

Exploring the Potential of Relational Approaches to Mental Capacity Law

A thesis submitted to The University of Manchester

for the degree of

PhD in Bioethics and Medical Jurisprudence

in the Faculty of Humanities

Beverley Clough

2015

School of Law

CONTENTS

ABSTRACT.....	5
DECLARATION & COPYRIGHT STATEMENT	7
ACKNOWLEDGEMENTS.....	9
TABLE OF CASES	11
INTRODUCTION.....	14
CHAPTER 1	18
1.1Theoretical Context.....	18
1.1.1 The Ethics of Care	19
1.1.2Care Ethics and Disability Studies- A Fraught Relationship?	23
1.1.3 Vulnerability and the Responsive State	31
1.2 Theoretical Approach.....	35
1.2.1 Capabilities.....	35
1.2.2 Care and Capabilities	37
1.2.3 Capabilities and the Social Model of Disability	40
1.2.4 The Responsive State	43
CHAPTER 2	46
2.1. Legal Context.....	46
2.1.1 The Mental Capacity Act 2005	47

2.1.2 The Medical Model in the Mental Capacity Act.....	49
2.1.3 Best Interests	51
2.1.4 Carers under the Mental Capacity Act 2005.....	57
2.1.5 The Deprivation of Liberty Safeguards	61
2.1.6 The MCA- An empowering legal framework?.....	64
2.1.7 The United Nations Convention on the Rights of Persons with Disabilities	66
2.2 Legal Approach.....	69
CHAPTER 3	76
Outline of Papers	76
CHAPTER 4	78
What About Us? A Case for Legal Recognition of Interdependence in Informal Care Relationships	78
4.1 Introduction	78
4.2 Concealing Interdependence	79
4.3 Situating Carers.....	85
4.4 The Mental Capacity Act- ‘Us’ or ‘Them’?	88
4.5 An Alternative Approach?.....	97
4.6 Translating Theory into Practice	102
4.7 Conclusion.....	109

CHAPTER 5	113
‘People Like That’: Realising The Social Model In Mental Capacity Jurisprudence	113
5.1 Introduction	113
5.2 Legal Responses to Disability and Cognitive Impairments	115
5.3 ‘The Kind of Lives That People like X Would Normally Expect to Lead’	121
5.4 Mental Capacity in the Supreme Court.....	125
5.5 Situating the Social Model	129
5.6 Building on the Social Model - From Legalism to Capabilities	132
5.7 Bridging the Gap	139
5.8 The Need for a Responsive Legal System	142
5.9 Conclusion.....	152
CHAPTER 6	155
Vulnerability and Capacity to Consent to Sex- Asking the Right Questions?	155
6.1 Introduction	155
6.2 Re-Conceptualising Vulnerability and Sexual Capacity.....	158
6.3 Situating Vulnerability.....	164
6.4 The Responsive State	171
6.5 Facilitating Sexual Autonomy.....	178
6.6 Responding to Vulnerability- Resilience and Capabilities.....	182

6.7 'The Great Safety Net'	187
6.8 Conclusion	192
CONCLUSION	194
7.1 A Relational Approach to Caring	196
7.2 The Social Model of Disability in Mental Capacity Jurisprudence	201
7.3 Autonomy and Incapacity: Challenging the Binary through Vulnerability Theory	211
7.4 Concluding Comments	218
BIBLIOGRAPHY	219
APPENDIX	232
Published Papers	232

Word Count (main text including footnotes) 75,636

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 through 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.

DECLARATION & COPYRIGHT STATEMENT

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

Copyright

The author of this thesis (including any appendices and/or schedules to this thesis) owns any copyright in it (the “Copyright”) and she has given the University of Manchester the right to use such Copyright for any administrative, promotional, educational and/or teaching purposes.

Copies of this thesis, either in full or in extracts, may be made only in accordance with the regulations of the John Rylands University Library of Manchester. Details of these regulations may be obtained from the Librarian. This page must form part of any such copies made.

The ownership of any patents, designs, trademarks and any and all other intellectual property rights except for the Copyright (the “Intellectual Property Rights”) and any reproductions of copyright works, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property Rights and Reproductions cannot and must not be made available for use without the prior written permission of the owner (s) of the relevant Intellectual Property Rights and/or Reproductions.

Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see <http://documents.manchester.ac.uk/DocuInfo.aspx?DocID=487>), in any relevant Thesis

restriction declarations deposited in the University Library, The University Library's regulations (see <http://www.manchester.ac.uk/library/aboutus/regulations>) and in The University's policy on Presentation of Theses

_Beverley Clough_____ **2015**

ACKNOWLEDGEMENTS

As with many things in life, this thesis was not an individual endeavour, and I am incredibly thankful to all those who have supported me along the way and helped to shape my ideas.

I am eternally grateful to my parents, Ann and Ian Clough, my family and my partner, David Bryan, for their constant and unwavering support. You have all been a source of courage and motivation throughout this thesis.

I have greatly benefitted from the expertise and understanding of my supervisors, Kirsty Keywood and Simona Giordano. You have both patiently read countless drafts of the papers and the thesis as a whole, and provided insightful comments and challenging ideas which have helped me to clarify my thoughts and have greatly enriched the papers. Your intellectual and personal support throughout has made this thesis possible.

I am incredibly fortunate to have undertaken this PhD in the School of Law at the University of Manchester. I have been surrounded by inspirational individuals, particularly Margot Brazier, Alex Mullock and Sarah Devaney, who have given me support and confidence throughout my time as an undergraduate and a postgraduate student.

The Bioethics and Medical Jurisprudence cohort has always provided a wealth of knowledge and good humour, and I am thankful to Becki Bennett and my fellow students who have listened to my ideas and provided food-for-thought on cohort days. I am particularly grateful to Laura Pritchard- Jones, Divine Banyubala, David Gibson and Paul Skowron for all of the encouraging comments and feedback along the way.

As a GTA, I have greatly benefitted from the support and companionship of my colleagues, including Mark Turner, Amber Dar and Craig Purshouse. Through my teaching, I have been privileged to be able to interact with students who have helped me to develop as an academic

with their thought-provoking questions and perspectives. I am grateful to the School of Law for believing in my abilities and providing me with the funding to enable this.

TABLE OF CASES

A Local Authority v A [2010] EWHC 1549 (Fam)

A Local Authority v DL and Others [2012] EWCA Civ 253

A Local Authority v H [2012] EWHC 49 (COP)

A Local Authority v TZ [2013] EWHC 2322 (COP)

A Local Authority v TZ (No.2) [2014] EWHC 973 (COP)

ACCG v MN [2013] EWHC 3859 (COP)

Aintree v James [2013] UKSC 67

Ashingdane v UK Series A no. 93, judgment of 28 May 1985

Austin v UK (2012) ECHR 459

B v Croydon Health Authority [1995] 1 ALL ER 683 (CA)

CC v KK and STCC [2012]

Cheshire West and Chester Council v P [2011] EWCA Civ 1257

D Borough Council v AB [2011] EWHC 101 (COP)

D County Council v LS [2010] EWHC 1544 (Fam)

DD v Lithuania [2012] ECHR 254

DH NHS Foundation Trust v PS [2010] EWHC 1217 (Fam)

FP v HM and A Health Board [2011] EWHC 2778

G v E, A Local Authority & F [2010] EWHC 621 (Fam)

HBCC v LG, JG and SG [2010] EWHC 1527 (Fam)

Heart of England NHS Foundation Trust v JB [2014] EWHC 342 (COP)

HL v UK [2004] ECHR 471

IM v LM and Others [2014] EWCA Civ 37

In the Matter of G(TJ) [2010] EWHC 3005 (COP)

Kedzior v Poland [2012] ECHR 1809

LBL v RYJ and VJ [2010] EWHC 2665

P v Cheshire West and Chester Council and P and Q v Surrey County Council [2014] UKSC 19

PC and NC v City of York Council [2013] EWCA Civ 478

Portsmouth Hospitals NHS Trust v Wyatt [2005] EWCA Civ 1881

R (A and B, X and Y) v East Sussex County Council and the Disability Rights Commission [2003] EWHC 167 (Admin)

R (Burke) v General Medical Council [2005] EWCA Civ 1003

R (Hughes) v Liverpool City Council [2005] EWHC 428 (Admin)

R (McDonald) v Royal Borough of Kensington and Chelsea [2011] UKSC 33

R v Cooper [2008] EWCA Crim 1155

R v Cooper [2009] UKHL 42

RB v Brighton and Hove CC

Re A (Male Sterilisation) [2009] EWHC 2525 (Fam)

Re AA [2013] EWCOP 4378

Re C (Adult: Refusal of Medical Treatment) [1994] 1 WLR 290

Re C [1994] 1 WLR 290

Re DE [2013] EWHC 2562 (Fam)

Re F (Mental Patient: Sterilisation) [1989] 2 WLR 1025

Re J (Wardship: Medical Treatment) [1991] Fam 33

Re M [2013] EWHC 3456 (COP)

Re M; ITW v Z and M [2000] 1 FLR 549, Para 560

Re MAB, X City Council v MB [2006] EWHC 168 (Fam)

Re MB (Medical Treatment) [1997] 2 FLR 426

Re MM (an adult) [2007] EWHC 2003 (Fam).

Re VW; NK v VW (2011) COP 27/10/10 11744555

ReWMA [2013] EWHC 2580 (COP)

Re Y (Mental Incapacity: Bone Marrow Transplant) [1997] 2 FCR 172

Reid v Secretary of State for Scotland [1999] 2 AC 512

Rochdale MBC v KW [2014] EWCOP 45

See *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 645

Sheffield City Council v E [2004] EWHC 2808

Stanev v Bulgaria (2012) ECHR 46

Storck v Germany [2005] 43 EHRR 96

The London Borough of Tower Hamlets v TB [2014] EWCOP 53

X City Council v MB, NB and MAB [2006] EWHC 168 (Fam)

XCC v AA and Others [2012] EWHC 2183 (CoP).

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 legislation¹. 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 Committee². The Law Commission are currently reviewing the DoLS legislation as a result and are due to report on this in 2017³. 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 MCA⁴. The Court of Protection is coming under increasing strain⁵, dealing with progressively contentious issues and attracting media

¹House of Lords Select Committee on the Mental Capacity Act 2005 Report of Session 2013-14, *Mental Capacity Act 2005 Post Legislative Scrutiny*, (London, TSO, 2014). Recent Parliamentary debate on the recommendations, however, suggests that progress is slow in terms of implementing these (Hansard, HL 10th March 2015 Vol 760 Col WA621-651).

²*Ibid.* 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.

³<http://lawcommission.justice.gov.uk/areas/capacity-and-detention.htm> [last accessed 19th Feb 2015].

⁴*An 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".

HM Government, *Valuing every voice, respecting every right: Making the case for the Mental Capacity Act* (London, HMSO, June 2014) Para 7.30.

⁵ See n1, Paras 205-211.

attention in light of this⁶. 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.

⁶*Re DE* [2013] EWHC 2562 (Fam) concerned the sterilisation of a man for non-therapeutic reasons under the Mental Capacity Act 2005. See attendant media attention <http://www.bbc.co.uk/news/uk-23721893>, <http://www.telegraph.co.uk/news/uknews/10247073/Man-with-learning-difficulties-to-be-sterilised-in-unprecedented-court-ruling.html>. Also see the controversy surrounding the case of *Re AA* [2013] EWCOP 4378 in which a woman was given a Caesarean Section under the Mental Capacity Act 2005 <http://www.independent.co.uk/news/uk/home-news/social-services-forcibly-remove-unborn-child-from-woman-by-caesarean-after-she-suffered-mental-health-breakdown-8975808.html>, <http://www.telegraph.co.uk/health/healthnews/10611575/Judge-orders-mentally-ill-woman-to-have-forced-caesarean.html>. A recent case on sterilisation of a woman with six children is *Re DD (No 4)* [2015] EWCOP 4 (Fam) which was widely reported in the media <http://www.theguardian.com/society/2015/feb/04/judge-sterilisation-mother-learning-disabilities-pregnant>; <http://www.bbc.co.uk/news/health-31128969>.

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

⁷ J. Nedelsky, ‘Laws Relations: A Relational Theory of Self, Autonomy and the Law’ (Oxford, OUP, 2012) p32.

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 individualism³. 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

¹ A. Ho, ‘Relational Autonomy or Undue Pressure? Family’s role in medical decision making’ (2008) 22 *Scandinavian Journal of Caring Science*, p129.

² J. Coggon, ‘Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?’ (2007) 15(3) *Health Care Analysis*, p240.

³ M. Sandel, *Liberalism and its Critics*, (New York, New York University Press, 1984).

⁴ M. Sandel, *Liberalism and the Limits of Justice* (2nd Ed, Cambridge, CUP, 1998) p63.

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”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 experiences⁷. 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 circumstances⁸. 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 interdependence⁹. The work of Carol Gilligan, *In a Different Voice*¹⁰, provided the impetus for the development of ethics of care theory. Much writing developed in

⁶ *Ibid.*

⁷ A. Allen and M. Regan, *Debating Democracy’s Discontent: Essays on American Politics, Law and Public Philosophy* (Oxford, Oxford University Press, 1998).

⁸ M. Donnelly, ‘Health Care Decision Making and the Law: Autonomy, Capacity and the Limits of Liberalism’ (Cambridge, CUP, 2010) p110.

⁹ O. Hankivsky, *Social Policy and the Ethic of Care*, (Vancouver, UBC Press, 2004).

¹⁰ C. Gilligan, *In a Different Voice* (Harvard, Harvard University Press, 1982).

this area after Gilligan's work. Initially, so called 'first generation'¹¹ 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 morality¹². 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 another¹³. 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 caring¹⁴. 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"¹⁵. 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

¹¹ To use a term coined by Hankivsky in 'Social Policy and the Ethic of Care', n9.

¹² N. Noddings, *Caring: A Feminine Approach to Ethics* (1984, Berkeley, University of California Press).

¹³ J. Spring, 'On the Rescuing of Rights in Feminist Ethics: A Critical Assessment of Virginia Held's Transformative Strategy' (2011) 3(1) *Praxis*, p69.

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

¹⁶ G. Clement, *Care, Autonomy, and Justice: Feminism and the Ethic of Care* (Boulder, Westview Press, 1996) p112

¹⁷ Hankivsky, n9, p14.

¹⁸ J. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York, Routledge, 1993) pxi.

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 own²³. 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 capacious 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

²² F. Robinson, *Globalizing Care: Ethics, Feminist Theory and International Relations* (Boulder, Westview Press, 1999) p23.

²³ D. Engster, *The Heart of Justice: Care Ethics and Political Theory* (Oxford, Oxford University Press, 2007), p11.

²⁴ J. Rawls, *A Theory of Justice* (Harvard, The Belknap Press of Harvard University Press, 1971). Here, in framing a theory of justice, Rawls utilises ‘the veil of ignorance’, behind which he claims rational individuals would choose and agree on his principles of justice.

approach to rights and capabilities²⁵. 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 state²⁶. 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,

²⁵ J. Spring, *Justice, Rights and Capabilities* (2013, University of Western Ontario- Electronic Thesis and Dissertation Repository) Paper 1447.

²⁶ S Goering, ‘Revisiting the Relevance of the Social Model of Disability’ (2010) 10(1) *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”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”²⁸. Disability, viewed from this perspective, is simply an “unfortunate state of functioning and being”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 disability³⁰ and potentially lead to a “social and moral marginalisation of people with impairments and gives permission to debar them from full participation in society”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 institutions³². Questions arise such as

²⁷ UPIAS and The Disability Alliance, ‘Discussion of a Fundamental Principle’ Nov 1975, available at <http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf> [last accessed 22nd September 2014].

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

²⁹ S. Vehmas, ‘Ethical Analysis of the Concept of Disability’ (2004) 42(3) *Mental Retardation*, p209.

³⁰ M Oliver, *The Politics of Disablement* (London, Palgrave Macmillan, 1990); M. Oliver, *Understanding Disability: From Theory to Practice* (London, Palgrave Macmillan, 1996).

³¹ Vehmas, n29 p210.

³² J. Gilliard *et al*, ‘Dementia Care in England and the Social Model of Disability: Lessons and Issues’ (2005) 4 *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

(2005) 4 *Dementia* 459-461; L. Terzi, ‘The Social Model of Disability: A Philosophical Critique’ (2004) 21(2) *Journal of Applied Philosophy*, 141-157; S. Vehmas, ‘Ethical Analysis of the Concept of Disability’ (2004) 42(3) *Mental Retardation*; E.F. Kittay and L. Carlson (Eds) *Cognitive Disability and its Challenge to Moral Philosophy* (New York, Wiley Blackwell, 2010); K. Shogren, ‘Considering Context: An Integrative Concept for Promoting Outcomes in the Intellectual Disability Field’ (2013) 51(2) *Intellectual and Developmental Disabilities*; D. Goodley, ‘Who is Disabled? Exploring the Scope of the Social Model of Disability’ in J. Swain, S. French, C. Barnes and C. Thomas (Eds) *Disabling Barriers- Enabling Environments* (2nd Ed London, Sage, 2004); A. Chappell, D. Goodley, R. Lawthorn, ‘Making Connections: The Relevance of the Social Model of Disability for People with Learning Difficulties’ (2001) 29 *British Journal of Learning Disabilities*, 45-50.

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.

³⁶ S. Tremain, ‘On the Subject of Impairment’ in M. Corker and T. Shakespeare (Eds) *Disability/Postmodernity: Embodying Disability Theory* (London, Continuum,2002); S. Tremain (Ed), *Foucault and the Government of Disability* (, University of Michigan, University of Michigan Press, 2005).

³⁷ E.F. Kittay and L. Carlson, n32.

³⁸ Shogren, n32, p133.

³⁹ P. Dorenlot, ‘Applying the Social Model of Disability to Dementia: Present Day Challenges’ (2005) 4 *Dementia* p459.

listening to personal experience of dementia; and foregrounds the influence of the social and built environment in enabling or disabling people with dementia”⁴⁰.

