taken by Kittay which can essentially privatise the obligations and dependence. She argues that “nesting disabled peoples’ needs and interests inside care relationships, rather than treating these as matters of public obligation and concern, risks reinforcing troubling patterns of exclusion”. As part of this, an important challenge (which is developed in the subsequent papers) is recognising the centrality of those with disabilities, and their carers, in society and political discourse. Part of this is recognising the universality of vulnerability and interdependence in society- seeing people as part of the universal difference of humanity, rather than positing them as the ‘other’ and by extension requiring different treatment.

9 Back, n1,p1, p8.
10 Ibid. p8.
This in effect is what one interpretation of the UNCRPD can facilitate. As noted throughout the papers, Quinn, among others, sees the Convention as an alternative, more contextually focused, approach to a social theory of justice at a broader level, rather than an instrument solely focused on disability. This is an approach that has been taken throughout this thesis in evaluating the potential of the UNCRPD for furthering the critiques in the papers. However, it is in the realm of carers’ interests that the UNCRPD may pose a real danger to realising this relational endeavour.

The UNCRPD does refer to family members or carers of persons with disability, however when it does so, they are essentially placed as the means by which the human rights of the person with disability can be achieved - there is no support given to facilitating the carers interests as an end in itself, nor focusing on the caring relationship as a whole. The Preamble, for example, states that

“the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.

Whilst on the face of it this statement appears to lend support to a relational ideal of recognising the interests of all of those within a caring relationship, a closer reading reveals that the support provided to families is to enable them to contribute to the enjoyment of rights of persons with disabilities. As Kayess and French discuss, in drafting the Convention the Ad

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11 M. Donnelly, and C. Murray, n5, p404.
12 Preamble, Art 16, Art 23(4) and 28(1).
13 Preamble, x.
Hoc Committee had keenly argued about whether the interests of family members ought to be included. This was answered in the negative,

“on the basis that in most societies family needs and rights tend to be privileged above those of persons with disabilities and, notwithstanding the enormous importance and contribution of persons with disability to the realisation of rights and dignity of person with disability, it is sometimes family members who are principally responsible for, or collude in, human rights violations against them”14.

Whilst a relational ethic of care must be cognisant of the ‘dark side of care’ and the very real possibility of abusive relationships15, this is an unhelpful and outmoded dichotomisation of the interests of those within caring relationships. The much lauded relational face of the UNCRPD, decipherable through the emphasis on positive obligations and the interrelationship between social, economic and cultural rights and civil and political rights, is distinctly absent in this context. This presents a disappointing and also politically dangerous obstacle to engendering good caring relationships which enable the facilitation of the rights of all those within it. Instead, a particularly ‘thin’ conceptualisation of rights and autonomy is employed in this regard, which is antithetical to the idea that the UNCRPD ushers in new ways of thinking about justice through revision of traditional concepts of autonomy and rights. As Nedelsky suggests, “what makes autonomy possible is the structuring of relationships and collective power to ensure a balance between the individual and the relationships on which they depend”16. Here, instead, we are faced with a divisive and atomistic presentation of the role of rights in the context of caring relationships. There is steady recognition of this issue in the literature. Muir and Goldblatt, for example, stress that if

we pit people against each other in this way, it is easy to lose sight of the values at stake and the relationships those values ought to foster\textsuperscript{17}. This is an area of the UNCRPD that requires further research and debate to ensure that the potential gains of the Convention translate into implementation in ways which are consistent with a relationally and contextually focused universal theory of justice.

7.2 The Social Model of Disability in Mental Capacity Jurisprudence

The second paper in this thesis set out to challenge the medicalised model of disability which is readily apparent in mental capacity jurisprudence, and to explore the legal and jurisprudential barriers to realisation of the social model insights. This is of key importance to the goals of centring disability concerns in legal and political discussion, and creating appropriate responses that facilitate the equal rights of those with disabilities. Quinn and Degener had emphasised the dominance of the medical model as one of the major barriers to people with disabilities accessing and enjoying their human rights\textsuperscript{18}. This medicalization of disability “justifies the limitation of state intervention to prevention and comfort. A distinction is then made between what falls within the public domain and what falls within the private”\textsuperscript{19}. In utilising a contextually focused social model here, the issue of accessing rights becomes a societal rather than a private issue, and attention is thus focused on what can be socially changed.

This proved to be a theoretically and practically important way to challenge some of the ingrained prejudices which can underpin judgements in the mental capacity context. The

\textsuperscript{17} K. Muir and B. Goldblatt, ‘Complementing or Conflicting Human Rights Conventions? Realising an inclusive approach to families with a young person with a disability and challenging behaviour” (2011) 26(5) Disability & Society 629-642.


statements of Munby LJ in *Cheshire West and Chester Council v P*\(^{20}\) were a stark example of this. In this case, Munby LJ had stated that in deciding whether somebody was being deprived of their liberty a ‘relevant comparator test’ was to be employed. Munby LJ stated that whilst in most contexts, the relevant comparator is ‘the ordinary adult going about the kind of life that the able bodied man or woman on the Clapham omnibus would normally expect to lead’, such a comparison ought not to be made in the context of the cases arising in the Court of Protection. He went on to say that the court instead must focus on an adult ‘like X’ and on ‘the kinds of lives that people like X would normally expect to lead’\(^{21}\). This set up a clear dichotomy between those with disabilities and those without-a theme which has been pursued throughout these papers and challenged with the assertion that we need an inclusive theory of justice which recognises the universality of difference in the human condition. Moreover, it accorded with much of the core language of a medical model of disability which situated any problematic aspects of disability as stemming from the disability itself, rather than in societal responses to the person.

The Supreme Court decision in this case was widely welcomed as it challenged this understanding, and statements were made which re-affirmed the universal nature of human rights, founded on the inherent dignity of all human beings\(^{22}\). However, it was suggested in the paper that this perhaps may not go far enough. Lady Hale’s judgement went on to say that “it may be that those rights have sometimes to be limited or restricted because of their disabilities”\(^{23}\). It is not difficult to trace the residue of the medical model here. It perpetuates the idea that rights can be restricted based on inherent characteristics, and focuses on management of these rather than looking externally at the contextual environment. Those

\(^{21}\) Para 102.
\(^{22}\) *P v Cheshire West and Chester Council; P and Q v Surrey County Council* [2014] UKSC 19, Para 45, per Lady Hale.
\(^{23}\) *Ibid.*
with disabilities are still seen as ‘other’ and potentially subject to a different legal regime, rather than part of the overall spectrum of people. I expressed a concern in the second paper that such an approach may clash with Article 14 of the UNCRPD, which states that,

‘State Parties shall ensure that persons with disabilities, on an equal basis with others:

a) Enjoy the right to liberty and security of person;

b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty’.

Indeed, the Office of the High Commissioner for Human Rights have recently released a statement on Article 14 to the effect that it entails a complete prohibition on detention on the basis of disability\(^{24}\). This raises a distinct challenge to legal frameworks such as DoLS.

A more recent judgement casts further doubt on the positive impact of the Supreme Court decision\(^{25}\). It is striking not just in its questioning and challenge to the Supreme Court, but more worryingly in its seeming agreement with Munby LJ’s ‘relevant comparator’ approach. This case concerned care of a 52 year old woman, Katherine, in her own home. She has physical and cognitive disabilities and is cared for under a package of care funded jointly by the council and the local CCG. Mostyn J described the arrangement thus,


“The arrangement entails the presence of carers 24/7. They attend to her every need in an effort to make her life as normal as possible. If she tries to wander off she will be brought back.”26

In determining whether Katherine was being deprived of her liberty under this arrangement, Mostyn J discussed the need to apply the ‘acid test’ from the Supreme Court. He was keen to stress that he found it “impossible to conceive that the best interests arrangements for Katherine...amounts to a deprivation of liberty under Art 5”27. He gave various reasons for this, resorting to an analysis of what liberty would mean for Katherine, adopting J.S. Mill’s approach to liberty. He stated that it is “utterly impossible”28 that Mill would have considered the provision of care for Katherine in her own home as impacting upon her liberty, and went on to say that he would have taken the same view of P, MIG and MEG in Cheshire West. Of interest for the purposes of the second paper, Mostyn J went on to say

“It is clear that the driving theme of the majority opinions [in Cheshire West] is a denunciation of any form of discrimination against the disabled. With that sentiment I naturally agree. Discrimination is found where like cases are not treated alike. However, when making Lord Kerr’s comparison you do not have two like cases. You are comparing on the one hand, a case where an 18 year old does not need protection, and on the other, a case where the 18 year old does. They are fundamentally dissimilar. The dissimilarity justifies differential treatment in the nature of protective measures. For me, it is simply impossible to see how such protective measures can linguistically be characterised as a ‘deprivation of liberty’. The protected person is, as Mill says, merely ‘in a state to require being taken care of by others [and] must be protected against their own

26 Para 6.
27 Para 7.
28 Para 14.
actions as well as against external injury’. And nothing more than that. In fact it seems to me to be an *implementation* of the right to security found in Article 5”

This raises the spectre of Munby LJ’s ‘relevant comparator test’ which was the foundation of paper 2. Indeed, Mostyn J noted that whilst he was bound by the Supreme Court, he could distinguish Katherine’s situation on various grounds, including that in relation to being free to leave for the purposes of the ‘acid test’, the person must have physical capacity to be able to leave. He stated that

“Katherine’s ambulatory functions are very poor and are deteriorating. Soon she may not have the motor skills to walk even with her frame. If she becomes house-bound or bed-ridden it must follow that her deprivation of liberty just dissolves”.

As discussed in relation to Munby LJ’s judgement, this is a very dangerous distinction to draw for the purposes of human rights protection, and relegates those with physical and cognitive disabilities to a lower tier of rights protection simply by virtue of their disability. It reverts back to the medical model which ignores the significant impact that the interaction of the individual with society can have on their experience of their disability. It also ignored the *positive* obligations on states, under the UNCRPD and also as discussed in relation to the capabilities approach, to ensure that rights are facilitated. However, the judgement also shines

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29 Para 17.
30 Para 22.
31 *Ibid.* Mostyn J has since sought to justify or expand on the reasoning in this case in *The London Borough of Tower Hamlets v TB* [2014] EWCOP 53. Here, he states that “…The state is obliged to secure the human dignity of the disabled by recognising that ‘their situation is significantly different from that of the able-bodied’. Thus measures should be taken to ‘ameliorate and compensate for those disabilities. But to characterise those measures as state detention is to my mind unreal…Article 5 was not aimed at Katherine, seriously physically and mentally disabled, who is living in her own home and cared for round the clock by carers paid for by an organ of the state” [Paras 57-58]. The appeal of *Rochdale MBC* was due to be heard in February 2015 by the Court of Appeal, but this has been allowed by consent. As such, the legal status of Mostyn J’s comments is uncertain, but it is likely that the debate around the applicability of DoLS in home care situations will continue. It is hoped that the Law Commission Review of DoLS will address this issue.
the spotlight on some very difficult questions which arise following the Supreme Court decision in *Cheshire West* and the broad ‘acid test’ put forward for establishing a deprivation of liberty. It has been seen that councils are straining under the weight of DoLS applications, and that this has led to significant delays and a backlog of cases\(^{32}\). Questions have also been left unanswered such as whether DoLS should be used when people are being cared for in their own home (either funded by the local authority, or self-funded) and who the obligation to apply for an authorisation falls on. This remains to be seen in the case law and given that the appeal in *Rochdale MBC v KW* has now been allowed by consent\(^{33}\), it is hoped that the Law Commission’s work on DoLS will address these important debates and shortcomings in the legislative framework. Sustained analysis at a legal level is required to fully appreciate this issue, and this is particularly evident following the theoretical debates surrounding the social model and capabilities approaches presented in this thesis. This is a particularly key issue for future research and discussion, at the very least because of the uncertain obligations stemming from the UNCRPD and the reach of these into community care.

A further aspect of the paper which is of importance to future research is the way in which a social model of disability is framed and utilised. Some, such as Kayess and French, have suggested that the UNCRPD may present too radical a model of disability. The social model is a vital addition to the literature here in that it sits with the capabilities approach and relational approaches in breaking down the public/private divide, and highlighting what can be socially changed. However, it is also of crucial importance that such an approach does not gloss over individual embodied experiences. There is a clear danger that if responses are not


\(^{33}\) As noted in the introduction, this debate is set to rumble on given that Mostyn J has now suggested that in allowing the appeal by consent, the Court of Appeal have acted *ultra vires* and that the process of making the consent order was ‘procedurally flawed’ *Rochdale MBC v KW* [2015] EWCOP 13, Para 22
tailored to individual circumstances then they will be built upon assumptions and false universalising about disability. Indeed, if we gloss over the importance of the interaction of the individual with their societal context, we will not be responsive to their actual needs. If an unsophisticated approach is built upon the UNCRPD, then the potential for the ‘paradigm shift’ will be lost. As Ward has pointed out “one of the worst forms of discrimination against anyone with a disability is to fail to recognise and provide for the extent and consequences of their disabilities and to pretend that these do not exist”\textsuperscript{34}. There is a need to ensure that an approach to disability is embodied and that we avoid disability becoming just an abstract discourse that denies experience at an experiential level. This is a point that is strongly reiterated in the final paper- that the UNCRPD should not be seen as being about ‘leaving people to it’ or rights in the negative sense. It is about responding to vulnerabilities at various levels; individual, societal, political.

This chimes with the capabilities approach which is drawn upon throughout this thesis. Some, such as Dean, have argued that the capabilities approach is itself a liberal individualistic model which can obscure or neglect the constitutive nature of human dependency\textsuperscript{35}, however it is suggested that this is why drawing on a contextually focused lens is of such importance. Informed by a relational approach, the capabilities approach can be alive to the existence of power and structural dynamics and the individual’s interaction with these which can impact in turn on their enjoyment of particular rights and capabilities. As Venkatapuram has argued, by “explicitly incorporating the contextual diversity of each human being…we are better able to create equality”\textsuperscript{36}. Despite this, as discussed in the second paper, this can present some difficulties when applied in practice in legal cases. For example, the case of Re WMA\textsuperscript{37} was

\textsuperscript{35} H. Dean, ‘Critiquing Capabilities: The Distractions of a Beguiling Concept’ (2009) 29(2) 261-278.
\textsuperscript{37} [2013] EWHC 2580 (COP).
highlighted as a situation in which a capabilities approach informed by the social model can quite easily come to ignore the expressed wishes of the individual. The theoretical approaches here pulled in quite different directions. This is an issue which will require further exploration as we look to implement supported decision making models in line with Article 12 of the UNCRPD\textsuperscript{38}. Whilst at a theoretical level, both the UNCRPD and capabilities discourse stress that they are interested in providing the means by which a person can make their choices and access support and opportunities, when it comes to the crux in situations like Re WMA it may be that this is difficult to implement.

Another means by which an individually focused and responsive social model, as opposed to a ‘radical social constructionist’ approach may be at play in the UNCRPD is via the mechanism of reasonable accommodation\textsuperscript{39}. In the paper, it is discussed how the requirement of ‘reasonable accommodation’ entails action beyond “bald discriminatory proscriptions in laws and policies”\textsuperscript{40} and instead requires positive affirmative action to ensure that the individual enjoys equal rights with others. It can be seen as operationalising the capabilities approach by acknowledging the need to look not just to societal factors in the abstract, but to focus on the particular individual and what steps ought to be taken to secure to them their purported rights. However, it is important to query whether this goes far enough. In terms of seeing the UNCRPD as ushering in a universal and inclusive theory of justice, which encompasses those with disabilities, the concept of reasonable accommodation may be seen as stopping short of this and instead saying that we ought to include those with disabilities in our current theory of justice (when it does not impose a disproportionate or undue burden to


\textsuperscript{39} UNCRPD Arts 2 and 5.

do so). Weber, for example, argues that the concept of reasonable accommodation continues to see the non-disabled person as the norm, and focuses at the way that departures from that norm can be ‘accommodated’\textsuperscript{41}. This resonates with the approach seen in the Supreme Court where Lady Hale noted that those with disabilities may have their rights restricted solely because of their disability. This may foster a legal and policy discourse which is the antithesis of the universal theoretical approach developed here and, as such, may be unsatisfactory for achieving this vision of social justice. Harnacke outlines how the capabilities approach, particularly that propounded by Nussbaum, is explicitly concerned with an inclusive theory of justice from the beginning, and holds that there is no reason to exclude some members of society from the domain of justice, or only take them into account later on\textsuperscript{42}. As well as this theoretical dissatisfaction with the concept, there is a related practical problem with the framing of the obligation in the UNCRPD. Kayess and French point to the limitations implicit in the idea that reasonable accommodation should not impose a ‘disproportionate or undue burden’ and argue that this is “far from optimal”\textsuperscript{43}. They state that this standard is “insufficiently challenging to penetrate to the core of exclusionary practices affecting persons requiring significant structural adjustments”\textsuperscript{44} and thus may lack the bite that is needed if the UNCRPD is going to achieve the impact envisaged. As such, it is important to be attentive in future research to the way in which reasonable accommodation is employed in legal discourse, and to consider at a theoretical level whether it advances the relational and universal approach called for.

A further barrier to achievement of the social models critical aims in this context is the issue of judicial pronouncements on resource allocation in cases coming before them in the Court

\textsuperscript{43} Kayess and French, n14,p27.
\textsuperscript{44} Ibid.
of Protection, and also in judicial review cases. As pointed out in the paper, cases such as _Aintree v James_[^45] and _ACCG v MN_[^46] clearly state that the MCA 2005 is only concerned with enabling the court to do for the patient what he could do for himself if of full capacity[^47] and so there is no scope for the individual, or the court, to demand a particular treatment or service. King J was anxious to point out that if the court were able to consider where P’s best interests lay first before deciding the issue of funding options, then this would potentially see the court using a best interests decision to put pressure on the local authority to allocate resources in a particular way[^48]. Yet, even if the individual were to bring their case for judicial review, we see a clear tendency for the judiciary to focus on procedural aspects of the case, rather than on substantive questions of justice which would, in effect, enable closer scrutiny of their resource allocation[^49]. As a political issue, and issue of public law, there is a clear reluctance to interfere with resource decisions of public authorities, particularly in these times of austerity. Yet it is precisely at times such as this that the courts can provide much needed scrutiny of decisions related to the funding of vital services that enable people with disabilities to access their purported human rights. As a matter of principle, it could be argued that if a different approach was taken, and if the Court of Protection did scrutinise best interests decisions in this way, then those lacking capacity would in effect be put in a more advantageous position than others. Yet, as discussed in the paper, equality is posited as potentially requiring different responses to different individuals to achieve the same goal and,

[^47]: Ibid. para 52 per King J.
[^48]: Ibid. It is worth noting that King J stated that: “There may be rare cases where it appears to those representing a party that a public authority, in failing to provide funding for a particular form of care package, is acting in a way which is incompatible with Convention rights. In those circumstances, notwithstanding the fact that such an option is not available and before the Court, the Court may exceptionally, pursuant to a formal application under s7(1)(b) HRA, conduct an assessment of the person’s best interests beyond the scope of the available options, in order to determine whether the public authority has acted in a way which is disproportionate and incompatible with a Convention right” (emphasis added) at Para 86(iii). It remains to be seen when these ‘exceptional’ cases will be deemed to have arisen, and to what extent the Court will probe the substantive aspects of rights enjoyment. It is worth noting, however, that the case is currently being appealed to the Court of Appeal. Further guidance on this issue may then be available.
[^49]: See _R (McDonald) v Royal Borough of Kensington and Chelsea_ [2011] UKSC 33.
as such, this difference in approach would not necessarily be antithetical to the theory of justice posited here. By focusing on the contextual position of each individual, the capabilities approach highlights the fact that treating people equally through providing identical responses can result in inequality. However, at a more fundamental level, the capabilities approach is not limited to group rights or focusing on people with disabilities. It argues that substantive equality ought to be applied in all cases, and so this dichotomy between those lacking capacity and those having capacity should be rejected. This would then call for judicial scrutiny of substantive barriers to equality and justice in all cases, resonating with Quinn’s interpretation of the UNCRPD as entailing a broader shift in theorising justice rather than being simply or solely about disability. There is scope here for further exploration of substantive equality and the capabilities approach at a broader level in legal reasoning in future research.

7.3 Autonomy and Incapacity: Challenging the Binary through Vulnerability Theory

The final paper in this thesis explored the stark binary which is created in law and policy between incapacity and autonomy and critiqued this through the lens of emerging theories on vulnerability. Presenting vulnerability as a universal feature of human existence advances the theoretical approach taken in the other papers by seeing our precariousness as a common concern, rather than ‘othering’ those with disabilities in order to create legal or philosophical ‘exceptions’ to the norm. The recognition of vulnerability as universal also helps to move recognition of the sources of vulnerability as central to society and, as such, a political issue. It recognises the fundamental role of relational and situational dynamics in facilitating

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50 Venkatapuram, n35, p412. Here, he stresses the importance of ‘conversion factors’ i.e. the personal situation (cultural, social, political environmental) which can affect both positively and negatively the ability to convert endowments and external conditions into capabilities and functionings.

51 Nussbaum states that group based policies may be effective instruments in the creation of individual capabilities, but this is the only way they can be justified. M. Nussbaum, *Creating Capabilities: The Human Development Approach* (Belknap Press, Harvard University Press, 2011) p35.
autonomy and resilience. The paper, however, also stressed the need to focus on the particular when responding to vulnerability. In parallel with a more responsive social model, the emphasis is on the subjective interaction of the embodied individual with their environment (social, cultural, political and physical) in order to ascertain which responses best facilitate their capabilities and autonomy.

This approach provides a critical foundation for analysis of the law in relation to capacity to consent to sex, which arguably shows this stark boundary between autonomy and incapacity in action, and also provides fertile ground on which to highlight the way that the legal approach ignores and potentially creates pathogenic vulnerability. A relational approach to autonomy, underpinned by an appreciation of universal vulnerability, allows us to focus on the shifting nature of autonomy and to build responses on the understanding that autonomy is not a static quality. However demonstrating the limitations of the current legal approach provokes some far-reaching questions about the legal framework upon which this binary is built, and blurs many of the distinctions that have been central to the development of the law surrounding mental capacity. The case law discussed in the paper has been developing at pace, and it is clear from the dicta within these cases that the law as it stands is far from satisfactory. A recent case, Derbyshire CC v AC, demonstrates the continuing dissatisfaction with the approach taken in IM v LM, which is the target of criticism in paper 3.

Here, Cobb J discusses the statement of a Dr Milne, who reported that the woman in the case, AC, “said that even if she did not want sex she would have to go along with it as she wants to be ‘lovey dovey’”. Cobb J expressed his unease with this and the way that the test for capacity to consent to sex as currently framed in IM v LM does not include this within its

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54 Ibid. Para 33.
Similarly, in the later case of *The London Borough of Tower Hamlets v TB*, Mostyn J revisited the test of capacity to consent to sex and added the need to understand that “he or she has a choice and can refuse”. This is an important addition, and one which moves some way towards Hedley J’s concerns in *A Local Authority v H* about the importance of choice. However, from the perspective of the vulnerability analysis presented in this thesis, this still relies on the binary between capacity and incapacity, and more importantly retains a focus on the ‘shortcomings’ or lack of understanding of the individual. TB, in this case, was found to lack capacity here because she was held not to understand that she had a choice and could refuse. This, however, was on the basis of her husband’s religious beliefs that as his wife, TB had a duty to have sexual relations with him. Relying on the lack of understanding of TB here to justify a finding of incapacity again side-steps the external and situational source of this vulnerability.

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55 ibid. Para 36.
57 ibid. “In my judgment this simply cannot be gainsaid. It was accepted by everyone in this case that sex between humans must involve more than mere animalistic coupling. It is psychologically a big deal, to use the vernacular. Hedley J’s formulation captures perfectly why and how that extra ingredient should be defined.” Para 40, and “Therefore I conclude that when determining the question of sexual capacity under the MCA the relevant information as referred to in section 3(1)(a) comprises an awareness of the following elements on the part of P:
   i) the mechanics of the act; and
   ii) that there are health risks involved; and
   iii) that he or she has a choice and can refuse” Para 41, Per Mostyn J.
58 [2012] EWHC 49 “And so one turns to the emotional component. It remains in my view an important, some might argue the most important, component; certainly it is the source of the greatest damage when sexual relations are abused. The act of intercourse is often understood as having an element of self-giving qualitatively different from any other human contact. Nevertheless, the challenge remains: can it be articulated into a workable test? Again I have thought long and hard about this and acknowledge the difficulty inherent in the task. In my judgment one can do no more than this: does the person whose capacity is in question understand that they do have a choice and that they can refuse? That seems to me an important aspect of capacity and is as far as it is really possible to go over and above an understanding of the physical component.” Para 25. Per Hedley J
59 “It remains in my view an important, some might argue the most important, component; certainly it is the source of the greatest damage when sexual relations are abused. The act of intercourse is often understood as having an element of self-giving qualitatively different from any other human contact. Nevertheless, the challenge remains: can it be articulated into a workable test? Again I have thought long and hard about this and acknowledge the difficulty inherent in the task. In my judgment one can do no more than this: does the person whose capacity is in question understand that they do have a choice and that they can refuse? That seems to me an important aspect of capacity and is as far as it is really possible to go over and above an understanding of the physical component.” Para 25. Per Hedley J.
By introducing the inherent jurisdiction as a more responsive and attentive vehicle for addressing the concerns highlighted by the vulnerability analysis, the paper could invite charges of paternalism. It may be argued that the inherent jurisdiction should be eyed with suspicion as it allows the judiciary free reign to override the autonomous wishes of individuals who have mental capacity. This, however, would be a particularly unreflective and unsophisticated argument given the critique of the traditional individualistic conception of autonomy, and associated language, that this thesis has presented. As Keywood has noted, the development of the inherent jurisdiction for people who are deemed to have capacity for the purposes of the MCA, shows ‘increasing dissatisfaction/unease with the language of choice and its implication in decisions resulting in serious neglect or harm’\(^60\). One of the key draws of the inherent jurisdiction, from the vulnerability perspective at least, is that it emphasises support to facilitate an autonomous decision. This is an issue that resonates with Art 12 of the UNCRPD, which is built upon support for individuals to exercise legal capacity. Like the capabilities approach discussed, the aim of any intervention ought to be to provide the background conditions that enable autonomous choice, rather than interfering and directing the particular decision itself. Ostensibly, it is contextually focused, rather than being premised on abstract rules and principles. As Mackenzie puts it

“There is no inconsistency between acknowledging the fact of universal vulnerability and recognizing our normative obligations to respond to vulnerability, on the one hand, and upholding the importance of autonomy, understood relationally, on the other. In fact, the obligation to respect and promote autonomy must be central to the normative obligations arising from

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vulnerability and, wherever possible, must be the guiding aim of interventions designed to mitigate vulnerability and enhance resilience"\(^{61}\).