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.

⁴¹ M. Miles, ‘The Social Model of Disability Met a Narrative of (In)credulity: A Review’ (2011) 22(1) *Disability, CBR and Inclusive Development*, 5-15; C. Barnes and G. Mercer, ‘Breaking the Mould’ in C. Barnes and G. Mercer (Eds) *Doing Disability Research* (Leeds, The Disability Press, 2006); T. Shakespeare *Disability Rights and Wrongs* (London, Routledge, 2006); S. McLean and L. Williamson, ‘Conceptualising Disability’ in S. McLean and L. Williamson, *Impairment and Disability Law and Ethics at the Beginning and End of Life* (Oxon, Routledge Cavendish, 2007).

⁴² T. Shakespeare and N. Watson, ‘The Social Model of Disability: An Outdated Ideology?’ (2002) 2 *Research in Social Science and Disability*, 9-28.

⁴³ L. Crow, ‘Including All Our Lives: Renewing the Social Model of Disability’ in C. Barnes and G. Mercer, *Exploring the Divide: Illness and Disability* (Leeds, The Disability Press, 1996).

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.

⁴⁷ P. Louhiala, ‘Philosophy Meets Disability’ (2009) 35 *Journal of Medical Ethics*, p570; S. Vehmas and P. Makela, ‘The Ontology of Disability and Impairment: A Discussion of the Natural and Social Features’ in K. Kristiansen, S. Vehmas and T. Shakespeare (Eds) *Arguing about Disability: Philosophical Perspectives* (London, Routledge, 2009).

⁴⁸ D. Goodley, ‘Dis/entangling Critical Disability Studies’ (2012) 5 *Disability & Society*, 631-644.

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 to them⁴⁹. 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 changed⁵⁰. 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”⁵¹ 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

⁴⁹ Vehmas, n29, p220; M. Brazier and N. Glover, ‘Does Medical Law have a Future?’ in D. Hayton (Ed) *Laws Future(s): British Legal Developments in the 21st Century* (Oxford, Hart, 2000) ‘Key questions of the responsibilities which individuals, families and society owe to the more vulnerable members of our community need answers’ p371.

⁵⁰ P. Bartlett, ‘Casenote: Winnipeg Child and Family Services (Northwest Area) v DFG Manitoba Queens Bench [1996] 10 WWR’ (1997) 31 *University of British Columbia Law Review*; S. McLean and L. Williamson, n41, p198; A. Kanter, ‘The Law: What’s Disability Studies got to do with it? Or, An Introduction to Disability Legal Studies’ (2011) 42 *Columbia Human Rights Law Review* p 406, p 420.

⁵¹ N. Watson, L. McKie, D. Hopkins, S. Gregory, ‘(Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theories to Develop an Emancipatory Model’ (2004) 38 *Sociology* 331-350, 335.

theory which emphasizes the burdens of care can present the disabled person as the source of this burden⁵². 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 *et al* contend, this is a “wrong-headed strategy”⁵³. It “does not adequately observe the role of interpersonal relations between parties involved in the caring nexus”⁵⁴. Similarly, as Herring suggests, such an approach reinforces the idea of separation rather than interdependence and relationship⁵⁵. 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”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 *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

⁵² J. Herring, ‘The Disability Critique of Care’ (2014) 8 *Elder Law Review* 1-15, p5.

⁵³ B. Hughes, L. McKie, D. Hopkins, N. Watson, ‘Love’s Labours Lost? Feminism, the Disabled People’s Movement and an Ethic of Care’ (2005) 39(2) *Sociology* 259-275.

⁵⁴ Watson *et al*, n51, p339.

⁵⁵ n52, p8.

⁵⁶ n41, p146.

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 for⁵⁷. 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.

⁵⁷ F. Williams, 'In and Beyond New Labour: Towards a Political Ethics of Care' (2001) 21(4) *Critical Social Policy* 467-493, p487. Quoted in Watson *et al*, n51., p340.

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 policy⁵⁸. 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 vulnerability⁵⁹. 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 invulnerable⁶⁰. 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 practices⁶¹, 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

⁵⁸ J Wallbank and J Herring, *Vulnerabilities, Care and Family Law* (Routledge, 2014); C Mackenzie, W Rogers and S Dodds, *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014); M Fineman and A Gear, *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013).

⁵⁹ M Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (2008) 20(1) *Yale Journal of Law & Feminism* 1.

⁶⁰ M. Fineman, ‘Equality, Autonomy and the Vulnerable Subject in Law and Politics’ in M. A Fineman and A. Gear, ‘Vulnerability: Reflections on a New Ethical Foundation for Law and Politics’ Ashgate Surrey 2013 p16.

⁶¹ M. Fineman, *The Vulnerable Subject and the Responsive State* (2010) 30 *Emory Law Journal*, p266.

society and the importance at a policy level of being attentive to and responding to these⁶². 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 level⁶³. 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”⁶⁴.

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 these⁶⁵. 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 pathogenic⁶⁶. Inherent

⁶² F. Sherwood Johnson, ‘Constructions of Vulnerability in Comparative Perspective: Scottish Protection Policies and the Trouble with ‘Adults at Risk’’ (2013) 28(7)*Disability and Society* 908-921, p910.

⁶³ Fineman, ‘The Vulnerable Subject and the Responsive State’, n61, p21.

⁶⁴ *Ibid.*

⁶⁵ *Ibid.* p13.

⁶⁶ In C Mackenzie, W Rogers and S Dodds, *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014) p7.

sources encompass intrinsic human characteristics, “arising from our corporeality...our dependence on others, and our affective social natures”⁶⁷. 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 situation⁶⁸. 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 vulnerability⁶⁹. 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”⁷⁰. 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* vulnerability⁷¹ 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

⁶⁷ *Ibid.*

⁶⁸ *Ibid.*

⁶⁹ *Ibid.* p9

⁷⁰ *Ibid.*

⁷¹ M. Dunn, I Clare and A Holland, ‘To Empower or Protect? Constructing the Vulnerable Adult in English Law and Public Policy’ (2008) 28(2) *Legal Studies* 234-253, p254.

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-relationality and universal vulnerability in society. Such recognition of interdependence and vulnerability invites a different set of ethical, legal and political

⁷² S. Dodds, ‘Depending on Care: Recognition of Vulnerability and the Social Contribution of Care Provision’ (2007) 21(9) *Bioethics* 500-510, p501.

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”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 thwarted⁷⁵. 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.

1.2.1Capabilities

The capabilities approach is essentially an international development approach first advocated by Amartya Sen and Martha Nussbaum⁷⁶. The focus of the approach is on the pre-requisites for achieving human potential and fulfilment. Crucially, the approach stresses the

⁷⁴ J. Nedelsky, ‘Laws Relations: A Relational Theory of Self, Autonomy and the Law’ (Oxford, OUP, 2012) p27.

⁷⁵ D. Meyers, ‘Choice and Control in Feminist Bioethics’ in C. Mackenzie and N. Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*, p226.

⁷⁶ See, for example, M. Nussbaum and A. Sen (Eds) *The Quality of Life (Wider Studies in Development Economics)* (Oxford, Oxford University Press, 1993); M. Nussbaum, *Creating Capabilities: The Human Development Approach* (Belknap Press, Harvard University Press, 2011); A. Sen, *Development as Freedom* (Anchor, 2000).

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”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”⁷⁸. This approach instead scrutinises “what people are actually able to do and be”,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”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

⁷⁷ A. Sen, *The Idea of Justice*, (London, Penguin, 2010)p231.

⁷⁸ *Ibid.* p218.

⁷⁹ Nussbaum, n76, p33.

⁸⁰ C. Arjona *et al.* ‘Senses of Sen: Reflections on Amartya Sen’s Ideas of Justice’ (2012) 8(1) *International Journal of Law in Context*, p159.

and circumstantial features”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.

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;

“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.”⁸²

⁸¹ L. Terzi, *Justice and Equality in Education: A Capability Perspective on Disability and Special Educational Needs*, (London, Continuum, 2008) p181.

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"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 responsiveness⁸⁴. In the first paper, these values are central to the critical evaluation of the MCA and 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"⁸⁵.

⁸³*Ibid.* p126.

⁸⁴*Ibid.* p127.

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 society⁸⁶. 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”⁸⁷. 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

⁸⁶ M. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* The Tanner Lectures on Human Values, (London, The Belknap Press of Harvard University Press, 2006) p160; Terzi, n81,. p96.

⁸⁷Tronto, n18, p140. Emphasis added.

ignoring or discouraging”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 humanrights theory, as will be discussed in the ‘Legal Approach’ section below. As Nussbaum discusses in her article ‘Capabilities and Human Rights’⁸⁹, the approach “looks at people one by one, insisting on locating empowerment in *this* life and *that* life, rather than in the nation as a whole”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”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.

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.

⁸⁸ Spring, n25 p121

⁸⁹ (1997) 66 (2) *Fordham Law Review* 273-301.

⁹⁰ *Ibid.* p285.

⁹¹ *Ibid.*

This shared affinity and complementarity between the social model of disability and capabilities approaches has been noted by authors such as Burchardt⁹² and Terzi⁹³. 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”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,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”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”⁹⁷. From the informational focus on a person’s actual

⁹² T. Burchardt, ‘Capabilities and Disability: The Capabilities Framework and the Social Model of Disability’ (2004) 19(7) *Disability and Society* 735-751.

⁹³ L. Terzi, ‘The Social Model of Disability: A Philosophical Critique’ (2004) 21(2) *Journal of Applied Philosophy* 141-157.

⁹⁴ C. Tollefsen, ‘Disability and Social Justice’ in D. Ralston and J. Ho (Eds) *Philosophical Reflections on Disability* (Springer: New York, 2010) 211-228.

⁹⁵ A. Sen, *The Idea of Justice*, n77, p246.

⁹⁶ S. Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York, Routledge, 1996) p71.

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,⁹⁸ 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.

⁹⁸ Sen, *The Idea of Justice*, *op.cit.* p232.

⁹⁹ M. Nussbaum, ‘*Beyond the Social Contract: Toward Global Justice*’ in *The Tanner Lectures on Human Values*, (University of Utah Press, 2004) p458.

¹⁰⁰ J. Ruger *Health and Social Justice* (Oxford, Oxford University Press, 2012) p1076.

¹⁰¹ *ibid.* p729. See also A. Samaha, ‘What good is the social model of disability?’ (2007) 74(4) *University of Chicago Law Review*, p1303; M. Fox and M. Thomson, ‘Realising Social Justice in Public Health Law’ (2013) 21 *Medical Law Review*, p288 and p304.

¹⁰² S. Wong. “Duties of Justice to Citizens with Cognitive Disabilities.” in E. F Kittay and L. Carlson (Eds), *Cognitive Disability and its Challenge to Moral Philosophy* (Malden, Wiley-Blackwell, 2010) 127-146. This is not a new idea - Carson earlier spoke of ‘utilizing positively valued services and ideas in order to enhance expectations of and dignity for the people concerned’. D. Carson, ‘Disabling Progress: The Law Commission’s Proposals on Mentally Incapacitated Adults Decision Making’ (1993) 15(5) *Journal of Social Welfare and Family Law*, 305.

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 possible¹⁰³. 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 approaches¹⁰⁴. 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 citizens¹⁰⁵. This is central to the third paper in this thesis, which looks at the

¹⁰³ C. Mackenzie, 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in C. Mackenzie, W Rogers and S Dodds (Eds) 'Vulnerability', n66, p33.

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 way¹⁰⁶. 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,

Also see M.I. Hall, ‘Mental Capacity in the (Civil) Law: Capacity, Autonomy and Vulnerability’ *McGill Law Journal* 58(1) (2012) 1-35—p28- Vulnerability and relational autonomy alike- “arise through interaction of personal characteristics (also shaped by context) and through those contextually derived factors that make up the individuals total life situation.” p42.

¹⁰⁶ I.M. Young, *Justice and the Politics of Difference* (Princeton, Princeton University Press, 1990).

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)¹; 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 individuals². 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

¹ G. Quinn, “Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD” (Harvard Law School, 2010).

² See United Nations Convention on the Rights of Persons with Disabilities, Article 4 ‘General Obligations’.

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*³ 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”⁴ 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 practice⁵. 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 area⁶.

In many ways, the resulting legislation consolidated and codified the existing law which had developed through various cases⁷. It is also supported by a Code of Practice which provides additional guidance and case studies to illustrate principles and sections in practice⁸. 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

³ Law Commission, *Mental Incapacity* (London, HMSO, 1995).

⁴ *Ibid.* Para 1.1.

⁵ *Ibid.* Para 1.5.

⁶ Para 2.31.

⁷ M. Brazier and E. Cave, *Medicine, Patients and the Law* (5th Ed, London, Penguin, 2011) p144.

⁸ Department for Constitutional Affairs, *The Mental Capacity Act Code of Practice* (2007 London: The Stationery Office) available at <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-code-practice-0509.pdf>.

those with disabilities⁹. 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.¹⁰

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”¹¹. Section 3 of the Act goes on to define what is meant by ‘unable to make a decision’¹² 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’ test¹³.

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 predominate¹⁴. 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. As discussed above, the medical model of disability situates problems stemming from disability within the individuals flawed

(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.

¹⁴ House of Lords Select Committee on the Mental Capacity Act 2005 Report of Session 2013-14, *Mental Capacity Act 2005 Post Legislative Scrutiny*, (London, TSO, 2014) Para 2 and Para 104.

¹⁵ Para 92.

mind or body¹⁶. Disability, viewed from this perspective, is simply an “unfortunate state of functioning and being”¹⁷ 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”¹⁸. 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 brain¹⁹. 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 lives²⁰. Capacity can in turn be questioned on “flimsiest evidence”²¹. 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 factors²². 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

¹⁶ C. Barnes and G. Mercer *Implementing the Social Model of Disability: Theory and Research* (Leeds, The Disability Press, 2004) p2.

¹⁷ Vehmas, *op. cit.* 209

¹⁸ K. Shogren, ‘Considering Context: An Integrative Concept for Promoting Outcomes in the Intellectual Disability Field’ (2013) 51(2) *Intellectual and Developmental Disabilities*, p133.

¹⁹ S(2)(1).

²⁰ A. Taylor, ‘“Lives Worth Living:” Theorizing Moral Status and Expressions of Human Life’ (2013) 33(4) *Disability Studies Quarterly* (online access only).

²¹ P. Bartlett, ‘The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law’, (2012) 75(5), *Modern Law Review*, p761.

²² N.F. Banner, ‘Can Procedural and Substantive Elements of Decision Making be Reconciled with Assessments of Mental Capacity?’ (2013) 9(1) *International Journal of Law in Context*, p84.

identity”²³. Furthermore, through this narrow lens, “patients become understood in terms of physical, mental or emotional frailty and dysfunction”²⁴ 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 oversight²⁵, and in cases that do go to

²³ 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).

²⁴ K. Keywood, "'I'd Rather Keep Him Chaste" Retelling the Story of Sterilisation, Learning Disability and (Non)Sexed Embodiment' (2001) 9 *Feminist Legal Studies*, p190.

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

-
- (i) that P lacks capacity in relation to the matter, and
 - (ii) that it will be in P’s best interests for the act to be done.

(2) D does not incur any liability in relation to the act that he would not have incurred if P—

- (a) had had capacity to consent in relation to the matter, and
- (b) had consented to D’s doing the act.

(3) Nothing in this section excludes a person’s civil liability for loss or damage, or his criminal liability, resulting from his negligence in doing the act.

²⁶ N. Munro, ‘Taking wishes and feelings seriously: the views of people lacking capacity in Court of Protection decision-making’, (2014) 36(1) *Journal of Social Welfare and Family Law* 59-60.

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 determinative³⁰. 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

“In my judgment it would be an abuse of power in such circumstances even to think about imposing a blood transfusion on RC having regard to my findings that he presently has capacity to refuse blood products and, were such capacity to

³⁰ P. Bartlett and R. Sandland, *Mental Health Law: Policy and Practice* (4th Ed, Oxford University Press: Oxford, 2014) p190.

³¹ [2013] UKSC 67.

³² Para 45, Per Lady Hale.

³³ G. Quinn and T. Degener, (Eds), *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (Geneva, Office of the United Nations Commissioner for Human Rights, 2002).

³⁴ [2014] EWHC 1317 (COP).

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 MHA”³⁵.

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.

³⁸ S. McLean and L. Williamson, *Impairment and Disability Law and Ethics at the Beginning and End of Life* (Oxon, Routledge Cavendish, 2007); P. Fennell, ‘Best Interests and Treatment for Mental Disorder’ (2008) 16 *Health Care Analysis*, 255-267.

*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 care⁴¹. 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. Munro⁴³ 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 death⁴⁵, whereas a closer

³⁹ [2013] EWHC 3859 (COP).

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.

⁴⁴ [2012] EWHC 1639 (COP).

⁴⁵ Para 115.

reading of the case suggests that E's views were much more subtle than this⁴⁶. 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 body⁴⁷. Similarly, in the case of *Re L*⁴⁸, 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 death⁴⁹ 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 die⁵⁰ and there is some brief discussion of L's desire to move to a nursing home⁵¹. 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 again⁵². 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 forward⁵³. 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. Engaging

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 Act⁵⁴. 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.

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 practitioners⁵⁷, 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”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”⁵⁹. In *G(TJ)*⁶⁰, the narrow view of best interests, which focused solely on an

⁵⁷ See, for example, Department of Health, *Six Lives: Progress Report* (Oct 2010) available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_120251

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

⁵⁹ M. Donnelly, ‘Commentary: Determining Best Interests Under the Mental Capacity Act 2005, In the Matter of G(TJ) [2010] EWHC 3005 (COP)’ (2011) 19 *Medical Law Review* p313.

⁶⁰ *In the Matter of G(TJ)* [2010] EWHC 3005 (COP).

individual's self-regarding interests (as advocated for by Samanta⁶¹) 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 capacity⁶³, 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 collapse⁶⁴. Yet, as Keywood discusses,

"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

⁶¹ J. Samanta 'Lasting Powers of Attorney for Healthcare under the Mental Capacity Act 2005: Enhanced Prospective Self-Determination for Future Incapacity or a Simulacrum?' (2009) 17 *Medical Law Review* 377, p402.

⁶² Para 56, Per Morgan J.

⁶³ Donnelly, n59, p313.

⁶⁴ H. Arksey, 'Combining Work and care: The Reality of Policy Tensions for Carers' (2005) 15 *Benefits*, p139.

⁶⁵ K. Keywood, 'Gatekeepers, Proxies, Advocates? The Evolving Role of Carers Under Mental Health and Mental Capacity Law Reforms' (2003) (25)4 *Journal of Social Welfare and Family Law*, p355.

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 area⁶⁶ 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 law⁶⁷ 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”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”⁶⁹.

⁶⁶ See, for example, J. Herring, 'Where are the Carers in Healthcare Law and Ethics?' (2007) 27(1) *Legal Studies* 51-73; J. Herring, 'Legal Issues Surrounding Dementia' (2011) 1 *Elder Law Journal* 182; J. Herring, 'The Legal Duties of Carers' (2010) 18 *Medical Law Review* 248; J. Herring, 'Losing it ? Losing what? The law and dementia' (2009) 3 *Child and Family Law Quarterly*; J. Herring, 'Caregivers in Medical Law and Ethics' (2008) 25 *Journal of Contemporary Health Law and Policy*.

⁶⁷ Keywood, n65.

⁶⁸ *Ibid.* p357

⁶⁹ M. Donnelly and C. Murray, 'Unpaid carers: an invisible presence in Irish health and care law' (2012) 18(1) *Medico-Legal Journal of Ireland*, p 6.

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*⁷⁰. 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 expense⁷¹.

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

⁷⁰ (2005) 40 EHRR 32.

⁷¹ A. Szerletics and T. O’Shea, *The Deprivation of Liberty Safeguards* (Essex Autonomy Project Briefing, 2011); also see CQC, *Monitoring the use of the Mental Capacity Act 2005 Deprivation of Liberty Safeguards 2011/12* available at <http://www.cqc.org.uk/public/reports-surveys-and-reviews/reports/deprivation-liberty-safeguards-2011/12>; R. Hargreaves, *Briefing Paper 1-Deprivation of Liberty Safeguards: An initial review of implementation*, (London, Mental Health Alliance, 2010) available at http://www.mentalhealthalliance.org.uk/resources/DoLS_report_July2010.pdf; Mental Health Alliance, *The Mental Health Act 2007: A Review of its Implementation* (London, Mental Health Alliance, 2012) available at http://www.mentalhealthalliance.org.uk/news/MHA_May2012_FINAL.pdf

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-*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 implementation⁷², more creative analytical concepts emerged emphasising purpose, normality and objections⁷³- 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 justified⁷⁴. Such concepts came to a head in the leading judgement of Munby LJ in *Cheshire West and Chester v P*, which further muddled the murky waters of the meaning of deprivation of liberty⁷⁵.

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

⁷² Stemming from *Guzzardi v Italy* App.7367/76 (1980) ECHR 5; *HL v UK* 45508/99 (2004) ECHR 471; *JE v DE and Surrey County Council* (2006) EWHC 3459 (Fam).

⁷³ See, for example, the lack of clarity stemming from the reasoning used in *MIG and MEG* (2010) EWHC 785 (Fam) and the Court of Appeal judgement in *P and Q* (2011). Considerations such as the effect of objection/no-objection; purpose; and relative normality are covered in some detail in the *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 *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 *A Local Authority v PB and P* [2011] EWHC 2675, implied that perhaps the emerging concepts in *P and Q* and *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 Court⁸¹, 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 liberty⁸². Furthermore, the DoLS are

⁷⁸ Para 102.

⁷⁹ *Ibid.*

⁸⁰ *Ibid.*

⁸¹ *P v Cheshire West and Chester Council and P and Q v Surrey County Council* [2014] UKSC 19.

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 1993⁸³. 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”⁸⁴.

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.

⁸³ D. Carson, ‘Disabling Progress: The Law Commission’s Proposals on Mentally Incapacitated Adults Decision Making’ *Journal of Social Welfare and Family Law* 15(5) (1993) 304-320.

⁸⁴ *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 Authority*⁸⁶. 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

⁸⁵ *Ibid.* p318.

⁸⁶ [2015] EWCOP 5.

⁸⁷ House of Lords Mental Capacity Act 2005 Select Committee, *Oral and Written Evidence, Vol 1 A-K*, available at <http://www.parliament.uk/documents/lords-committees/mental-capacity-act/mental-capacity-act-2005-vol1.pdf> [last accessed 16th Feb 2015] p632, para 7.

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 approaches⁹¹, 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

⁹⁰ F. Owens and D. Griffiths, *Challenges to the Human Rights of People with Intellectual Disabilities* (London, Jessica Kingsley, 2009) p35.

⁹¹ C. O’Mahony, Legal Capacity and Detention: Implications of the UN Disability Convention for the Inspection Standards of Human Rights Monitoring Bodies’ (2012) 16(6) *International Journal of Human Rights*; A. Samaha, ‘What good is the social model of disability?’ (2007) 74(4) *University of Chicago Law Review* 1251-1308.

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 disability⁹². It reinforces and reaffirms the importance of enforceable rights and entitlements⁹³. More importantly, the ethos of the CRPD is very much about taking positive steps to enable rights to be protected⁹⁴. 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 liberty⁹⁵.

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 Convention⁹⁶. 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

⁹² See for example P. Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities' n 21; D. Mackay, 'The United Nations Convention on the Rights of Persons with Disabilities' (2006/7) 34 *Syracuse Journal of International Law and Commerce*; A. Dhanda, 'Constructing a New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities' (2008) *International Journal of Human Rights*.

⁹³ E. Flynn, 'Making Human Rights Meaningful for People with Disabilities: Advocacy, Access to Justice and Equality before the Law' *International Journal of Human Rights* 17(4) (2013) 497; F. Owen and D. Griffith, *Challenges to the Human Rights of People with Intellectual Disabilities*, n90.

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.

⁹⁶ L. Series, A. Arstein-Kerslake, E. Flynn, P. Gooding, 'Mental Capacity Law Discussion Paper-The Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and the Convention on the Rights of Persons with Disabilities: The Basics' 39 Essex Street Newsletter, June 2014, available at http://www.39essex.com/docs/newsletters/crpd_discussion_paper_series_et_al.pdf [last accessed 22nd Sept 2014].

ensuring that people have opportunities to express or develop their will and preferences as well as having choice and control over their everyday lives⁹⁷. 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 law⁹⁸. 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-making⁹⁹. 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 CRPD¹⁰⁰. 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”¹⁰¹.

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

⁹⁷ ‘General Comment (Number 1) on Art 12: Equal Recognition Before the Law’ (April 2014) available at <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> [last accessed 15th August 2014].

⁹⁸ *Ibid.* Para 1.

⁹⁹ *Ibid.* Para 8.

¹⁰⁰ *Ibid.* Para 13-15.

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”¹⁰². This has provoked much debate at a domestic level about what this means in terms of the compatibility of the MCA with the CRPD¹⁰³.

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

¹⁰² Bartlett and Sandland, n30,p564.

¹⁰³ See Bartlett, n20.; W. Martin *at al*, *Achieving CRPD Compliance: Is The Mental Capacity Act Of England And Wales Compatible With The UN Convention On The Rights Of Persons With Disabilities? If Not, What Next?*, Essex Autonomy Project (2014); E. Flynn and A. Arstein-Kerslake 'Legislating personhood: realizing the right to support in exercising legal capacity,' (2014) 10(1) *International Journal of Law in Context*, 81; G. Richardson, 'Mental Capacity in the Shadow of Suicide: What can the law do?' (2013) 9(1) *International Journal of Law in Context* 87-105, 97; G. Szumukler, R. Daw, F. Callard, 'Mental health law and the UN Convention on the rights of persons with disabilities', (2013) 17(3) *International Journal of Law and Psychiatry*, 245–252; P. Fennell. and U. Khaliq, 'Conflicting or complementary obligations? The UN Disability Rights Convention on Human Rights and English law', (2011) 6, *European Human Rights Law Review*, 662-674.

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 obligations¹⁰⁴. 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”¹⁰⁵. He characterises the CRPD as an antidote to the “reductionist and essentialist picture in liberal theories of justice”¹⁰⁶ - 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

¹⁰⁴ M. Bach and L. Kerzner, ‘A New Paradigm for Protecting Autonomy and the Right to Legal Capacity’ (2010) Prepared for the Law Commission of Ontario; Also see G. Quinn, ‘Personhood and Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD’ HPOD Conference, Harvard Law School (2010).

¹⁰⁵ G. Quinn ‘Rethinking Personhood: New Questions in Legal Capacity Law and Policy’ (2011 Vancouver University of British Columbia) p.52.

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”¹⁰⁷. Similarly, rights will be seen as important “as a break on the dangers that might otherwise flow from a relational perspective”¹⁰⁸, particularly when there is a possibility that considerations of a ‘good’ caring relationship may overlook the 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”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 actualised¹¹⁰. 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 rights¹¹¹.

¹⁰⁷ J. Nedelsky, ‘Reconceiving Rights as Relationships’, 95-107 in C. Koggel (Ed) *Moral Issues In Global Perspective* (2nd Ed, Broadview Press, 2006) p 101.

¹⁰⁸ J. Herring, ‘Forging a Relational Approach: Best Interests or Human Rights?’ (2013) 13(1) *Medical Law International*, p48.

¹⁰⁹ Nedelsky, n108, p101.

¹¹⁰ See discussion of Capabilities in Theoretical Approach.

¹¹¹ M. Donnelly, *Health Care Decision Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (2010 Cambridge University Press) p271.

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”¹¹² 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 2¹¹³ 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”¹¹⁴ 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”¹¹⁵, 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

¹¹² R. Kayess and P. French ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8(1) *Human Rights Law Review* 1-34.

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”.

¹¹⁴ J. Lord and R. Brown, ‘The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities’ in M. Rioux, L. Bassier and M. Jones (Eds) *Critical Perspectives on Human Rights and Disability Law*,. (Martinus Nijhoff, UK: 2011) p277.

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,

¹¹⁶ A. Sen, *The Idea of Justice*, (London, Penguin, 2010) p246.

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”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 dichotomies¹¹⁹. 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 diagnosis¹²⁰. 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”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”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

¹¹⁸ D. Surtees, ‘What can elder law learn from disability law?’ in I. Doron (Ed.) *Theories on Law and Ageing*. (Berlin, Springer, 2009) p102.

¹¹⁹ P. Weller, ‘Lost in Translation: Human Rights and Mental Health Law’, in, B. McSherry and P. Weller *Rethinking Rights Based Mental Health Law* (Hart Publishing: Oxford, 2010), p72.

¹²⁰ See J. Herring, ‘Entering the Fog: On the Borderlines of Mental Capacity’ (2008) 83 *Indiana Law Journal*, 1620 and M. Gunn, ‘The Meaning of Incapacity’ (1994) 2(1) *Medical Law Review*, 8, for discussion of the problems stemming from dichotomising capacity and incapacity, and the need to respond to the competent yet vulnerable person.

¹²¹ D. Carson, ‘Disabling Progress: The Law Commission’s Proposals on Mentally Incapacitated Adults’ Decision Making’ (1993) 15(5) *Journal of Social Welfare and Family Law*, p315.

¹²² J. E. Bickenbach, ‘Minority Rights or Universal Participation: The Politics of Disablement’ in M. Jones and L.A.B Marks (Eds) *Disability, Divers-Ability and Legal Change* (The Hague, Kluwer Law International, 1999).

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 million¹, saving the public purse around £119 billion per year². The value of these informal carers, often family members, is not simply monetary³. 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 possible⁴. 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 resource⁵.

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

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

² L. Buckner and S. Yeandle, *Valuing Carers* (Carers UK and University of Leeds, 2011).

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.

⁴ See G. Quinn, *Rethinking Personhood: New Directions in Legal Capacity Law and Policy: Or, how to put the Shift back into Paradigm Shift*, (April 2011) available at http://cic.arts.ubc.ca/fileadmin/user_upload/CIC/July_2011/Gerard_Quinn_s_Keynote_-_April_29__2011.pdf [last accessed 12th Feb 2013] Also see M. Holstein, J. Parks and M. Waymack, *Ethics, Aging and Society: The Critical Turn* (New York, Springer Publishing, 2011) 125.

⁵ J. Berger, E. DeRenzo, J. Schwartz ‘Surrogate Decision Making: Reconciling Ethical Theory and Clinical Practice’ (2008) 149 *Annals of Internal Medicine*, 48-53; H. Arksey and C. Glendinning, ‘Choice in the context of informal care giving’ (2007) 15(2) *Health and Social Care in the Community*, 165-175.

⁶ K. O'Donovan and R. Gilbar, ‘The Loved Ones: Families, Intimates and Patient Autonomy’ (2003) 23(2) *Legal Studies*, 332-358.

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.

⁷ A. Ho, 'Relational Autonomy or Undue Pressure? Family's role in medical decision making' *Scandinavian (2008) 22 Journal of Caring Science*, 129.

⁸ J. Coggon, 'Varied and principled understandings of autonomy in English law: justifiable inconsistency or blinkered moralism?' (2007) 15(3) *Health Care Analysis*, p240.

⁹ M. Sandel, *Liberalism and its Critics*, (New York, New York University Press, 1984).

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 theories¹¹. 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 experiences¹².

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 ignored¹⁴. One focus of the feminist critique of liberal rights approaches is thus a “strategy of inclusion of those who might be

¹⁰ M. Sandel, *Liberalism and the Limits of Justice* (2nd Ed Cambridge, CUP, 1998) p63.

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]

¹² A. Allen and M. Regan, *Debating Democracy’s Discontent: Essays on American Politics, Law and Public Philosophy* (Oxford, OUP, 1998).

¹³ N. Naffine, ‘The Body Bag’ in N. Naffine and R. Owens (Eds) *Sexing the Subject of Law* (Sweet & Maxwell, 1997) p85.

¹⁴ N. Lacey, *Unspeakable Subjects: Feminist essays in legal and social theory* (Oxford, Hart, 1998) p28.

excluded from the liberal tradition”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”¹⁶.

This dominance of the individualistic concept of the ‘self’ can be seen to be embedded in law¹⁷. In health care law, the ethical principle of autonomy has been perceived as entailing many of the philosophical notions of the abstract, unencumbered individual¹⁸. Legal principles regarding informed consent to medical interventions, for example, view family or other external involvement with suspicion¹⁹. 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”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

¹⁵ F. Kelly, ‘Conceptualising the child through an ‘ethic of care’: lessons for family law’ (2005) *International Journal of Law in Context*, p383; J. Nedelsky ‘Law, Boundaries and the Bounded Self’ (1990) *Representations: Special Issue: Law and the Order of Culture*, p30.

¹⁶ R. Harding, ‘Legal Constructions of dementia: discourses of autonomy at the margins of capacity’ (2012) 34(4) *Journal of Social Welfare and Family Law* p427.

¹⁷ 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; K. O’Donovan, ‘With sense, consent or just a con? Legal subjects in the discourse of autonomy’ 47-64 in N. Naffine and R. Owens (Eds) *Sexing the Subject of Law* (Sweet & Maxwell, 1997) A. Norrie, *Crime, Reason and History: A Critical Introduction to Criminal Law* (1993); N. Naffine ‘The Body Bag’ in N. Naffine and R. Owens, n17, p85.

¹⁸ See, for example, M. Brazier, ‘Do No Harm- Do Patients Have Responsibilities Too?’ (2006) 65 *Cambridge Law Journal*, 397-422; J. Montgomery, ‘Law and the Demoralisation of Medicine’ (2006) 26 *Legal Studies* 185-210; R. Fletcher, M. Fox and J. McCandless, ‘Legal Embodiment: Analysing the Body of Health Care Law’ (2008) 16(3) *Medical Law Review*; J. Coggon, ‘Harmful Rights Doing? The Perceived Problem of Liberal Paradigms in Public Health’ (2008) 34 *Journal of Medical Ethics*, 798-801.

¹⁹ See *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 645 Per 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.

²⁰ A. Ho, ‘Relational autonomy of undue pressure: Family’s role in medical decision making’ (2008) 22 *Scandinavian Journal of Caring Science*, p129.

responsibilities of others, or the state, for those in need of care remains relatively unexamined”²¹.

This is despite research by Gilbar suggesting that patients and relatives views reflect “a relational approach to patient autonomy”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 reconsidered²³. 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* 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”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”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”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 -

²¹ J Bridgeman, ‘Accountability, Support or Relationship? Conceptions of Parental Responsibility’, (2007) 58(3) *Northern Ireland Legal Quarterly* 307-324, p308.

²² R. Gilbar, ‘Family Involvement, Independence and Patient Autonomy in Practice’ (2011) 19 *Medical Law Review*, p192.

²³ *Ibid* p233.

²⁴ J. Berger, E. DeRenzo, J. Schwartz ‘Surrogate Decision Making: reconciling Ethical Theory and Clinical Practice’ (2008) 149 *Annals of Internal Medicine*, p48.

²⁵ *Ibid*, p48.

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”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 Herring²⁸, Bridgeman²⁹ and Pettersen³⁰ 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 Gilligan³¹, 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 reasoning³². Noddings characterises, and criticises, the liberal concept of the individual as “the wrong start”³³ and instead advocates a better start being built upon relation and encounter³⁴. At the heart of care theory is thus the inevitability and necessity of care and dependence at various stages of our lives- most clearly around birth but also to varying degrees throughout our

²⁷ M. Donnelly, *Health Care Decision Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge, CUP, 2010) p47.

²⁸ J. Herring, *Caring and the Law* (Oxford, Hart Publishing, 2013); J. Herring, ‘Caregivers In Medical Law and Ethics’, (2008) 25 *Journal of Contemporary Health Law & Policy* 1-37; J. Herring, ‘Where are the carers in healthcare law and ethics?’ (2007) 27(1) *Legal Studies*, 51-73.