Yet, one of the potential problems with this is whether—once support is offered and the background conditions created that will be deemed to foster this resilience—the decision will be respected if it seems contrary to the interests of the individual. In theory, and in accordance with both a capabilities approach and the UNCRPD, this decision should, of course, be respected. Whether we can create a legal approach which is able to foster and sustain this in reality is challenging. Linked to this point is whether the supports themselves and the conditions created to foster an autonomous decision may become coercive—which then prompts further questions about what exactly is a coercive influence upon somebody’s decision making. As Quinn points out, we all navigate external influences on our decisions and actions in daily life\(^{62}\). This is not something ‘new’ or ‘special’ for those with cognitive impairments. A legal framework attentive to this relationality should not seek to intervene in every situation in which choices are impacted upon by others—indeed, this would be impossible given that decisions are rarely, if ever, made in isolation and free from influence. No decision would then be free from question. The law ought instead to clarify what kind of influence it is willing to tolerate and how autonomy can be maximised and facilitated whilst being cognisant of the inevitability of external influence—be it benign or otherwise.

With this in mind, the crux of the issue becomes ‘on what basis do we intervene in a decision or action’. If mental capacity is an unreliable and discriminatory basis on which to base intervention, can vulnerability instead provide the benchmark? This may satisfy many who envisage disability-neutral laws as being an appropriate response to the UNCRPD, as it can


\(^{62}\) G Quinn, ‘Re-thinking Personhood: New Directions in Mental Capacity Law and Policy— or— How to put the shift back into paradigm shift’ (University of British Columbia, 2011).
de-link support or intervention from the status of having a disability. If we are committed to being attentive and responsive to vulnerability in society, then we must also be aware that it is not only or always those with disabilities who may be vulnerable. However, vulnerability itself is a slippery concept which commentators have suggested is very difficult to pin down as a usable legal term\textsuperscript{63}. Indeed, there is a danger also that relying on vulnerability as a basis for intervention may just entail the same individuals coming under the legal purview, but on the basis of their vulnerability rather than their disability. On the other hand, an equally problematic consequence of this may be that those who do need assistance and support to exercise their autonomy may be deemed to fall outside of the boundaries of this new legal concept.

Aside from issues about ‘who’ should fall within a legal framework based on vulnerability, the question of ‘when’ or ‘why’ the law should get involved is also pertinent. What is the appropriate legal response. The papers in this thesis have stressed the need for background conditions which foster the capabilities and autonomy of individuals, which calls for a universal theory of justice which is focused on equality. In this way, a vulnerability approach functions as a useful preventative theory which may seek to minimise the numbers of occasions on which particular decisions are questioned, by focusing on enabling conditions and eligibility for resources among other structural societal changes. However, in reality, cases will arise where an individual is making a decision or pursuing a course of action which others seek to call into question. If the law is to be responsive in these situations, it is important to consider the point at which it steps in and what the justification for this is. Ideally, it should be before a decision is made, so that support is then provided to enable an autonomous decision- although stepping in to provide support in itself may seem like a

\textsuperscript{63}J Wallbank and J Herring, Vulnerabilities, Care and Family Law (London, Routledge, 2014).
‘paternalistic’ intervention. A conceptual difficulty here is that decisions are often not isolated and cannot always be divided into distinct categories—often a decision will have significant and ongoing repercussions on other aspects of the individual’s life and on those surrounding them. People make numerous decisions on a daily basis. Deciding what precisely the support is directed to here thus presents a challenge. On what basis we measure the need for support is conceptually and practically tricky, and here the suggestion that we may need to abolish the concept of mental capacity may cause some issues. If we have no benchmark against which to measure decisions, then in practice we do not know what we are aiming for in supporting a decision. Flynn and Arstein-Kerslake suggest the retention of a mental capacity approach may be necessary, but only for deciding on what support is necessary for enabling a person to make a decision. However, this becomes a circular issue as we need to know when and on what basis we step in to question whether a person has mental capacity in order to decide whether they need support.

It is clear then that, following the UNCRPD, and the critiques of autonomy and the mental capacity framework here, new boundaries or ‘lines in the sand’ will need to be drawn to lend some clarity if the theoretical insights are to provide the basis of laws. This is implicitly recognised by the Committee on the Rights of Persons with Disabilities, who state that,

Para 29(i) …new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.

It is incredibly difficult to translate this ethical complexity into legal doctrine, which is perhaps why the binary approach to autonomy and capacity has been so revered. However, if

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64 The theoretical approach advocated for in this thesis invites us to question and critique dominant conceptions of ‘paternalism’ and to more closely question responses that are deemed to be ‘paternalistic’.


we seek to have an attentive and responsive legal framework here which genuinely seeks to foster autonomy, these issues will need to be addressed and openly debated. Often, suggestions based on relational autonomy will be dismissed by arguments about paternalism. A more nuanced debate ought to be had here which avoids falling into this sort of dichotomous thinking, and which recognises and addresses the grey areas that this thesis seeks to illuminate. Whilst vulnerability may not be a legal panacea, it can provoke a discussion which is cognisant of the potential tensions and pitfalls discussed above in respect of framing a new legal framework

7.4 Concluding Comments
The papers in this thesis, whilst focusing on quite distinct aspects of capacity law, have had, at their core, the common intention of moving the issues surrounding disability and care from the margins and into the centre of our understandings of and approaches to justice. The blurring of the public and private realms is a key aspect of this, as it enables societal and state obligations to become more prominent in these debates. Theoretical debates about care ethics, critical disability theory, relational autonomy and vulnerability have been shown to have conceptual affinities which further the force of the arguments presented and combine with aspects of capabilities theory to highlight the problems with the legal framework surrounding mental capacity. The questions which have been prompted by this analysis suggest some key areas for future research, but also provoke a revisiting of some of the foundational assumptions about the difference in legal provisions that apply to those with cognitive disabilities, and whether these can withstand sustained scrutiny through the lens of more relational theories.
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APPENDIX

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3. B. Clough, ‘Vulnerability and capacity to consent to sex – asking the right questions?’ (2014) 4 Child and Family Law Quarterly 371-396
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What about us? A case for legal recognition of interdependence in informal care relationships

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What about us? A case for legal recognition of interdependence in informal care relationships

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As the number of people being cared for by relatives and friends rises, it is vitally important to examine whether legal frameworks surrounding care and treatment sufficiently account for the realities of informal caring. This paper undertakes such an analysis through the lens of care ethics, arguing that relational and contextual aspects of caring ought to be brought further to the fore. The Mental Capacity Act 2005 forms the central focus of criticism and it is suggested that the legislation and case law surrounding best interests decisions fails to heed the interdependence which permeates informal caring. In contrast to earlier care theories, however, the importance of retaining a focus on the rights and capabilities of individuals within the web of caring relationships is emphasised.

Keywords: informal care; care ethics; Mental Capacity Act 2005; best interests; capabilities

Introduction

Estimates place the number of informal carers in the UK at around 6.4 million (NHS Information Centre, 2010) saving the public purse around £119 billion per year (Buckner & Yeandle, 2011). The value of these informal carers, often family members, is not simply monetary. Informal care allows the person needing care to continue living at home, in turn enabling their community relationships to endure. Remaining in familiar surroundings, with family and friends, can also act as a buttress to identity for the person and help them to maintain independence for as long as possible (Quinn, 2011; Holstein, Parks, & Waymack, 2011, p. 125). However, the growing body of literature on informal carers conveys a sense of carers having unmet needs, being left to cope alone, and being viewed simply as a resource (Berger, DeRenzo, & Schwartz, 2008; Arksey & Glendinning, 2007).

In this paper, the ‘ambivalent way’ (O’Donovan & Gilbar, 2003) in which the law views and utilises informal carers will be critically analysed in order to inform an argument in favour of a more nuanced relational approach. The theoretical basis of law and policy in this area will be explored, and it will be shown that, in the main, law and policy are underpinned by an individualistic approach. This will be criticised for failing to reflect the realities of human relationships, and moreover caring relationships. Best interests’ decision making under the Mental Capacity Act 2005 will then be focused on more specifically, with a view to advocating an approach which reflects the relational actuality of informal caregiving within the family. The ethics of care will be presented as an approach which places contextual aspects of the caring relationship as a primary focus. At the same time, the imperative of keeping a watchful eye on the rights and capabilities of individuals within caring relationships to participate in and challenge decisions made will be acknowledged. The reality of care is that it is not experienced in isolation, and it is

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argued that an alternative discourse is needed, enabling room for inclusion of legitimate considerations which would otherwise fall outside the scope of an individualistic approach.

Concealing interdependence

Criticism of the individualistic philosophy of health care law and policy is not novel. There has been considerable rejection by feminist and communitarian theorists alike of what has been argued to be a reductionist and atomistic view of the person promulgated by liberal theories and its counter-part in legal principles. The concept of the ‘self’ contained in traditional liberal theories has been criticised as being ‘individualistic, isolated, and ahistorical’ (Ho, 2008, p. 129). According to some philosophers, liberal theorists have often assumed the existence of individuals in an ‘untenable vacuum’ in which various societal aspects are overlooked (Coggon, 2007, p. 40). Sandel (1984), for example, is heavily critical of exaggerated individualism. He is disapproving of the atomistic individual presupposed by Rawlsian theories of justice, suggesting instead a holistic conception of the self which is both intersubjective and intrasubjective – one which sees community ties as morally relevant to the individual identity. He notes that often there will be ‘a plurality of selves within a single, individual human being’ (Sandel, 1998, p. 63) which exposes a more complex concept of the self than that residing in liberal theories (MacIntyre, 1984, p. 204). The image of the individual promulgated in liberal theories is in many ways unlike the individual in society. As a result, our dependencies, obligations, responsibilities and relationships with others in society become almost obsolete in mainstream moral and ethical thinking. Instead, the focus is on zones of non-interference, as opposed to interrogating the moral quality of inter-personal actions. More importantly for the purposes of this paper, those who are not independent, atomistic, self-sufficient individuals are marginalised as attention is diverted away from the structural underpinnings of our relationships. Essentially, the charge against a liberal conception of the person entails a rejection of a restricted and impoverished view of our moral and social experiences (Allen & Regan, 1998).

Many feminist theorists have been particularly strong in their rejection and criticisms of the liberal individualistic concept of the self. Naffine (1997, p. 85) draws upon the image of the boundaried, atomistic self as akin to a ‘closed body bag’ – situated in isolation as opposed to belonging within a community. This is problematic for some feminists as it effectively silences the voices of those who do not or cannot achieve the characteristics ascribed to the liberal ‘self’. But their critique points to a more general problem: a result of the liberal focus on the individual is that the less powerful are marginalised or ignored (Lacey, 1998). One focus of the feminist critique of liberal rights approaches is thus a ‘strategy of inclusion of those who might be excluded from the liberal tradition’ (Kelly, 2005, p. 383; Nedelsky, 1990). This critique instead advocates a move away from ‘masculine’ accounts of the self and towards a relational approach which pays attention to ‘the ways that individuals exist within relations of social support and community’ (Harding, 2012).

This dominance of the individualistic concept of the ‘self’ can be seen to be embedded in law (Norrie, 1993; O’Donovan, 1997; Harding, 2012). In health care law, the ethical principle of autonomy has been perceived as entailing many of the philosophical notions of the abstract, unencumbered individual (Brazier, 2006; Montgomery, 2006; Fletcher, Fox, & McCandless, 2008; Coggon, 2008a). Legal principles regarding informed consent to medical interventions, for example, view family or other external involvement with
suspicion (Re T 1992, para. 662). Ho (2008, p. 129) perceives ‘a general concern that family involvement will muddle the patient’s decision-making process, such that a focused, individual decision is more valid and well-considered than a tainted one that involves the voices and considerations of others’. As Bridgeman (2007, p. 308) contends, [the] work of caring for dependents and emotional interdependency with our children, spouses, partners and families must remain concealed lest we appear not to be independent souls suited for the public world. Consequently, the nature of dependency, the responsibilities of those who care for dependents and responsibilities of others, or the state, for those in need of care remains relatively unexamined.

This is despite research by Gilbar (2011, p. 192), suggesting that patients and relatives views reflect ‘a relational approach to patient autonomy’. He argues that the individualistic legal approach taken in English law does not correspond with experiences of patients and relatives, and as such the legal and bioethical reliance on such an approach should be reconsidered. Such research illustrates that individuals do often discuss their health issues with their family in order to obtain advice and guidance, and moreover that they may consider their family ties and responsibilities when making decisions. As Berger et al. (2008, p. 48) found,

many patients do not necessarily want their surrogates to adhere to specific treatment preferences . . . but instead wish them to respond dynamically to actual clinical situations in order to maximise their evolving, contemporaneous interests and to make judgements that integrate medical and non-medical considerations.

They further went on to describe how ‘some patients modify their preferences to accommodate their family members concerns and some give weight to the distress they anticipate their family will experience from unavoidable choices’ and that ‘concerns held primary by patients may include minimizing emotional, financial or other burdens on a spouse or adult children, even if such a decision is not optimal in narrow health objectives’ (Berger et al., 2008, p. 50; Deber, Kraetschmer, Urowitz, & Sharpe, 2007). In contrast to this, health care law appears to maintain a broadly individualistic approach to consent and autonomy. As Donnelly discusses, perhaps one of the reasons why the liberal conception of autonomy as non-interference – with its individualistic undertones – is so ‘enthusiastically received by the law is the ease with which this particular ethical concept can be converted into legal doctrine’ (2010, p. 47). However, it is argued that this ease comes at the cost of nuance, and that the individualistic conception of the person fails to accord with the reality of human interdependence.

Whilst from a different conceptual and theoretical position than some more general critiques of liberalism, care ethics focuses more acutely on some of the gaps left in a purely individualistic approach to the law and policy, particularly in the context of care. Care ethics has gained significant and increasing attention in legal circles over the past couple of decades, with authors such as Herring (2007, 2008, 2012), Bridgeman (2007) and Pettersen (2011) more recently advocating for legal recognition of the values underpinning this approach, with many others having being influenced by the insights from the literature. Stemming from the work of Carol Gilligan (1982), the ethic of care has developed into a normative approach to law and policy which focuses on relationships and context as opposed to individualism and abstract reasoning (Gilligan, 1982; Noddings, 1984; Kittay & Meyers, 1987; Ruddick, 1989; Clement, 1996). Noddings characterises, and criticises, the liberal concept of the individual as ‘the wrong start’ (2002, p. 77) and instead advocates a better start being built upon relation and encounter. At the heart of care theory is thus the inevitably and necessity of care and dependence at various stages of our lives – most clearly
around birth but also to varying degrees throughout our lives – which traditional liberal theories cannot capture (Kittay & Feder, 2002). Indeed, it has been suggested that ‘by excluding this dependency from social and political concerns, we have been able to fashion the pretence that we are independent’ (Kittay, 1999, p. xii). As Yeates (2007, p. 438) describes, ‘an analysis of the different facets of the legal status of carer ... reveals that most of these roles are predicated on the capacity to exercise choice, a capacity that is often signally absent from carer’s actual experiences’. Care ethics, conversely, ‘has at its core a central mandate to care for the relationships that sustain life’ (West, 1997, p. 8).

Building upon these insights in an attempt to explore care as a more general political theory, as opposed to a critique of liberal individualism, Tronto (1987) constructs care as a contextual theory requiring modification of an abstract approach to justice. At this more political level, care ethics ‘encapsulates a constructive critical perspective on the norm of independent citizenship’ (Sevenhuijsen, 2003, p. 183) – one which perceives of actors as intertwined and interdependent and which structures policy and legal responses on the basis of this. Rather than being peripheral concerns, care and interdependence become central to societal responses. As Pettersen describes it, ‘the approach is to scrutinize real life experience, and use this knowledge as a basis for developing analytical concepts and theories in order to better understand and handle what one empirically faces up to’ (Pettersen, 2011, p. 61).

Whilst not exhaustive accounts, the above observations begin to give some understanding of the main recognised failures in a theoretical framework inspired by liberalism. These observations illustrate the need to broaden our scope of analysis if we want to ensure that the essential features of life and social interaction do not get ‘lost in translation’ (Sandland, 1995, p. 8) into legal or ethical principles. As Shanley (1998, p. 4) notes, ‘law shapes the way we conceptualise human relationships, we should make sure that the “tale told by law” reflects an understanding of the importance of communal interdependence to both individuals and society’. This can perhaps be most starkly illustrated in the context of caring relationships which are characterised by varying degrees of dependence and interdependence, reciprocal emotional needs and interwoven interests. In the following sections, policy and legal shortcomings of an individualistic approach to informal care will be explored in more depth.

**Situating carers**

The very nature of informal family caring defies this caricature of the self-determining, self-sufficient individual. As a direct result of illness, age (young or old) and vulnerability, people are more likely to be dependent on others for care and welfare support; they are also often disempowered by virtue of this ‘in the sense that their ability to effect change on their own lives and environments may be more likely to be overruled or limited by the relationships of care and dependency that support them’ (Harding, 2012). Dependence, viewed through the lens of liberal individualism, becomes a negative and undesired trait. Similarly, Dodds (2007, p. 501) contends that ‘human vulnerability and dependency have come to be viewed as evidence of a failing to attain or retain autonomous agency, rather than as conditions for agency and autonomy among humans’. This obscures from dominant ethical debate those who are “legitimately dependent because of age, ill-health or other features of their lives” (Holstein et al., 2011, p. 8). Whilst the intertwining of interests entailed in informal care remains antithetical to the norm characterised in legal and policy responses infused with the individual and autonomous self, the responses within these structures will remain impoverished and inappropriate.
However, it must be recognised that there has been a concerted effort in the past decade to enhance the rights of carers and draw attention to their interests in the political domain (British Institute of Human Rights, 2012; Department of Health, 2009, 2010). Dicta in *R (A and B, X and Y) (Munby J. Paras 116–117, 2003)* further stresses the importance of recognition of carers’ rights, namely to physical and psychological integrity in the context of carrying out physical care work based on Article 8 of the European Convention on Human Rights. The relevance of this in the wider context of informal caring is unclear and remains to be fully articulated, particularly with regard to the consideration of informal carers’ interests when making best interests decisions, which will be considered in more detail later. Despite such developments, insights from the social work literature depicts attitudes to informal carers as being centred on their utility as a resource, rather than as connected partners in care with a stake in decisions taken about care arrangements and medical decisions (Barnes & Brannelly, 2008, p. 392). Heavy burdens are placed upon informal carers without due regard to their competence to perform such tasks, and also the effects of such tasks upon them as individuals (Pickard, Jacobs, & Kirk, 2003, p. 82). Whilst there are positive aspects of caring for a relative, which are often given less attention in the literature, many disadvantages are apparent, such as the impact of exhaustion, physical and psychological and social problems and socio-economic implications (Yannamani, Zia, & Khalil, 2009; Barnes & Brannelly, 2008; Princess Royal Trust for Carers, 2011). Hardwig (1990) argues that in this way, informal carers are treated unfairly – they are expected to provide support but their interests are often not acknowledged, let alone respected. There is also evidence that carers are reluctant to seek help as the focus is intensively on the person they are caring for (Hardwig, 1990). As such, the position of informal carers has been characterised as akin to ‘coworkers without employment rights’ (Yeates, 2007, p. 437).

This lack of recognition of the informal carer as a rights-bearing entity is underscored further in the context of respite care. Here, the legal right to respite care attaches to the service user, rather than the carer. This is despite the fact that the ultimate beneficiary of the respite care is the carer. This has not gone unnoticed – as Mitting J stated in *R (Hughes) v Liverpool City Council (2005)* ‘the benefit to him [the service user] is indirect’ and ‘arises because his mother, upon whom the strains are otherwise intolerable, is given respite from having to look after him’. According to Yeates (2007, p. 452) ‘this legal nicety sidesteps the issue of articulating the opposition between carers and service users’ interests and hampers honest debate’.

A sense is now developing of legal and policy approaches that are one-dimensional and not sufficiently nuanced to appreciate or resolve the complex interplay of interests inherent in the caring relationship. The avoidance of sustained debate on the issue at a legal and policy level is unsatisfactory and betrays a sense of incompleteness in the rhetoric regarding carers’ ‘rights’. In the following section, the legal role of the family carer in ‘best interests’ decision making will be scrutinised in light of the deficiencies in theoretical and policy approaches discussed above, in the hope of moving the debate forward and away from the current “exclusionary attitude … towards the role of relatives” (Gilbar, 2011, p. 192).

The Mental Capacity Act- ‘us’ or ‘them’?

Having seen the influence of individualism at a policy level, we now move to examine the more particular legal issue of the extent to which the ‘best interests’ decision-making framework under the Mental Capacity Act 2005 compounds the problematic
individualistic stance considered above. ‘Best interests’ is the gold standard to be attained in any decision made regarding a person found to lack capacity – yet one without any explicit normative moral guidance for consideration (Donnelly, 2010, p. 176). As a conceptual and legal notion, ‘best interests’ has certainly not escaped criticism, having being described as ‘elusive and controversial’ (Szerletics, 2011, p. 30). Interestingly, there is no definition of best interests in legislation or the attendant Code of Practice. The justification provided for this, contained in the Code of Practice itself, is that it is due to the sheer range and types of decisions which the Act potentially covers (Department for Constitutional Affairs, 2007, para. 5.5), thus understandably making it difficult to legislate for all eventualities. Nevertheless, we can decipher shades of individualism underlying the best interests sections of the legislation.

Section 4 of the Mental Capacity Act outlines the approach to be taken in deciding on what is in the individual’s best interests. More importantly, s. 4(7) anticipates the consulting of others when making best interests decisions, with s. 4(7)(b) indicating the requirement to consult anyone engaged in caring for or interested in the welfare of the person lacking capacity. It has been acknowledged that failure to involve significant others, with whom the cared-for person has a relationship, may be in breach of Article 8 ECHR (G v E, 2010).

At first glance, s. 4(7)(b) appears then to give some authority to the views of carers and relatives. Quigley (2008, p. 235), for example, suggests that this allows room for the interests of others around the person lacking capacity to be considered. However, the section later goes on to emphasise that such views are only of importance in relation to finding out what is in the best interests of the person lacking capacity. The interests of the carer – contemporaneous or conflicting – or of the effect of the decision on the carer or the overall caring relationship are not relevant considerations. As Herring (2007, p. 70) has argued,

> This is misguided – it is not possible to consider the incompetent person without considering the well-being of the incompetent person’s carer. The interests of the two are intertwined. No carer could possibly undertake the task of caring if every decision which has to be made was solely on the basis of what is in the best interests of the person lacking capacity. The interests of the carer – contemporaneous or conflicting – or of the effect of the decision on the carer or the overall caring relationship are not relevant considerations. As Herring (2007, p. 70) has argued,

Whilst it is suggested that the argument which Herring makes here – that nobody wanting to be cared for in a relationship in which carers’ interests count for nothing – is not supported by evidence and indeed may presume too much, it is an important point which ought to be recognised and taken seriously by policy makers. Whilst it is not impossible to imagine an individual who does not particularly care whether the carers’ interests are being considered, the point is that a caring relationship cannot function well or justly if the carer is overburdened (Pettersen, 2011, p. 54).

Coggon (2008b) conversely argues that “as a non-ideal construct, however, best interests’ is capable of accommodating this. When we allow tacitly for ‘real world’ limitations we see that it is not blind to the needs of others, despite its ostensible focus on the individual directly in question at the time” (Coggon, 2008b, p. 221). One way in which the informal carer’s interests may legitimately be taken into account, perhaps in the way which Coggon envisages, is if an argument is framed that the carer is unable to care for the individual then this might not be in the individual’s best interests. Such an argument was made in the case of Re Y (1997).

This case involved a 35-year-old mentally and physically disabled woman who was incapable of understanding others’ needs but could express her own basic needs. Her older
sister had the pre-leukemic bone marrow disorder Myelodisplastic Syndrome. She needed a bone marrow transplant, preferably from a sibling, to significantly prolong her life. The Court referred to evidence that Y benefited from her sister’s visits and that it helped her maintain a link with the outside world. It was further submitted that if the application was unsuccessful then there was evidence that this would have an adverse effect on her mother’s health so that her relationship and contact with Y would be affected. Therefore it was of benefit to Y to act as donor. The Court also relied on the argument that disadvantages were very small and involved no real long-term risks. As such, it was to Y’s emotional, psychological and social benefit to grant the declaration that she should be a bone marrow donor for her sister. The court emphasised that ‘the root question remains the same, whether the procedures here envisaged will benefit the defendant and accordingly, benefits which may flow to the plaintiff are relevant only in so far as they have a positive effect on the best interests of the defendant’ (Per Connell J). Such an approach was predicated upon the debates in Re F (1989) in which it was stressed by Lord Goff that whilst it may be good practice to consult relatives, the overriding consideration is the best interests of the individual patient.

At worst, the approach taken in Re Y can be seen as ‘tortuous’ (Szerletics, 2011); at best, ‘inventive’ (Coggon, 2008b, p. 224). Instead of explicitly recognising the plurality of interests at stake, issues such as the interests of the sister in receiving the bone marrow, and gratitude from the mother and sister were viewed as aspects of the best interests of Y. This consequently prevents the real reasons behind a decision from being openly reflected, which in turn denies an open basis for challenging the decision or more openly and transparently grappling with the undoubtedly complex issues at stake, such as relationality and obligations (Herring & Foster, 2012). Moreover, it is not clear if or when such reasoning will be applied by decision makers, leaving the carers in a position in which they rely on professional discretion to apply the capacity legislation in such a way. This is not to say that the outcome of the case is ‘wrong’ or that Y should not act as a bone marrow donor. The problem lies in the approach taken by the court, which sidestepped an opportunity to open up debate as to the more open appraisal of the various interests at stake.