²⁹ J. Bridgeman ‘Accountability, support or relationship? Conceptions of parental responsibility: legal constructions of unpaid caregiving’ (2007) 58 (3) *Northern Ireland Legal Quarterly*, 307-24.

³⁰ T. Pettersen, ‘The Ethics of Care: Normative Structures and Empirical Implications’ (2011) 19 *Health Care Analysis*, 51-64.

³¹ C. Gilligan, *In A Different Voice* (Cambridge Massachusetts, Harvard University Press 1982).

³² See C. Gilligan, *Ibid.*; Nel Noddings, *Caring: A Feminine Approach to Ethics* (Berkeley, University of California Press, 1984); E. F. Kittay and D. T. Meyers *Women and Moral Theory* (New Jersey, Rowman and Littlefield, 1987); S. Ruddick, *Maternal Thinking* (Boston Massachusetts, Beacon 1989); G. Clement *Care, Autonomy and Justice* (Colorado, Westview, 1996).

³³ N. Noddings, *Starting at Home: Caring and Social Policy* (California, University of California Press, 2002) p77.

³⁴ *Ibid.* p79.

lives- which traditional liberal theories cannot capture³⁵. 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”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”³⁷. Care ethics, conversely, “has at its core a central mandate to care for the relationships that sustain life”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 justice³⁹. At this more political level, care ethics “encapsulates a constructive critical perspective on the norm of independent citizenship”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

³⁵ E. Feder Kittay and E K. Feder (Eds) *The Subject of Care: Feminist Perspectives on Dependency*(Maryland, Rowman & Littlefield, 2002).

³⁶ E. F. Kittay, *Love’s Labor:Essays on Women, Equality and Dependency* (Routledge: 1999) pxii.

³⁷ *Ibid.* p438.

³⁸ R. West, *Caring for Justice*(New York, New York University Press, 1997) p8.

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) 32 *The 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.

⁴⁰ S. Sevenhuijsen, ‘The Place of Care: The Relevance of the feminist Ethic of Care for Social Policy’ (2003) 4(2) *Feminist Theory* p183.

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”⁴¹.

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”⁴² 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”⁴³. 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”⁴⁴. Dependence, viewed through the lens of liberal individualism, becomes a negative and undesired trait. Similarly, Dodds

⁴¹T.Pettersen, n30, p61.

⁴² R. Sandland, ‘Between “Trust” and “Difference”: Poststructuralism, Law and the Power of Feminism’ (1995) 1 *Feminist Legal Studies* p8.

⁴³ M. Shanley, ‘Unencumbered Individuals and Embedded Selves: Reasons to Resist Dichotomous Thinking in Family Law’ in A. Allen and M. Regan, n7, p4.

⁴⁴ 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.

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 domain⁴⁷. 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

⁴⁵ S. Dodds, ‘Depending on Care: Recognition of Vulnerability and the Social Contribution of Care Provision’ (2007) 21(9) *Bioethics*, p501.

⁴⁶ M. Holstein, J. Parks, M. Waymack, *Ethics, Aging and Society: The Critical Turn* (New York, Springer, 2011) p8.

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.bih.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.

⁴⁸ *R (A and B, X and Y) v East Sussex County Council and the Disability Rights Commission* [2003] EWHC 167 (Admin) Para 116-117, Per Munby J

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 decisions⁴⁹. 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 individuals⁵⁰. 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 implications⁵¹. 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 respected⁵². There is also evidence that carers are reluctant to seek help as the focus is intensively on the person they are caring for⁵³. As such, the position of informal carers has been characterised as akin to “coworkers without employment rights”⁵⁴.

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*

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].

⁵⁰ S. Pickard, S Jacobs, S Kirk ‘Challenging Professional Roles: Lay Carers’ Involvement in Health Care in the Community’ (2003) 37(1) *Social Policy and Administration* p82.

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

⁵² J.Hardwig, ‘What About the Family? The Role of Family Interests in Medical Decision Making’ *Hastings Centre Report* (1990) 5-10.

⁵³ *Ibid.*

⁵⁴ V Yeates, ‘Ambivalence, Contradiction and Symbiosis: Carers’ and Mental Health users’ Rights’ (2007) 29(4) *Law and Policy*, p437.

*Council*⁵⁵“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.

⁵⁵ [2005] EWHC 428 (Admin).

⁵⁶ *Ibid.*

⁵⁷ V. Yeates, n54, p452.

⁵⁸ R. Gilbar, ‘Family Involvement, Independence and Patient Autonomy in Practice’ (2011) 19 *Medical Law Review*, p192.

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.

⁶⁰ A. Szerletics, *Best interests decision-making under the Mental Capacity Act Essex Autonomy Project Green Paper Report* (University of Essex: Essex Autonomy Project, 2011) p30.

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 covers⁶¹, 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 ECHR⁶².

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 considered⁶³. 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

[<http://autonomy.essex.ac.uk/best-interests-decision-making-under-the-mental-capacity-act>]; S. Holm and A. Edgar, 'Best Interest: A Philosophical Critique' (2008) 16 *Health Care Analysis*, p197 and S. McGuinness, 'Best Interests and Pragmatism' (2008) 16 *Health Care Analysis*, p208.

⁶¹ Department for Constitutional Affairs, *Mental Capacity Act 2005 Code of Practice* (London, The Stationery Office, 2007) Para 5.5.

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

⁶³ M. Quigley, 'Best Interests, the Power of the Medical Profession, and the Power of the Judiciary' (2008) 16 *Health Care Analysis*, p235.

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

⁶⁴ *Op. Cit.* Herring, *Where are the Carers?* n28,p70.

⁶⁵ See 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 Empirical Implications’ (2011) 19 *Health Care Analysis*, p54.

⁶⁶ J. Coggon, ‘Best Interests, Public Interests and the Power of the Medical Profession’(2008)16 *Health Care 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 Myelodysplastic 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, 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.

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”⁷⁰; at best, “inventive”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 obligations⁷². 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 way⁷³. 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*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 son⁷⁵, 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

⁷⁰ A. Szerletics, n60.

⁷¹ J. Coggon, n66, p224.

⁷² J. Herring and C. Foster ‘Welfare means relationally, virtue and altruism’ (2012) 32(3) *Legal Studies* 480-498.

⁷³ 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.

⁷⁴ *Re VW; NK v VW* (2011) COP 27/10/10 11744555

⁷⁵ 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”.

emotional/welfare needs”⁷⁶. 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 for⁷⁷. 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 practitioner⁷⁸.

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.

⁷⁶*Ibid.*

⁷⁷R. Harding and E Peel, ‘Dementia Project News: Findings Summary 1’ (2011) available at http://www.dementiaproject.net/assets/user/files/1330689267_d2claysummary1a_august2011.pdf [last accessed 20th Feb 2013] Also see. Barnes and Brannelly, n49, p391.

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 Review* 767.

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 Y*⁸¹ 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”⁸³ 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”⁸⁴. 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”⁸⁵. 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 Act⁸⁶. 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

⁸³ N. Stanley and J. Manthorpe, ‘Small Acts of Care: Exploring the Potential Impact of the Mental capacity Act 2005 on Day-to-Day Support’ (2009)8(1) *Social Policy and Society*, p39.

⁸⁴ *Ibid.* p45.

⁸⁵ M. Dunn, I Clare, A Holland, ‘Living ‘a life like ours’: support workers’ accounts of substitute decision-making in residential care homes for adults with intellectual disabilities’ (2010) 54(2) *Journal of Intellectual Disability Research*, p146.

⁸⁶ Office of the Public Guardian, *Making Decisions: A Guide for family, friends and other unpaid carers* (4th Ed 2009) available at <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf> (Last accessed 19th Feb 2013).

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 balanced⁸⁷. 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 capacity⁸⁸. 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

⁸⁷ P. Case, ‘Confidence Matters: The Rise and Fall of Informational Autonomy’ (2003) 11(2) *Medical Law Review* 208-236; See also N. Glover and M. Brazier, ‘Ethical Aspects of the Law Commission Report on Mental Incapacity’, (1996) 6(4) *Reviews of Clinical Gerontology* 365-370. “Perhaps the flaw in the Report is not its proposals relating to research, but its failure elsewhere to recognize that third party interests, particularly the interests of carers, can never wholly be disregarded” (p370).

⁸⁸ See Law Commission, *Mental Incapacity* (London, HMSO, 1995) Para 6.31.

research does not entail an abandonment of the interests of the individual or a prioritising of society over the individual⁸⁹.

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.

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 relationship⁹⁰. 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 them⁹¹. The focus becomes the preservation and protection of

⁸⁹Code of Practice Ch 11.

⁹⁰ N. Noddings, *Starting at Home: Caring and Social Policy* (California, University of California Press, 2002) p5.

⁹¹T. Pettersen, n30, p54.

good caring relationships⁹² 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”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 this⁹⁴. 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 central⁹⁵. 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 needs⁹⁶. Responsiveness, under Tronto’s model, also entails the recognition of vulnerability, and the moral consequences of it⁹⁷. 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

⁹²F. Kelly, n15,p390.

⁹³E.F. Kittay, *Love’s Labor: Essays on Women, Equality and Dependency* (New York: Routledge, 1999) p66.

⁹⁴ See, for example, J. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York, Routledge, 1993); S. Sevenhuijsen, *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics* (London, Routledge, 1998); D. Engster, *The Heart of Justice: Care Ethics and Political Theory* (Oxford, OUP, 2007).

⁹⁵J. Tronto, *ibid*.p130.

⁹⁶*Ibid*,p136.

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.

dependency⁹⁸. 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 member⁹⁹. 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

⁹⁸ M. Fineman, *Cracking the Foundational Myths: Independence, Autonomy and Self- Sufficiency* (2000) *Gender, Work & Family Project Inaugural Feminist Legal Theory Lecture* 13-29, p20; M. Fineman, *The Autonomy Myth: A Theory of Dependency* (New York, New Press, 2004).

⁹⁹ K. Keywood, ‘Gatekeepers, Proxies, Advocates? The Evolving Role of Carers Under Mental Health and Mental Capacity Law Reforms’ (2003) (25)4 *Journal of Social Welfare and Family Law*, p355.

¹⁰⁰ J. Tronto, n94, p133.

¹⁰¹ S. Sevenhuijsen, ‘The Place of Care: The Relevance of the feminist Ethic of Care for Social Policy’ (2003) 4(2) *Feminist Theory*, p186.

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 opportunities¹⁰².

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 equality¹⁰³. 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”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”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 capabilities¹⁰⁶. 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 goals¹⁰⁷. 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

in C..Koggel, *Moral Issues in Global Perspective* (2nd Ed, Ontario, Broadview Press, 2006) p101] and Brennan’s suggestion that it is open to us to develop rights approaches based upon a relational view of the self [S. Brennan, ‘Reconciling Feminist Politics and Feminist Ethics on the Issue of Rights’ (1999)30(2) *Journal of Social Philosophy*, p266]. 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. [T. Pettersen, n30, p55].

¹⁰⁴ Dodds, n45, p502.

¹⁰⁵ Nedelsky, n107,p98.

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, *Social Policy and the Ethic of Care* (Vancouver, UBC Press, 2004) p31.

¹⁰⁷ D. Engster, ‘Care Ethics and Natural Law Theory: Toward an Institutional Political Theory of Caring’ (2004) 66(1) *Journal of Politics* p131.

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 interests¹⁰⁸. 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 decisions¹⁰⁹. Compromise and inclusive negotiation are key characteristics in many decisions affecting families and the consideration of this is lacking in the current legal provisions¹¹⁰. 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

¹⁰⁸ J. Nedelsky, n107, J. Herring and C. Foster, n72; M. Minow, *Making All the Difference: Inclusions, Exclusion and American Law* (Ithaca, Cornell University Press, 1990).

¹⁰⁹ M. Donnelly, 'Commentary: Determining Best Interests Under the Mental Capacity Act 2005, In the Matter of G(TJ) [2010] EWHC 3005 (COP)' (2011) 19 *Medical Law Review* p313.

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”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”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.

¹¹² K. Keywood and M. Flynn ‘Healthcare Decision Making by Adults with Learning disabilities; Ongoing Agendas, Future Challenges’ (2006) 5(10) *Psychiatry* 361.

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 formality¹¹³. 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”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 patient¹¹⁵. 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’

¹¹³Dunn, Clare and Holland, n85.

¹¹⁴ Seen in *Re MM (An Adult)* [2007] EWHC 2003 (Fam) Para 99 Per Munby J.

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"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 decision¹¹⁷. 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 prevail¹¹⁸. In many ways, this approach which posits the family as the primary unit has echoes of the familist traditions of the China and Hong-Kong¹¹⁹. 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 else¹²⁰. A more appropriate response to the nature of interdependence in caring relations is thus to encourage a more open dialogue

¹¹⁶ Dunn *et al*, n85, p157.

¹¹⁷ J. Hardwig. 'Is there a duty to die? (1997) 27*Hastings Centre Report*, p36.

¹¹⁸ *Ibid.* p35.

¹¹⁹ See R. Fan, J. Tao 'Consent to Medical Treatment: The Complex Interplay of Patients, Families, and Physicians' (2004) 29(2) *Journal of Medicine and Philosophy*; Ho Mun Chan, 'Informed Consent Hong Kong Style: An Instance of Moderate Familism' (2004) 29(2) *Journal of Medicine and Philosophy* 195-206; Yali Cong, 'Doctor-Patient-Family Relationship: The Chinese Paradigm of Informed Consent' (2004) 29(2) 149—178.

¹²⁰ H. Lindemann Nelson and J. Lindemann Nelson, *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 recognised¹²¹. 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 interests¹²². Additionally, the research provisions are attentive to the vulnerability of those lacking capacity when wider interests are being brought into the balance¹²³, directing researchers to look for signs of objection¹²⁴. 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 making¹²⁵. Collaborative decision making is being

¹²¹ Donnelly similarly points out that “[t]here 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 this¹²⁶. 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 difference¹²⁷. 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 families¹²⁸. 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 conflicts¹²⁹. 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 way¹³⁰.

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) *Current Legal Problems* 1-22, p10.

¹²⁷ S. Benhabib, *Situating the Self: Gender, Community and Postmodernism in Contemporary Ethics* (Routledge 1992).

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, *Rethinking Feminist Ethics: Care, Trust and Empathy* (New York, Routledge, 1998) p27.

¹²⁹ J. Herring and C. Foster 'Welfare means relationally, virtue and altruism' (2012) 32(3) *Legal Studies* 480-498.

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) *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 home¹³². 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 them¹³⁴.

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 precedence¹³⁵. 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.

¹³³ [2011] EWHC 2778.

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 needs¹³⁶. Traditional justice based models do not always capture these factors¹³⁷. 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 for¹³⁸ 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 relationship¹³⁹. 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”¹⁴⁰. The focus of reforms here should thus be on “empowerment rather than non-interference”¹⁴¹ - both for carers and for the person being cared for.

4.7 Conclusion

¹³⁶ Research into older people and human rights has highlighted that significant attitudinal and practical barriers exist which prevent older people from exercising their rights. [British Institute for Human Rights and Age UK, *Older People and Human Rights: A Guide for Professionals Working with Older People*, 2nd Ed (March 2011) p7 available at

http://www.bihhr.org.uk/sites/default/files/Older_People_Human_Rights__Expert_series_pro.pdf; F. Butler, *Rights for Real: Older people, human rights and the CEHR* (London, Age Concern, 2006).

¹³⁷ N. Ward, ‘Care Ethics and Carers With Learning Disabilities: A challenge to dependence and paternalism’ (2011) 5(2) *Ethics and Social Welfare* p176.

¹³⁸ Yannamani et al. n51, p442.

¹³⁹ Hankivsky, n106, p120.

¹⁴⁰ K. Rummery, ‘A Comparative Analysis of Personalisation: Balancing an Ethic of Care with User Empowerment’ (2011) 5(2) *Ethics and Social Welfare*, p148.

¹⁴¹ M. Donnelly, ‘Best interests, patient participation and the Mental Capacity Act 2005’ (2009) 17 *Medical Law Review*, p7.

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 deemphasize 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 *al*, n24,p51.

¹⁴³ E. Skaerbaek, ‘Navigating in the Landscape of Care: A Critical Reflection on Theory and Practise of Care and Ethics’, (2011) 19 *Health Care Analysis*,p47.

with¹⁴⁴. 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 makers¹⁴⁵, 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 challenged¹⁴⁶. 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?"¹⁴⁷

¹⁴⁴ See, for example, M. Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' *Medical Law Review* 17 (2009) 1-29 for an analysis of the problems entailed in participatory decision making.

¹⁴⁵ Dunn *et al*, n85.

¹⁴⁶ Ho, n7, p132.

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.) *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 rights¹⁴⁸. 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*¹⁴⁹ 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;¹⁵⁰ however, it serves as a

¹⁴⁸ G. Quinn, ‘Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD’ (Harvard, Harvard Project on Disability, 20 February 2010).

¹⁴⁹ *Cheshire West and Chester Council v P* [2011] EWCA Civ 1257.

¹⁵⁰ *P v Cheshire West and Chester Council and P and Q v Surrey County Council* [2014] UKSC 19.

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*¹⁵¹ and *Aintree v James*¹⁵² 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 liberty¹⁵³. 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

¹⁵¹ *Ibid.*

¹⁵² *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

¹⁵³ J. Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy and Law* (Oxford, OUP, 2012).

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”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 state¹⁵⁵ 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 disabilities¹⁵⁶. 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 body¹⁵⁷. Disability, viewed from this perspective, is simply an “unfortunate state of functioning and being”¹⁵⁸ with a resultant focus on biological cure or management of the condition or person. The medical model thus sees “diagnosis and classification

¹⁵⁴ C. Unsworth, *The Politics of Mental Health Legislation* (Oxford, Clarendon Press, 1987) p5.

¹⁵⁵ M.A. Fineman, ‘The Vulnerable Subject and the Responsive State’, (2011) 60 *Emory Law Journal* (Symposium Issue on ‘The New Deal’).

¹⁵⁶ G. Quinn and T. Degener, (Eds), *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, (Geneva, Office of the United Nations Commissioner for Human Rights, 2002).

¹⁵⁷ C. Barnes and G. Mercer, *Implementing the Social Model of Disability: Theory and Research* (Leeds, The Disability Press, 2004)p2.

¹⁵⁸ Nedelsky, n6, p209.

functioning as ends”¹⁵⁹. 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 grip¹⁶⁰. 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 model¹⁶¹. 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 professionals¹⁶². 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”¹⁶³. 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

¹⁵⁹ K. Shogren, ‘Considering Context: An Integrative Concept for Promoting Outcomes in the Intellectual Disability Field’ (2013) 51(2) *Intellectual and Developmental Disabilities*, p133.

¹⁶⁰ P. Bartlett, ‘Judging Disability: The Problem of Ableism’ (1997) 2(3) *Human Rights Law Review* p2; P. Beresford *et al*, *Towards a Social Model of Madness and Distress? Exploring What Service Users Say* (York, Joseph Rowntree Foundation, 2010); P. Bartlett, ‘The United Nations Convention on the Rights of Persons with Disability and Mental Health Law’ (2012) 75(5) *Modern Law Review* 752-778.

¹⁶¹ The Mental Health Act 1983 (Amended 2007) ss2 and 3.

¹⁶² P. Conrad and C. Slodden, ‘The Medicalization of Mental Disorder’ in C. Aneshensel, J. Phelan and A. Bierman (Ed) *Handbook of the Sociology of Mental Health* (Netherlands, Springer, 2013) 61-73.

¹⁶³ J.K. Burns, ‘Mental Health and Inequity: A Human Rights Approach to Inequality’ (2007) 11(2) *Health and Human Rights*, p21.

pharmacological means combined with psychotherapy, with the Mental Health Act circumscribing and legitimising the provision of such treatments¹⁶⁴. 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 impairment¹⁶⁶. 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 brain¹⁶⁸ - 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 Act¹⁶⁹. A recent worrying example of this can be seen in *Re AA*,¹⁷⁰ a case

¹⁶⁴ Mental Health Act 1983, Part IV.

¹⁶⁵ P. Bartlett and R. Sandland, *Mental Health Law: Policy and Practice* (3rd Ed, Oxford, OUP, 2007) p9.

¹⁶⁶ See cases such as *B v Croydon Health Authority* [1995] 1 ALL ER 683 (CA) and *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 *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 *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.

¹⁶⁷ P. Beresford *et al*, above n13, p13.

¹⁶⁸ Mental Capacity Act 2005 s2(1).

¹⁶⁹ The Mental Capacity Act 2005, s3(1). See, for example, *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.’

¹⁷⁰ [2012] EWHC 4378 (COP) (In Private).

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 happen¹⁷¹

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

¹⁷¹*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 incapacity¹⁷². Whilst there is a presumption of capacity in the Act, the demands of impartiality may be difficult to achieve in practice for medical professionals¹⁷³. Taylor draws attention to how assumptions of rationality, independence and normalcy can produce wrongful and harmful views of disability and humanity of disabled lives¹⁷⁴. Capacity can in turn be questioned on the “flimsiest evidence”¹⁷⁵. 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”¹⁷⁶. 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 factors¹⁷⁷.

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

¹⁷² See *Re C* [1994] 1 WLR 290 and, more recently *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 (COP).

¹⁷³ J. Bellhouse *et al*, ‘Decision Making Capacity in Adults: It’s Assessment in Clinical Practice’ (2001) 7 *Advances in Psychiatric Treatment*, p296.

¹⁷⁴ A. Taylor, “‘Lives Worth Living:’ Theorizing Moral Status and Expressions of Human Life’ (2013) 33(4) *Disability Studies Quarterly*, available online only at <http://dsq-sds.org/article/view/3875/3404> [last accessed 8th July 2014].

¹⁷⁵ Bartlett, n13, p461.

¹⁷⁶ B. Secker, ‘Labelling Patient (In)Competence: A Feminist Analysis of Medico-Legal Discourse’ (1999) 30(2) *Journal of Social Philosophy*, p296.

¹⁷⁷ N.F. Banner, ‘Can Procedural and Substantive Elements of Decision Making be Reconciled with Assessments of Mental Capacity?’ (2013) 9(1) *International Journal of Law in Context*, p84.

be reduced to clinical interests¹⁷⁸. This was reflected in the Select Committee's conclusions, where it was highlighted that clinical judgements or resource-led decision-making predominate¹⁷⁹. 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'¹⁸⁰. Furthermore, through this narrow lens, "patients become understood in terms of physical, mental or emotional frailty and dysfunction"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 society¹⁸².

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

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

¹⁷⁹ House of Lords Select Committee on the Mental Capacity Act 2005, 'Mental Capacity Act 2005 : Post-Legislative Scrutiny' (London: The Stationery Office, 13th March 2014).

¹⁸⁰ 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* (Aldershot, Dartmouth, 1995).

¹⁸¹ K. Keywood, "'I'd Rather Keep Him Chaste" Retelling the Story of Sterilisation, Learning Disability and (Non)Sexed Embodiment' (2001) 9 *Feminist Legal Studies*, p190.

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: Boundaried and Relational Rights' (2005) 13 *International Journal of Children's Rights*, p110, 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 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?' *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 DoLS¹⁸⁵ 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 Rights¹⁸⁶.

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.

¹⁸⁶ The DoLS have attracted significant criticism since their commencement in April 2009: A. Szerletics and T. O’Shea, *The Deprivation of Liberty Safeguards* (Essex Autonomy Project Briefing, 2011); also see CQC, *Monitoring the use of the Mental Capacity Act 2005 Deprivation of Liberty Safeguards 2011/12* available at <http://www.cqc.org.uk/public/reports-surveys-and-reviews/reports/deprivation-liberty-safeguards-2011/12>; R. Hargreaves, *Briefing Paper 1-Deprivation of Liberty Safeguards: An initial review of implementation*, (London, Mental Health Alliance, 2010) available at http://www.mentalhealthalliance.org.uk/resources/DoLS_report_July2010.pdf; Mental Health Alliance, *The Mental Health Act 2007: A Review of its Implementation* (London, Mental Health Alliance, 2012) available at

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,¹⁸⁷ 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”,¹⁸⁸ and that instead the task should be to “identify what it is that we are comparing X’s concrete situation with”¹⁸⁹. 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”,¹⁹⁰ 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

http://www.mentalhealthalliance.org.uk/news/MHA_May2012_FINAL.pdf. Concerns about the practical effects of the DoLS, and the Mental Capacity Act 2005 more generally were expanded upon in the evidence submitted to the House of Lords Select Committee on the Mental Capacity Act 2005, in which DoLS featured heavily. <http://www.parliament.uk/business/committees/committees-a-z/lords-select/mental-capacity-act-2005/> Reporting deadline 28th Feb 2014. The Select Committee have recommended a comprehensive review of the Deprivation of Liberty Safeguards and their replacement. See above, n 32.

¹⁸⁷ D. Hewitt, ‘Objection, Purpose and Normality; Three ways in which the courts have inhibited safeguarding’ *Journal of Adult Protection* (2012) 14(6) 280-286.

¹⁸⁸ Para 38.

¹⁸⁹ Para 39.

¹⁹⁰ Para 102.

are ‘inherently restricted’ or ‘dictated’ by their own ‘cognitive limitations’¹⁹¹. 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”¹⁹². 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 *ibid.*

¹⁹² *ibid.*

and learning disabilities, *whose lives are dictated by their own cognitive and other limitations*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,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 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"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 community¹⁹⁶ and the framing of individual responses based on this. An approach predicated on "false universalising"¹⁹⁷ prevents such

¹⁹³ Para 120 (emphasis added).

¹⁹⁴ Barnes and Mercer, n10, p2.

¹⁹⁵ Hewitt, n40, p284.

¹⁹⁶ C. O'Mahony, Legal Capacity and Detention: Implications of the UN Disability Convention for the Inspection Standards of Human Rights Monitoring Bodies' (2012) 16(6) *International Journal of Human Rights*, p884.

¹⁹⁷ *Ibid*; AsShakespeare 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 issue¹⁹⁸ and in particular the right to liberty in the context of institutional care has been repeatedly asserted in Strasbourg¹⁹⁹. 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”²⁰⁰.

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 liberty²⁰¹. Lady Hale delivered a resounding statement of the “universal character of human rights, founded on the inherent dignity of all human beings”²⁰² and stated that this serves as a

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’ T. Shakespeare and N. Watson, ‘The Social Model of Disability: An Outdated Ideology?’ (2002) 2 *Research in Social Science and Disability*, 9-29, p30.

¹⁹⁸ C. Baylies, ‘Disability and the Notion of Human Development: questions of rights and capabilities’ (2002) 17(7) *Disability and Society*, p728.

¹⁹⁹ See, for example, *Ashingdane v UK* Series A no. 93, judgment of 28 May 1985; *HL v UK* [2004] ECHR 471; *Storck v Germany* [2005] 43 EHRR 96; *Stanev v Bulgaria* (2012) ECHR 46; *DD v Lithuania* [2012] ECHR 254; *Austin v UK* (2012) ECHR 459; *Kedzior v Poland* [2012] ECHR 1809.

²⁰⁰ Hewitt, n40, p284.

²⁰¹ *P v Cheshire West and Chester Council and P and Q v Surrey County Council* [2014] UKSC 19.

²⁰² Para 45, per Lady Hale.

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*²⁰⁶. 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 prevail²¹⁰. 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

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.

²¹¹ McLean and Williamson, n35; P. Fennell, ‘Best Interests and Treatment for Mental Disorder’ (2008) 16 *Health Care Analysis* 255-267.

from P's perspective²¹². The 'touchstone of intolerability', itself a medicalised concept residing in much of the case law involving children,²¹³ 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 model²¹⁴.

The case of *RB v Brighton and Hove CC*,²¹⁵ 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"²¹⁶. Whilst regard is had to the requirement to take into account RB's wishes, these are perfunctorily dismissed with little explanation²¹⁷. 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.

²¹² See, for example, Para 41.

²¹³ *Re J (Wardship: Medical Treatment)* [1991] Fam 33; *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1881.

²¹⁴ See literature in n35 for discussion about the medical model in decision making at the beginning of life.

²¹⁵ (2014) EWCA Civ 561.

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 state²¹⁸. In essence, the core of the social model, in its original formulation, is that societal structures and institutions, rather than impairments, cause disability²¹⁹. 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 perspectives²²⁰. Commentators have emphasised the need to bring individual experiences back into social approaches to disability²²¹ 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 cultural²²². 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

²¹⁸ S Goering, ‘Revisiting the Relevance of the Social Model of Disability’ (2010) 10(1) *American Journal of Bioethics*, p54.

²¹⁹ M Oliver, *The Politics of Disablement* (Palgrave Macmillan, 1990); M. Oliver, *Understanding Disability: From Theory to Practice* (Palgrave Macmillan, 1996).

²²⁰ M. Miles, ‘The Social Model of Disability Met a Narrative of (In)credulity: A Review’ (2011) 22(1) *Disability, CBR and Inclusive Development* 5-15; C. Barnes and G. Mercer, ‘Breaking the Mould’ in C. Barnes and G. Mercer (Eds) *Doing Disability Research* (Leeds, The Disability Press, 2006) 1-14; T. Shakespeare *Disability Rights and Wrongs* (London, Routledge, 2006); S. McLean and L. Williamson, Ch1 ‘Conceptualising Disability’ in McLean and Williamson, n 35, 11-36.

²²¹ T. Shakespeare and N. Watson, n50; L. Crow, ‘Including All Our Lives: Renewing the Social Model of Disability’ in C. Barnes and G. Mercer, *Exploring the Divide: Illness and Disability* (Leeds, The Disability Press, 1996); J. Morris, *Pride Against Prejudice: Transforming Attitudes To Disability* (California, New Society, University of California, 1991); J. Morris, *Encounters with Strangers: Feminism and Disability* (University of Michigan, Women’s Press, , 1996).

²²² Shakespeare and Watson, *ibid.* 28.

from the medical model perspective who define people by their impairment”²²³. 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”²²⁴. However, commentators are engaging more with the interplay between cognitive impairment and disability²²⁵. 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 themselves²²⁶. 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 circumstances²²⁷. Thus, a polarised distinction between the social and medical

²²³ Shakespeare and Watson, *ibid.* 23-26.

²²⁴ J. Gilliard *et al*, ‘Dementia Care in England and the Social Model of Disability: Lessons and Issues’ (2005) 4 *Dementia*, p573.

²²⁵ J. Gilliard *et al*, *ibid.* 571-586; P. Dorenlot, ‘Applying the Social Model of Disability to Dementia; Present day challenges’ (2005) 4 *Dementia* 459-461; L. Terzi, ‘The Social Model of Disability: A Philosophical Critique’ (2004) 21(2) *Journal of Applied Philosophy* 141-157; S. Vehmas, ‘Ethical Analysis of the Concept of Disability’ (2004) 42(3) *Mental Retardation* 209-222; E.F. Kittay and L. Carlson (Eds) *Cognitive Disability and its Challenge to Moral Philosophy* (New York, Wiley Blackwell, 2010); K. Shogren, ‘Considering Context: An Integrative Concept for Promoting Outcomes in the Intellectual Disability Field’ (2013) 51(2) *Intellectual and Developmental Disabilities*, 132-137; D. Goodley, ‘Who is Disabled? Exploring the Scope of the Social Model of Disability’ in J. Swain, S. French, C. Barnes and C. Thomas (Eds) *Disabling Barriers- Enabling Environments* (Sage: London, 2nd Ed, 2004) 118-124; A. Chappell, D. Goodley, R Lawthorn, ‘Making Connections: The Relevance of the Social Model of Disability for People with Learning Difficulties’ (2001) 29 *British Journal of Learning Disabilities* 45-50.

²²⁶ Beresford *et al*, n13.

²²⁷ J. Rothman, ‘The Challenge of Disability and Access: Reconceptualizing the Role of the Medical Model’ (2010) 9(2) *Journal of Social Work in Disability and Rehabilitation*, p205.

models is perhaps unhelpful and inappropriate. A bio-psychosocial model has been advocated for by commentators recently²²⁸. Such an approach seeks to carve a ‘third way’ between the extremes of the social and medical models;²²⁹ one which recognises that “bodies are lived in, but in the social spaces that they inhabit”²³⁰. 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,²³¹ 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”²³². 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

²²⁸ Rothman, *ibid.*; McLean and Williamson, n35; P. Louhiala, ‘Philosophy Meets Disability’ (2009) 35 *Journal of Medical Ethics* p570; S. Vehmas and P. Makela, ‘The Ontology of Disability and Impairment: A Discussion of the Natural and Social Features’ in K. Kristiansen, S. Vehmas and T. Shakespeare (Eds) *Arguing about Disability: Philosophical Perspectives* (London, Routledge, 2009) 42-56; D. Goodley, ‘Dis/entangling Critical Disability Studies’ (2013) 28(5) *Disability & Society* 631-645.

⁸² P. Louhiala, *ibid.*

⁸³ D. Goodley, ‘Dis/entangling Critical Disability Studies’ n81.

⁸⁴ T. Burchdardt, ‘Capabilities and Disability: the Capabilities Framework and the Social Model of Disability’ (2004) 19(7) *Disability and Society* 735; Also see A. Samaha, ‘What good is the social model of disability?’ (2007) 74(4) *University of Chicago Law Review* 1251-1308.

²³² C. Barnes, G. Mercer and T. Shakespeare, *Exploring Disability: A Sociological Introduction* (Cambridge, Polity, 1999) p227.

claim is being made, fosters or undermines the achievement of such goals²³³. 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 1980s²³⁴. 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 support²³⁵. The sense is that the resulting legal framework has simply created "medical freedom with the appearance of legal control",²³⁶ with the ethos informing Gostin's original work being "lost in translation into domestic law"²³⁷. 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.

²³⁴ L. Gostin, *A Human Condition 1* (London, National Association for Mental Health, 1975); L. Gostin, *A Human Condition 2* (London, National Association for Mental Health, 1977); L. Gostin, 'Contemporary Social Historical Perspectives on Mental Health Reforms', (1983) 10 *Journal of Law and Society*, 47-70.

²³⁵ P. Fennell, 'Institutionalising the Community' in B. McSherry and P. Weller (Eds) *Rethinking Rights Based Mental Health Law* (Oxford, Hart Publishing, 2010) 17; P. Gooding 'Supported Decision Making- A Rights-Based Disability Concept and its Implications for Mental Health Law' (2013) 20(3) *Psychiatry Psychology and Law*, p430.

²³⁶ Bartlett and Sandland, n18, p347.

²³⁷ P. Weller, 'Lost in Translation: Human Rights and Mental Health Law', in McSherry and Weller, n88, p54.

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.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”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 valuable²⁴⁰. 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”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”²⁴².

²³⁸ G. Richardson, ‘Rights-Based Legalism: Some Thoughts from the Research’ in McSherry and Weller, n88, p182.

²³⁹ E. Palmer, *Judicial Review, Socio-economic Rights and the Human Rights Act* (Oxford, Hart: 2007) p24.

²⁴⁰ 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.

²⁴¹ D. Pilgrim, ‘Lessons from the Mental Health Act Commission for England and Wales: The Limitations of Legalism-Plus-Safeguards’ (2012) 40(1) *Journal of Social Policy*, p78.

²⁴² A. S. Kanter, ‘The Law: What’s Disability Studies got to do with it, or an introduction to disability legal studies’ (2011) 42(2) *Columbia Human Rights Law Review*, p32.

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’²⁴³ 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”²⁴⁴.

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 context²⁴⁵. 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”²⁴⁶. 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”²⁴⁷ 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

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 recognised²⁴⁸ 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 Sen²⁵⁰ 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

²⁴⁸ N. Rose, 'Unreasonable Rights: Mental Illness and the Limits of the Law' (1985) 12(2) *Journal of Law and Society*, 199-218.