In the more recent case of Re VW (2011) the Court of Protection was faced with the issue of whether a lady with dementia could be moved to a care home closer to her son at his request. His aim, essentially, was to facilitate more frequent contact with fewer restrictions than were imposed at the time. In refusing this application, Macur J placed substantial weight on the importance of viewing benefit from the perspective of VW, rather than her son (para. 9), and further on the evidence of Dr A, who is ‘unable to conceive that any living conditions, no matter how physically superior to those in the present home occupied by VW will benefit her emotional/welfare needs’. Macur J is clear that;

The sad fact of the matter is that NK lives at a considerable geographical distance from VW. His journeys to exercise contact with VW are difficult and costly. They are uncertain in that dependent upon VW’s moods, she may not be in a fit state to receive him. Those difficulties, unfortunately, are his, and I am not required to have regard to the benefits that would flow from the proposed order or directions to anyone other than VW. (para. 13)

In approaching the issue in such a unilateral manner, it is clear that arguments that family or carers interests are capable of being considered as part of the best interest’s analysis are not consistently substantiated.

Despite this, there are instances in the literature in which health care practitioners have considered and reflected the interests of carers and the enduring relationship in their
decision making. Harding and Peel (2011) saw evidence of this in their study on carers, finding that 49% of carers felt that their needs were taken into account when considering the best interests of the person they cared for. Whilst this may be positive, there is no clear legal backing for such practices and, as such, no open basis for scrutiny of the resulting decisions. The lack of safeguards within the Act here denies the person deemed to lack capacity a clear route to challenge decisions made on a basis not envisaged or endorsed by the legislation, as well as leaving whose interests will be considered down to the discretion of the practitioner.

Interestingly, however, there is some appreciation of the interdependence entailed in caring relationships, as the Code of Practice states that:

Para 5.47 – S4(6)(c) of the act requires decision makers to consider any other factors the person who lacks capacity would consider if they were able to do so. This might include the effect of the decision on other people, obligations to dependants or the duties of a responsible citizen.

Para 5.48 The act allows actions that benefit other people as long as they are in the best interests of the person who lacks capacity to make the decision. Best interests goes beyond the person’s medical interests.

For example, courts have previously ruled that possible wider benefits to a person who lacks capacity to consent, such as providing or gaining emotional support from close relationships, are important factors in working out the person’s own best interests. See Re A and Re Y.

Such recognition is indeed laudable. However, it is a matter of concern that no guidance is given as to what this means for decision making in practice, or how the balance of interests is to be achieved and resolved. It is noteworthy that Re A (2000) and Re Y (1997) are mentioned, yet not discussed. This may of course be due to the great difficulty in elucidating any clear legal framework to guide decision makers from these cases – in which case, why mention them at all? These cases are complex and controversial and the principles arising from them are unclear. The Code of Practice is purportedly to advise and assist those acting under the remit of the legislation – thus including lay people such as relatives and carers. Indeed, in Re Y, it was emphasised that ‘this is rather an unusual case and that the family of the plaintiff and the defendant are a particularly close family’ (Per Connell J). The inclusion of reference to this case in the Code of Practice, without explanation of its relevance, is thus a matter of concern and it is not envisaged that those relying upon the Code will be sufficiently clear about the reasons for alluding to these cases here. In essence, much is left to the discretion of the decision maker, which is of little assistance to both the person lacking capacity, and their carers.

It is important to bear in mind the various individuals who will be making decisions for those lacking capacity – either knowingly or unwittingly. The legislation applies to family, friends and informal carers, not just health and social care professionals. Stanley and Manthorpe (2009, p. 39) have highlighted the ease with which this is forgotten in debates about the application of the ‘best interests’ criteria, and the lack of ‘open dialogue’ resulting from this. As a result, it is very difficult to discern how family carers themselves assess best interests, or the extent to which judicial offerings trickle down into practice. As they argue, ‘those receiving informal care in their own homes may be least accessible to such influences and much day-to-day care is shaped by interpersonal relationships between those providing and receiving care rather than by formal structures of care plans or Codes of Practice’ (2009, p. 45). Dunn, Clare and Holland (2010, p. 146) recently suggested the problematic nature of this, as ‘substitute decision making relating to day-to-day care and support will likely be more frequent and more pervasive (although less invasive and controversial) than substitute decision-making relating to medical treatment’.
This is compounded by the lack of clear, tailored guidance available to informal carers. The Office of the Public Guardian (2009) has published a guide for informal carers and relatives on using the Mental Capacity Act. Whilst this is of undoubted utility to those in need of advice, it is simplistic and as such it does little to elucidate some of the areas of uncertainty highlighted here.

Interestingly, there is evidence elsewhere within the legislation of an at least implicit recognition of the social context of decision making. This is evident in the rather different approach that is taken to research involving people who lack capacity — an approach which does not rely on a ‘best interests’ analysis. Case for example discusses how, in relation to research, interests of a third party—namely, society—are taken into account and explicitly balanced (Case, 2003, also see Glover & Brazier, 1996, p. 370). The Mental Capacity Act states that the research must:

S31(5) (a) have the potential to benefit P without imposing on P a burden that is disproportionate to the potential benefit to P, or

(b) be intended to provide knowledge of the causes or treatment of, or of the care of persons affected by, the same or a similar condition.

This framework demonstrates an explicit balancing of the individual and society’s interest in research. This reflects the idea of person as a member of society and that society’s interests in research and advancement of knowledge may trump individualistic views of the person. Also, it implies recognition of the fact that individuals should not be prevented from being allowed to be involved in research just because they are deemed to lack capacity (Law Commission, 1995, para. 6.31). Notably, the best interests test is absent from the framework, and an element of risk is permitted. Whilst not disputing the value of the approach taken here, it is questionable why there is recognition of the fact that the person is situated within a broader society, without recognising that often (although not always) the person is situated within a family and often being cared for by that family. Arguably, the ties between the individual and the family are much more direct and immediate than the ties between the individual and society, so the recognition of one relational aspect but not the other lacks clear justification. Moreover, the approach taken to research does not entail an abandonment of the interests of the individual or a prioritising of society over the individual.

Why is this approach not taken ‘closer to home’? Clearly, the Mental Capacity Act does have the tools to give effect to relational values, albeit on a broad social scale, without losing sight of the vulnerability of those lacking capacity. If the law can develop an approach which situates the individual in a broader context, and balances their needs (contemporaneous and competing) against the needs of the other without losing sight of the potential vulnerability of the person lacking capacity, why is this approach not taken in the informal care context? It is argued that in the family context, the ties are much clearer, much closer and much more direct.

**An alternative approach?**

These shortcomings apparent in the individualistic approach in the Mental Capacity Act reveal the need for a more sophisticated approach to decision making, one which recognises the complexities involved in the family context. The potential of care ethics, with its central concerns of context and relationship, can be explored as a viable alternative since an important part of this is recognising that interests within caring relationships are often entwined and decisions should not be taken without consideration of the impact that
this will have upon those within the relationship (Noddings, 2002, p. 5). This then equips us with the analytical breadth to address the multi-faceted and admittedly complex nature of caring relationships and the interplay of interests within them (Pettersen, 2011, p. 54). The focus becomes the preservation and protection of good caring relationships albeit in ways which do not allow the carer to become ignored or over-burdened, that is ‘without care giving becoming a liability to one’s own well-being’ (Kelly, 2005, p. 390).

Care ethicists such as Tronto (1993), Sevenhuijsen (1998) and Engster (2007) have developed arguments for care as a socio-political concern and the values which should guide this. In terms of the values which Tronto advances as underpinning a political ethic of care, the current legal position in relation to carers who lack capacity is unsatisfactory. The care ethics values of attentiveness and responsiveness require policy makers to be alert to such needs and respond to them accordingly. Attentiveness, according to Tronto, requires that ‘caring becomes more prominent in social life’ and involves making certain issues that are ‘currently obscured by their peripheral location’ to be made central (1993, p. 130). Currently, the legal position and the Code of Practice has been shown to offer a simplistic view of informal family caring. Responsiveness requires more than simply inserting your own view of what you think person lacking capacity or their carer would want, but actually involving them and responding to their actual needs as opposed to perceived needs (Tronto, 1993, p. 132). Responsiveness, under Tronto’s model, also entails the recognition of vulnerability, and the moral consequences of it. Tronto here emphasises that

Vulnerability belies the myth that we are always autonomous, and potentially equal citizens ... A political order that presumes only independence and autonomy as the nature of human life thereby misses a great deal of human experience, and must somehow hide this point elsewhere. (1993, p. 135)

This resonates with Fineman (2000, 2004, p. 20) who similarly stresses the need to centralise vulnerability and dependency in responses to caring, and develops further the notion of ‘derivative dependency’. Such dependency emphasises the idea that those who undertake caring become dependent on others, including the state, to provide the resources – material as well as structural – to enable them to carry out their role.

Competence is also a crucial value for analysing informal care provision through a care ethics lens. As Keywood (2003) discusses, many family carers are undertaking more and more complex medical tasks at home for their family member. Without support to do so, which comes from recognition of their interests and the realities of the informal care context, competence cannot be fully addressed. As Tronto (1993, p. 133) argues, ‘intending to provide care, even accepting responsibility for it, but then failing to provide good care, means that in the end the need for care is not met’. The current approach to informal carers, viewing them as a resource rather than a partner in care, does not adequately equip them with the competence to care. Making decisions based upon the best interests of the person lacking capacity, without a thorough consideration of the impact of this upon the family carers’ abilities, and without their involvement or opportunity to balance the variety of interests prevents adequate scrutiny from the perspective of care ethics and good care.

The value of trust must also be acknowledged, since it ‘evolves around the willingness to establish and sustain connections, even when aversion, mistrust or fear for the unknown initially prevails. The establishment of trust demands moral effort’ (Sevenhuijsen, 2003, p. 186). As a corollary of this, it is argued that transparency and openness should be regarded as central to a care ethics approach. A commitment to the value of trust entails
transparency in the appreciation and awareness at judicial and professional levels of the inter-dependency and relational aspects of informal caring. Explicit recognition of this in a visible way would enable discussions between the patient, family and healthcare professionals to take place in a more open and responsive way- and also, more importantly, allows decisions to be challenged on a more tangible basis.

The ethic of care can highlight the inadequacies of policies which fail to reflect the relational aspects of care. However, it is also salient to note that if we focus purely on relational interdependence, not only do we run the risk of essentialising those within the relationship in terms of pre-defined roles and obligations, we also run the risk of subjugating individual interests to the interests of the family as a whole. Relationships are not always benign. In addition to a strategy that asserts and values attentiveness, responsiveness, responsibility, competence and transparency, there must also be an explicit focus on the capabilities, or opportunities, of those within the relationships- to be involved in decisions which will affect them; to have their voice heard; to challenge and express disagreement; to have needs taken into account. Without a background conception of justice, care theory does not necessarily provide these opportunities.

I suggest that care ethics does not necessitate a rejection of rights per se, and that we can achieve a focus on care within a background conception of society informed by liberal frameworks, such as justice, democracy and equality (Nedelsky, 2006; Brennan, 1999; Spring, 2011; Pettersen, 2011). A vital addition to an ethics of care response here is thus the placing of capabilities as a key legal and policy focus, rather than a more individualised concept of rights. By this, it is meant that that we should focus on the actual position that the individual is in and then consider whether they are capable of accessing their purported rights or furthering their interests, as a means to furthering social justice arguments. The focus on context and personal or societal obstacles to the achievement of rights as capabilities necessarily opens up the scope of analysis to include relational factors. Seeing rights in this way also allows us to reconsider how rights can foster caring relationships, bringing aspects to light which traditional rights theories can obscure. Whilst under a liberal rights paradigm, ‘it is up to citizens to accrue the material, social and emotional supports that make the exercise of those rights meaningful’ (Dodds, 2007, p. 502), the capabilities focus instead entails scrutiny of societal, relational and material conditions affecting the actualisation of these rights. In moving away from viewing rights as ‘barriers that protect the individual from intrusion by other individuals or by the state’ (Nedelsky, 2006, p. 98) we can instead focus on the contextual and relational aspects of rights, such as how they structure relationships, in order to foster autonomy and capabilities (Hankivsky, 2004, p. 31). Rights retain their importance as means of protecting bodily integrity, bolstering claims to justice and in providing a wide scope of scrutiny of the opportunities to achieve goals (Ensgter, 2004; Fox & Thomson, 2013). This is vitally important in the context discussed above, in which relational issues are left out of an exclusive focus on the interests of the person lacking capacity in care and treatment decisions. More explicitly addressing and balancing the undoubtedly complex variety of interests at stake in decisions enables a much more reflexive and just approach in which background inequalities or obstacles to autonomy come under the spotlight. Whilst such considerations may factor in to decision making at present, the key to the approach advocated for here is the importance of bringing such factors to the forefront of jurisprudence in this context, in turn enabling a more inclusive and transparent interrogation of relevant interests (Nedeslky, 2006; Herring & Foster, 2012; Minow, 1990). Here, care ethics and justice become mutually interdependent and each informs the response of the other.
Translating theory into practice

The contextual and relational nature of caring ought to be brought to the fore in our legal and policy responses, with an explicit acceptance of the fact that these factors may impact on how we make health and social care decisions (Donnelly, 2011, p. 313). Compromise and inclusive negotiation are key characteristics in many decisions affecting families and the consideration of this is lacking in the current legal provisions (Gilbar, 2011; Berger et al., 2008). As demonstrated above, the current legal approach to decision making fails to fully appreciate such aspects of decision making or the fact that relationships endure beyond a finding of incapacity. A finding of incapacity should not act as an arbitrary boundary in this way. Suggestions as to how a legal approach could meet this body of criticism will follow.

It is perhaps problematic that the Mental Capacity Act 2005 and the Code of Practice potentially apply to such a broad range of people that more nuanced appreciation of contextual issues is difficult. However, this should not detract from the importance of providing usable guidance, tailored to the needs of informal carers, which anticipates and recognises the complexity of issues at stake and variety of situations in which best interests decisions will be required.

As discussed above, perhaps part of the problem relates to the outright privileging of ‘best interests’ of the person lacking capacity in s. 4(7), without concurrent recognition that such privileging can be at the expense of others with a stake in the decision. As Nedelsky puts it, ‘when the dominant metaphors turn our attention away from relationships, we cannot give either the relationships or the legal concepts that mask them the critical scrutiny they require’ (1990, p. 178). Recognition of this in the legislation and Code of Practice could be achieved through a clearer direction to consider and weigh the interests and abilities of those involved in caring for the individual lacking capacity and the impact of decisions upon the caring relationship. This would provide the space within which discussions of all of the relevant interests could take place, without the need to frame carers’ interests as parasitic on the best interests of the person lacking capacity. It would entail the plurality of interests being taken into account in an explicit way, which in turn provides a more open basis for discussion and challenge. Placing such a direction on a legislative footing would ensure that the level of considerations of wider interests was not left to professional discretion, and would further empower carers with a route to challenge professionals when they felt that such views were not being considered.

There has long been recognition of the ‘danger of giving legal force on the assumption that carers always make decisions that are best for the patient’ (Keywood & Flynn, 2006, p. 261). It is agreed that it is incredibly difficult to expect a family member to divorce themselves from their own emotional ties and interests and view the interests of their relative in an objective and unbiased manner - an approach which the current approach in the Mental Capacity Act seems to require. Rather than perpetuating this statutory fiction that the route of uncovering best interests can be achieved in this unilateral manner, and that carers can switch off other interests and focus solely on the ‘best’ interests of their family member, the legislation needs to grapple with the fact that a plurality of interests are at stake and balance these in a more open and transparent way. Carers should no longer be portrayed as a resource for helping to glean knowledge of the person lacking capacity, but should be seen as parties whose own interests and caring abilities will be affected by decisions.

Based on their research, Dunn et al. (2010) advocate re-engaging with ‘best interests’ as a broad ethical principle, rather than as a procedural ‘check list’ style formality. This
may provide the space needed for considerations which are lost in the procedural framework of decision making in the legislation, entailing an ‘all things considered’ approach to deciphering and balancing the relevant interests. The ‘balance sheet’ approach to best interests decisions may thus signify such a broad approach, as it is deemed to entail the consideration of “ethical, social moral, emotional and welfare considerations” (Re MM, 2007, para. 99). However, the guidance on best interests decisions and the balance sheet approach contained in the Practice Note and in case law still retains the focus on the benefits and disadvantages to the patient. It is suggested that instead we need a much more open and inclusive approach which is clear about what and whose interests are at stake, rather than defining others’ interests as simply an aspect of the individual’s best interests. Whilst doing so may reveal both contemporaneous and conflicting interests, it paves the way for a much more transparent debate which does not obscure the real reasons for the decision. Dunn et al. suggest that on this approach, ‘best interests’ assessments ‘would be recognised as leading to a range of outcomes, many of which will be assessed as being sub-optimal and therefore requiring ongoing revision’ (2010, p. 157). Indeed, such an approach is thus much more attentive and responsive to the interests of all concerned.

In a similar tenor to the discussions on interdependence, Hardwig (1997) has argued that when relatives are affected by a decision, justice and fairness require that they have a role in reaching this decision. However, he went further to contend that when a treatment decision dramatically affects the lives of the patients’ family, the interests of relatives might well prevail. In many ways, this approach which posits the family as the primary unit has echoes of the familist traditions of the China and Hong Kong (Fan & Tao, 2004; Chan, 2004; Cong, 2004). In contrast to this, the approach advocated for here does not necessitate a commitment to the privileging of familial interests. Rather than placing duties and responsibilities by virtue of family membership, we need to focus instead on what is at stake in the decision – realising that ultimately the patient has a much greater stake in many respects than anyone else (Lindemann Nelson & Lindemann Nelson, 1995). A more appropriate response to the nature of interdependence in caring relations is thus to encourage a more open dialogue which recognises these elements, rather than continuing as though they do not exist, and which appreciates that other interests are at stake and ought to be recognised. In many ways we all compromise our individual ‘best interests’ in family or social situations. However, the threat may be greater for those who lack capacity, and the care and capabilities approach being advocated requires that we are alive to this risk and respond to it.

As has been highlighted above, the Act does have the tools within it to broaden the scope of analysis in such a way. The provisions governing research are not circumscribed by a ‘best interests’ analysis, but instead we see an approach infused by considerations of the individual as situated in society, and an explicit balancing of interests (s. 33(4) Mental Capacity Act). Additionally, the research provisions are attentive to the vulnerability of those lacking capacity when wider interests are being brought into the balance (s33 Mental Capacity Act), directing researchers to look for signs of objection (s. 33(2)(a) Mental Capacity Act). Reform could thus be considered in light of the approach taken to research.

Key to the acceptability of moves away from a focus on procedural assessment of interests is the need to consider the capabilities of the individuals in these caring relationships when making decisions. In adopting more collaborative models of appreciation, negotiation and compromise it is essential that both carers and cared-for are given a voice. However, it is also important to ensure that views of the person lacking capacity are not readily dismissed, and that efforts are made to facilitate decision making (Donnelly, 2011, p. 313). Collaborative decision making is being advocated for, as a
means by which to allow open and accessible discussions on decisions and caring practices and the contemporaneous and conflicting interests inherent in this. As Benhabib (1992) has written, integration of values may not be achievable, but ethical practice is more likely to emerge from participation in environments which recognize and debate difference (also see Koehn, 1998). Thus, the relational approach being advocated may possibly attract a similar decision in a case that a best interest analysis would, but would necessitate a much more open appreciation of the family dynamics and the nature of balancing and compromise which occurs within families. This would require, as a first step, judicial explicitness as to the plurality of interests when making declaratory statements as to best interests. As I have argued above, such openness and transparency is vitally important for enabling decisions to be challenged. The convoluted reasoning and mental gymnastics which permeated Re Y detracts from this and prevents an open appraisal of interests and resolution of conflicts (Herring & Foster, 2012). Indeed, as it is clear that carers' interests do figure in judicial and health care decisions, it is better to do so in a candid and transparent way.

Moreover, we need considerations of whether carers are being provided with support to enable them to carry out their caring activities competently. Looking at complex safeguarding cases such as HBCC v LG, JG and SG (2010), there can be a tendency to emphasise the unsuitability of the family carer, without a corresponding focus being placed upon support (existing or future) to facilitate good care in the home. Similarly, in FP v HM and A Health Board (2011) we see a laudable effort in the Court of Protection to recognise the importance of family ties, but without any clear regard for the welfare of the wife and son and risks associated with the return to the family home of a man with dementia associated with alcoholism. Inclusion of such considerations is necessary in order to reflect the impact that caring has on those around the individual needing care. An approach is needed which acknowledges that caring relationships cannot function or thrive without background conditions enabling them (Holstein et al., 2011, p. 139).

Aside from legal procedural aspects, attention needs to be given to helping carers to consider their own interests and the contextual obstacles to this, which the research suggests is difficult for them to do in a relationship in which the interest of the cared for is repeatedly given precedence. With the ageing population meaning that increasing numbers of older people will rely on care it is salient to note the impact that this will have on spousal carers. Attention should also be drawn to obstacles that older people more generally face in accessing justice and their conceptions of ‘rights’, as this will undoubtedly impact on how older carers perceive and react to care and support needs (Butler, 2006; British Institute of Human Rights and Age UK, 2011). Traditional justice based models do not always capture these factors (Ward, 2011, p. 176). It is vitally important then to provide assistance to enable carers to recognise, and to have the opportunities to communicate, their interests.

In practical terms, this would entail a supportive and collaborative approach, involving carers early on in decision making processes alongside those they care for and throughout, but also explicitly considering their interests and needs in an open and transparent way (Yannamani et al., 2009, p. 442). This would guard against an approach which would place undue burdens or expectations on the caregiver without a clear appraisal of the consequences of this for the caring relationship (Hankivsky, 2004, p. 120). The care ethics values discussed ought to apply on micro and macro levels, necessitating that law and policy consider them in relation to how they affect carers at a policy level, but furthermore how this affects caring relationships on the ground. As Rummery (2011, p. 148) points out,
‘carers are in a much stronger position to be able to be attentive, competent, responsive and take responsibility for people if they entered into caring relationships on a basis which enables them to exercise choice over which elements of care they provide and how’. The focus of reforms here should thus be on “empowerment rather than non-interference” (Donnelly, 2010, p. 7) – both for carers and for the person being cared for.

Conclusion
This paper has considered the shortcomings of the current individualistic approach taken in dementia law and policy as it affects family carers. It has been suggested that the current approach fails to regard the interests of carers and the relationship as a whole as a legitimate considerations in decision making. The relational approach advocated for ought not to be framed as a move towards giving precedence to third party interests. The real issue is that the current legal and policy approach, focusing on procedure and ‘best interests’, is not sufficiently nuanced enough to appreciate the realities of caring. The decision-making criteria ‘oversimplifies a process that is complex, dynamic, personal and even idiosyncratic and tends to deemphasize other ethically valid considerations, including morally relevant emotions and virtues such as mutual responsibility’ (Berger et al., 2008, p. 51). The problem is thus with unsophisticated decision making frameworks – whether they place decision making discretion in the hands of the family, or in the hands of health or social care professionals.

Challenging legal individualism will be an important starting point for progress here. Yet relational approaches may be difficult to translate into legal doctrine. As Skaerbaek (2011, p. 47) contends, ‘not one ethical approach can cover the complexity of the challenging dilemmas of health and social arenas. It is, however, necessary that ethical theory and practice takes into account that all of us are embodied and gendered human beings, dependent and independent, constructing and being constructed by various factors in our personal and public lives’. Combining complex ideas of individual and interdependent interests in a context infused with valid safeguarding concerns will undoubtedly be difficult for policy makers to grapple with (Donnelly, 2009). However, the law should not ignore the realities of informal caring and perpetuate an unsophisticated approach to decision making in this context.

An approach is needed which allows all parties with a relevant interest to have a voice, and crucially to have the impact of a decision being made upon them to be acknowledged as a relevant consideration. To do otherwise ignores the realities of the caring relationship, and renders the carer simply as a resource. Legal recognition or reforms which emphasise the need to consider wider interests will undoubtedly be an important step to achieve this. In essence, the changes would require a change in process, not necessarily outcome. However, this will not do all of the work. The matter is much more complex than simply being a ‘legal’ problem and more research is needed into the extent to which different factors impede open and inclusive decision making. Moreover, legal tests do not always operate on the ground in the way envisaged by policy makers (Dunn et al., 2010) and so reform of the capacity legislation or Code of Practice would not necessarily effect the required changes. Wider professional and societal attitudes, and an overarching fear of diverging interests creating irreconcilable conflict, need to be challenged (Ho, 2008, p. 132). What the law can do, however, is provide much needed safeguards for the open scrutiny of decisions. At present, the lack of explicit judicial and professional acknowledgement that wider interests are being considered – perhaps due to the need to fit decisions into the procedural framework entailed in the legislation –
prevents this transparency. To quote a family carer ‘it’s all about transparency; we need to be true and honest with each other. We’re all in this together, aren’t we?’ (Watson, 2011, p. 45).

Notes

1. Traditionally, care ethicists such as Noddings (1984) and Held (1993) have positioned themselves in opposition to a theory of justice which sits in contrast to care – namely, one which is abstract and built upon boundaried rights. However, as will be discussed later, this does not require a rejection of justice or rights per se, but instead invites a re-evaluation of how we conceptualise justice (Engster, 2004; Spring, 2011). I take this view as the basis of my argument that care considerations can be aligned with considerations of social justice; an approach which allows for a much more responsive evaluation of current law and policy.

2. The Care and Support Bill (Department of Health, 2012) proposes a duty on local authorities to assess the carers’ needs separately to the care-recipient, and furthermore a duty to meet this need. Whilst this is laudable in principle, it is not clear that the provisions are sufficiently nuanced to appreciate the interpersonal, relational needs of the carer and cared-for. In effect, the proposed reforms perpetuate an individualistic division between carer and cared-for. The procedural division of services can obstruct the process of attending to individual and interdependent needs and choices and act as an obstacle to nuanced consideration of the needs of the care relationship as a whole and to the inclusive negotiation of interests in decisions being made.

3. The Code of Practice (2007) is not particularly helpful here as it similarly reflects the atomistic approach to best interests. See, for example, the discussion of Pedro at para 5.7. The scenario, provided in order to assist those using and applying the legislation, presents the respective interests in such an unsophisticated way that an appreciation of the complex relational factors inherent in caring relationships is side-stepped.

4. Recognition of this, and advocating a justice dimension to care ethics, is antithetical to many early ethics of care theorists (Noddings, 1984; Ruddick, 1989). Early debates in the care ethics sphere were framed as viewing care and justice as dichotomous concepts, focusing in particular on rights as a masculine and atomistic concept. This unease with the place of rights within a care ethics framework still creeps into the literature (see Herring, 2007). Spring (2011) has explored the potential of an integrated view of care and social justice in order to bridge the apparent gap between the concepts. He builds upon Nedelsky’s contention that ‘once rights are conceptualised in terms of the relationships they structure, the problem of individualism is at least radically transformed’ (Nedelsky, 2006, p. 101) and Brennan’s suggestion that it is open to us to develop rights approaches based upon a relational view of the self (Brennan, 1999, p. 266). Rejection of an individualistic concept of the self and society does not necessitate a rejection of rights- we do not want to throw out the baby with the bathwater. As Pettersen describes, ‘no single ethical theory is all-inclusive, and illuminates why it is often necessary and beneficial to review ethical challenges from several normative perspectives before drawing conclusions, making decisions or passing judgment’ (Pettersen, 2011, p. 55).

5. Also see Thorpe LJ guidance in Re A [2000] 1 FLR 549 which directed a balance sheet approach to best interests. Whilst taking into account a range of factors, the approach is still solely focused on the best interests of the individual. However, see the dicta of Morgan J in In the Matter of G (TJ) [2010] EWHC 3005 (COP) in which he stated that the balance sheet approach has the effect of ‘considerably widening the matters which fall to be considered’ (para. 36). He went on to state that ‘[T]he word “interest” in the best interests test does not confine the court to considering the self-interest of P. The actual wishes of P, which are altruistic and not in any way, directly or indirectly self-interested, can be a relevant factor. Further, the wishes which P would have formed, if P had capacity, which may be altruistic wishes, can be a relevant factor’ (para. 56). This is certainly encouraging; however the focus is still very much on P’s interests and attributing these in a way which includes others, rather than being open and explicit about the existence of other relevant considerations.

6. This similarly reflects the findings of Gilbar’s (2011) study which suggested that although individuals want involvement of family members, they also want to retain the final say over decisions. Like Coggon (2008b), I agree that the injunction to focus on the person lacking capacity entailed in the direction to consider their ‘best interests’ reflects the fact that ultimately
they will be most affected by the decision. So long as this does not prevent other considerations from being considered- and I don’t think it has to, provided some direction is given to consider other relevant interests- then this is an appropriate balance.

7. The concepts of relational autonomy and supported decision making have gained prominence in legal commentary recently with regard to the literature on the United Nations Convention on the Rights of Persons with Disabilities 2006. This is a positive development in this context for emphasising the voice of the person lacking capacity and enhancing their capabilities in decision making. As Richardson discusses, ‘[a] relational approach tends to a supported decision-making model: autonomy, or its legal counterpart mental capacity, is not to be assessed in the individual in isolation, rather she is to be supported and helped’ (Richardson, 2012, p. 10).

8. Talking Mats are perhaps one means by which such collaborative discourse can be facilitated in the context of dementia. ‘Talking Mats provides a framework whereby the needs and views of the person with dementia and their carer can be articulated and shared [enabling them to] jointly discuss and make decisions’ (Murphy & Oliver, 2012, p. 178).

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‘PEOPLE LIKE THAT’: REALISING THE SOCIAL MODEL IN MENTAL CAPACITY JURISPRUDENCE

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ABSTRACT

Through critical analysis of the law’s traditional response to mental disorders in mental health and mental capacity law, it will be argued that a medicalised model of disability has been predominant, and still permeates jurisprudence in this area. It will be suggested that insights from the social model and relational understandings of rights can highlight the ways in which wider contextual and structural relations can impact upon the lived experience of mental impairment. Moreover, an understanding of the various dimensions of mental illness can help elucidate how the law can respond effectively to structural, institutional, and contextual factors in order to facilitate the enjoyment of purported rights and values. In light of this, it will further be argued that the lingering precedence given to a narrow, medical view of cognitive impairment is outmoded given the more richly textured understanding of cognitive impairments which has recently emerged. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has harnessed the insights from the social model of disability and the capabilities approach to justice, and will be presented as the legal articulation of such understandings. This article seeks to build upon these understandings of disability and social justice and argue for the need for a more responsive state and judiciary in addressing the concerns highlighted by the UNCRPD and embedding these into judicial discourse.

KEYWORDS: Capabilities, Deprivation of Liberty, Responsive State, Social Model of Disability, United Nations Convention on the Rights of Persons with Disabilities

I. INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (2006) (UNCRPD) has been heralded as signalling a ‘paradigm shift’ in thinking about disability rights.1 Many commentators have lauded the potential success of this instrument in securing rights to people with disabilities by providing a renewed focus on

the positive obligations of states to facilitate the enjoyment of rights. In the context of mental disability, this could have a profound impact on the lives of many with mental health problems or who are deemed to lack mental capacity.

Despite these grand claims, an analysis of the domestic case law in this context tells a different story. This article will consider the entrenchment of a narrow, medical understanding of mental disability which permeates judicial discourse in many cases. A particularly stark illustration of this, namely the ‘relevant comparator’ test propounded by the Court of Appeal in Cheshire West and Chester Council v P\(^2\) will be explored in more detail. This is presented as a strong manifestation of a medicalised understanding of the experience of mental disability, which situates the problematic aspects of disability firmly within the individual, and perpetuates the illusion that the state or society has no role in this. This is an attitude that the aforementioned UNCRPD has been praised for shifting away from—yet it clearly still resides in this context and is proving stubborn to move. As will be discussed, the ‘relevant comparator’ test has now been rejected by the Supreme Court\(^3\); however, it serves as a particularly stark illustration of the pervasive role of the medical model in judicial reasoning and the ease with which it can be endorsed despite the changing rhetoric which has accompanied the UNCRPD. The recent Supreme Court judgements in Cheshire West\(^4\) and Aintree v James\(^5\) ostensibly signal a desire to shift away from the medical model, yet still present some ambiguities which suggest that the social model is yet to be legally embedded.

By focusing on the way in which the law has framed and responded to mental disorders, through the lens of the social model of disability and relational theories such as the capabilities theory of justice, this article seeks to argue that despite the gains in political discourse surrounding disability, and mental impairments more specifically, these will not become a reality for many people without judicial awareness of the social situation from which claims are being made, and the need to facilitate the enjoyment of rights and access to justice. In light of this, it will be argued that the lingering precedence given to a narrow, medical view of mental disorder is outmoded given the more richly textured understanding which has emerged through theoretical insights focusing on the social and relational nature of the experience of impairment. Consideration of the broader dimensions intersecting in the experience of mental illness casts the spotlight on structural and systemic relations which can either facilitate or undermine the enjoyment of rights and fostering of core values such as equality and liberty.\(^6\) At the same time, critical developments in our theorising of the social model and capabilities theory highlight the importance of a focus on the particular and the contextual barriers for particular individuals. The law is in a position to impact upon the structural relations between people with mental disabilities and the state and, moreover, to positively enable access to rights in this vein. This is particularly evident in the context of mental health and capacity law, which manifestly structures the

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4 ibid.
relationship between the state and the person with a mental disorder. Unsworth pointedly recognised this when arguing that ‘law actually constitutes the mental health system, in the sense that it authoritatively constructs, empowers and regulates the relationship between the agents who perform mental health functions’. The UNCRPD serves as a crucial vehicle for a facilitative approach to rights by harnessing the understandings gleaned from the social model of disability and the capabilities approach to justice within a legal instrument. This article seeks to advance these understandings of disability and social justice and argue that there is still work to be done to firmly embed these understandings into legal responses. The need for a more responsive state and judiciary will be central to addressing the concerns highlighted by the UNCRPD and entrenching these into judicial discourse in the context of mental disabilities. Without judicial responsiveness in this regard, the hard-won gains envisaged by the UNCRPD will remain an ideal.

II. LEGAL RESPONSES TO DISABILITY AND COGNITIVE IMPAIRMENTS

It has been said that the dominance of the medical model has been one of the greatest barriers to the enjoyment of human rights by persons with disabilities. This is certainly borne out in a cursory analysis of the law’s traditional response to mental illness and capacity. The medical model of disability situates problems stemming from disability within the individual’s flawed mind or body. Disability, viewed from this perspective, is simply an ‘unfortunate state of functioning and being’ with a resultant focus on biological cure or management of the condition or person. The medical model thus sees ‘diagnosis and classification functioning as ends’. Consequences and limitations stemming from the disability are thus seen as regrettable but inherent to the condition. This is perhaps an understandable stance, given that the very notion of disability evokes the idea of being ‘less’ than others at least in a biological sense. However, this is a rather one-dimensional view which ought to be scrutinised, particularly when it can have serious and far-reaching implications in terms of the enjoyment of particular rights.

In the context of mental health law, there has been a long held dissatisfaction with the medical model’s grip. Due in part to the foregrounding of a medical diagnosis and a reliance on medical experts, it is not surprising, and perhaps understandable,
that there is a high level of recourse in law to a medical model.\textsuperscript{14} A medical diagnosis of a mental disorder is the gateway to the provisions of the Mental Health Act 1983 (as amended), and legitimisation of detention for assessment or treatment is largely in the hands of medical professionals.\textsuperscript{15} Burns has argued that the ‘institutionalised medical language of mental disability . . . situates mental conditions squarely within an individual disease framework. Terms such as “mental disease” and “mental disorder” construct psychological, emotional, and behavioural conditions as innate, biological, pathological states independent of socioeconomic, cultural, and political context’.\textsuperscript{16} The narrow lens of the medical model focuses attention on control, care, and treatment as a consequence of the mental disorder and defines these responses in a medicalised way. The focus of detention under the legislation is treatment, often by pharmacological means combined with psychotherapy, with the Mental Health Act circumscribing and legitimising the provision of such treatments.\textsuperscript{17} Non-compliance with such responses is ‘perceived as an unacceptable act of deviance’.\textsuperscript{18} The broad definition of treatment residing in the Mental Health Act 1983 and case law stemming from it widens the remit of the medicalised response to mental illness in this context, marginalising more nuanced understandings of the situational factors impacting on the experience of the impairment.\textsuperscript{19} Service users report the negative impact that this has on professional understandings of their illness, noting that ‘it’s a deficit deviant model . . . they don’t see it as a social issue, it’s a biological thing full stop’.\textsuperscript{20}

The Mental Capacity Act 2005 similarly foregrounds the existence of an impairment of, or disturbance in, the functioning of the mind or brain\textsuperscript{21}—without such an impairment or disturbance, the individual is unable to be deemed to lack capacity for the purpose of the Act. This again places an emphasis on medical diagnostic criteria. In various cases involving people deemed to lack capacity, we see that the judges often accept the professional’s view that the person lacks capacity without necessarily scrutinising the particular requirements outlined in the Act.\textsuperscript{22} A recent worrying

\begin{footnotesize}
\textsuperscript{14} The Mental Health Act 1983 (Amended 2007) ss 2 and 3.
\textsuperscript{15} P Conrad and C Slodden, ‘The Medicalization of Mental Disorder’ in C Aneshensel, J Phelan, and A Bierman (eds), Handbook of the Sociology of Mental Health (Springer, Netherlands 2013) 61–73.
\textsuperscript{17} Mental Health Act 1983, Part IV.
\textsuperscript{19} See cases such as \textit{B v Croydon Health Authority} [1995] 1 ALL ER 683 (CA) and \textit{Reid v Secretary of State for Scotland} [1999] 2 AC 512 which demonstrate the broad definition of ‘treatment’ which will satisfy the requirements under Part IV of the Act. For example, in \textit{B v Croydon} we see that medical treatment for the mental disorder includes treatment of the symptoms of the disorder (as well as the disorder itself) and includes a range of acts ancillary to the core treatment. In this case, force-feeding was deemed to be medical treatment under s145 (1) of the Mental Health Act 1983. Similarly in \textit{Reid}, a broad definition of medical treatment was endorsed which was said to include things done under medical supervision to alleviate or prevent a deterioration of the mental disorder, or the symptoms of it.
\textsuperscript{20} P Beresford and others, above, n 13, 13.
\textsuperscript{21} Mental Capacity Act 2005 s 2(1).
\textsuperscript{22} The Mental Capacity Act 2005, s 3(1). See, for example, \textit{DH NHS Foundation Trust v PS} [2010] EWHC 1217 (Fam) Para 3, PS is 55. As the Official Solicitor accepts she has “a significant impairment in intellectual functioning as a consequence of a learning disability” and thus lacks the capacity to make decisions about her healthcare and treatment. She also lacks the capacity to conduct or defend proceedings.
\end{footnotesize}
example of this can be seen in Re AA, a case involving the decision to undertake a Caesarean on a woman detained under the Mental Health Act 1983. The question of her capacity was briefly touched upon, but Mostyn J seemingly accepted that she lacked capacity based on her mental illness without scrutinising the requirements in s3. A rather interesting exchange is recorded in the transcript between Mostyn J and Counsel for the Official Solicitor which implicitly places a strong emphasis on medical understandings of mental illness:

MR. LOCK: . . . We invite your Lordship to approach it in this way. First of all the question is: does she have capacity? She plainly does not, because there is evidence of delusional beliefs. We have thought carefully as to whether we ought to ask your Lordship to adjourn this so that we can get further into capacity, but given that this is the treating psychiatrist and she has been in his care since at least June of this year, there appears to be evidence, therefore, based on a fair amount of background information; not like a psychiatrist who has seen a patient on one occasion and just gives a view where there is always a concern that there may be some background that the psychiatrist was not fully aware of. This appears to be a reasoned report based on a good knowledge of the patient. Therefore we do not propose to ask your Lordship to adjourn.

MR. JUSTICE MOSTYN: No, I agree with that. I am struggling to envisage a circumstance where a patient detained under section 3 as an inpatient with a diagnosed mental illness has got capacity. It is possible, but I am struggling to imagine how it could happen.24

As will be returned to in due course, it is imperative the judiciary grapple with and closely scrutinise assessments of capacity which rely heavily on clinical judgement, particularly when core right are at stake. Cases such as this are not only an affront to the principles of the Mental Capacity Act 2005, but employ a dangerous misunderstanding that a diagnosis of mental disorder is sufficient for establishing mental incapacity.25 While there is a presumption of capacity in the Act, the demands of impartiality may be difficult to achieve in practice for medical professionals.26 Taylor draws attention to how assumptions of rationality, independence, and normalcy can produce wrongful and harmful views of disability and humanity of disabled lives.27 Capacity can in turn be questioned on the ‘flimsiest evidence’.28 Preconceptions about the impact that a cognitive impairment can have on competence and functional

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24 ibid. Transcript of Proceedings, 11.
28 Bartlett (2012), above, n 13, 761.
ability can colour professional assessments. Conversely, Secker has argued that, ‘once the value laden, socially constructed nature of competence is recognised, the potential for biases in competence assessment becomes more readily apparent’. This narrow understanding of capacity can lead to a sterile and unsophisticated assessment which does not take adequate account of the relational nature of capacity, in that people’s decision-making abilities are highly context dependent and can be undermined or fostered by situational factors.

Such a response to cognitive impairment has similarly permeated understandings of best interests for people deemed to lack capacity. In recent evidence to the House of Lords Select Committee on the Mental Capacity Act, a concern was raised that best interests can seem to be reduced to clinical interests. This was reflected in the Select Committee’s conclusions, where it was highlighted that clinical judgements or resource-led decision-making predominate. In the context of sterilisation, there is a long recognised tendency for professionals and judges to defer to a medicalised understanding of learning disability and ‘ignore crucial questions about the importance of men and women with learning disabilities leading socially valued lives and produce a deeply problematic conception of sexed identity’. Furthermore, through this narrow lens, ‘patients become understood in terms of physical, mental or emotional frailty and dysfunction’ thus situating risks within the person with a cognitive impairment and eschewing a broader consideration of the various sources of concerns and the means by which to support the person to meaningfully access their rights and participate fully in society.

As will be discussed in turn, progress is being made as more nuanced theoretical understandings of disability and cognitive impairment have emerged in professional and legal discourse. However, a recent example of the narrow conception of cognitive

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30 NF Banner, ‘Can Procedural and Substantive Elements of Decision Making be Reconciled with Assessments of Mental Capacity?’ (2013) 9 (1) Int JLC 84.
33 K Keywood, ‘Sterilising the Woman with Learning Difficulties—In Her Best Interests?’ in J Bridgeman and S Millns (eds), Law and Body Politics: Regulating the Female Body (Dartmouth, Aldershot 1995).
35 This medicalised understanding outlined above is not limited to the context of mental health and capacity law, but can further be seen in other contexts such as best interests decisions relating to children born with disabilities. See J Bridgeman, ‘Caring for Children with Severe Disabilities: Boundary and Relational Rights’ (2005) 13 Int J Child Rts 110, where it is argued that in cases such as A NHS Service Trust v D [2000] FLR 677, parents feel that doctors are not looking at quality of life in a holistic sense, but instead drawing on a medical perspective, from their own non-disabled experience. This is reiterated by McLean and Williamson who highlight that best interests decisions risk not being made from the perspective of the impaired infant but a third party—usually an able-bodied adult—who may all too readily assume that all disabled experience is bad experience (S McLean and L Williamson, Ch 7 ‘Countering Discrimination Against the “Disabled”: What good are ethics and law?’, Impairment and Disability: Law and Ethics at the Beginning and End of Life (Routledge, Oxon 2007) 183, 189).
impairment warrants closer scrutiny as it serves to highlight how the medical model is still active in judicial dicta, and further illustrates the consequences of this in terms of the protection of the rights of persons with cognitive disabilities. The case of *Cheshire West and Chester Council v P*36 in the context of the Deprivation of Liberty Safeguards (DoLS) is a stark example of judicial endorsement of a narrow, medical conceptualisation of mental disability. As noted in the introduction, this is of particular concern given the supposed ‘paradigm shift’ in political discourse in this context.

III. ‘THE KIND OF LIVES THAT PEOPLE LIKE X WOULD NORMALLY EXPECT TO LEAD’37

*Cheshire West* centred around whether P, an adult with cerebral palsy and Down’s Syndrome, is being deprived of his liberty in a residential home known as ‘Z House’. Details about his care reveal that P frequently presented with challenging behaviours, such as refusing to move or comply, and stripping off his clothes and throwing objects. Furthermore, he has a history of continence problems and has developed a habit of tearing his continence pads and putting them in his mouth. In response to these behaviours, staff attempted various techniques, including a ‘finger sweep’ of his mouth to check for the pads, and also the wearing of an all in one body suit which prevents P’s hands from touching his groin area and so preventing him from touching the pads. The question arose as to whether some of the mechanisms used by staff, such as physical interventions and restraint, amounted to a deprivation of P’s liberty. If they did, then the DoLS38 would be triggered in order to provide a legal mechanism through which the deprivation of liberty can be authorised and subjected to safeguards, in conformity with the European Convention on Human Rights.39

The Court of Appeal, with the leading judgment delivered by Munby LJ, concluded that P was not being deprived of his liberty. The reasoning applied to this question by Munby LJ is certainly detailed and complex. While aspects of the judgement such as the objective purpose, and the concept of relative normality he employed have attracted significant criticism,40 of greatest interest here is the attempt

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36 *Cheshire West and Chester Council v P* [2011] 9 November 2011 EWCA.
37 ibid. para 102.
38 Mental Capacity Act 2005, s 4A, Schedules A1 and 1A.
to carve out the ‘relevant comparator’ test. While the central approach in the case has since been overruled by the Supreme Court, it is important here for our purposes as it serves to illustrate how a medicalised understanding of cognitive impairment has been drawn into judicial reasoning in this context at appellate level, despite the rhetoric that has accompanied the UNCRPD. It is argued that the approach taken is symptomatic of a medical model of disability and portrays a narrow view of the lived experience of cognitive impairment and the various factors which impact upon this.

Munby LJ reasoned that a comparator is necessary in these types of cases, as simply focusing on the concrete situation of the individual when considering whether they have been deprived of their liberty ‘does little more than describe a forensic process’, and that instead the task should be to ‘identify what it is that we are comparing X’s concrete situation with’. Munby LJ contended that while in most contexts, the relevant comparator is ‘the ordinary adult going about the kind of life which the able bodied man or woman on the Clapham omnibus would normally expect to lead’, such a comparison ought not to be made in the context of cases arising under the DoLS framework. He pointed out that the Court of Protection in such cases is dealing with adults with ‘significant physical and learning disabilities’ whose lives are ‘inherently restricted’ or ‘dictated’ by their own ‘cognitive limitations’. As a result of this, he reasoned that the relevant comparator ought to be ‘an adult of similar age with the same capabilities as X, affected by the same condition or suffering the same inherent mental and physical disabilities and limitations as X’. The court must focus on ‘the kind of lives that people like X would normally expect to lead’. In essence, this approach seems to require that rather than comparing the situation of P to that of a ‘normal’, ‘able-bodied’ adult, and focusing on whether the situation of P is a deprivation of liberty in light of this, the judge instead must factor in the ‘inherent’ limitations that are ‘expected’ of people with a certain condition in determining whether they are objectively being deprived of their liberty. This is of key importance in terms of triggering the DoLS—if the comparator is someone ‘like’ P, and it is deemed that their circumstances are therefore ‘normal’, then it is less likely that the situation will be deemed to be a deprivation of liberty, and thus the procedural safeguards necessary to oversee and challenge the circumstances are not triggered. This ignores the institutional and situational factors which can hinder or undermine liberty, and further perpetuates the illusion that the state and society play no role in the lived experience of those with cognitive impairment.

The ‘relevant comparator’ test is infused with comments situating the problematic consequences of illness or disability firmly within the person lacking capacity. Perhaps the most telling example of this is where Munby LJ stated that:

Some adults are inherently restricted by their circumstances. The Court of Protection is dealing with adults with disabilities . . . adults with significant physical

41 Para 38.
42 Para 39.
43 Para 102.
44 ibid.
45 ibid.
and learning disabilities, whose lives are dictated by their own cognitive and other
limitations.46

Whether or not intended by Munby LJ, such comments resonate strongly with the
central principles of the medical model of disability, which similarly situates problems
stemming from disability within the individual’s flawed mind or body47 and chimes
with Munby LJ’s characterisation of disability and impairment as inherently restrictive.
This narrow characterisation precludes sustained consideration of wider factors which
may exacerbate the disabling aspects of the impairment, such as cultural assumptions,
resources, environmental and psychological factors. Instead, people with cognitive
impairments who are deemed to lack mental capacity are ‘judged according to their
peers’48 based upon a diagnostic classification and ‘inherent’ impairing consequences
of this. Munby LJ’s casting of cognitive and other limitations as inherently restrictive
presents an unsophisticated and one-dimensional account of the totality of the lives
of those who are deemed to lack mental capacity. Obfuscating the structural and insti-
tutional relations which impact upon the lived experience of people with mental
health problems impedes a clear understanding of what is needed to actually secure
the enjoyment of values, such as liberty in this context, to a person with disabilities.
Attentiveness to such difference and to the background conditions external to a diag-
nosis that impact upon experiences is being called for by the social model. The social
model demands a broader focus on the barriers preventing persons with disabilities
from exercising legal capacity and living in the community49 and the framing of indi-
idual responses based on this. An approach predicated on ‘false universalising’50 pre-
vents such scrutiny. In the case itself, this would have required the judges to focus not
on the supposed inherent restrictions posed by a cognitive disability, but instead on
the ways in which the societal and environmental factors impacting upon the individ-
ual are causing or exacerbating the disability—and more importantly, how these can
be augmented so as to avoid or ameliorate this.

Furthermore, the Court of Appeal judgment in Cheshire West raised worrying
implications for human rights protections of people who lack capacity due to cogni-
tive impairments. Disability is increasingly a human rights issue51 and in particular the
right to liberty in the context of institutional care has been repeatedly asserted in
Strasbourg.52 The ‘relevant comparator’ test in Cheshire West, however, could be seen
to ‘abandon the idea that there are common standards, common liberties . . . or

46 Para 120 (emphasis added).
47 Barnes and Mercer, above, n 10, 2.
48 Hewitt, above, n 40, 284.
49 C O’Mahony, ‘Legal Capacity and Detention: Implications of the UN Disability Convention for the
50 Ibid; As Shakespeare and Watson contend, ‘[d]isability cannot be reduced to a singular entity: it is a multi-
plicity, a plurality’, and moreover that, ‘many people are simultaneously situated in a range of subject posi-
tions. To assume that disability will always be the key to their identity is to recapitulate the error made by
those from the medical model perspective who define people by their impairment’; T Shakespeare and N
51 C Baylies, ‘Disability and the Notion of Human Development: Questions of Rights and Capabilities’
common protections that are available to everyone; and it implies that the mentally ill or the mentally incapable are entitled to fewer protections, to lower grade liberty’.53

IV. MENTAL CAPACITY IN THE SUPREME COURT

It is on this understanding of the universal nature of human rights that the Supreme Court allowed the appeal in the case and found that P was in fact being deprived of his liberty.54 Lady Hale delivered a resounding statement of the ‘universal character of human rights, founded on the inherent dignity of all human beings’55 and stated that this serves as a starting point for decisions as to whether a person is being deprived of their liberty. Adding to this, important recognition was given to the fact that:

Far from disability entitling the state to deny such people human rights, rather it places upon the state (and upon others) the duty to make reasonable accommodation to cater for the special needs of those with disabilities.56

This clearly resonates with the underlying principles of the social model which emphasise the importance of recognising the social and environmental constraints upon rights such as liberty, but also the responsibilities that this generates to ameliorate these effects. Furthermore, the relevant comparator approach was rejected on the basis that it elided the question of deprivation of liberty with the issue of whether this was justified. As Lady Hale stated, ‘a gilded cage is still a cage’.57 However, while the rejection of the relevant comparator test is to be welcomed, the Supreme Court decision does not necessarily reflect a wholesale shift towards judicial appreciation of the social model. The statement above about the universal nature of human rights is entangled with the assertion that:

It may be that those rights have sometimes to be limited or restricted because of their disabilities, but the starting point should be the same as that for everyone else.58

This perpetuates the idea that rights can be restricted on the basis of the inherent characteristics of an individual, i.e. their disability, and focuses attention on such characteristics and the management of them, rather than externally on the social environment. Similarly, the recognition of the concept of ‘reasonable accommodation’ is laudable. However, the interpretation of this alongside the limited role of the Court of Protection in best interests decisions (a point which will be returned to later) may

53 Hewitt, above, n 40, 284.
55 Para 45, per Lady Hale.
56 Ibid.
57 Para 46.
58 Para 45.
delimit the potential for the legal recognition of, and response to, the external context in individual cases.