²⁴⁹ C. O'Cinneide. 'Legal accountability and social justice' in P. Leyland, N. Bamforth (Eds.), *Accountability in the contemporary constitution* (Oxford, OUP, 2013). See also J. King, *Judging Social Rights* (Oxford, OUP, 2012).

²⁵⁰ A. Sen, 'Equality of What?' *Tanner Lecture* (Stanford University, 1979); A. Sen, *The Idea of Justice*, (Penguin, 2010).

²⁵¹ M. Nussbaum and A. Sen, *The Quality of Life* (Oxford, Oxford University Press, 1993); M. Nussbaum, 'Capabilities and Human Rights', (1997) 66(2) *Fordham Law Review*, 293-4; M. Nussbaum, 'Capabilities as Fundamental Entitlements: Sen and Social Justice' (2003) 9(2) *Feminist Economics* 33-59.

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

²⁵⁴ C. Arjona *et al.* 'Senses of Sen: Reflections on Amartya Sen's Ideas of Justice' (2012) 8(1) *International Journal of Law in Context*, p159.

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'.

²⁵⁶ T. Burchardt, 'Capabilities and Disability: The Capabilities Framework and the Social Model of Disability' (2004) 19(7) *Disability and Society* 735-751.

²⁵⁷ L. Terzi, 'The Social Model of Disability: A Philosophical Critique' (2004) 21(2) *Journal of Applied Philosophy* 141-157.

²⁵⁸ C. Tollefsen, 'Disability and Social Justice' in D. Ralston and J. Ho (Eds) *Philosophical Reflections on Disability* (New York, Springer, 2010) 211-227.

²⁵⁹ A. Sen, *The Idea of Justice*, (2nd Ed, London, Penguin, 2010) p246.

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”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 rights²⁶¹. 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”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.

²⁶⁰ S. Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York, Routledge, 1996) p71.

²⁶¹ *ibid.* p37.

²⁶² M. Nussbaum, *The Frontiers of Justice* (Cambridge, MA, Harvard University Press, Belknap Press, 2006) p54.

One of the crucial aspects of the capabilities approach is that it can serve as a device “to justify the making of political claims”²⁶³. From the informational focus on a person’s actual ability to achieve certain basic capabilities,²⁶⁴ 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”²⁶⁵. 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 justice²⁶⁶. 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”²⁶⁷ based on an understanding that given appropriate and adequate enabling conditions, individuals with intellectual disabilities can become fully cooperating members of society²⁶⁸.

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

²⁶³ Baylies, n 51, p735.

²⁶⁴ Sen, n 112, p232.

²⁶⁵ M. Nussbaum, ‘*Beyond the Social Contract: Toward Global Justice*’ in *The Tanner Lectures on Human Values*, (University of Utah Press, 2004) p458.

²⁶⁶ J. Ruger *Health and Social Justice* (Oxford, Oxford University Press, 2012) p1076.

²⁶⁷ *ibid.* p729. See also Samaha, n 73, p1303; M. Fox and M. Thomson, ‘Realising Social Justice in Public Health Law’ (2013) 21 Med LR p288 and p304.

²⁶⁸ S. Wong. “Duties of Justice to Citizens with Cognitive Disabilities.” in E. F Kittay and L. Carlson (Eds), *Cognitive Disability and its Challenge to Moral Philosophy* (Malden, Wiley-Blackwell, 2010) 127-146. This is not a new idea - Carson earlier spoke of ‘utilizing positively valued services and ideas in order to enhance expectations of and dignity for the people concerned’. D. Carson, ‘Disabling Progress: The Law Commission’s Proposals on Mentally Incapacitated Adults Decision Making’ (1993) 15(5) *Journal of Social Welfare and Family Law*, p305.

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, Jessica Kingsley, 2009) p35.

²⁷⁰ O’Mahony, n49; Samaha, n73.

²⁷¹ United Nations Convention on the Rights of Persons with Disability 2006, Preamble.

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’.

and policies”²⁷³ 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 occur²⁷⁴. Denial of reasonable accommodation under the Convention forms a basis upon which a claim for discrimination can be made,²⁷⁵ 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 Convention²⁷⁶. 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

²⁷³ J. Lord and R. Brown, ‘The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities’ in M. Rioux, L. Basser and M. Jones (Eds) *Critical Perspectives on Human Rights and Disability Law*, (UK, Martinus Nijhoff, 2011) p277.

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’.

²⁷⁶ A. Dhanda, ‘Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?’ (2006-7) 34 *Syracuse Journal of International Law and Commerce*, p429; Gooding, n88.

resonates with the theoretical insights presented above in calling for the facilitation of abilities to realise capabilities²⁷⁷.

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 disability²⁷⁸. However, it should be seen as providing more than simply a ‘radical social constructionist’ approach to disability rights²⁷⁹. It reinforces and reaffirms the importance of enforceable rights and entitlements,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 secured²⁸¹. 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 liberty²⁸². 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

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

²⁷⁸ See for example Bartlett (2012) n13; D. Mackay, ‘The United Nations Convention on the Rights of Persons with Disabilities’ (2006/7) 34 *Syracuse Journal of International Law and Commerce* 323-332; A. Dhanda, ‘Constructing a New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities’ (2008) 5(8) *International Journal of Human Rights*, p43.

²⁷⁹ Contra R. Kayess and P. French ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8(1) *Human Rights Law Review* 1-34.

²⁸⁰ E. Flynn, ‘Making Human Rights Meaningful for People with Disabilities: Advocacy, Access to Justice and Equality Before the Law’ (2013) 17(4) *International Journal of Human Rights* 497; Owen and Griffith, n122.

²⁸¹ UNCRPD Article 4, ‘General Obligations’.

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 lives²⁸³. 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 ground²⁸⁴. 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

²⁸³ Office of the High Commissioner for Human Rights, *'Committee on the Rights of Persons with Disability General Comment No 1: Article 12 Equal Recognition Before the Law'* (Eleventh Session, 31st March-11th April 2014) Para 7, available at http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD/C/GC/1&Lang=en [last accessed 2nd April 2014].

²⁸⁴ T. Collingbourne, 'Administrative Justice? Realising the Right to Independent Living: Power, Systems, Identities' (2013) 35(4) *Journal of Social Welfare and Family Law* 475-489.

transparency, accountability and responsiveness²⁸⁵. 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 disabilities²⁸⁶. Concerns have been raised about the level of advice being offered when services are sought out²⁸⁷ alongside recommendations for training for those in the legal professions on good practice²⁸⁸. The fact remains that those most at risk of abuse, neglect or exploitation, remain the least likely to access advice or representation²⁸⁹ 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 be²⁹⁰. 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

²⁸⁵ S. Ortoleva, 'Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System' (2011) 17(2) *ILSA Journal of International and Comparative Law*, 281-317.

²⁸⁶ P. Swift *et al*, 'What Happens When People with Disabilities Need Advice about the Law?' (University of Bristol: Norah Fry Research Centre, 2013).

²⁸⁷ A. Lawson and E. Flynn 'Disability and Access to Justice in the European Union: Implications of the United Nations Convention on the Rights of Persons with Disabilities', (2013) 4 *Yearbook of European Disability*, 7-44

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”²⁹²

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 home²⁹³. 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

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 proceedings²⁹⁴. 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 these²⁹⁵. 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*²⁹⁶ 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 development²⁹⁷. 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:

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

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 here³⁰¹. 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 approaches³⁰³.

A similar problem with the traditional legal framework being applied in individual cases in the mental capacity context is the concept of best interests³⁰⁴. There is a sense, at a general level, that best interests decision making- and in particular the emphasis on objective

³⁰¹ S. Meckled- Garcia and B. Cali, *The Legalization of Human Rights-Multidisciplinary Perspectives on Human Rights and Human Rights Law* (Oxon, Routledge, 2006).

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 considerations³⁰⁵. 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’³⁰⁶. However, scope for doing so may be limited. Cases such as *Aintree v James*³⁰⁷ and *ACCG v MN*³⁰⁸ 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’³⁰⁹. Thus, there is no scope for demanding particular treatments or services, as this is not a right afforded generally in health and social care³¹⁰. 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”³¹¹. 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.

³⁰⁶ J. Lord, D. Suozzi and A. Taylor, ‘Lessons from the experience of the United Nations Convention on the Rights of Persons with Disabilities: Addressing the Democratic Deficit in Global Health Governance’ 38(3) (2010) *Journal of Law, Medicine and Ethics*, p568.

³⁰⁷ [2013] UKSC 67.

³⁰⁸ [2013] EWHC 3859 (COP).

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 individual³¹². 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 behalf³¹³. 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 justice³¹⁴. 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 around³¹⁵. 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.

³¹² Para 73.

³¹³ n152.

³¹⁴ J. Ruger *Health and Social Justice* (Oxford, OUP, 2012) 1076.

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

³¹⁶ G. Quinn, *Rethinking Personhood: New Questions in Legal Capacity Law and Policy* (Vancouver, University of British Columbia, 2011) p52.

³¹⁷ O’Cinneide, n102, J. Herring *Caring and the Law* (Oxford, Hart, 2013).

justice are engaged³¹⁸. 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 ingrained³¹⁹.

There are undoubtedly public law concerns to be raised when calls are made for more judicial intervention in such decisions³²⁰. This is particularly the case when resources are at stake such as in community care funding assessments, and - less visibly - in the DoLS context³²¹. 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 resources³²² 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

³¹⁸ H. Carr, 'Rational men and difficult women – R (on the application of McDonald) v. Royal Borough of Kensington and Chelsea [2011] UKSC 33' (2012) 34(2) *Journal of Social Welfare and Family Law*, p227.

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.

³²² K. Syrett, *Law, Legitimacy and the Rationing of Healthcare: A Contextual and Comparative Perspective* (Cambridge, Cambridge University Press, 2007).

voice for many with mental impairments, the judiciary play a vital role in providing recourse³²³. 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”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”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 *Cheshire West* welcome recognition of the universal nature of human rights, and the obligations stemming from reasonable

³²³ Herring, n170, p147.

³²⁴ O’ Cinneide, n102.

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 UNCPRD 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 UNCPRD 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 disabilities³²⁷ 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 UNCPRD,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.

³²⁷ See The University of Warwick Centre for Human Rights in Practice, *The Human Rights and Equality Impact Assessments of Public Spending Cuts - A Resource Database* available at <http://www2.warwick.ac.uk/fac/soc/law/chrp/projects/spendingcuts/resources/database/> [last accessed 6th June 2014].

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”³³⁰

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.

³³⁰ Carson, n121,p309.

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 beings¹. 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, 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”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.

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 law³. 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

¹ M Fineman and A Grear, *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (London, Ashgate, 2013).

² S Dodds, ‘Depending on Care: Recognition of Vulnerability and the Social Contribution of Care Provision’ (2007) 21(9) *Bioethics* 500, p501.

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 in⁴, 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 capacity⁵. 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 infections⁶. In adopting such an approach, the judiciary have repeatedly asserted that they are upholding private rights and sexual autonomy⁷, 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?”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

⁴ See J Herring, ‘Mental Disability and Capacity to Consent to Sex: A Local Authority v H [2010] EWHC 49 (CoP)’ (2012) 34 *Journal of Social Welfare and Family Law*, p471.

⁵ See *X City Council v MB, NB and MAB* [2006] EWHC 168 (Fam) and *Re MM (an adult)* [2007] EWHC 2003 (Fam).

⁶ *D Borough Council v AB* [2011] EWHC 101 (COP).

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 MCA¹⁰. 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.*

¹⁰ L Series, ‘Comparing Old and New Paradigms of Legal Capacity’ (2014) 1 *Elder Law Journal*, p62.

¹¹ K Keywood, ‘Supported to be Sexual? Developing Sexual Rights for People with Learning Disabilities’ (2003) 8(3) *Tizard Learning Disability Review*, p31.

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 policy¹². 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 vulnerability¹³. 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 invulnerable¹⁴. 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’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’,

¹² J Wallbank and J Herring, n3); C Mackenzie, W Rogers and S Dodds, *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford, OUP, 2014); M Fineman and A Gear, n1.

¹³ M Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (2008) 20(1) *Yale Journal of Law & Feminism* p1.

¹⁴ M. Fineman, ‘Equality, Autonomy and the Vulnerable Subject in Law and Politics’ in M. A Fineman and A. Gear, n1, p16.

¹⁵ Department of Health, *No Secrets* (London, TSO, 2000) Para 2.3.

“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 health¹⁷. 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 practices¹⁸, 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 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 these²⁰. 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

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.

¹⁸ M Fineman, ‘The Vulnerable Subject and the Responsive State’ (2010) 30 *Emory Law Journal* p266.

¹⁹ See J Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York, Routledge, 1993); V Held, *The Ethics of Care* (Oxford, OUP, 2006); D Engster, *The Heart of Justice: Care Ethics and Political Theory* (Oxford, OUP, 2007); J Herring, *Caring and the Law* (London, Hart, 2013)

²⁰ F Sherwood Johnson, ‘Constructions of Vulnerability in Comparative Perspective: Scottish Protection Policies and the Trouble with ‘Adults at Risk’ (2013) 28(7) *Disability and Society*, p910.

vulnerability²¹. 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 level²². 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”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 resilience²⁴. 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 pathogenic²⁶. Inherent sources are characterised as intrinsic to the human condition and inevitable need and dependence, although this can vary depending on age, gender, disability

²¹ B Clough, ‘What about us? A case for legal recognition of interdependence in informal care relationships’ (2014) 36(2) *Journal of Social Welfare and Family Law* p129.

²² M Fineman and A Grear, n1, p21.

²³ *Ibid.*

²⁴ C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford, OUP, 2014), p 46.

²⁵ A. Timmer, ‘A Quiet Revolution? Vulnerability in the European Court of Human Rights’ in M Fineman and A Grear, n1), p148.

²⁶ C Mackenzie, W Rogers and S Dodds, n24,p7.

and health status²⁷, whilst situational refers to context specific sources, which may be caused or exacerbated by the personal, social, political, economic and environmental situation²⁸. 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 vulnerability²⁹. 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 judgement in *IM v LM and Others*³¹ 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.*

³¹ *IM v LM and Others* [2014] EWCA Civ 37.

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 autonomy³⁷. 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.

³⁷ D Richardson, ‘Constructing Sexual Citizenship: Theorising sexual rights’ (2000) 20 *Critical Social Policy* 105, p110.

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 abuse³⁸. 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 cases³⁹ - 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 support⁴⁰. 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 this⁴¹. 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

³⁸ A Hollomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach* (London, Jessica Kingsley, 2011), p54.

³⁹ *D Borough Council v AB* [2011] EWHC 101.

⁴⁰ A Saxe and T Flanagan, 'Factors that impact on support workers' perceptions of the sexuality of adults with developmental disabilities: A quantitative analysis' (2014) 32 *Sexuality and Disability* 48.

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 curtailed⁴². 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 expression⁴³, 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 boundaries⁴⁴. This can lead to a high risk of abuse, pregnancies and sexually transmitted infections⁴⁵. 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 expression⁴⁶. 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

⁴² D Richardson, 'Constructing Sexual Citizenship: Theorising sexual rights' (2000) 20 *Critical Social Policy* 105, p110

⁴³ F Owen and D Griffiths, *Challenges to the Human Rights of People with Intellectual Disabilities* (Jessica Kingsley, 2009) p187

⁴⁴ A Hollomotz and The Speakup Committee, 'May We Please Have Sex Tonight? People With Learning Difficulties Pursuing Privacy in Residential Group Settings' (2008) 37 *British Journal of Learning Disabilities* p91.

⁴⁵ M McCarthy, 'Women with intellectual disability: Their sexual lives in the 21st century' (2014) 39(2) *Journal of Intellectual and Developmental Disability*, p125

⁴⁶ L. Tarzia, D. Fetherstonhaugh and M. Bauer, 'Dementia, Sexuality and Consent in Residential Aged Care Facilities' (2012) 38 *Journal of Medical Ethics* p609.

in a cupboard each morning and has to request it to be signed out whenever she wants it⁴⁷. This means that staff are inevitably aware of her sexual life, diminishing her control over private matters, with little clear justification⁴⁸. 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 these⁴⁹. 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 relationships⁵⁰. Thompson points to a "learned helplessness" which is manifested when individuals have to 'fit' into existing services⁵¹. Here, attention is drawn to the way in which individuals may be too afraid to challenge their violator⁵²; may feel helpless and powerless; or may not think that they have a choice about participation in sexual activity⁵³. Without the opportunity to experience intimate relationships, and to exercise choice and control in these (and in other aspects of life), sexual autonomy is impeded⁵⁴. 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.

⁴⁸ M McCarthy, 'Women with intellectual disability: Their sexual lives in the 21st century' (2014) 39(2) *Journal of Intellectual and Developmental Disability* 125.

⁴⁹ CHANGE, 'Talking About Sex and Relationships: The Views of Young People with Learning Disabilities' (2007-2010) Final report'.

⁵⁰ M McCarthy, n48, p128.

⁵¹ S A Thompson, 'Subversive political praxis: Supporting choice, power and control for people with learning difficulties' (2003) 18(6) *Disability & Society* 730.

⁵² Mencap *Behind Closed Doors* (London, Mencap, 2001)

⁵³ M McCarthy, *Sexuality and Women with Learning Disabilities* (London, 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 1st July 2014] p7- "development of capacity requires experience of living independently and being included in the community and forming relationships".

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*⁵⁵. 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 disorder⁵⁶; 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 refuse⁵⁷. With regard to the inability to refuse, this centres on the lack of capacity to choose, or being unable

⁵⁵ [2009] UKHL 42.

⁵⁶ s30(1)(c).

⁵⁷ s30(1)(d).

to communicate such a choice⁵⁸. 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 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’”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 it⁶¹. 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.

⁶⁰ *R v Cooper* [2009] UKHL 42, para 24, citing *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 290 and *Re MB (Medical Treatment)* [1997] 2 FLR 426.