The potential for a shift towards an approach informed by the social model is even less clear when we look at the other recent Supreme Court case involving the Mental Capacity Act 2005: Aintree v James.\(^{59}\) This case, which centred on when it is legally permissible to withhold life-sustaining treatment, signalled a resounding recognition of the centrality of the views of the individual as being ‘a component in making the choice which is right for him as an individual human being’.\(^{60}\) This recognition of the importance of focusing on P as an individual and being attentive to his views represents a crucial step towards seeing individuals with disabilities as ‘subjects, not objects’\(^{61}\) and can be viewed as an important antidote to the medical model. Yet it is unclear, following Aintree v James, to what extent the status quo has been affected. Lady Hale was keen to stress that nothing in the judgment changed the law as previously understood,\(^{62}\) and that the person’s wishes will not always prevail.\(^{63}\) Indeed, an objective best interests test remains; it is just that the subjective wishes and preferences of the individual are seen as an important component of this decision. Concerns have been raised on numerous occasions as to whether prejudicial ideas about the preferences and abilities of disabled people may be masked by supposedly objective assessments of best interests and clinical prognosis or diagnosis.\(^{64}\) P effectively remains a medicalised subject in the best interests assessment, as concepts of ‘futility’ and ‘prospect of recovery’ remain as signposts for decision makers, albeit ones that are meant to be viewed from P’s perspective.\(^{65}\) The ‘touchstone of intolerability’, itself a medicalised concept residing in much of the case law involving children,\(^{66}\) is noted by Lady Hale but not clearly endorsed or disapproved, leaving its legitimacy unclear. Concepts such as ‘intolerability’, ‘quality of life’, and ‘futility’ have been heavily criticised in the past by those challenging the medical model.\(^{67}\)

The case of RB v Brighton and Hove CC,\(^{68}\) following the other Supreme Court decisions, indicates that the medical model is still very much alive in the jurisprudence. The judgment in the case, which involved the deprivation of liberty of an alcoholic man following severe brain injury, is peppered with the language of the medical model, some of which is reminiscent of Munby LJ’s ‘relevant comparator’ test. It was asserted by Jackson LJ that ‘RB’s physical and mental disabilities are such that he is not currently capable of independent living outside an institutional setting’.\(^{69}\) While regard is had to the requirement to take into account RB’s wishes,

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60 Para 45, per Lady Hale.
61 Quinn and Degener, above, n 9.
62 Para 47.
63 Para 45.
65 See, for example, para 41.
67 See literature in above, n 35, for discussion about the medical model in decision making at the beginning of life.
68 (2014) EWCA Civ 561.
69 Para 80.
these are perfunctorily dismissed with little explanation. The control and cure response, associated with the medical model, prevailed in this case without any exploration of the ostensibly more human rights orientated dicta from the Supreme Court in Cheshire West. The law is still presenting the relevant starting point as seeing coercive responses to mental disabilities as being appropriate in some circumstances, with the role of the law being to delineate when and how this is appropriate. Thus, while the Supreme Court decision in Cheshire West is to be welcomed for providing an important reminder as to the human rights of people with mental disabilities, it will not necessarily facilitate the legal shifts required to realise the social model.

V. SITUATING THE SOCIAL MODEL

In light of this, the need for a new perspective which captures the various dimensions of mental disability is clear. The critical importance of insights from the social model taking hold in judicial consciousness lies in the need for judges to challenge and question assumptions being made through a narrow medical lens. The social model of disability holds that much of the disadvantage experienced by those with disabilities or impairments is socially imposed rather than pertaining to their bodily or mental state. In essence, the core of the social model, in its original formulation, is that societal structures and institutions, rather than impairments, cause disability. Such an approach, denying a causal link between impairment and disability, has been subject to criticism, debate, and refinement both from within the social model itself and also from external perspectives. Commentators have emphasised the need to bring individual experiences back into social approaches to disability and frame a more refined and inclusive approach which considers and builds responses to disability on the basis of a variety of levels such as physical, psychological, societal, political, and cultural. As Shakespeare and Watson contend, ‘[d]isability cannot be reduced to a singular entity: it is a multiplicity, a plurality, and moreover they note that, ‘many people are simultaneously situated in a range of subject positions. To assume that disability will always be the key to their identity is to recapitulate the error made by those from the medical model perspective who define people by their impairment’.

70 Para 81.
72 M Oliver, The Politics of Disablement (Palgrave Macmillan 1990); M Oliver, Understanding Disability: From Theory to Practice (Palgrave Macmillan 1996).
74 T Shakespeare and N Watson, above, n 50; L Crow, ‘Including All Our Lives: Renewing the Social Model of Disability’ in C Barnes and G Mercer (eds), Exploring the Divide: Illness and Disability (The Disability Press, Leeds 1996); J Morris, Pride Against Prejudice: Transforming Attitudes To Disability (University of California, New Society 1991); J Morris, Encounters with Strangers: Feminism and Disability (Women’s Press, University of Michigan 1996).
75 Shakespeare and Watson, ibid, 28.
76 Shakespeare and Watson, ibid, 23–6.
In essence, there is a need to situate the social model within the particular experiences and context of the individual. This is particularly pertinent in the realm of cognitive impairments. Until relatively recently, little consideration was given in the social model discourse to potentially incapacitating cognitive impairments such as dementia and learning disabilities. This may be because there seemed to be a lack of affinity between a social model of disability primarily concerned with societal structures and physical disabilities, and less visible mental disabilities. Furthermore, as Gilliard et al. point out in the context of dementia, ‘it is hard (and probably impossible) to argue that their impairment does not have a significant impact upon their lives’.77 However, commentators are engaging more with the interplay between cognitive impairment and disability.78 Certainly, there is a higher degree of complexity involved in aligning the concerns of the social model and cognitive impairments, which is a concern that has been relayed by mental health service users themselves.79 There is a more general concern that the social model of disability can inhibit an understanding of the lived experience of an impairment and marginalise other relevant factors affecting the individual in different contexts and circumstances.80 Thus, a polarised distinction between the social and medical models is perhaps unhelpful and inappropriate. A bio-psychosocial model has been advocated for by commentators recently.81 Such an approach seeks to carve a ‘third way’ between the extremes of the social and medical models;82 one which recognises that ‘bodies are lived in, but in the social spaces that they inhabit’.83 Indeed, the need for a more nuanced understanding is particularly pertinent in the legal context.

Moreover, while the insights from a broad social model of disability can provide a way of conceptualising social, economic, and environmental disadvantages and barriers faced by people with impairments,84 the practical implications or obligations stemming from this require further elucidation. As Barnes et al. have suggested, ‘there is generally a much changed political rhetoric responding to disabled people’s

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79 Beresford and others, above, n 13.
82 P Louhiala, ibid.
83 D Goodley, above, n 81.
Central to the claims in this article is the notion that insights from the social model alone are necessary but not sufficient to effect real legal progress in this context. What the social model does do is provide the critical tools to scrutinise previously entrenched assumptions about the experience of cognitive impairment, and it has the potential to shatter illusions that society and its structures and institutions have no role to play in this. However, the responsibilities stemming from these more nuanced understandings require further elucidation. The focus should thus be on whether the way the law is applied to the particular individual, considering the contextual situation from which the claim is being made, fosters or undermines the achievement of such goals. In exploring this further, it is important to scrutinise concepts of justice and equality and the law's characterisation of these through rights discourse in the context of cognitive disability. Through doing this, it will be suggested that capabilities theory, as an approach to justice, can provide the basis for more particular and contextual responses to previously obscured sources of disadvantage and inequality in this context.

VI. BUILDING ON THE SOCIAL MODEL: FROM LEGALISM TO CAPABILITIES

Attention was drawn to the need to create justiciable rights for people with mental illness through the work of Larry Gostin, then legal officer for MIND in the 1980s. The focus of his work was on the need for procedural safeguards in mental health law to offset the power of the medical professions, and it was prominent in the debates leading up to the Mental Health Act 1983. While this work was and is still highly valuable and instructive, there is a sense in which the 'legalism' which developed as a result of it has failed to produce the changes anticipated. As Fennell suggests, the focus has remained on procedural issues, with little scope to use the rights to challenge coercive treatment or secure support. The sense is that the resulting legal framework has simply created 'medical freedom with the appearance of legal control', with the ethos informing Gostin's original work being 'lost in translation into domestic law'. Viewed through the relational lens being advocated for here, which focuses on the external structures and institutions which can impact upon rights enjoyment, it is clear that this procedural approach has not provided an

86 Nedelsky, above, n 6.
89 Bartlett and Sandland, above, n 18, 347.
adequate conceptual framework within which broader understandings have been able to be accommodated or responded to. Procedural safeguards do not necessarily invite the decision maker to consider whether or not wider structural and societal factors impacting upon the person foster the achievement of the right or value in question.

Such failings of legalism in the context of mental health law are echoed on a wider scale in general rights discourse. There is dissatisfaction with the procedural focus of rights instruments such as the European Convention on Human Rights, which Richardson claims is mainly concerned with the protection of individuals from unjustified interference.91 The Convention essentially contains public law, due process rights, to ensure that limitations imposed on protected individual rights are imposed only if they are ‘prescribed by law, intended to achieve a legitimate objective, and necessary in a democratic society’.92 However, such rights are of doubtful utility for those who are not in a position in society to meaningfully access or enjoy them. There is a widespread dissatisfaction with the limitations of the procedural face of rights-based legalism to address broader questions of social justice, or recognise and facilitate claims to access supports to enable rights to be valuable.93 Focusing on procedural aspects of rights tends to ignore the background conditions in which the rights instrument is being employed and so is questionable as a means for bringing discriminatory powers to attention, or ‘reversing the differential impact of pathogenic social forces’.94 Thus, as Kanter claims, ‘even when laws, policies and programs value equality, the valuing of people subjected to those rules, laws and programs cannot be assumed’.95 This is particularly concerning in the context of mental health and cognitive impairments, where it has been suggested that the government has taken an essentially ‘Convention proof’ approach. Fennell outlines how, in the process of the reform of the Mental Health Act 1983, the government aimed for ‘the minimum restraint on compulsory powers consonant with Convention compliance’.97

Similarly, the DoLS discussed above are deliberately tied to the Strasbourg Article 5 jurisprudence, effectively ensuring that the government need only comply with the Convention in their obligations in this context.98 Indeed, we saw above Lady Hale’s recognition of the need to recognise deprivations of liberty separately from their justification, as ‘a gilded cage is still a cage’.99 However, it is to be questioned whether a procedural check on this—ensuring that it is in compliance with the requirements of Article 5—makes the experience for the individual any less of a cage, or is able to adequately scrutinise or address the way in which the right to liberty may be facilitated. While procedural protection entails an assessment of the individual’s best

91 G Richardson, ‘Rights-Based Legalism: Some Thoughts from the Research’ in McSherry and Weller, above, n 88, 182.
93 This has recently been recognised in MH v UK [2013] ECHR 1008, see in particular para 82. The ramifications of this across mental health and mental capacity law are as yet unclear.
96 Fennell, above, n 88, 20–2.
97 ibid.
98 Endorsed in House of Lords Select Committee Report, above, n 32, Ch 7.
99 P v Cheshire West and Chester Council and P and Q v Surrey County Council, above n 3, para 46.
interests, it is not necessarily clear that this will be undertaken in a way which adequately scrutinises the way in which the social environment may be augmented to enable liberty, or that best interests assessments can give effect to the changes necessary to enable this. Indeed, acting in a person’s ‘best interests’ in this regard may serve to further gild their cage by ‘locking them into cycles of dependency and despondency’ rather than focusing on the barriers to the achievement of particular rights for the individual. This is a point that will be returned to subsequently; however, it is important here to highlight this given the concerns about the limited utility of essentially procedural Convention rights in contexts in which wider issues of social justice have a bearing on the actual enjoyment of such rights.

Such problems with the procedural face of rights have long been recognised and are tied to a wider concern about law’s ‘liberal legalist’ orientation which focuses on the denial of civil or political rights, without sustained recognition on a deeper level that such rights can also be ‘eroded or rendered meaningless if the bare necessities of life are missing’. A broader understanding of the context in which rights are operating calls for a more substantive appreciation of the social, cultural, and economic obstacles to rights enjoyment—in essence, a bridging of the gap between substantive and procedural rights. This resonates with the burgeoning literature on the capabilities theory and the obligations stemming from such understandings of justice, rooted in the work of Amartya Sen and Martha Nussbaum. According to Sen, what is missing from traditional liberal theories ‘is the notion of “basic capabilities”- the person being able to do certain basic things’. This approach instead scrutinises ‘what people are actually able to do and be’, with a particular focus on just background conditions and the way in which societal structures and institutions can hinder access to certain purported rights or values.

In this way, the capabilities approach shares a relational starting point with social understandings of disability. The focus is on the way in which the environmental, cultural, political, and economic context can hinder or facilitate an individual’s enjoyment of certain capabilities. Without paying attention to these factors, claims about particular individuals’ enjoyment of certain rights and freedoms are incomplete. Sen’s critiques of traditional theories of justice highlight particularly how they tend to miss the ‘relevance of actual human lives and social behaviour in pursuit of justice, as well as the real consequences that different actions and decisions have on people’s lives’. The capabilities approach requires a focus on wider contextual aspects of a given

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100 G Quinn and T Degener, ‘Expanding the System: The Debate about a Disability-Specific Convention’ in Quinn and Degener, above, n 9.
105 Sen, above, n 103, 218.
106 Nussbaum, above, n 104, 33.
situation, as opposed to a detached and abstract conception of justice, further echoing insights from the social model of disability, in which intersecting factors impacting upon the person with disability are considered. This shared affinity and complementarity between the social model of disability and capabilities approaches has been noted by authors such as Burchardt and Terzi. However, while both approaches can highlight background social, political, environmental, or cultural obstacles to the achievement of capabilities, ‘concern for justice seems to require going beyond merely a critical approach to the hurdles society can place against the disabled, to a question of what further steps can be taken’. The capabilities approach requires a focus not just on the social, environmental, political, and economic context, but importantly emphasises the need to situate such considerations within a particular individual. It is thus not concerned with group rights in the abstract, but entails a focus on the societal obstacles facing a particular individual. In some ways then, this speaks to the concerns discussed above as to the social model and its potential to disengage from the actual experiences of individuals. As Wendell noted in critiquing the social model in this way, while people with a certain disability may have many experiences in common, ‘their social experiences, their opportunities, their economic welfare, and their status in their communities will have profound effects on how disabling their [condition] is . . . and on how they experience their disability’. The capabilities approach is a more contextually focused approach which seeks to avoid broad brush assumptions about particular disabilities or other characteristics.

Such an understanding has particular resonance in examining approaches to human rights. Thus, as noted above, while traditional liberal rights theories focus on non-interference and zones of inviolability, the capabilities approach requires that we ask whether the right is substantively capable of being achieved, and whether unjust background conditions or other barriers are inhibiting the actual opportunities for the particular individual to enjoy or secure the right. As Nussbaum asserts, securing a right ‘involves affirmative material and institutional support, not simply a failure to impede’. This enjoins those who are in a position to secure rights to citizens—such as the government and the judiciary—to consider the way in which structural relations can facilitate the enjoyment of such rights and to respond to claims on this basis. The social model as outlined above can illuminate areas in which this could

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108 Vehmas, above, n 78, 216: ‘the well-being or ill-being of all individuals depends primarily on their relation to other people . . . Humanity and human well-being are, thus, mainly granted to us by other people; the humanity of all individuals . . . depends on other peoples’ recognition’.
114 ibid, 37.
generate such commitments in the realm of cognitive impairment, while the capabilities approach calls for responses to this which are attentive to the particular individual. This involves a more intense scrutiny of the contextual aspects of rights enjoyment than an approach which concerns itself with whether procedural requirements have been adhered to.

One of the crucial aspects of the capabilities approach is that it can serve as a device 'to justify the making of political claims'. From the informational focus on a person’s actual ability to achieve certain basic capabilities, ethical assertions can be made about the required form of measures or policies aimed to facilitate such capabilities. Consideration of structural and institutional relations is central to this. Nussbaum argues that the capabilities approach acts as an ethical paradigm which serves to argue for 'the greatest freedom of functioning of our basic capabilities, justifying expenditures that allow people with disabilities to have access to that which they require to have the freedom to function and develop their capabilities'. As a corollary of this, states have a duty to provide the social basis for central human capabilities if they are to actually achieve social justice. This may require different approaches to the achievement of a similar goal, depending on background conditions and context pertaining to different people. In accordance with this, in relation to disability, there is a political duty to ensure that, so far as possible, 'impairments do not disable' based on an understanding that given appropriate and adequate enabling conditions, individuals with intellectual disabilities can become fully cooperating members of society.

These critical theoretical insights help develop a more textured understanding of cognitive impairments and the wider societal obligations stemming from these in order to facilitate social justice. This involves moving beyond an approach to rights based on procedural elements and focusing instead on more substantive aspects of justice. Indeed, I suggest that the UNCRPD in many ways provides a vehicle for this shift in approach by harnessing the critical insights from the social model and enjoining states to respond accordingly in order to facilitate the achievements of the rights contained within it.

VII. BRIDGING THE GAP

The UNCRPD marks a recognition that ‘reliance on formal structures alone is not adequate to ensure full enactment of human rights . . . the convergence of formal and informal social forces is necessary for the roots of human rights to grow deep into social structures’. The UNCRPD is an important milestone in this respect, as it demonstrates recognition at an international level of the centrality of law and policy in

116 Baylies, above, n 51, 735.
117 Sen, above, n 112, 232.
empowering people with disabilities. Indeed, the Preamble and Articles of the Convention are infused with the language of the social model and capabilities approaches, echoing the need for equality and positive actions to achieve this. The Preamble, for example, stresses the importance of recognising that disability results from the interaction between persons with impairments and attitudinal and environmental barriers to equality, and the need to promote and protect human rights for people with disabilities, including those who require more intensive support.

One of the key concepts of the UNCRPD is that of reasonable accommodation. This obligation is enshrined in the Convention in Articles 2 and 5, and strongly captures the practical requirements of substantive equality discussed above. Reasonable accommodation requires that steps are taken 'beyond embedding bald discriminatory proscriptions in laws and policies,' which will entail positive action to ensure equality and the enjoyment of rights. As a concept, it operationalises the capabilities insights by acknowledging the need to look not just to societal factors in the abstract, but to focus on the particular individual and what steps ought to be taken to secure to them their purported rights. Further, it echoes the idea that impairment and disability are experienced differently by different individuals, and so different responses are needed to enable reasonable accommodation to occur. Denial of reasonable accommodation under the Convention forms a basis upon which a claim for discrimination can be made, which explicitly provides an enriched and robust understanding of positive obligations to facilitate rights. Despite the concept being part of existing legal frameworks prior to the UNCRPD, its use was diffuse and thin, and the renewed and more robust emphasis on it in this context is to be welcomed as a mechanism to address underlying factors creating or exacerbating inequality and discrimination.

Another innovative aspect of the UNCRPD in relation to cognitive impairments is the emphasis in Article 12 on equal legal capacity, and the obligation upon states to provide supports to achieve this. Supported decision-making is a key aspect of this obligation and is seen as one of the more innovative requirements of the Convention. This demonstrates vital recognition of the relational and situational impacts upon an

123 O’Mahony, above, n 49; Samaha, above, n 84.
125 Defined as ‘[N]ecessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment of exercise on an equal basis with others of all human rights and fundamental freedoms.’
127 Bartlett (2012), above, n 13, 761.
128 Art 2: Disability discrimination defined as '[a]ny distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including the denial of reasonable accommodation'.
individual’s abilities and the ways in which these can be enhanced through appropriate and attentive responses. This emphasis on measures to empower and support people with cognitive impairments strongly resonates with the theoretical insights presented above in calling for the facilitation of abilities to realise capabilities.130

For many commentators, the UNCRPD thus provides a timely and welcome catalyst to strengthen many of the claims emerging from the developing literature on the social model of disability.131 However, it should be seen as providing more than simply a ‘radical social constructionist’ approach to disability rights.132 It reinforces and reaffirms the importance of enforceable rights and entitlements,133 but it goes beyond this, with a much needed focus on the individual and securing these rights to them through attentiveness to their lived experience. More importantly, in line with the capabilities approach, the ethos of the UNCRPD is very much about taking positive steps to enable an individual’s enjoyment of rights to be secured.134 The UK, having ratified the UNCRPD in June 2009, is committed to taking concrete actions to comply with the Articles of the Convention, which span various aspects such as equality and discrimination, gender issues, children with disabilities, the right to life, access to justice, employment opportunities, privacy, and liberty.135 The UN Committee on the Rights of Persons with Disabilities has published a General Comment on Article 12 recently in which it affirmed the importance of Article 12 for those with cognitive and psychosocial disabilities and the need for states to holistically examine all areas of the law with a view to ensuring that people have opportunities to express or develop their will and preferences as well as having choice and control over their everyday lives.136 The UNCRPD signals recognition of both the micro and macro levels of action needed to substantively secure rights to people with disabilities. The notion of a responsive state is thus central to this and the law—and judicial personnel within the legal system—have a key role to play in effecting this shift through the implementation of the UNCRPD’s aims and embedding these into socio-legal debates.

VIII. THE NEED FOR A RESPONSIVE LEGAL SYSTEM
As we have seen, while the insights gained from a relational understanding of the social context of cognitive impairment are vital, the commitments and responses

130 T Carney, ‘Involuntary Mental Health Treatment Laws: The “Rights” and Wrongs of Competing Models?’ in McSherry and Weller, above, n 88, 263.
134 UNCRPD Art 4, General Obligations.
135 We have seen the domestic courts gradually begin to mention the UNCRPD in judgements, see for example AH v West London MHT [2011] UKUT 74 (AAC) para 16.
stemming from such understandings require further elucidation. When seen as the means to operationalise core societal values, facilitating and securing rights involves scrutiny of the ways in which the law structures relations with a view to evaluating whether the right is in fact capable of being actualised. The UNCRPD has been shown to be an important political recognition of this in the context of disabilities. However, for the gains envisaged by this to firmly take root in the everyday lives of people with disabilities, there is a need for both micro and macro level change. The impact of the UNCRPD for many people with disabilities depends heavily on the extent to which it influences decision-making on the ground. Once these decisions have been made however, there are further barriers facing disabled people, particularly those with cognitive impairments, if they want to challenge them. Access to justice is multidimensional and involves the interplay of environmental factors, governmental transparency, accountability, and responsiveness. Without concerted action at all these levels, the gains envisaged by the UNCRPD will have little impact in reality.

Evidence is emerging which suggests that knowing where to seek advice and being able to access legal services is a serious obstacle for access to justice for people with disabilities. Concerns have been raised about the level of advice being offered when services are sought out alongside recommendations for training for those in the legal professions on good practice. The fact remains that those most at risk of abuse, neglect or exploitation, remain the least likely to access advice or representation and this is particularly true for those with cognitive impairments. Without such concerns being adequately addressed, there will be little challenge to the status quo for many with disabilities.

When disputes are taken further, it is crucially important that the voice of the person is heard in proceedings. It is vital that in framing responses, we are attentive to their actual views rather than what we perceive them to be, or indeed what we think they should be. Here, supported decision-making and the centrality of the individual is key. While a relatively simple concept, it is crucial, as such views can become overlooked in complex multidisciplinary discussions. The courts are beginning to recognise this in the mental capacity context, and it is here that we can see the impact that this can have on decision-making. In KK v STCC for example, Baker J was faced with the issue of KK’s capacity and best interests in relation to residence. Attention was drawn to KK’s over-use of the emergency lifeline service, and the impact that

139 P Swift and others, What Happens When People with Disabilities Need Advice about the Law? (University of Bristol: Norah Fry Research Centre 2013).
141 See above, n 126.
142 H Brown, Safeguarding Adults and Children with Disabilities Against Abuse (Council of Europe, Strasbourg 2003).
143 See J Tronto, Moral Boundaries: A Political Argument for an Ethic of Care (Routledge, New York 1993) for an outline of central principles to a political ethic of care.
144 (2012) EWHC 2136 (COP).
this has had on professionals’ assessment of her capacity to make a decision about where to live. He clearly noted the obligation on the local authority to assist KK in this matter, stating that:

To my mind, however, the local authority has not demonstrated that it has fully considered ways in which this issue could be addressed, for example by written notes or reminders, or even by employing night sitters in the initial stage of a return home . . . Ultimately, however, I am not persuaded that calling an emergency service because one feels the need to speak to someone in the middle of the night, without fully understanding that one has that need or the full implications of making the call, is indicative of a lack of capacity to decide where one lives.145

While in many cases, much more will need to be done than simply posting notes and reminders around a person’s house, the dicta here demonstrate at least some piece-meal recognition of the need to emphasise support and to be attentive to ways in which capacity can be facilitated for the individual by changes to the social and relational environment. There is at least implicit recognition in this case of the way that institutional relations between KK and the various professionals could be structured differently in order to facilitate her capacity and decision-making.

Of further importance in this case is that the experts’ view of KK’s capacity was overturned as a stronger focus was had on KK as an individual and the steps that could be taken to facilitate her in living at home.146 The presence of the person can thus be crucial in offsetting a narrow medicalised approach to their capacity, but also for making them feel connected to the proceedings.147 It is envisaged that if this trend continues, a much more holistic assessment of capacity and best interests will permeate the jurisprudence in line with the UNCRPD.

However, both the capabilities approach and the UNCRPD emphasise the non-coercive nature of supports and the importance of the choice to refuse to engage with these.148 At the same time as emphasising supports to facilitate autonomy then, it is imperative not to lose sight of the individual and their subjective experience in this process. It is all too easy to replace the medical model with a social model which then enables interventions which may ignore the wishes of the individual, on the basis that societal or cultural relations or attitudes have shaped that individual’s refusal. Looking at the case of Re WMA149 we see judicial recognition of wider relational factors

145 ibid, para 71.
146 Similarly in Re SB [2013] EWHC 1417 (COP) we see that the involvement of P in proceedings can result in professional views being challenged (see para 63).
147 Re M [2013] EWHC 3456 (COP) para 42, per Jackson J.
148 See for example Bartlett and Sandland, above, n 18, 169, who note in relation to reasonable accommodation that it ‘does not follow that people with disabilities can be required to use the services provided by way of reasonable accommodation’. See also Sen, above n 112, 238, who notes that, in relation to the capabilities approach ‘. . . claims of individuals on society may be best seen in terms of freedom to achieve (given by the set of real opportunities) rather than actual achievements . . . If a person has the opportunity for socially supported healthcare but still decides, with full knowledge, not to make use of that opportunity, then it could be argued it is not as much of a burning social concern as would be the failure to provide the person with the opportunity to healthcare’.
149 [2013] EWHC 2580 (COP).
impacting upon a person’s capabilities. This case involved a 25-year-old man with atypical autism and a pervasive development disorder. He had lived at home with his mother; however, there was a history of local authority and police involvement due to concerns about WMA’s care at home. In this judgment, there is consistent reference to the way in which MA (WMA’s mother) had hindered WMA’s development. The professionals and the judge in this case were in agreement that WMA’s abilities were limited not by his impairment, but by his mother. The evidence of the care manager neatly encapsulates this attitude:

She felt that WMA needed to be moved, to be “encouraged to push the boundaries” in B [the care home]. He would be “empowered”, she thought.

Ostensibly, the case illustrates recognition of a wider, relational impact on the experience of cognitive impairment and an appetite for removing such obstacles in order to enable ‘a more fulfilling life’. However, at a deeper level, questions can be raised about the lack of engagement with WMA’s own clearly expressed wishes. We see his views briefly noted but equally briefly dismissed in the case:

WMA unequivocally told me he wanted to be “permanently” with his mother. The work done by Delos, he said, was too much and he thought three hours of support four days a week was just not acceptable. He wanted one hour two days a week. Delos did not leave the home when he asked them to go. They would not listen to him. He wanted proper appointments and did not want extra people turning up on visits. As to spending his time, he liked to watch DVDs and watch the TV. He likes to take his dog, Joe, for a walk in the park. He does not like mixing with people. “That’s my choice,” he said. But, of course, he really has not experienced a life that is other than isolated hitherto.

The legitimacy of WMA’s views here were questioned because of the focus on the external constraints on his development, and so the social model and capabilities approaches here seem to clash. In incorporating social model and capabilities understandings here, the judiciary will be faced with the task of grappling with issues of a complex interdisciplinary nature which may be beyond their expertise. Disentangling these issues in individual cases, against a backdrop of theorising of disability which can seem to be pulling in different directions, is a task which currently is beyond the judiciary. Indeed, such factors undoubtedly need to be addressed at a macro level and encompass broader questions of service provision and policy goals. Yet while it is difficult for judges to get to the root causes of injustice in this sense in individual cases, it is crucially important that they seek to question assumptions about the effects of particular impairments, and the impact of this on capacity, as well as scrutinising the supports made available to facilitate their capabilities.

150 Para 15.
151 Para 88.
152 Para 67.
153 Para 45. See also para 47.
However, legal practices or accepted rules of law can ‘stultify or nullify’ any anticipated gains in terms of substantive equality here.\textsuperscript{154} As we saw above, the concept of reasonable accommodation may provide an inroad into capturing the concerns of social model and capabilities theorists legally. Yet, much of the success of this depends on the readiness of the judiciary to apply the concept in a robust way and to closely scrutinise the obligations of the state and others in this regard. The UNCRPD obliges reasonable accommodation via ‘necessary and reasonable adjustments not imposing a disproportionate or undue burden’,\textsuperscript{155} but if judicial unwillingness to closely scrutinise resource-led decisions continues then the substantive justice envisaged here will not be achieved at a domestic level. As Kayess and French point out, given the potential downward pressure on the extent of the obligation, the anticipated gains of the concept of reasonable accommodation may fall victim to the problems we have seen with traditional, procedural rights approaches.\textsuperscript{156}

A similar problem with the traditional legal framework being applied in individual cases in the mental capacity context is the concept of best interests.\textsuperscript{157} There is a sense, at a general level, that best interests decision-making—and in particular the emphasis on objective assessments of best interests—can stifle the overall empowering aims of the UNCRPD, by enforcing choices upon people rather than enabling their autonomy. Further, the Select Committee Report highlighted the way in which best interests decisions are often driven by clinical judgements and resource-led considerations.\textsuperscript{158} This is an area in which the judiciary need to challenge medicalised or individualistic assumptions underlying best interests assessments and the options presented by care providers in light of these. There needs to be a shift away from framing options in line with the aims of the medical model and focusing on the opportunity to provide ‘more than medical or physical rehabilitation directed at individuals’.\textsuperscript{159} However, scope for doing so may be limited. Cases such as Aintree v James\textsuperscript{160} and ACCG v MN\textsuperscript{161} have firmly stated the principle that the Mental Capacity Act 2005 is only concerned with ‘enabling the court to do for the patient what he could do for himself if of full capacity, but it goes no further’.\textsuperscript{162} Thus, there is no scope for demanding particular treatments or services, as this is not a right afforded generally in health and social care.\textsuperscript{163} King J outlined how, if the court were allowed to consider where MN’s best interests lay first, before deciding the issue of funding options, this would entail the Court of Protection potentially ‘using a best interests


\textsuperscript{155} Art 2 (emphasis added).

\textsuperscript{156} Kayess and French, above, n 132, 9.

\textsuperscript{157} See Bartlett (2012), above n 13 and also Bartlett and Sandland, above n 18, 199, for further discussion of the extent to which best interests decision-making is, or can be, compliant with the UNCRPD.

\textsuperscript{158} Above, n 32. See also paras 90–91.


\textsuperscript{160} [2013] UKSC 67.

\textsuperscript{161} [2013] EWHC 3859 (COP).

\textsuperscript{162} ibid, para 52 per King J.

\textsuperscript{163} R (Burke) v General Medical Council [2005] EWCA Civ 1003.
decision as a means of putting pressure upon the ACCG to allocate their resources in a particular way.\textsuperscript{164} It is through judicial review that challenges to the irrational or unreasonable allocation of resources ought to be challenged, not through best interests decisions. However, it is questionable whether this approach furthers the goals of the social model or capabilities insights argued for here, as discriminatory practices or attitudes—demonstrated in the options available in a person’s best interests—may be allowed to continue unchallenged. King J did note that there may be exceptional cases in which a court may choose to hear a best interests argument showing that a provider, in failing to agree to fund a particular package of care, has breached or may breach the human rights of the individual.\textsuperscript{165} Quite when these exceptional cases will arise is as yet unclear, but, if the courts are ready to engage with such arguments, it is necessary that this is undertaken in a way which is attentive to the social context of the claim, and which will move beyond the procedural face of rights claims in responding to this.

It might be suggested that if indeed the Court of Protection were to begin to press these human rights issues further and consider public law questions in best interests decisions, this would put people with mental impairments in a more advantageous position than those without such disabilities. It is clear from cases such as Burke that a patient cannot demand a particular treatment or service and that the courts are not willing to order this on their behalf.\textsuperscript{166} Yet this is precisely what is entailed by a focus on the societal and institutional barriers to the achievement of rights in a positive manner and the cognisance of the social basis for central human capabilities if they are to actually achieve social justice.\textsuperscript{167} This may require different approaches to the achievement of a similar goal, depending on background conditions and context pertaining to different people. Sen employs the simple example of a wheelchair-user to illustrate this, outlining how such a person will require more resources than a person with ‘normal’ mobility if the two are to attain a similar level of ability to get around.\textsuperscript{168} Thus, recognition needs to be had of the barriers facing the individual—particularly the lack of meaningful choices and options available to facilitate certain rights and freedoms—and the judiciary in given cases are in a position to recognise and respond to this.

Moreover, the capabilities approach is not limited to focusing on group rights, or the rights of people with disabilities. This calls into question the dichotomy created by arguments positing the rights of persons with disabilities as in competition with the rights of people without disabilities. Moreover, it calls into question at a general level the reluctance of the judiciary to probe further substantive questions of rights and justice when there are potential resource issues at stake. The capabilities approach can thus reinvigorate claims for substantive equality in all cases, not exclusively those involving people with disabilities. This is precisely the shift in approach that Quinn was referring to in his assertion that the UNCRPD is not simply a Convention concerned with the rights of persons with disabilities, but instead represents a shift in theoretical debates about justice on a broader level. He sees the Convention as ‘the latest

\begin{itemize}
\item \textsuperscript{164} ibid.
\item \textsuperscript{165} Para 73.
\item \textsuperscript{166} Above, n 152.
\item \textsuperscript{168} Sen, above, n 103.
\end{itemize}
iteration of a long extended essay at the international level about a theory of justice—a theory that is applied to disability to be sure, but one that is woven from a much deeper cloth and has universal reach. It is clear then that a significant obstacle to be overcome in achieving the paradigm shift envisaged by the UNCRPD is the level of judicial appetite to challenge accepted wisdom in this area. To embed the transformatory ideas into decisions affecting people with cognitive disabilities, we need the judiciary to ensure that they are eschewing the traditional narrow focus which we have seen in mental health and capacity law. The trend of focusing attention on definitional or technical considerations in contentious areas is not unique to the mental health context. In the community care context, we see a long held dissatisfaction with the judicial method of attending to more technical procedural aspects of decisions, and avoiding broader notions of substantive justice. The majority judgements in the case of McDonald are testament to this tradition of confining the scope of analysis when tricky issues of social justice are engaged. This is the very thing that the UNCRPD seeks to address through its conception of substantive equality and justice. Without a shift in the judicial approaches in this regard, it is difficult to see how the aims of the UNCRPD can be actualised in individual cases. The successful and meaningful implementation of the Convention requires close scrutiny and the challenging of assumptions and narrow understandings regarding disabilities. These will continue to dominate unless there is a sustained effort to move beyond these at a judicial level. While the ability of the judiciary in individual cases to address issues of deeply ingrained inequalities may be rather limited, and the vessel for such macro considerations ought to be the state, it is clear that a more sustained and responsive approach to substantive questions of equality and rights is required here to uncover and illuminate these, rather than allow them to continue and become more ingrained.

There are undoubtedly public law concerns to be raised when calls are made for more judicial intervention in such decisions. This is particularly the case when resources are at stake such as in community care funding assessments, and—in less visibly—in the DoLS context. In the current climate of cuts to public services and an austerity agenda, this is all the more salient. Syrett has argued that judges lack the democratic legitimacy to determine who should receive resources and that, instead, the utility of

170 O’Cinneide, above, n 102, J Herring, Caring and the Law (Hart, Oxford 2013).
172 See Carr, ibid.
173 Palmer, above, n 92.
174 This was noted in P & Q v Surrey County Council [2011] EWCA Civ 190, where Wilson J pointed to the vast, unquantifiable number of cases that would be before the courts if an appeal were to be allowed (para 4). However, he goes on to state that this resource implication is an irrelevant factor. Similarly, Ruck-Keene argues that we should not allow the tail of resources to wag the dog of statutory interpretation when it comes to DoLS. A Ruck-Keene, Tying Ourselves into (Gordian) Knots? Deprivation of Liberty and the MCA 2005 (2012) available at <http://www.39essex.com/docs/articles/ark_deprivation_of_liberty_paper_december_2012.pdf> 42.
their role lies in open and transparent reasoning to enable political debate. However, like Herring, I argue that in this context, where there is a lack of sustained political attention or challenge combined with a lack of political voice for many with mental impairments, the judiciary play a vital role in providing recourse.\textsuperscript{176} If judges do not engage with such issues, then there is no real and effective route for remedial action. Furthermore, as O’Cinneide has argued, ‘it is one thing to be wary about extending the reach of legal controls to cover the whole terrain of resource allocation; it is another thing to insulate public authorities from any form of legal accountability for how they address issues of social justice’.\textsuperscript{177} This is particularly important in the context of the UNCRPD as this is an area which, through ratification, the state has indicated support for a broader concept of justice. Without this permeating judicial discourse, the UNCRPD will simply be another re-statement of rights, which history has shown have done little to affect the actual lived experience of people with mental disabilities.

**IX. CONCLUSION**

Much progress has been made at a theoretical level to offset the predominance of the medical model in discourse surrounding mental impairment and disorder. The extent to which this has trickled down into mental health and capacity jurisprudence has currently been rather limited, and progress has been piecemeal and isolated to particular cases. The UNCRPD has been much lauded, and serves as a vital vehicle for more textured relational understandings of mental disorder to take hold in the legal and policy arena. The Convention moves beyond the ‘artificial boundaries of the health care context’\textsuperscript{178} and turns much needed attention to the wider socio-political aspects impacting upon the lived experience of mental illness. However, for this ‘paradigm shift’ to take root and impact upon the lives of those with disabilities, more needs to be done than simply paying lip-service to the transformative potential of the Convention. We saw in the Supreme Court in *Cheshire West* welcome recognition of the universal nature of human rights, and the obligations stemming from reasonable accommodation in this context. Rights discourse is but one aspect of progress here, and ‘cannot be the total sum of any strategy of empowerment’.\textsuperscript{179} The limitations of traditional rights discourse to translate into effective rights protection have been well-documented, and while the UNCRPD serves as a timely reminder that positive and negative rights are tightly intertwined and interdependent, it is imperative that this translates into legal and policy understandings. Without such understandings taking hold in day-to-day decisions affecting people with disabilities, or providing an impetus to provide meaningful access to justice to question such decisions, the gains envisaged by the UNCRPD will not materialise. At the same time, questions about the costs of such gains in an economic climate that has seen cuts to public services impact heavily upon those with disabilities\textsuperscript{180} need to be debated and brought to the fore.

\textsuperscript{176} Herring, above, n 170, 147.
\textsuperscript{177} O’Cinneide, above, n 102.
\textsuperscript{178} Secker, above, n 29, 304.
\textsuperscript{179} Bartlett and Sandland, above, n 18, 350.
We have seen that we are not yet there in achieving the anticipated shift entailed by the Convention. In the same breath that lauded the importance of universal rights, Lady Hale noted that:

It may be that those rights have sometimes to be limited or restricted because of their disabilities, but the starting point should be the same as that for everyone else.¹⁸¹

Not only is this contrary to Article 14 of the UNCRPD,¹⁸² such a statement also suggests that the paradigm shift in attitudes away from narrow, medicalised understandings of disability and cognitive impairments is not yet realised. If the judiciary do not become fluent in the language of the Convention or question the current narrow understandings residing in mental health and capacity law, recourse for those able to challenge decisions will be non-existent. As Carson has previously stated:

The law can, and should, incorporate a dynamic which keeps the pressure on all involved to minimise disability, to maximise habilitation and rehabilitation. That it may lead to unorthodox or non-traditional forms of legislation is no excuse: legislation must be a tool and a servant of social policy, not its master.¹⁸³

While strides are being made in this respect, a ‘responsive state’ is key to the success of the emerging ideas in this context. The various mechanisms within the legal system need to work together in order to ensure that meaningful recognition is given to appropriate responses which facilitate enjoyment of the rights of those with mental disabilities.

¹⁸¹ Above, n 58.
¹⁸² Art 14.1 requires State Parties to ‘ensure that persons with disabilities, on an equal basis with others, enjoy the right to liberty and security of persons . . . and the existence of a disability shall in no case justify a deprivation of liberty’.
¹⁸³ Carson, above, n 121, 309.
Articles

Vulnerability and capacity to consent to sex – asking the right questions?

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Keywords: Vulnerability – Mental Capacity Act 2005 – consent to sex – sexual autonomy – capabilities

The burgeoning body of literature seeking to conceptualise vulnerability has provoked new and interesting perspectives for legal and ethical debates. Commentators are beginning to explore the potential for vulnerability theories in various contexts and to challenge prevailing attitudes and accepted beliefs in doing so. This article seeks to add to this growing body of discourse by examining the recent legal developments in the context of capacity to consent to sexual relations. It will be suggested that, viewed through the lens of vulnerability, the current judicial approach takes a narrow, individualised stance which obscures many of the situational and relational dynamics which interact and shape the landscape of consent to sexual relations. Moreover, and perhaps more importantly, it is argued that the current legal response here does not facilitate resilience and sexual autonomy, despite judicial statements to the contrary. Through uncovering the situational and pathogenic factors which are otherwise obscured by an approach hinging on the concept of mental capacity, the vulnerability approach opens up space for debates about the appropriate legal response to foster resilience and capabilities.

INTRODUCTION

Emerging theories on vulnerability have the potential to reinvigorate legal and ethical discourse in various contexts, inviting a shift in thinking away from vulnerability as a characteristic inherent in certain individuals, towards seeing it as a universal concern which impacts on all human beings.1 As Susan Dodds puts it:

‘Attention to vulnerability . . . changes citizen’s ethical relations from those of independent actors carving out realms of rights against each other and the state,

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to those of mutually-dependent and vulnerable-exposed beings whose capacities to develop as subjects are directly and indirectly mediated by the conditions around them.\textsuperscript{2}

This renewed focus on the universal nature of vulnerability provides the basis for arguments against traditional liberal and individualistic understandings of autonomy as non-interference, and instead pays heed to the fundamental role of relational and situational dynamics in facilitating autonomy and resilience.

While the normative impact of this burgeoning area of discourse on law and policy is still being explored, commentators have begun to debate its significance in various areas of public and private law.\textsuperscript{3} This article seeks to add to this growing literature in considering the potential for vulnerability theories to elucidate the concerns at the heart of debates about capacity to consent to sexual relations. While the issue of capacity to consent to sex was previously hidden from the medico-legal arena, as it was not seen as an activity that those with disabilities were – or ought to be – engaging in,\textsuperscript{4} there has been a steadily increasing legal awareness of such intimate relationships as the judiciary, mainly through first instance decisions, has had to grapple with the thorny question of the appropriate test for capacity to consent to sexual relations. The vulnerability perspective calls into question the current state of the law in this context, which has adopted a low-threshold, act-specific approach to capacity.\textsuperscript{5} This focuses on the mechanistic aspects of sexual relations, primarily on whether the individual has a basic understanding of what is involved in sexual activity and the risks of pregnancy and sexually transmitted infections.\textsuperscript{6} In adopting such an approach, the judiciary have repeatedly asserted that they are upholding private rights and sexual autonomy,\textsuperscript{7} and that a balance is to be struck between the conflicting values of empowerment and protection for those with cognitive disabilities. In a recent significant case, the issues was framed as ‘When is it appropriate for society to intervene paternalistically in a decision or decisions that individuals make as to their sexual relations?’\textsuperscript{8}

The emerging literature on vulnerability emphasises the contextual and situational factors impacting on all individuals, in a disability-neutral sense, as well as the way in which legal, policy and societal responses can either entrench vulnerability, or foster resilience. In contrast, the capacity framework can be characterised as having a much narrower focus – primarily on the intrinsic or inherent vulnerability accompanying a disability, and a person’s inabilities, often in terms of understanding the relevant information. From this perspective a capacity approach may obscure from the legal gaze the power dynamics and situational factors which will impact on the individual. As such, responses to incapacity will be centred on the individual, rather than addressing


\textsuperscript{3} See J Wallbank and J Herring, Vulnerabilities, Care and Family Law (Routledge, 2014), and M Fineman and A Grear, Vulnerability: Reflections on a New Ethical Foundation for Law and Politics (Ashgate, 2013) for recent developments in the legal literature.


\textsuperscript{5} See X City Council v MB, NB and MAB [2006] EWHC 168 (Fam), [2006] 2 FLR 968 and Re MM Local Authority X v MM and Another [2007] EWHC 2003 (Fam), [2009] 1 FLR 443 (Re MM).


\textsuperscript{7} A Local Authority v TZ (By His Litigation Friend, the Official Solicitor) [2013] EWHC 2322 (COP), [2013] COPLR 477.

\textsuperscript{8} IM v (1) LM (By Her Litigation Friend the Official Solicitor) (2) AB (3) Liverpool City Council [2014] EWCA Civ 37, [2014] COPLR 246 (IM v LM and Others).
on a broader level what can be done to facilitate sexual autonomy. Conversely, for those deemed to be capacitous and thus capable of making an autonomous decision, these sources of vulnerability will remain uncovered as they will be seen as ‘invulnerable’. The literature on vulnerability casts a much wider gaze than the mental capacity approach, looking not at assumed inherent characteristics but instead at the interaction between multi-variant sources which impact on all individuals universally, and in doing so exposes previously ‘hidden’ vulnerabilities – such as access to supports, power dynamics and cultural and societal attitudes – which have fallen outside of traditional capacity/autonomy binaries.

It will be suggested that the pivotal role that mental capacity plays here results in an abstract and artificial understanding of the experience of sexual vulnerability, and hinders an effective response to facilitating resilience. It is contended that the current legal approach, as seen in IM v LM and Others,9 instead simply respects liberty, in terms of non-interference, rather than sexual autonomy as is claimed. If instead the state seeks to be responsive to the sources of vulnerability – as is incumbent in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) – a much more nuanced understanding is needed of what is required to secure sexual autonomy. As will be seen, the UNCRPD ushers in new ways of conceptualising and responding to disabilities – including cognitive impairments – which may call into question the very basis of the Mental Capacity Act (MCA 2005).10 As Keywood has argued, a ‘more robust conception of sexual empowerment will help us to understand that empowerment and protection are not mutually exclusive goals’.11 Insights from the vulnerability literature allow us to break the empowerment/protection dichotomy down and focus in on more nuanced understandings of, and responses to, vulnerability in a sexual sense.

RE-CONCEPTUALISING VULNERABILITY AND SEXUAL CAPACITY

There is a growing body of literature seeking to conceptualise ‘vulnerability’ and theorise the implications of this for law and social policy.12 At the forefront of this is the work of Martha Fineman who has sought to re-imagine, at a political level, what we mean by vulnerability.13 Central to Fineman’s thesis is the notion of ‘universal vulnerability’, advancing the idea that all human beings, by the very nature of being social beings, are vulnerable. This is in stark contrast to notions of vulnerability which have traditionally pervaded discourse, being based on subpopulations being vulnerable, and positing those standing outside of these ‘constructed vulnerability populations’ as invulnerable.14 Such an understanding has been embedded in adult safeguarding policy, and provided the basis for potentially disempowering interference

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9 Ibid.
in the lives of those falling within the definitional remit. For example, the No Secrets guidance on adult protection provided a definition of a vulnerable adult as:

‘A person aged 18 or over who is or who may be in need of community care services by reason of a mental or other disability, age or illness; and who is or who may be unable to protect himself or herself against significant harm or exploitation.’15

Similarly, in Setting the Boundaries, a report on the reform of sexual offences, we see a focus on the individual characteristics of the disability as constitutive of their ‘vulnerability’: ‘Mentally impaired people are a particularly vulnerable group – they are obedient and suggestible, and once adult they may well have sexual feelings and not be able to resist inappropriate behaviour’.16

This starkly locates the source of the vulnerability as inherent to the individual and as causally connected with their disability, age or ill health.17 Instead, a much broader conceptualisation of vulnerability, divorced from ideas about a particular status, allows for more attentiveness to the multi-variant sources of this vulnerability. In essence, this is a more outward-looking understanding which seeks to identify sources of vulnerability which have otherwise been hidden in legal, social and cultural practices,18 and to directly challenge the idea that vulnerability is inherent to certain individuals within a demarcated subpopulation. As social and relational beings, we are all vulnerable to natural disasters, ill-health, loss, economic hardship, and constraints on social institutions such as welfare, healthcare and education.

In many ways, this theoretical starting point echoes the work of some care ethicists19 and those writing on relational autonomy, as it highlights the networks of interdependence that permeate society and the importance at a policy level of being attentive to and responding to these.20 At the heart of this is the argument that the traditional liberal individualistic conception, which is central to many of our policies and laws, misrepresents the relational nature of human beings and hides much of the messy reality of relationships, dependency and vulnerability.21 While an understanding of universal vulnerability may seem to gloss over the individual embodied experience of vulnerability, theorists emphasise that the particular experience of vulnerability must be understood at the individual level.22 It is important to focus on the particular experience of vulnerability here, as a theory premised solely on the universal nature of vulnerability runs the risk of down-playing the experience of it and negating its conceptual and normative importance. Fineman refers to this as ‘embodied difference’,

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15 Department of Health, No Secrets (TSO, 2000), at para 2.3.
16 Home Office, Setting the Boundaries: reforming the law on sexual offences (TSO, 2000), at para 4.1.2.
stressing that the ‘experience of vulnerability varies according to the quality and quantity of resources we possess or can command’.23 An inherent condition may seem to place an individual at risk of harm or exploitation; however they may not subjectively experience themselves as vulnerable, perhaps due to access to material and social supports promoting resilience.24 Thus the vulnerability thesis draws attention to the experience of vulnerability, rather than the presence of a particular condition and in this way can conceptually ‘bridge the gap between the legal subject as currently conceived of and real human beings’.25

Other theorists have built upon Fineman’s work to elucidate more clearly the multi-variant sources of vulnerability. Mackenzie, Rogers and Dodds propose three broad – but not necessarily distinct – categorisations of sources of vulnerability; inherent; situational and pathogenic.26 Inherent sources are characterised as intrinsic to the human condition and inevitable need and dependence, although this can vary depending on age, gender, disability and health status,27 while situational refers to context specific sources, which may be caused or exacerbated by the personal, social, political, economic and environmental situation.28 Notably, their category of ‘pathogenic vulnerability’ refers to the way in which abusive interpersonal or social relationships, and socio-political oppression or injustice can generate vulnerability.29 Moreover, they note that ‘pathogenic vulnerabilities may also arise when a response intended to ameliorate vulnerability has the paradoxical effect of exacerbating existing vulnerabilities or generating new ones’.30 This is particularly salient as it invites a deeper analysis of the impact of laws and policies – their ability to achieve their stated aims and, more importantly, to foster resilience in those rendered vulnerable – which is a point which will be turned to now in evaluating the legal responses in the context of sexual capacity.