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”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”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”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 retained⁶⁵. 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*⁶⁶. The case concerned a 41 year old woman, LM,

⁶²*Ibid.* para 27.

⁶³*Ibid.* para 26.

⁶⁴C. Saunders, ‘Making it count: sexual offences, evidential sufficiency, and the mentally disordered complainant’ (2010) 31(2) *Liverpool Law Review*, p189.

⁶⁵*D County Council v LS* [2010] EWHC 1544 (Fam) *D Borough Council v AB* [2011] EWHC 101 (CoP).

⁶⁶*IM v LM and Others* [2014] EWCA Civ 37.

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 decisions⁶⁷. 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"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 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,

⁶⁷*Sheffield City Council v E* [2004] EWHC 2808, para 136.

⁶⁸*Ibid.*

for a court assessing *capacity* to make a general evaluation which is not tied down to a particular partner, time and place”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 partners⁷⁰. 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”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”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 *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

⁶⁹ *IM v LM and Others* [2014] EWCA Civ 37, para 76.

⁷⁰ Noted by Wood J in *D County Council v LS* (2010), para 42.

⁷¹ *D Borough Council v AB* [2011] EWHC 101 (Fam), paras 34-35.

⁷² M Donnelly, ‘Capacity Assessment Under the Mental Capacity Act 2005: Delivering on the Functional Approach?’ (2009) 29(3) *Legal Studies* 464.

doubt about his or her capacity to consent to sexual relations showed signs of immediate interest in experiencing a sexual encounter with another person”⁷³ - as such, it is seemingly impossible to apply this functional, decision specific approach which is entailed in the statute⁷⁴.

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 Act⁷⁵. 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* 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”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.

⁷³ *IM v LM*, para 77.

⁷⁴ See J Herring and J Wall, ‘Capacity to Consent to Sex’ (2014) 22 *Medical Law Review* 260 for a more in depth legal critique of *IM v LM*.

⁷⁵ Mental Capacity Act 2005, s 27.

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 these⁷⁷. 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 possible⁷⁸. 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 approaches⁷⁹. 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 citizens⁸⁰. 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

⁷⁷ M Fineman and A Grear, n1, p13.

⁷⁸ C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, n24, p33.

⁷⁹ *Ibid.* p35; J. Nedelsky, *Laws Relations: A Relational Theory of Self, Autonomy and the Law* (Oxford, OUP, 2012)

⁸⁰ *Ibid.* p42. “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 opportunities⁸¹. 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 entitlements⁸⁴. More importantly, the ethos of the UNCRPD is very much about taking positive steps to enable rights to be protected⁸⁵. 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

⁸¹ C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, n24, p34.

⁸² M Nussbaum, *The Frontiers of Justice* (Harvard, Harvard University Press, 2006), p54.

⁸³ F Owen and D Griffiths, *Challenges to the Human Rights of People with Intellectual Disabilities* (London, Jessica Kingsley, 2009), p35.

⁸⁴ E. Flynn, ‘Making Human Rights Meaningful for People with Disabilities: Advocacy, Access to Justice and Equality before the Law’ (2013) 17 *International Journal of Human Rights* 497.

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 liberty⁸⁶.

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 lives⁸⁷. 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 law⁸⁸. 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-making⁸⁹. 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

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.

⁸⁷ 'General Comment (Number 1) on Art 12: Equal Recognition Before the Law' (April 2014) available at <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> [last accessed 15th August 2014].

⁸⁸ *Ibid.* para 1.

⁸⁹ *Ibid.* para 8.

UNCRPD⁹⁰. 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 UNCRPD⁹²- 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 engendered through non-interference and recognises that background social and political contexts are central to facilitating autonomy. Indeed, many have commented on

⁹⁰ *Ibid.* paras 13-15.

⁹¹ *Ibid.* para 14.

⁹² See e.g. P Bartlett, ‘The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law’ (2012) 75(5) *Modern Law Review* 752.

⁹³ C Harnacke, ‘Disability and Capability: Exploring the Usefulness of Martha Nussbaum’s Capabilities Approach for the UN Disability Rights Convention’ (2014) 41(4) *The Journal of Law, Medicine and Ethics* 769.

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 obligations⁹⁴. 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”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-discrimination⁹⁷. 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

⁹⁴ M Bach and L Kerzner, ‘A New Paradigm for Protecting Autonomy and the Right to Legal Capacity’ (2010) Prepared for the Law Commission of Ontario.

⁹⁵ G Quinn ‘Rethinking Personhood: New Questions in Legal Capacity Law and Policy’ (Vancouver: University of British Columbia, 2011), p52.

⁹⁶ *Ibid.* p57.

⁹⁷ R Kayess and P French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8(1) *Human Rights Law Review* 1, p10.

⁹⁸ J Bickenbach, ‘Minority Rights or Universal Participation: The Politics of Disablement’, in M Jones and L Bassar Mark (Eds) *Disability, Diversity-Ability and Legal Change* (London, Martinus Nijhoff, 1999) p101.

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 impairments⁹⁹. 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 protection¹⁰⁰. 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”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

⁹⁹ Mencap *Behind Closed Doors* (London, Mencap, 2001)

¹⁰⁰ A Hollomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach* (Jessica Kingsley, 2011), 34.

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 resources¹⁰². 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 autonomy¹⁰³. 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”¹⁰⁴. 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 making¹⁰⁵. 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”¹⁰⁶. In focusing on the informational aspect, the

¹⁰² M. Burdhardt, ‘Common frailty, Constructed Oppression: tensions and debates on the subject of vulnerability’ (2013) 28(4) *Disability & Society* 559.

¹⁰³ *Ibid.*

¹⁰⁴ A Hollomotz, n38, p41.

¹⁰⁵ K Keywood, Commentary: Safeguarding Reproductive Health? The Inherent Jurisdiction, Contraception and Mental Incapacity. *A Local Authority v A* [2010] EWHC 1549 (Fam)’ (2011) 19 *Medical Law Review* 326, p329.

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"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 with¹⁰⁸. Tied to this liberal understanding of autonomy is the corollary idea that autonomy increases with the reduction of state interference or restrictions¹⁰⁹. 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 interference¹¹⁰. 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"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"¹¹². The MCA, however, is not in a position to facilitate this here as it struggles to fit the reality into a workable framework.

¹⁰⁷ J Coggon and J Miola, 'Autonomy, Liberty and Medical Decision Making' (2011) 70(3) *Cambridge Law Journal* 524.

¹⁰⁸ MI Hall, 'Mental Capacity in the (Civil) Law: Capacity, Autonomy and Vulnerability' (2012) 58(1) *McGill Law Journal* 1.

¹⁰⁹ J Anderson and A Honneth, 'Autonomy, Vulnerability, Recognition and Justice' in J Christman and J Anderson (Eds) *Autonomy and the Challenges to Liberalism: New Essays* (Cambridge University Press, 2005) p128

¹¹⁰ S Doyle, 'The Notion of Consent to Sexual Activity for Persons with Mental Disabilities' (2010) 31 *Liverpool Law Review*, p119.

¹¹¹ F Sherwood Johnson, 'Constructions of Vulnerability in Comparative Perspective: Scottish Protection Policies and the Trouble with 'Adults at Risk' (2013) 28(7) *Disability and Society* p917.

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 capacitous and thereby autonomous, are left outside of its remit, even if they are vulnerable¹¹³. 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*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”¹¹⁵, 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 dog¹¹⁶. 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.

¹¹³ D.Hewitt, ‘Not just in the Mental Capacity Act: Using the Law to Protect Vulnerable Adults’ (2009) 11(2) *Journal of Adult Protection* 25, p26.

¹¹⁴ [2012] EWHC 49 (COP).

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* 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. 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”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, 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

¹¹⁷ *A Local Authority v TZ* [2013] EWHC 2322 (COP); *A Local Authority v TZ (No.2)* [2014] EWHC 973 (COP)

¹¹⁸ *Ibid* (No.2), para 18.

¹¹⁹ *Ibid*. para 17.

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 relations¹²⁰. 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 individual¹²¹, rather than supporting him to make the decision for himself, and seems to perpetuate the legal interference with the validity of his actions¹²². 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’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

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.

¹²³ J Wall and J Herring, ‘Capacity to Cohabit: Hoping Everything Turns out well in the end- *PC v City of York*’ (2013) 25(4) *Child and Family Law Quarterly* 471.

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.*

¹²⁶ MI Hall, ‘Mental Capacity in the (Civil) Law: Capacity, Autonomy and Vulnerability’ (2012) 58(1) *McGill Law Journal* 1-35, p29.

¹²⁷ P Bartlett and R Sandland, *Mental Health Law Policy and Practice* (Oxford University Press, 2014) p182.

¹²⁸ MI Hall, ‘Mental Capacity in the (Civil) Law: Capacity, Autonomy and Vulnerability’ (2012) 58(1) *McGill Law Journal* p33.

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 place¹³⁰. 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 life¹³¹. External and environmental factors can have an impact on choices far beyond the impact of the impairment or disability¹³². 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.

¹³⁰ A Hollomotz, ‘Are We Valuing People’s Choices Now? Restrictions to Mundane Choices Made by Adults with Learning Difficulties’ (2012) *British Journal of Social Work* 1.

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

¹³² M. McCarthy, ‘Drawing a Line between consented and abusive sexual experiences: The complexities for women with learning disabilities’ (2003) 5(3) *The Journal of Adult Protection*, p34.

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 objects¹³⁴. 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 out¹³⁶. Similarly, Emma discussed how she had a long term partner who became controlling and sometimes locked her

¹³³ A Hollomotz, n38,p47.

¹³⁴ G Quinn and T Degener, ‘Human Rights and Disability : The current use and future potential of United Nations human rights instruments in the context of disability’ (United Nations, 2002) available at <http://www.ohchr.org/Documents/Publications/HRDisabilityen.pdf> [last accessed 28th June 2014]

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 relationships¹³⁷. 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?”¹³⁸

It similarly reflects the UNCRPD focus on taking measures to prevent exploitation, violence and abuse of people with disability¹³⁹, 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 autonomy¹⁴⁰. It could similarly be added to this that, on the other hand, setting a low threshold which ignores the situational vulnerability

¹³⁷ *Ibid.* p137.

¹³⁸ [2007] EWHC 2003 (Fam) para 120.

¹³⁹ Art 16.

¹⁴⁰ Centre for Disability Law and Policy NUI Galway, ‘Submission on Law Reform Commission Consultation Paper: Sexual Offences and Capacity to Consent (2011)’, p7.

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 risks¹⁴¹. 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”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 *PC v York*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

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.

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.

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”¹⁴⁴. Indeed, in *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 incapacity¹⁴⁵, 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 elsewhere¹⁴⁶. 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 autonomy¹⁴⁸, particularly when this is threatened by others. In a similar vein, it is also stated

¹⁴⁴ J Wall and J Herring, ‘Capacity to Cohabit: Hoping Everything Turns out well in the end- *PC v City of York*’ (2013) 25(4) *Child and Family Law Quarterly* 471.

¹⁴⁵ *Ibid.*

¹⁴⁶ B. Clough, ‘People Like That’: Realising the Social Model in Mental Capacity Jurisprudence’ (2015) 23(1) *Medical Law Review* 53-80.

¹⁴⁷ A term coined by Lord Donaldson in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.

¹⁴⁸ *A Local Authority v DL and Others* [2012] EWCA Civ 253.

that the exercise of the inherent jurisdiction is “facilitative rather than dictatorial”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 facilitated¹⁵⁰. Parker J in *XCC v AA and Others*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.”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 *A Local Authority v A*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

¹⁴⁹ *LBL v RYJ and VJ* [2010] EWHC 2665- Macur J. Endorsed by McFarlane LJ in *DL Ibid.*, para 67.

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).

¹⁵¹ *XCC v AA and Others* [2012] EWHC 2183 (CoP).

¹⁵² *Ibid.*, para 54.

¹⁵³ *A Local Authority v A* [2010] EWHC 1549 (Fam)

conceived¹⁵⁴. 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 approach aimed at achieving a capacitous decision, through support and a discussion without undue pressure from her husband¹⁵⁵. 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"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"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 mechanism¹⁵⁸- 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

¹⁵⁴ *Ibid.* paras 63-64.

¹⁵⁵ *Ibid.* para 79.

¹⁵⁶ P Bartlett and R Sandland, *Mental Health Law Policy and Practice* (Oxford University Press, 2014), p187.

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.

¹⁵⁸ K Keywood, Commentary: Safeguarding Reproductive Health? The Inherent Jurisdiction, Contraception and Mental Incapacity. *A Local Authority v A* [2010] EWHC 1549 (Fam)' (2011) 19 *Medical Law Review* p326.

a macro level¹⁵⁹. In addition to this, we have seen that the inherent jurisdiction is of imprecise scope, and the principles underpinning it are even less clear¹⁶⁰. 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 MCA¹⁶¹- 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 navigate¹⁶². 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 decision¹⁶³. 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.

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

¹⁶⁰ J. Collins, 'The Contours of Vulnerability' in J Wallbank and J Herring, n4.

¹⁶¹ House of Lords Select Committee on the Mental Capacity Act 2005, Report of Session 2013-14, *Mental Capacity Act 2005: post-legislative scrutiny* (London, TSO, March 2014)

¹⁶² 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) available at http://cic.arts.ubc.ca/fileadmin/user_upload/CIC/July_2011/Gerard_Quinn_s_Keynote_-_April_29__2011.pdf [last accessed 13th June 2014]

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 avoided¹⁶⁴. 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

¹⁶⁴ M. Verkerk, ‘A Care Perspective on Coercion and Autonomy’ (1999) 13 *Bioethics* 363.

¹⁶⁵ J. Williams, ‘Public Law Protection of Vulnerable Adults: The Debate Continues, So Does the Abuse’ (2002) 2 *Journal of Social Work* 298.

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 response¹⁶⁶.

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 wishes¹⁶⁷. 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"¹⁶⁸.

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.

¹⁶⁷ G Richardson, 'Mental Capacity in the Shadow of Suicide: What can the law do?' (2013) 9(1) *International Journal of Law in Context* 87-105, p97.

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.

¹L. Back, ‘Private Dependence, Public Personhood: Rethinking ‘Nested Obligations’ (2014) *Hypatia* online first. p13.

²A. Knight, ‘Disability as Vulnerability: Redistributing Precariousness in Democratic Ways’ (2014) 76(1) *The Journal of Politics* 15-26, p22.

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 interpretation³ and controversy⁴, 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

³ H. Dean, ‘Critiquing Capabilities: The Distractions of a Beguiling Concept’ (2009) *Critical Social Policy* 29(2) 261-278

⁴ C. Harnacke, ‘Disability and Capability: Exploring the Usefulness of Martha Nussbaum’s Capabilities Approach for the UN Disability Rights Convention’ (2013) *The Journal of Law, Medicine and Ethics* 41(4) 768-780

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

⁵ N. Lacey, ‘Theory into Practice? Pornography and the Public/Private Dichotomy’ (1993) 20 *Journal of Law and Society* p97. Also see M. Donnelly and C. Murray ‘The role of family in mental health law: a framework for transformation’ (2013) 25(4) *Child and Family Law Quarterly* 380-405.

⁶ G. Quinn ‘Rethinking Personhood: New Questions in Legal Capacity Law and Policy’ (Vancouver, University of British Columbia, 2011) p52.

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"⁷. 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

⁷ M. Donnelly, 'A Legal Overview' in C. Foster, J. Herring and I. Doron, *The Law and Ethics of Dementia* (Oxford: Hart, 2014), p279.

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.⁸ 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 dependence⁹. 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”¹⁰. 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.

⁸ B. Hughes., L. McKie,, D. Hopkins, and N. Watson, ‘Love’s Labours Lost? Feminism, the Disabled People’s Movement and an Ethic of Care’ (2005) 39(2) *Sociology* 259-275; J. Herring, ‘The Disability Critique of Care’ (2014) 8 *Elder Law Review*, 1-15.

⁹ Back, n1, p1, p8.

¹⁰ *Ibid.* p8.

This in effect is what one interpretation of the UNCRPD can facilitate¹¹. 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 disability¹², 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”¹³.

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

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

¹⁴ R. Kayess, and P. French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8(1) *Human Rights Law Review* p25.

¹⁵ Herringn8; V. Held ‘Can the ethics of care handle violence?’ (2010) *Ethics and Social Welfare* 4(2) 115-129.

¹⁶ J. Nedelsky, ‘Reconceiving autonomy: Sources, thoughts and possibilities.’ (1989) 1(7) *Yale Journal of Law and Feminism* 7–36.

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 foster¹⁷. 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 rights¹⁸. 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”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

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.

¹⁸ G. Quinn, and T. Degener (Eds) *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (Geneva, Office of the United Nations Commissioner for Human Rights 2002).

¹⁹ M. Rioux and F Valentine, ‘Does Theory Matter? Exploring the nexus between disability, human rights and public policy’ in D. Pothier (Ed) *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver, UBC, 2005) p51.

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 beings²². 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

²⁰ [2011] EWCACiv 1257.

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 disability²⁴. 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 decision²⁵. 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,

²⁴ Committee for the Rights of Persons with Disabilities, ‘Statement on Article 14 of the Convention on the Rights of Persons with Disabilities’ (Geneva, Office of the High Commissioner for Human Rights September 2014) available at <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15183&LangID=E> [last accessed 6th January 2015].

²⁵ *Rochdale MBC v KW* [2014] EWCOP 45.

“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"²⁹.

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 leave³⁰. 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"³¹.

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

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 cases³². 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 consent³³, 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

³² A. McNicoll, ‘Half of Deprivation of Liberty Safeguards Cases Breaching Legal Timescales’ *Community Care* (1st October 2014) <http://www.communitycare.co.uk/2014/10/01/50-deprivation-liberty-safeguards-cases-breaching-legal-timescales> [last accessed 21st November 2014] Also see Health and Social Care Information Centre, *Mental Capacity Act 2005, Deprivation of Liberty Safeguards (England) Quarter 1 Return, 2014-1* (HSCIC, 2nd October 2014) [last accessed 21st November 2014].