Until recently, the question of mental capacity to consent to sexual relationships was grappled with in the lower courts, and there was a lack of authoritative guidance from appellate level. Similarly, the criminal law has struggled to define a workable test in relation to capacity for the purposes of section 30 of the Sexual Offences Act 2003. However, with the Court of Appeal judgment in IM v LM and Others31 we have a clear statement of the assessment to be undertaken in considering whether an individual has the mental capacity to consent to sex. This was accompanied by a resounding endorsement of pragmatism in this context, and the importance of the right to engage in sexual relationships. The development of the law in this area provides a backdrop to

23 Ibid.
27 C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’, in C Mackenzie, W Rogers and S Dodds, ibid, at p 38.
28 Ibid, at p 7.
30 Ibid.
31 IM v (1) LM (By Her Litigation Friend the Official Solicitor) (2) AB (3) Liverpool City Council [2014] EWCA Civ 37, [2014] COPLR 246.
explore whether in fact sexual rights and autonomy are being prioritised by the capacity framework, and what a vulnerability analysis can contribute.

The struggle in the courts can best be viewed as one between an act-specific approach to capacity, and a person – or situation – specific approach. The roots of the judicial approach in the civil law lie in Re E (An Alleged Patient); Sheffield City Council v E and S\(^{32}\) which was primarily concerned with capacity for marriage. The case involved a 37-year-old woman with physical and intellectual disabilities who had moved in with, and was intending to marry, a man with a significant record for crimes of sexual violence. Munby J outlined how a contract of marriage was a simple one, and that accordingly the test for capacity to enter into this contract has a low threshold. In particular, the test was to be focused on the particular nature of the act, and not on the person with whom the contract of marriage was to be entered into. This was followed subsequently in X City Council v MB, NB and MAB (By His Litigation Friend the Official Solicitor)\(^{33}\) and Re MM\(^{34}\), where Munby J again asserted that in relation to sex, the level of understanding required ‘need not be complete or sophisticated’ and that ‘rudimentary knowledge of what the act comprises and its sexual character’\(^{35}\) is sufficient. He saw the issue of capacity as either/or, noting that ‘it is difficult to see how it can sensibly be said that she had capacity to consent to a particular sexual act with Y whilst at the same time lacking capacity to consent to precisely the same act with Z’.\(^{36}\)

This provides a valuable lens through which to scrutinise certain assumptions about the sexual vulnerability of people with cognitive impairments, and in doing so it will be argued that it is perhaps not quite so difficult to see how this could be the case once attention is paid to the situational aspects of the decision elucidated by a focus on sexual vulnerability. This has been a relatively under-explored area, despite increased debates around the social model of disability and growing appreciation of the situated nature of autonomy.\(^{37}\) We saw above the way in which information and understanding of basic information are central to the act-specific capacity approach. However, the empirical literature is rich with examples of the way in which this lack of information provided to people with disabilities can in turn render them more vulnerable to sexual abuse. A study by Hollomotz revealed that a participant, Tyler, had been sexually violated by a fellow pupil at his school, but that as he did not understand that sex between men was possible, he did not immediately identify this as abuse.\(^{38}\) This in effect meant that Tyler was in a vulnerable position, not due to his learning disability, but in a large part due to his inability to adequately recognise what happened as sexual abuse because of a lack of knowledge and information about this. This is a recurring theme in the mental capacity cases\(^{39}\) – not necessarily because of an inability in their mental functioning, but because the information simply has not been provided, or has not been communicated in an appropriate way. It is well-documented

\(^{32}\) [2004] EWHC 2808 (Fam), [2005] 2 WLR 953.

\(^{33}\) X City Council v MB, NB and MAB (By His Litigation Friend the Official Solicitor) [2006] EWHC 168 (Fam), [2006] 2 FLR 968.

\(^{34}\) Re MM Local Authority X v MM and Another [2007] EWHC 2003 (Fam), [2009] 1 FLR 443.

\(^{35}\) Ibid, at para [74].

\(^{36}\) Ibid, at para [87].


that people with intellectual disabilities are reliant on care-givers and support workers for sex education, and that attitudes of such gatekeepers can be a barrier to information and proactive support. Furthermore, it is widely acknowledged that for many people, most sex education is gained through informal channels such as discussions with peers, as well as experience and experimentation in intimate relationships. However, many people with intellectual disabilities have fewer friends and spend a large proportion of time with adults under supervision, and so are not exposed to this. Such examples directly challenge the charge that sexual vulnerability is inherent to people with disabilities and thus renders them in need of protection. We see how social and situational factors can impede knowledge and understanding about sex and abuse. If information is withheld in the name of protection, a pathogenic source of vulnerability is in fact created, as a response intended to ameliorate vulnerability had a paradoxical effect of increasing it.

**SITUATING VULNERABILITY**

Aside from informational aspects, the situational factors may have a further impact on the sexual autonomy of people with cognitive impairments. Power and relational dynamics do not just stem from individual interaction, and structural phenomena can shape choices and opportunities. In a residential care setting, for example, rights to sexual expression and choices in this regard are often curtailed. Owen and Griffiths outline how opportunities for healthy sexuality are often lacking and are routinely restricted as people are denied privacy or choice about sexual expression, due in large part to accommodation arrangements. This in turn can create pathogenic vulnerability as a result of the lack of safe and private spaces to explore sexual relationships – both in residential and group settings – often people need to resort to rushed activity in isolated public spaces or semi-isolated private spaces, which provides little real opportunity to consider personal boundaries. This can lead to a high risk of abuse, pregnancies and sexually transmitted infections. In relation to aged and dementia care facilities, similar findings are prevalent, and the lack of lockable doors or private spaces and also staff attitudes are highlighted as standing in the way of safe opportunities for sexual expression. In Hollomotz’s study, a participant named Rachel, living in a residential group setting, has access to her own vibrator. However, she needs to give this back to staff to lock in a cupboard each

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41 A Jahoda and J Pownall, ‘Sexual understanding, sources of information and social networks; the reports of young people with intellectual disabilities and their non-disabled peers’ (2014) 58(5) *Journal of Intellectual Disability Research* 430.


46 L Tarzia, D Fetherstonhaugh and M Bauer, ‘Dementia, sexuality and consent in residential aged care facilities’ (2012) 38 *Journal of Medical Ethics* 609.
morning and has to request it to be signed out whenever she wants it. This means that staff are inevitably aware of her sexual life, diminishing her control over private matters, with little clear justification. Further examples of situational constraints on sexual autonomy and control are found in the CHANGE Report on the views of young people with learning disabilities, which highlighted how many young people want to be in relationships but don't have the opportunity to develop these. This lack of opportunity to embark upon or develop intimate relationships demonstrates an aspect of the situational impact upon sexual vulnerability. Linked to this is the concern that the lack of opportunity to effect any real choice and control over more mundane daily choices, such as how to spend the day and who with, will impact upon the assertiveness of the individual when it comes to intimate relationships.

Thompson points to a 'learned helplessness' which is manifested when individuals have to 'fit' into existing services. Here, attention is drawn to the way in which individuals may be too afraid to challenge their violator; may feel helpless and powerless; or may not think that they have a choice about participation in sexual activity. Without the opportunity to experience intimate relationships, and to exercise choice and control in these (and in other aspects of life), sexual autonomy is impeded. Similarly, the power dynamics within a relationship can impede upon the individual's ability to express their choice, making it entirely conceivable that consent to a sexual act can be given to Y but not to the same sexual act with Z. This undoubtedly leaves the individual at risk of having their will over-borne in a way that the capacity framework seems not to be cognisant of, and which directly challenges Munby J's statement above.

Such criticisms were touched upon to a certain extent in the criminal law context in the case of R v Cooper. This case involved a 28-year-old woman with a diagnosis of schizoaffective disorder, an emotionally unstable personality disorder, and an IQ of less than 75. She had a history of admissions under the Mental Health Act 1983, and had recently been discharged from hospital to a hostel. There was evidence that she was struggling to cope, and on the day of the incident she had been seen by a consultant psychiatrist who recommended her compulsory admission to hospital. Later that day she met the defendant and told him she wanted to leave Croydon as people were after her. The defendant offered to help her so she went with him to his friend's house. In this time, he sold her mobile phone and bicycle and gave her crack. When she went to the bathroom, the defendant followed her and asked her for a 'blow job'.

52 Mencap, Behind Closed Doors (Mencap, 2001).
53 M McCarthy, Sexuality and Women with Learning Disabilities (Kingsley, 1999).
54 Centre for Disability Law and Policy NUI Galway, 'Submission on legal capacity – The Oireachtas Committee on Justice, Defence and Equality' available at http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality_.pdf (last accessed 1 July 2014), at p 7 – 'development of capacity requires experience of living independently and being included in the community and forming relationships'.
She stated in her evidence that she was very afraid and panicky and wanted to leave, but as she did not want to die she stayed and was subjected to a number of sexual acts by the defendant and his friend. She was later found by the police wandering the streets in great distress.

The case was brought under section 30 of the Sexual Offences Act 2003. Unlike the non-consensual sexual offences, the focus of section 30 is on proving that the complainant was unable to refuse the sexual activity because of or for a reason related to the mental disorder;\(^56\) that the defendant knew or could reasonably be expected to know that the complainant had a mental disorder, and that because of it, or for reasons related to it, was likely to be unable to refuse.\(^57\) With regard to the inability to refuse, this centres on the lack of capacity to choose, or being unable to communicate such a choice.\(^58\) At first instance, the defendant was convicted, but this was set aside on appeal. The Court of Appeal relied heavily on the dicta of Munby J in the civil cases outlined above, noting that an ‘irrational fear that prevents the exercise of choice cannot be equated with lack of capacity to choose. We agree with Munby J’s conclusion that a lack of capacity to choose to agree to sexual activity cannot be “person specific” or, we would add, “situation specific”’.\(^59\) On appeal, a unanimous House of Lords overturned the Court of Appeal decision. Baroness Hale delivered the leading judgment, which advocates a situation specific appraisal of capacity in relation to sex. She highlighted how the case-law on capacity has:

‘for some time recognised that, to be able to make a decision, the person concerned must not only be able to understand the information relevant to making it, but also be able to “weigh that information in the balance to arrive at a choice”.’\(^60\)

This put a renewed focus on the ability to use and weigh the information given, given the situation that the individual is in. In this regard, Baroness Hale noted that the approach encompasses a wide range of circumstances in which the mental disorder may rob them of the ability to make an autonomous choice, despite having sufficient understanding of the information relevant to making it.\(^61\) This is a significant step away from viewing the question of capacity as a matter of setting the level of information required. In a resounding dismissal of a narrow, act-specific approach, Baroness Hale stated that:

‘It is difficult to think of an activity which is more person and situation specific than sexual relations. One does not consent to sex in general. One consents to this act of sex with this person at this time and in this place. Autonomy entails the freedom and the capacity to make a choice of whether or not to do so.’\(^62\)

This signals a clear endorsement of a situational analysis noting the power dynamics which can impede choice and consent. Attention is here paid to the ‘vulnerable,
terrifying position\textsuperscript{63} in which the complainant was in, noting the impact that this must have had on her ability to exercise a choice. Viewed from the vulnerability perspective, this offers a much richer appraisal of capacity and the reality of consent. Yet it is still problematic in that section 30 relies on proving that the mental disorder, rather than external factors, was the cause of vulnerability. As Saunders has put it:

‘attributing the complainant’s non-communication to her mental disorder, rather than to the defendant’s behaviour, is questionable to say the least. This complainant was not momentarily mad to consent or communicate. Rather she was repeatedly raped.’\textsuperscript{64}

There may be pragmatic issues of evidence here which prevent or discourage prosecutors from relying on non-consensual offences in these circumstances, yet it is lamentable that proceeding under section 30 involves a primary focus on the effects of the complainant’s mental disorder.

Following \textit{R v Cooper}, there was a lack of clarity about whether the situation specific approach taken by Baroness Hale would be followed in the civil cases. However, it is clear in the subsequent cases that it would not be, and that the low threshold, ‘act-specific’ approach would be retained.\textsuperscript{65} These cases, however, are all first instance decisions, and there was a need for an authoritative appellate level statement on the correct legal approach. This opportunity came in \textit{IM v LM and Others}.\textsuperscript{66} The case concerned a 41-year-old woman, LM, who had a history of drug and alcohol abuse and convictions for prostitution. She had three children already from a former abusive partner, and these were raised either by her mother, IM, or her sibling. While in hospital in 2010 for surgery related to liver disease, she suffered a cardiac arrest which led to hypoxic brain injury. As a result, she suffered significant distressing memory loss and amnesia. Questions arose as to LM’s capacity in relation to contact with her current partner AB, who had been barred from visiting her in hospital for ‘inappropriate behaviour’, and who also had a significant criminal record. During the course of discussions in relation to this, the issue arose as to her capacity to consent to sex with AB after LM suggested that she would like to re-establish a sexual relationship with him.

In the eagerly anticipated Court of Appeal decision, Sir Brian Leveson pointed to Munby J’s statement that there is a distinction to be drawn between ‘complex decisions such as medical treatment’ and ‘marriage or sex decisions’ and that while a refined analysis of the ability to use and weigh the information may be necessary in complex decisions, this is not the case in simple decisions.\textsuperscript{67} He went on to state that ‘I do not say that these analyses are irrelevant; they are not. I merely say that in this particular context it is unlikely to be either necessary or even particularly helpful to refer to them’.\textsuperscript{68} Sir Brian Leveson here sought to suggest that the extent of the judicial investigation is what is key and confirmed that in cases about sex and marriage a low

\textsuperscript{63} Ibid, at para [26].


\textsuperscript{66} \textit{IM v (1) LM (By Her Litigation Friend the Official Solicitor) (2) AB (3) Liverpool City Council} [2014] EWCA Civ 37, [2014] COPLR 246.

\textsuperscript{67} \textit{Re E (An Alleged Patient); Sheffield City Council v E and S} [2004] EWHC 2808 (Fam), [2005] 2 WLR 953, at para [196].

\textsuperscript{68} Ibid.
threshold is to be set. Moreover, the situation specific approach which Baroness Hale endorsed in Cooper was distinguished by Sir Brian Leveson, noting that:

‘the fact that a person either does or does not consent to sexual activity with a particular person at a fixed point in time, or does or does not have capacity to give such consent, does not mean that it is impossible, or legally impermissible, for a court assessing capacity to make a general evaluation which is not tied down to a particular partner, time and place.’

The notion of person-specificity, as the situation-specific test is sometimes presented as, has been dismissed by judges as conflating capacity with best interests, and in effect amounting to social-engineering through vetting particular partners. Furthermore, as Mostyn J noted in D Borough Council v AB, a person-specific test would conflate ‘capacity to consent to sex with the exercise of this capacity’.

However, the situation specific approach advanced by Baroness Hale does not necessitate an evaluative focus on the suitability of a partner, or social engineering in the way feared. Baroness Hale is drawing attention to the situational factors which can impact upon a decision, echoing many of the concerns of vulnerability theorists. The particular characteristics or identity of the partner is not the issue – it is whether the individual can make a choice if another individual in the particular circumstances, or the situation itself, is overbearing this. Here, the concern is about the ability to freely exercise a choice, regardless of how high or low the level of information required is pitched at.

Embedded in the judgments above are allusions to pragmatic concerns and the limitations of the MCA 2005 as a mechanism in these cases. As is well-established, the MCA 2005 takes a functional approach, focusing on the particular decision to be made and assessing capacity in relation to this, ‘a person is not capable or incapable in an abstract or general way’. Yet, what is clear from these sexual capacity cases is that the judges are keen to assess capacity in relation to sex in a more global manner. As Sir Brian Leveson pointed out in IM v LM and Others:

‘It would be totally unworkable for a local authority or the Court of Protection to conduct an assessment every time an individual over whom there was doubt about his or her capacity to consent to sexual relations showed signs of immediate interest in experiencing a sexual encounter with another person …’

As such, it is seemingly impossible to apply this functional, decision specific approach which is entailed in the statute.

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69 IM v (1) LM (By Her Litigation Friend the Official Solicitor) (2) AB (3) Liverpool City Council [2014] EWCA Civ 37, [2014] COPLR 246, at para [76].
73 IM v (1) LM (By Her Litigation Friend the Official Solicitor) (2) AB (3) Liverpool City Council [2014] EWCA Civ 37, [2014] COPLR 246, at para [77].
74 See J Herring and J Wall, ‘Capacity to consent to sex’ (2014) Medical Law Review (online June 2014), for a more in depth legal critique of IM v LM and Others.
THE RESPONSIVE STATE

A further concern ought to be raised about the ability of the MCA 2005 to provide an appropriate legal response here. Section 27 precludes a best interests decision from being made if the person is deemed to lack mental capacity under the Act. In effect, if a person is deemed to lack capacity to consent to sexual relations, then their freedom to engage in sexual relations will be curtailed by supervision and control to prevent it. On the other hand, if someone is deemed to have capacity, then the scope for judicial intervention ends, as the person is deemed to be capacitous and so autonomous. It is perhaps then understandable that given this all-or-nothing approach, the judges are somewhat constrained by pragmatic concerns – and the empowerment/protection binary that accompanies the dichotomy between capacity and autonomy – and a low-threshold may be seen as the optimal way to protect sexual rights. Indeed, this is clear in Baker J’s assertion in *A Local Authority v TZ (By his Litigation Friend, the Official Solicitor)* that ‘with respect to Baroness Hale, it seems to me that the approach favoured by Munby J and Mostyn J is more consistent with respect for autonomy in matters of private life’. However, this statement with regard to respecting autonomy needs to be unpacked further. It will be considered below whether this emphasis on non-interference does indeed respect autonomy in the way that is being suggested, or adequately address the issues illuminated by vulnerability theorists.

Crucially, Fineman hones in on the need for a ‘responsive state’ as a central aspect of her vulnerability thesis, contending that an understanding of the various sources of vulnerability forms the basis of a claim that the state must be responsive to these. This signals an important recognition of the role that the state and societal institutions play in the formation of sources of vulnerability, and conversely that the state is in a position to ameliorate this and instead foster resilience. Once the interplay of various sources in the creation of vulnerability is revealed, responses can be framed with the purpose of fostering resilience in the individual. As suggested by the *particular* nature of vulnerability, responses cannot be framed on a one-size-fits-all approach, and must be tailored in light of the individual experience. Akin to the idea of facilitating resilience, Mackenzie has argued that the focus of responses to mitigate vulnerability ought to be informed by an overall background aim of fostering autonomy wherever possible. Here, she reiterates that autonomy as a value should not be rejected by a vulnerability analysis, and instead what is needed is a re-conceptualisation of autonomy as relational, rather than the individualistic conception residing in liberal approaches. This understanding illuminates the way in which the development and sustained exercise of the capacity for self-determination requires ongoing interpersonal, social and institutional scaffolding which can be thwarted by social domination, oppression and disadvantage; and that the state has obligations to develop social, political and

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75 Mental Capacity Act 2005, s 27.
legal institutions that foster the autonomy of citizens.80 This attentiveness to the role of societal institutions in the development and sustainment of autonomy brings into question the idea that autonomy and rights are best protected by non-interference, and thus poses new questions about the role of the state in facilitating the enjoyment of autonomy and rights. Viewing rights in this way resonates with the capabilities approach to justice, which entails a focus on the contextual situation of justice claims and a more substantive exploration of equality and opportunities.81 In terms of rights discourse, the capabilities approach instead requires that we ask whether the right is capable of being achieved, and whether unjust background conditions or other barriers are inhibiting the actual opportunities to secure the right. As Nussbaum asserts, securing a right 'involves affirmative material and institutional support, not simply a failure to impede'.82 This enjoins those who are in a position to secure rights to citizens – such as the government and the judiciary – to consider the way in which structural relations can facilitate the enjoyment of such rights and to respond to claims on this basis.

In this regard, the UNCRPD can be seen as a turning-point in conceptualising and responding to disability. It is significant in that it marks a recognition that:

‘reliance on formal structures alone is not adequate to ensure full enactment of human rights . . . the convergence of formal and informal social forces is necessary for the roots of human rights to grow deep into social structures’.83

The preamble, for example, stresses the importance of recognising that disability results from the interaction between persons with impairments and attitudinal and environmental barriers to equality, the need to promote and protect human rights for people with disabilities, including those who require more intensive support. It reinforces and reaffirms the importance of enforceable rights and entitlements.84 More importantly, the ethos of the UNCRPD is very much about taking positive steps to enable rights to be protected.85 The UK, having ratified the UNCRPD in June 2009, is committed to taking concrete actions to comply with the Articles of the Convention, which span various aspects such as equality and discrimination, gender issues, children with disabilities, the right to life, access to justice, employment opportunities, privacy and liberty.86

Article 12 is concerned with the right to equal recognition before the law for persons with disabilities and is seen as one of the pivotal – and most controversial – articles in the UNCRPD. The UN Committee on the Rights of Persons with Disabilities (the Committee) published a General Comment on Article 12 recently in which they

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80 Ibid, at p 42. ‘It is therefore not just when our physical capacities are diminished when we need others. We are dependent on others for the social world that enables us to develop all of our core capacities’, at p 28.
83 F Owen and D Griffiths, Challenges to the Human Rights of People with Intellectual Disabilities (Jessica Kingsley, 2009), at p 35.
85 See Art 4 of the UNCRPD, General Obligations.
86 We have seen the domestic courts gradually begin to grapple with the UNCRPD in judgments, see, for example, AH v West London MHT [2011] UKUT 74 (AAC), at para [16].
affirmed its importance for those with cognitive and psychosocial disabilities and the need for states to examine holistically all areas of the law with a view to ensuring that people have opportunities to express or develop their will and preferences as well as having choice and control over their everyday lives.87 The Committee stated that Article 12 does not set out any additional rights but instead simply describes the specific elements that state parties are required to take into account to ensure equality before the law.88 However, this in itself is quite a radical step when considering the measures that the Committee foresees as necessary to ensure compliance with this. The General Comment outlines the importance of the concept of legal capacity for the exercise of civil, political, economic, social and cultural rights and also how, historically, the denial of legal capacity has led to people with disabilities being deprived of such rights through systems of guardianship and substitute decision-making.89 The Committee are keen to stress here that the conflation of legal capacity (comprised of legal standing and legal agency) with mental capacity (judgments about decision-making skills) which has been used to justify systems of substitute decision-making or guardianship are to be abolished under the UNCRPD.90 In particular, and a clear reflection of the social model underpinning the UNCRPD, the Committee stress that:

'Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.'91

Instead of relying on such an approach, the Committee stress the need to provide support to exercise legal capacity, including supported decision-making. This has provoked much debate at a domestic level about what this means in terms of the compatibility of the MCA with the UNCRPD,92 in particular, the way in which the legislative framework hinges on the concept of mental capacity, and endorses responses based on the ‘best interests’ of the individual.

The contextual understanding of sources of vulnerability, and emphasis on the obligations of the state in responding to these, is reflected in the ethos of the UNCRPD, ‘both aim at societal measures to empower individuals regardless of their own abilities’.93 Crucially, both approaches aim at augmenting capabilities, rather than particular functionings or outcomes, and so prioritise autonomy through supports, rather than substituted decisions. One of the innovative legal aspects of the UNCRPD is the shift in focus from state non-intervention and procedural rights to the need for states to address background conditions and obstacles to facilitate and enable rights for those with disabilities. This is a direct challenge to the idea that autonomy is

91 Ibid, at para 14
engendered through non-interference and recognises that background social and political contexts are central to facilitating autonomy. Indeed, many have commented on the fact that the value of the UNCRPD is not in creating new rights – many of the rights are already stated in other Conventions and human rights instruments – but instead resides in the shift in emphasis towards support and obligations.94 Quinn, for example, suggests that the UNCRPD represents ‘the latest iteration of a long extended essay at the international level about a theory of justice – a theory that is applied to disability to be sure, but one that is woven from a much deeper cloth and has universal reach’,95 and is an antidote to the ‘reductionist and essentialist picture in liberal theories of justice’.96 Viewed from this perspective, the UNCRPD and discourse flowing from it opens up the space for broader consideration of state responsibility in relation to all citizens, not just those with disabilities. An understanding of, and focus on, vulnerability directs states to develop structures to address inequality and disadvantage not on the basis of certain protected characteristics (as it common in many jurisdictions and rights documents, including the UNCRPD) but on the basis of the universal vulnerability that resides in all human beings in society. This focus on the universality of vulnerability avoids the ‘othering’ which can result from a legal approach predicated on a dichotomy between capacity and autonomy, and is reflected in some of the writing on the UNCRPD which sees this new paradigm of ‘universalism’ as uncovering the limitations of traditional approaches to equality and non-discrimination.97 As Bickenbach maintains, this is based on a concept of impairment as ‘an infinitely various but universal feature of the human condition’.98 This approach has the potential to open up more expansive ways of framing responses to vulnerability within society, being based on broad understandings of the sources of vulnerability rather than distinct categorisations of particular group membership and capacity. Might this approach guide us in understanding and responding to sexual vulnerability in a way which fosters resilience and autonomy?

Focusing on the interplay between situational factors and the embodied experience of the individual, and noting the caveat that responses can potentially aggravate vulnerability in the pathogenic sense, can help to elucidate more appropriate responses if the overall aim is to facilitate sexual autonomy. It is important not to lose sight of the disquieting high incidence of sexual abuse against people with cognitive impairments.99 However, the narrow approach to sexual vulnerability which can be seen at present, situating the source of vulnerability within the person and framing protective responses to the perceived risk are directly called into question by the insights highlighted above. Without a full understanding of the variety of sources involved, the focus of intervention becomes risk management and protection.100 As Leach Scully has noted:

95 G Quinn ‘Rethinking personhood: new questions in legal capacity law and policy’ (University of British Columbia, 2011), at p 52.
96 Ibid, at p 57.
99 Mencap, Behind Closed Doors (Mencap, 2001).
'It is true that cognitive impairments more than physical ones expose a person to the significantly different vulnerabilities of exploitation by others, lack of self-care or self-protection, and simple failure to be offered a place of security and comfort in complex societies. But it is also true that some of those vulnerabilities could be reduced by social and attitudinal change.'

As seen above, a contextual, situational analysis reveals the nature of power imbalances that permeate relationships, particularly abusive ones. A vulnerability analysis can centralise such concerns and necessitate responses to these which facilitate autonomy through various means, providing a theoretical model which accounts for power dynamics, sexual knowledge, situational concerns and the diverse levels of capacity and the ability to exercise this, not just within the population of people with cognitive impairments and mental disorders, but also as a universal concern. Account can also be taken of the way in which abilities can be diminished due to inadequate support and resources. Little has been done to address such issues in the context of mental capacity and consent and to how these intersect with sexual vulnerability and autonomy. With this in mind, the article now turns to the current legal response to capacity to consent to sexual relations in order to question whether it has the potential to secure sexual rights and autonomy.

**FACILITATING SEXUAL AUTONOMY**

The provision of information, and education about sexual relationships, is undoubtedly important and emphasis is rightly placed on it. However, focusing only on information ignores the importance of choice and control, ‘in order to successfully self-defend against sexual violence an individual must be able to utilise their self-determination skills’. Adopting a low informational threshold signals to those charged with facilitating sexual capacity that we are only concerned with providing a limited amount of information, rather than a more holistic and reflective understanding which empowers that person to exercise choice. A similar point was raised by Keywood in the context of contraceptive decision-making, who noted that while there may be good reasons for adopting a low informational threshold for capacity, we need to question whether we can isolate all of the broader dimensions of decision-making. She went on to note that ‘to exclude an appraisal of some of the broader consequences as they are perceived as being relevant to the person does not necessarily ensure respect for autonomy’. In focusing on the informational aspect, the courts are effectively asking in an abstract vacuum about a person’s ability to make a decision. Here, the commitment may be to ‘ostensible, rather than substantive protection of autonomy’.

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103 Ibid.


106 Ibid.

This may be seen as part of a wider problem with the binary nature of autonomy and capacity which is seen in medical law more generally. The assumption is that once a person is deemed to have capacity, they are capable of acting autonomously and thus their decisions ought not be interfered with.\textsuperscript{108} Tied to this liberal understanding of autonomy is the corollary idea that autonomy increases with the reduction of state interference or restrictions.\textsuperscript{109} Capacity assessments under the MCA 2005 thus may obscure from view the power dynamics and situational impacts upon a person’s autonomy, in the name of freedom from interference.\textsuperscript{110} Furthermore, this understanding of autonomy promotes a ‘questionable equation of non-intervention with respect for human rights in circumstances where individuals are disempowered relative to their abusers and by their abuse’.\textsuperscript{111} The vulnerability lens, and the UNCRPD, show that a respect for autonomy and rights does not hinge on non-interference. On the contrary, without adequate background conditions which foster resilience and choice, autonomy and capabilities are an illusion. Vulnerability requires us to ‘rethink, rather than discard, the concept of autonomy’.\textsuperscript{112} The MCA 2005, however, is not in a position to facilitate this here as it struggles to fit the reality into a workable framework.

The capacity framework also has the potential to leave people in vulnerable and abusive situations, as it only ‘protects’ those who are ‘incapable’; those deemed to be capacitous and thereby autonomous, are left outside of its remit, even if they are vulnerable.\textsuperscript{113} It does not engage with the crux of the problem. We also see in this sense the way in which the response of the MCA 2005 can leave people in a vulnerable position both when they are deemed to have capacity and when they are deemed not to. In \textit{A Local Authority v H},\textsuperscript{114} for example, we see how a focus on individual disability or impairment can ignore many of the situational factors which have affected her decision-making abilities. H was a 29-year-old woman with mild learning difficulties, atypical autism and an IQ of 64. The evidence in the case suggested an ‘early and deep degree of sexualisation’,\textsuperscript{115} and Hedley J noted that while H may have consented to such sexual encounters, these may have been exploitative or unconventional as they involved multiple sexual encounters at a time, much older men, bisexual oral and anal sex and attempted sex with a dog.\textsuperscript{116} H was deemed to lack capacity for sexual relations because she realised about sexual health but not how to protect herself; she struggled to say no and she did not fully understand the relevant issues. The response of the MCA 2005, in holding her to lack capacity, is to deprive her of her liberty and to control and manage aspects of her life to prevent

\begin{footnotesize}
\begin{enumerate}
\item M I Hall, ‘Mental capacity in the (civil) law: capacity, autonomy and vulnerability’ (2012) 58(1) McGill Law Journal 1.
\item [2012] EWHC 49 (COP), [2012] COPLR 305.
\item Ibid, at para [6].
\item Ibid, at para [9].
\end{enumerate}
\end{footnotesize}
sexual relationships from occurring. She was subject to ‘1:1 supervision at all times whether in or out of the property and not free to leave the property on any other basis’. Viewed through the lens of vulnerability and capabilities, this does not foster autonomous decision-making, as decisions are taken out of her hands, actively entrenching her vulnerability.

On the other hand, if a person is deemed to have capacity to consent to sex under the MCA, they may equally be left in a vulnerable situation, as opportunities to facilitate autonomous decision-making are precluded by a focus on non-interference. If situational sources of vulnerability have been obscured by a narrow capacity focus, these cannot be responded to and so will endure. Moreover, the need to frame the capacity questions carefully in light of the pragmatic limitations of the statute has resulted in artificial and arbitrary distinctions being drawn between capacity to consent to sex, and capacity to consent to contact. We see this starkly in the line of TZ cases117 – after declaring that TZ had capacity to consent to sexual relations, there was a concern that TZ, in exercising this in particular instances, may lack capacity. While this may reflect some of the situational vulnerability concerns that have been explored in this article, the way that these become framed in the capacity framework are troubling. To avoid the pragmatic pitfall that a best interests decision cannot be made with regard to sexual consent, the question in TZ (No 2) was posed, ‘whether TZ has the capacity to make a decision whether or not an individual with whom he may wish to have sexual relations is safe’.118

According to Baker J, this focuses in on the ‘specific factual context’;119 however it is contended that this is no less abstract or artificial than a general declaration of either capacity or incapacity in relation to sex. It is clear, however, that in framing the question this way, the court is entitled to then make best interests decisions on behalf of TZ in relation to particular relationships, as it becomes not a question of sexual capacity, but a point of emphasis on contact. In doing so in this case, the court were able to purportedly make declarations to support, in a positive way, the individual to have contact and sexual relations with another individual. Interestingly, it was also raised that if TZ lacked capacity in relation to this first point, then it also had to be asked whether he has the capacity to make a decision as to the support that he requires when having contact with an individual with whom he may wish to have sexual relations.120 Thus, while the notion of support ostensibly chimes with the UNCRPD and vulnerability arguments, the approach here inverts the logic of these and hinges the type of support on what is deemed to be in their best interests in relation to contact. This allows ‘support’ to then be imposed against TZ’s own will and preferences in his best interests. This approach allows for the control and management of that individual,121 rather than supporting him to make the decision for himself, and seems to perpetuate the legal interference with the validity of his actions.122 If vulnerability can be created

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117 A Local Authority v TZ (By his Litigation Friend, the Official Solicitor) [2013] EWHC 2322 (COP), [2013] COPLR 477; A Local Authority v TZ (By His Litigation Friend the Official Solicitor) (No 2) [2014] EWHC 973 (COP), [2014] COPLR 159.

118 Ibid (No 2), at para [18].

119 Ibid, at para [17].

120 Ibid, at para [18].

121 In this case, seemingly in perpetuity as the declaration of incapacity was global and not dependent on who the other party was, and was also accompanied by evidence from an expert that it may take 4–5 years for TZ to acquire capacity with regard to such decisions, at para [59].

122 Also see Re MM Local Authority X v MM and Another [2007] EWHC 2003 (Fam), [2009] 1 FLR 443 – contact with partner highly regulated despite being found to have capacity in relation to sex.
through a lack of choice and control over one’s life, then such an approach simply perpetuates this and creates a pathogenic source of vulnerability.

RESPONDING TO VULNERABILITY – RESILIENCE AND CAPABILITIES

As seen above, the vulnerability critique can highlight the pitfalls of a binary approach to capacity and autonomy, tied to the traditional liberal concept of autonomy as non-interference. The focus on setting a low threshold for capacity in this context can be shown to create pathogenic vulnerability through either necessitating non-interference and ‘hoping for the best’\(^\text{123}\) when a person is deemed to be autonomous, or, conversely, control and management of a person deemed to lack capacity. A vulnerability analysis instead shifts the focus away from tests for capacity, and instead on responding to multiple sources of vulnerability in a way which promotes resilience and autonomy. It is cognisant of the way in which ‘state attempts to protect the vulnerable can simply exacerbate powerlessness’\(^\text{124}\). In this way, vulnerability is disability-neutral and can highlight how a mental capacity framework can be both under and over inclusive.

However, focusing on vulnerability rather than capacity may seem problematic. As the discussion of vulnerability at the outset of this article demonstrates, vulnerability and the sources of it are very difficult to pin down,\(^\text{125}\) and responding to these requires more than can be delivered by the courts alone. Capacity, on the other hand, has been seen as providing an objective legal standard.\(^\text{126}\) Despite this, it is an illusion to think of capacity as objective in this sense. It is itself a socially determined concept\(^\text{127}\) – albeit one which draws a bright line distinction in a way which may be attractive to some seeking at least pretence of clarity. A vulnerability perspective enables a much more explicit focus on the identification of situations or contexts which justify a social response, and moves us to think about what responses are appropriate to address vulnerability, with a subjective focus on the ‘particular and embodied problem identified’\(^\text{128}\).

Crucially, the approach called for here advocates the need to link embodied experience to embodied resilience. Structural and institutional responsiveness ought to be accompanied by micro level, individually focused supports. Thus while emphasising the universal nature of vulnerability, and the way in which all humans, as social beings, are impacted upon by institutions and societal structures, the approach also strongly prioritises attention to the particular and the need to frame responses which are appropriate and tailored to the individual to achieve the same goal. As Mackenzie suggests, inherent and situational dimensions of vulnerability don’t always need to correlate exactly:


\(^{124}\) J Wallbank and J Herring, Vulnerabilities, Care and Family Law (Routledge, 2014), at p 1.

\(^{125}\) Ibid.


\(^{127}\) P Bartlett and R Sandland, Mental Health Law Policy and Practice (Oxford University Press, 2014), at p 182.

'An inherent condition may seem to place an individual at risk of harm or exploitation but they may not subjectively experience themselves as vulnerable, perhaps because of access to material resources or social supports that promote resilience.'

Insights from the empirical literature can illustrate the ways in which a much more nuanced approach to sexual vulnerability is required than one which focuses on the provision of information. Looking at the everyday ability to make ‘mundane choices’ of adults with learning disabilities, Hollomotz has highlighted how there is a distinct lack of control over daily decisions – there is often a choice to be made from a pre-arranged menu of activities at a day centre, but no choice about whether to attend in the first place. This is disempowering and can lead to passivity, which in turn will impact upon the ability to make choice in other areas of life. Hingsburger echoes this by asserting that sending people on sex education training about the right to make choice and say ‘no’ is not sufficient when they do not have such options in everyday life. External and environmental factors can have an impact on choices far beyond the impact of the impairment or disability. A focus on vulnerability can centralise attention to these factors, and prioritise the need for responses which address choices more generally, rather than being focused on a particular abstract decision in a vacuum.

In promoting resilience through experience and choice, such an approach is in stark contrast to the control and management paradigm that is often seen when people are deemed to lack capacity. This is informed by an understanding that interventions which are guided by an assumption of vulnerability and carried out by practitioners on behalf of a passive individual ‘do little to equip him or her with the skills necessary to manage risk themselves’. This resonates with statements as to the need to view people with disabilities as subjects, not objects. Hollomotz and the Speak Up Committee, a group of self-advocates, stated that, ‘We want our partners to be allowed into our bedroom. We want to be private and safe. Then we could call for help if we need to. We would be comfortable. We would be able to take time and enjoy each other’.

Thus, promoting autonomy and resilience through responsive and appropriate support can be contrasted from an approach which sees non-interference as preferable. The background need is for the availability of support – the challenge is to ensure that this support in itself does not become coercive. The threat to autonomy in

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this way can be seen not as the existence of potential ‘interference’ by others, but
instead in the way in which this support needs to be responsive in a way which does
not become controlling. This is further illustrated by Hollomotz’s study in which she
discussed relationships with people with learning disabilities. She discussed one of the
participants, Rachel, who had lived with her boyfriend and had initially been happy but
after a year this partner had become abusive. As she had a support agency, she
sought help from them who enabled her to move out.136 Similarly, Emma discussed
how she had a long-term partner who became controlling and sometimes locked her in
a room. Her father eventually enabled her to move out. These illustrate the way in
which a supportive response from an agency or relative may be needed to enable
people to escape an abusive situation. Without these, it is difficult to see how their
autonomy could be respected by leaving them in vulnerable situations. Yet it is
important to also note that both women discussed how such negative experience have
enabled them to learn and develop their relationship skills and are now happier in other
relationships.137 This focus on fostering autonomy and resilience through experience
and support echo to a certain extent the ‘dignity in risk’ argument that has been in the
literature and also judicially advocated for by Munby J. In Re MM Local Authority X v
MM and Another, he stated:

‘The emphasis must be on sensible risk appraisal, not striving to avoid all risk,
whatever the price, but instead seeking a proper balance and being willing to
tolerate manageable or acceptable risks as to the price appropriately to be paid in
order to achieve some other good – in particular to achieve the vital good of the
elderly or vulnerable persons happiness. What good is it making someone safer,
if it merely makes them miserable?’138

It similarly reflects the UNCRPD focus on taking measures to prevent exploitation,
violence and abuse of people with disability,139 but ensuring that this is done in keeping
with the other Articles of the Convention. A submission by NUI Galway on legal
capacity highlights how a high standard or rigorous test for capacity is not the most
effective form of protection from abuse, as control and management does not foster
autonomy.140 It could similarly be added to this that, on the other hand, setting a low
threshold which ignores the situational vulnerability of an individual and thus does not
respond to this can equally be seen as contrary to autonomy.

There are certainly barriers to such an approach taking hold at present. Dunn et al
highlight how care workers report that they can face negative responses from their
agencies when they try to support people to take risks.141 Similarly, the culture of risk
aversion which permeates much of social care may struggle at present to accept such
risks. Yet, the vulnerability thesis can highlight the ways in which responding to sources
of vulnerability to risk, rather than simply focusing on the management of the
individual, can pose different questions and elicit different responses. As we have

136 A Hollomotz, Learning Difficulties and Sexual Vulnerability: A Social Approach (Jessica Kingsley, 2011),
at p 135.
137 Ibid, at p 137.
139 Article 16.
140 Centre for Disability Law and Policy NUI Galway, Submission on Law Reform Commission Consultant
141 M Dunn, I Clare, and A Holland, ‘ “Living a life like ours”: Support workers’ accounts of substitute
decision-making in residential care homes for people with intellectual disabilities’ (2010) 54(2) Journal of
Intellectual Disabilities Research 144.
seen, the current approach necessitated through the use of the MCA 2005 takes as a starting point a concern about the apparent conflict between protection and autonomy or rights to sexual expression, and is constrained by the individual and disability focused mechanisms of the statute. Instead, focusing on vulnerability and capabilities invites us to ‘focus on the importance of choice or freedom with attention to the social conditions of choice’.142 If the MCA 2005 cannot reflect these nuances, might other areas of the law be better equipped to do so?

‘THE GREAT SAFETY NET’

Deflecting attention from the individual and onto the situational constraints on autonomy invites a more nuanced response than is available through the MCA 2005. The inherent jurisdiction may provide a more appropriate vehicle within which to respond to the situational impacts on individual decision-making. Such an argument has been raised by Wall and Herring, in relation to the case of PC v City of York Council143 which involved the question of capacity for contact. They characterised the non-interference stance taken by the Court of Appeal here as ‘hoping for the best’, and noted with incredulity that given the obligations on the state to protect vulnerable adults, it is ‘extraordinary that that the Court of Appeal limited itself to the analysis of the MCA and did not consider the use of the inherent jurisdiction’.144 Indeed, in PC, MacFarlane LJ highlighted the importance of the ‘causal nexus’ in the MCA 2005 between the mental disorder and the lack of capacity. It is not enough that there is a coincidence between having a mental disorder and lacking capacity – the former much cause the latter. This is an important point to note, and one which has not been routinely emphasised in the case-law. Being mindful of this invites more scrutiny of the situational factors which may equally impact upon decision-making, and while it is clearly difficult to pin-point precisely the source of incapacity,145 it enables much more rigorous consideration of appropriate responses. The alternative – to view the coincidence of a mental disorder and an inability to make decisions as enough to necessitate making a decision on behalf of the person – clearly perpetuates a medical approach to disabilities, which I have argued against elsewhere.146 Such considerations may thus point to the inherent jurisdiction as being a more appropriate forum within which to respond to facilitating decision-making, being focused not on the individual but on external impacts upon them.

The scope of the inherent jurisdiction is notoriously wide, and its parameters are unclear. Case-law does however seek to elicit the overarching purpose of this ‘great safety net’147 and it is often reiterated that the focus is on the need to enable people to regain and maximise autonomy,148 particularly when this is threatened by others. In a similar vein, it is also stated that the exercise of the inherent jurisdiction is ‘facilitative

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145 Ibid.
146 B Clough, ‘ “People like that”: realising the social model in mental capacity jurisprudence’ Medical Law Review (forthcoming).
147 A term coined by Lord Donaldson in Re F (Mental Patient: Sterilisation) [1990] 2 AC 1.
rather than dictatorial. This reflects in many ways the ethos of the vulnerability critique, and the UNCRPD, by focusing on responding to the particular individual and the ways in which their autonomous decision-making can be facilitated. Parker J in XCC v AA and Others sought to clarify the relationship of the inherent jurisdiction with the MCA 2005, noting that:

‘The protection or intervention of the inherent jurisdiction of the High Court is available to those lacking capacity within the meaning of the MCA as it is to capacitous but vulnerable adults who have had their will overborne, and on the same basis, where the remedy sought does not fall within the repertoire of remedies provided for in the MCA 2005. It would be unjustifiable and discriminatory not to grant the same relief to incapacitated adults who cannot consent as to capacitous adults whose will has been overborne.'

However she went on to note how the principles entailed in the MCA 2005 are not exported into the inherent jurisdiction, which is a point which will be returned to later. In essence, it is clear that the inherent jurisdiction endorses a flexible approach, seeking to facilitate decision-making by using a range of responses tailored to the individual situation.

We see this at work in the case of A Local Authority v A which involved a woman with severe learning difficulties, and the question before the court was whether she had capacity in relation to contraceptive decisions. Bodey J, as we saw above, noted that the scope of what needed to be understood was limited and did not require consideration of a woman’s ability to foresee the realities of parenthood or the demands of caring for a child not yet conceived. However, he then went on to consider that in relation to the need to be able to use or weigh this information, she was unable to do so not because of her impairment, but because of the overpowering control that her husband, Mr A, exercised over her. Bodey J, however, did not make a decision based on Mrs A’s best interests to order the use of contraception instead, invoking the inherent jurisdiction, he favoured an approached aimed at achieving a capacitous decision, through support and a discussion without undue pressure from her husband. Thus we see that the focus becomes on situational factors, rather than the disability itself, and responses are framed in light of this, rather than ‘controlling people of marginal capacity’. This perhaps leaves more scope for engaging with the embodied individual, and to take into account the multi-faceted nature of vulnerability in the particular situation and how resilience can be fostered in light of this. Highlighting the need to facilitate autonomous decision-making accords with Mackenzie’s emphasis on the capabilities framework, as she argues that without it, ‘discourses of vulnerability and protection may open the door to objectionably

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150 Echoing, for example, the impetus in the UNCRPD to provide support for decision making (Art 12(3)); respect for will and preferences (Art 12(4)) and promoting autonomy (Art 4).
152 Ibid, at para [54].
153 A Local Authority v Mrs A (Test for Capacity as to Contraception) [2010] EWHC 1549 (Fam), [2011] 1 FLR 26.
154 Ibid, at paras [63]–[64].
155 Ibid, at para [79].
paternalistic and coercive forms of intervention’. Approaching sexual vulnerability in this way may pave the way for a more nuanced understanding of the way in which responses can be augmented towards facilitating sexual autonomy, in a way which is obscured when using the mechanism of the MCA 2005.

Having said this, the inherent jurisdiction will not solve all of the problems in the context. As Keywood has pointed out, it is a piecemeal and incremental mechanism – being focused on particular cases coming before the court – and so it is unable to feed into practice on the ground, or into wider policy change to give effect to facilitating autonomy and capabilities at a macro level. In addition to this, we have seen that the inherent jurisdiction is of imprecise scope, and the principles underpinning it are even less clear. The statements by Parker J that the principles guiding the MCA 2005 – which have been lauded by commentators and by the recent House of Lords Select Committee report on the Act – are not exported to the inherent jurisdiction, may be a cause for concern for some. There is a legitimate concern that if principles such as a presumption of capacity, the least restrictive alternative, and the protection of unwise decisions, are ignored, then there is a possibility of purportedly supported decisions becoming coercive, rather than empowering. In the context of debates surrounding the UNCRPD, the idea that supported decision-making may become coercive is similarly agonised over, although Quinn suggests that when we view autonomy as relational, this is a reality for us all when we make decisions, and a threat we must all navigate. Dunn similarly suggests that the mere fact that there was external pressure involved in a decision is not sufficient to attract the claim that it is an invalid decision. We cannot be blind to this, or assume it is unique to people with mental disabilities (or any other protected characteristic). Instead, we need to be attentive to this reality. When looking at vulnerability in the universal sense, we can expose this fact and question what, precisely, are we seeking to respond to. It is not decision-making in the abstract – divorced from the reality of social situatedness – which is aimed for. It is decision-making which is cognisant of the situational constraint and impact, but which seeks to ensure that these situational factors are responded to where possible, to facilitate autonomous decision-making.

157 C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’, in C. Mackenzie, W Rogers and S Dodds (eds), 


159 However, the fact that it is exercised by the courts, rather than non-judicially like the MCA 2005, may support an argument that the inherent jurisdiction is more compliant with Art 12(4) of the UNCRPD in providing more robust safeguards than the informal mechanisms contained in the MCA 2005.


163 M Dunn, ‘When are Adult Safeguarding Interventions Justified?’, in J Wallbank and J Herring (eds), Vulnerabilities, Care and Family Law (Routledge, 2014).
CONCLUSION

It is clear, based on the state of the domestic law and international legal developments in this area, that debates as to whether capacity to consent to sex should be approached in a situation or act specific way will persist. The vulnerability critique provides an alternative perspective from which to consider sexual autonomy, and to highlight the ways in which the current approach obscures many relevant considerations from view. It is clear that the MCA 2005, and the criminal law, by maintaining the focus on the existence of a mental disorder, are too blunt mechanisms for attending to the nuances entailed in a vulnerability analysis. Furthermore, both the MCA 2005 and the criminal law are reactive mechanisms, and only tend to arise when a concern is raised, or sexual activity has taken place. This does little to address the commitments entailed by both the UNCRPD, and the vulnerability analysis, to promote autonomy and resilience in a more broad sense as an ongoing concern. The vulnerability approach is, as such, not necessarily so concerned with the content of a particular, isolated decision, but the resources available to individuals in navigating choices and opportunities throughout their lives. As Verkerk suggests, we need to think about how coercive interventions can be prevented and how a situation in which only two strategies remain (non-interference or coercion) can be avoided.\(^{164}\) This more nuanced response is not enabled by debates which are framed as a conflict between state intervention and autonomy and in which legal responses hinge upon the concept of mental capacity.

Such an analysis can also highlight the way in which facilitating autonomy is not just a question for law – laws and their institutions cannot eradicate vulnerability. As Williams has put it ‘laws do not solve social problems, but they can promote resilience and mediate or lessen vulnerability’.\(^{165}\) Focusing through the lens of vulnerability emphasises the need for a range of responses. In the context of sexual vulnerability, this points to the need for education, training, access to justice, as well as services being augmented towards choice and control through positive risk taking. Central to this is a responsive state providing supportive background conditions. This is not currently provided by the MCA 2005 in the context of sexual capacity, as it is evident that the legal approach is erroneously premised on non-interference as a means to promoting sexual rights. The focus needs to be not on whether state interference is appropriate – as relational beings, we all navigate various sources of state and social interference – but rather on the appropriate response, and whether this seeks to secure autonomy and capabilities. Until relational vulnerabilities, such as those at play in the context of sexual relationships, are recognised, then we cannot question what, if any, should be the appropriate legal response.\(^{166}\)

Taking the next step and thinking through the overarching legal repercussions of these conceptual considerations is a difficult task which warrants sustained consideration in another article. However, it is clear that it requires a significant rethinking of the boundaries used to determine when support is to be offered and on what basis, and the justification, if any, for intervention in a decision against a person’s


\(^{166}\) J Bridgeman, ‘Relational Vulnerability, Care and Dependency’, in J Wallbank and J Herring (eds), Vulnerabilities, Care and Family Law (Routledge, 2014), at p 202; R West, Caring for Justice (New York University Press, 1997), at p 176.
apparent wishes. As Richardson has pointed out, the process of defining these boundaries ‘would at least generate express consideration of the underlying moral dilemmas’ which the law can currently avoid confronting ‘by flexible interpretation of established concepts’.

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168 Ibid, at p 104.