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”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 dependency³⁵, 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”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*³⁷ was

³⁴ A. Ward, ‘Abolition of all Guardianship and Mental Health Laws?’ (2014) *Elder Law Journal* p5.

³⁵ H. Dean, ‘Critiquing Capabilities: The Distractions of a Beguiling Concept’ (2009) 29(2) 261-278.

³⁶ S. Venkatapuram, ‘Mental Disability, Human Rights and the Capabilities Approach: Searching for the Foundations’ (2014) 26(4) *International Journal of Psychiatry*, p412.

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 UNCRPD³⁸. 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 accommodation³⁹. In the paper, it is discussed how the requirement of ‘reasonable accommodation’ entails action beyond “bald discriminatory proscriptions in laws and policies”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

³⁸ UN Committee on the Rights of Persons with Disabilities, General Comment (Number 1) on Art 12: Equal Recognition before the Law. (2014, Geneva: Office of the High Commissioner for Human Rights) <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> [last accessed 6th January 2015]

³⁹ UNCRPD Arts 2 and 5.

⁴⁰ J. Lord and R. Brown, ‘The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities’, in M. Rioux, L. Bassier and M. Jones (eds) *Critical Perspectives on Human Rights and Disability Law* (UK, Martinus Nijhoff, 2011) p277.

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’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 anti-thesis 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’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”⁴³. They state that this standard is “insufficiently challenging to penetrate to the core of exclusionary practices affecting persons requiring significant structural adjustments”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

⁴¹ M. Weber, ‘Disability Rights, Welfare Law’ (2011) 32(6) *cardozo Law Review* 2483-2531, p2503.

⁴² C. Harnacke, ‘Disability and Capability: Exploring the Usefulness of Martha Nussbaum’s Capabilities Approach for the UN Disability Rights Convention’ (2013) *Journal of Law, Medicine and Ethics*, p770.

⁴³ Kayess and French, n14,p27.

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 capacity⁴⁷ 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 way⁴⁸. 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 allocation⁴⁹. 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,

⁴⁵ [2013] UKSC 67.

⁴⁶ [2013] EWHC 3859 (COP).

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 inequality⁵⁰. However, at a more fundamental level, the capabilities approach is not limited to group rights or focusing on people with disabilities⁵¹. 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

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 quality⁵². 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*⁵³, 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’”⁵⁴. 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

⁵² J. Nedelsky, *Laws Relations: A Relational Theory of Self, Autonomy and the Law* (Oxford, OUP, 2012), p119; Donnelly and Murray, n5, p399.

⁵³ [2014] EWCOP 38.

⁵⁴ *Ibid.* Para 33.

scope⁵⁵. Similarly, in the later case of *The London Borough of Tower Hamlets v TB*⁵⁶, 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”⁵⁷. This is an important addition, and one which moves some way towards Hedley J’s concerns in *A Local Authority v H*⁵⁸ about the importance of choice⁵⁹. 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.

⁵⁵ *Ibid.* Para 36.

⁵⁶ [2014] EWCOP 53.

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

⁶⁰ K. Keywood, ‘Vulnerable Adults, Mental Capacity and Social Care Refusal’ (2010) *Medical Law Review* 18(1) p110.

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 life⁶². 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

⁶¹ C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C Mackenzie, W Rogers and S Dodds, *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford, OUP, 2014) p45,

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 term⁶³. 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

⁶³ J Wallbank and J Herring, *Vulnerabilities, Care and Family Law* (London, Routledge, 2014).

‘paternalistic’⁶⁴ 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 capacity⁶⁵ 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 capacity⁶⁶

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

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’.

⁶⁵ E. Flynn and A. Arstein-Kerslake ‘Legislating personhood: realizing the right to support in exercising legal capacity,’ (2014) 10(1) *International Journal of Law in Context*, p94.

⁶⁶ Also see G. Richardson, ‘Mental Capacity in the Shadow of Suicide: What can the law do?’ (2013) 9(1) *International Journal of Law in Context* 87-105.

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.

BIBLIOGRAPHY

- Allen, A. and Regan, M. 1998. *Debating Democracy's Discontent: Essays on American Politics, Law and Public Philosophy*. Oxford: Oxford University Press
- Anderson, J and Honneth, A. Autonomy, Vulnerability, Recognition and Justice in Christman, J. and Anderson, J. (Eds) 2005. *Autonomy and the Challenges to Liberalism: New Essays* Cambridge: Cambridge University Press
- Arjona, C. *et al.* 2012. Senses of Sen: Reflections on Amartya Sen's Ideas of Justice *International Journal of Law in Context* 8(1) 155-178
- Arksey, H. 2005. Combining Work and care: The Reality of Policy Tensions for Carers. *Benefits* 15(2) 139-149
- Arksey, H and Glendinning, C. 2007. Choice in the context of informal care giving. *Health and Social Care in the Community*, 15(2) 165-175
- Bach, M. and Kerzner, L. 2010. A New Paradigm for Protecting Autonomy and the Right to Legal Capacity. Prepared for the Law Commission of Ontario
- Back, L. 2014. Private Dependence, Public Personhood: Rethinking 'Nested Obligations'. *Hypatia* (online first)
- Banner, N.F., 2013. Can Procedural and Substantive Elements of Decision Making be Reconciled with Assessments of Mental Capacity? *International Journal of Law in Context* 9(1) 71-86
- Barnes, M. and Brannelly, T. 2008. Achieving Care and Social Justice for People with Dementia. *Nursing Ethics*, 15(3) 394-395
- Barnes, C, and Mercer, G. 2004. *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press
- Barnes, C. and Mercer, G. 'Breaking the Mould' in Barnes, C. and Mercer, G. (Eds) 2006. *Doing Disability Research* Leeds: The Disability Press
- Barnes, C., Mercer, G and Shakespeare, T. 1999. *Exploring Disability: A Sociological Introduction*. Cambridge: Polity
- Bartlett, P. 1997a. 'Casenote: Winnipeg Child and Family Services (Northwest Area) v DFG Manitoba Queens Bench [1996] 10 WWR' *University of British Columbia Law Review* 31
- Bartlett, P. 1997b. Judging Disability: The Problem of Ableism *Human Rights Law Review* 2(3)2
- Bartlett, P. 2012. The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law. *Modern Law Review* 75(5) 752-778
- Bartlett, P. and Sandland, R. 2007. *Mental Health Law: Policy and Practice*. 3rd Ed Oxford University Press: Oxford
- Baylies, C. 2002. Disability and the Notion of Human Development: questions of rights and capabilities *Disability and Society* 17(7) 725-739
- Bellhouse, J. *et al.*, 2001. Decision Making Capacity in Adults: Its Assessment in Clinical Practice. *Advances in Psychiatric Treatment* 7 294-301
- Benhabib, S. 1992, *Situating the Self: Gender, Community and Postmodernism in Contemporary Ethics* New York: Routledge
- Beresford, P. 2010. *Towards a Social Model of Madness and Distress? Exploring What Service Users Say*. York: Joseph Rowntree Foundation
- Berger, J., DeRenzo, E. , Schwartz, J. 2008. Surrogate Decision Making: Reconciling Ethical Theory and Clinical Practice. *Annals of Internal Medicine* 149, 48-53
- Brazier, M. 2006. Do No Harm- Do Patients Have Responsibilities Too? *Cambridge Law Journal* 65, 397-422
- Brazier, M. and Cave, E. 2011. *Medicine, Patients and the Law*. London: Penguin

- Brazier, M. and Glover, N. 2000. Does Medical Law have a Future? in Hayton, D. (Ed) *Laws Future(s): British Legal Developments in the 21st Century* Oxford: Hart
- Brennan, S. 1999. Reconciling Feminist Politics and Feminist Ethics on the Issue of Rights. *Journal of Social Philosophy* 30(2) 260-275
- Bridgeman, J. 2007. Accountability, Support or Relationship? Conceptions of Parental Responsibility. *Northern Ireland Legal Quarterly* 58(3) 307-324
- British Institute for Human Rights and Age UK, 2011. *Older People and Human Rights: A Guide for Professionals Working with Older People*, 2nd Ed
- British Institute of Human Rights, 2012. *Your Human Rights: A Pocket Guide for Carers* available at <http://www.bihhr.org.uk/sites/default/files/BIHR%20Pocket%20Guide%20for%20Carers.pdf>
- Brown, H. 2003. Safeguarding Adults and Children with Disabilities Against Abuse. Strasbourg: Council of Europe
- Buckner, L. and Yeandle, S. 2011. *Valuing Carers* Leeds: University of Leeds
- Burchardt, T. 2004. Capabilities and Disability: The Capabilities Framework and the Social Model of Disability *Disability and Society* 19(7) 735-751
- Burdhardt, M. 2013. Common frailty, Constructed Oppression: tensions and debates on the subject of vulnerability. *Disability & Society* 28(4) 556-568
- Burns, J.K. 2007. Mental Health and Inequity: A Human Rights Approach to Inequality. *Health and Human Rights* 11(2) 19-31
- Butler, F. 2006. *Rights for Real: Older people, human rights and the CEHR*. London: Age Concern
- Care Quality Commission, 2013. *Monitoring the use of the Mental Capacity Act 2005 Deprivation of Liberty Safeguards 2011/12* available at <http://www.cqc.org.uk/public/reports-surveys-and-reviews/reports/deprivation-liberty-safeguards-2011/12>
- Carr, H. 2012. Rational men and difficult women – R (on the application of McDonald) v. Royal Borough of Kensington and Chelsea [2011] UKSC 33. *Journal of Social Welfare and Family Law* 34(2) 219-230
- Carson, D. 1993. Disabling Progress: The Law Commission's Proposals on Mentally Incapacitated Adults Decision Making *Journal of Social Welfare and Family Law* 15(5) 304-320
- Case, P. 2003. Confidence Matters: The Rise and Fall of Informational Autonomy, *Medical Law Review* 11(2) 208-236
- Centre for Disability Law and Policy NUI Galway. 2011. *Submission on Law Reform Commission Consultation Paper: Sexual Offences and Capacity to Consent*
- Centre for Disability Law and Policy NUI Galway, 2012. *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
- Clement, G. 1996. *Care, Autonomy and Justice*. Colorado: Westview,
- Chan, H.M. 2004. Informed Consent Hong Kong Style: An Instance of Moderate Familism' *Journal of Medicine and Philosophy* 29(2) 195-206
- Chappell, A., Goodley, D. and Lawthorn, R. 2001. Making Connections: The Relevance of the Social Model of Disability for People with Learning Difficulties *British Journal of Learning Disabilities* 29 45-50
- Coggon, J. 2007. Varied and principled understandings of autonomy in English law: justifiable inconsistency or blinkered moralism? *Health Care Analysis*, 15(3) 235-255

- Coggon, J. 2008a. Harmful Rights Doing? The Perceived Problem of Liberal Paradigms in Public Health. *Journal of Medical Ethics* 34 798-801
- Coggon, J. 2008b. Best Interests, Public Interests and the Power of the Medical Profession' *Health Care Analysis* 16 219-232
- Coggon, J. and Miola, J. 2011. Autonomy, Liberty and Medical Decision Making. *Cambridge Law Journal* 70(3) 523-547
- Collingbourne, T. 2013. Administrative Justice? Realising the Right to Independent Living: Power, Systems, Identities. *Journal of Social Welfare and Family Law*.35(4) 475-489
- Committee on the Rights of Persons with Disabilities, 2014. Statement on Article 14 of the Convention on the Rights of Persons with Disabilities. Geneva:Office of the High Commissioner for Human Rights
- Cong, Y. 2004. Doctor-Patient-Family Relationship: The Chinese Paradigm of Informed Consent' *Journal of Medicine and Philosophy* 29(2) 149-178
- Conrad, P. and Slodden, C. 'The Medicalization of Mental Disorder' in Aneshensel, C., Phelan, J. and Bierman, A. (Eds) 2013. *Handbook of the Sociology of Mental Health*.Netherlands: Springer
- Corker, M and Shakespeare, T. (Eds) 2002. *Disability/Postmodernity: Embodying Disability Theory*, London: Continuum
- Crow, L. Including All Our Lives: Renewing the Social Model of Disability in Barnes, C. and Mercer, G. 1996. *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press
- Dean, H. 2009. Critiquing Capabilities: The Distractions of a Beguiling Concept. *Critical Social Policy* 29(2) 261-278
- Deber, R. *et al*, 2007. Do people want to be autonomous patients? Preferred roles in treatment decision making in several patient populations *Health Expectations*. 10 248-258
- Department for Constitutional Affairs, 2007. *Mental Capacity Act 2005 Code of Practice* London: The Stationery Office
- Department of Health, 2009. *National Dementia Strategy: Living Well with Dementia*. London: The Stationery Office
- Department of Health, 2010. *Recognised, Valued and Supported: Next Steps for the Carers Strategy*. London: The Stationery Office
- Department of Health, 2010. *Six Lives: Progress Report*. London:TSO
- Dhanda, A. 2008. Constructing a New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities' *International Journal of Human Rights* 5(8) 42-59
- Dodds, S. 2007. Depending on Care: Recognition of Vulnerability and the Social Contribution of Care Provision. *Bioethics* 21(9) 500-510
- Donnelly, M. 2009a. Best Interests, Patient Participation and the Mental Capacity Act 2005 *Medical Law Review*. 17 1-29
- Donnelly, M. 2009b. Capacity Assessment Under the Mental Capacity Act 2005: Delivering on the Functional Approach?*Legal Studies*29(3) 464-491
- Donnelly. M. 2010. *Health Care Decision Making and the Law: Autonomy, Capacity and the Limits of Liberalism*. Cambridge: Cambridge University Press)
- Donnelly, M. 2011. Commentary; determining best Interests under the Mental Capacity Act 2005: In The Matter of G(TJ) [2010] EWHC 3005 (COP) *Medical Law Review*. 19 304-313
- Donnelly, M. and Murray, C. 2012. Unpaid carers: an invisible presence in Irish health and care law *Medico-Legal Journal of Ireland*18(1) 6-12
- Donnelly, M. and Murray, C. 2013. The role of family in mental health law: a framework for transformation. *Child and Family Law Quarterly* 25(4) 380-405

- Dorenlot, P. 2005. Applying the Social Model of Disability to Dementia; Present day challenges. *Dementia* 4 459-461
- Doyle, S. 2010. The Notion of Consent to Sexual Activity for Persons with Mental Disabilities. *Liverpool Law Review* 31 111-135
- Dunn, M., Clare, I. and Holland, A. 2008 'To Empower or Protect? Constructing the Vulnerable Adult in English Law and Public Policy' *Legal Studies* 28(2) 234-253
- Dunn, M., Clare, I. and Holland, A. 2010. Living 'a life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities' *Journal of Intellectual Disability Research*. 54(2) 144-160
- Engster, D. 2004. Care Ethics and Natural Law Theory: Toward an Institutional Political Theory of Caring *Journal of Politics* 66(1) 113-135
- Engster, D. 2007. *The Heart of Justice: Care Ethics and Political Theory*. Oxford: Oxford University Press
- Fan, R. and Tao, J. 2004. Consent to Medical Treatment: The Complex Interplay of Patients, Families, and Physicians. *Journal of Medicine and Philosophy* 29(2) 139-148
- Fennell, P. 2008. Best Interests and Treatment for Mental Disorder. *Health Care Analysis* 16 255-267
- Fennell, P. Institutionalising the Community in McSherry, B and Weller, P (Eds) 2010 *Rethinking Rights Based Mental Health Law*. Oxford: Hart
- Fennell, P. and Khaliq, U. 2011. Conflicting or complementary obligations? The UN Disability Rights Convention on Human Rights and English Law. *European Human Rights Law Review* 6 662-674
- Fineman, M. 2000. Cracking the Foundational Myths: Independence, Autonomy and Self-Sufficiency. *Gender, Work & Family Project Inaugural Feminist Legal Theory Lecture* 13-29
- Fineman, M. 2004. *The Autonomy Myth: A Theory of Dependency*. New York: New Press
- Fineman, M. 2008. 'The Vulnerable Subject: Anchoring Equality in the Human Condition' *Yale Journal of Law & Feminism* 20(1) 1-22
- Fineman, M. 2010, 'The Vulnerable Subject and the Responsive State' *Emory Law Journal* 30 251-292
- Fineman, M. and Grear, A. 2013 *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* London: Ashgate
- Fletcher, R. Fox, M. and McCandless, J. 2008. Legal Embodiment: Analysing the Body of Health Care Law *Medical Law Review* 16(3) 321-345
- Flynn, E. 2013. Making Human Rights Meaningful for People with Disabilities: Advocacy, Access to Justice and Equality before the Law. *International Journal of Human Rights* 17(4) 491-510
- Flynn, E. and Arstein-Kerslake, A. 2014 Legislating personhood: realizing the right to support in exercising legal capacity. *International Journal of Law in Context* 10(1) 81-104
- Foster, C., Herring, J. and Doron, I. (Eds) 2014. *The Law and Ethics of Dementia*. Oxford: Hart
- Fox, M. and Thomson, M. 2013. Realising Social Justice in Public Health Law. *Medical Law Review* 21 278-309
- Gilbar, R. 2011. Family Involvement, Independence and Patient Autonomy in *Medical Law Review* 19(2) 192-234
- Gunn, M. 1994. The Meaning of Incapacity. *Medical Law Review* 2(1) 8-29
- Gilliard, J. et al, 2005. 'Dementia Care in England and the Social Model of Disability: Lessons and Issues' *Dementia* 4 571-586
- Gilligan, C. 1982. *In A Different Voice*. Cambridge: Harvard University Press

- Glover, N. and Brazier, M. 1996. Ethical Aspects of the Law Commission Report on Mental Incapacity *Reviews in Clinical Gerontology* 6(4) 365-370
- Goering, S. 2010. Revisiting the Relevance of the Social Model of Disability *American Journal of Bioethics* 10(1) 54-55
- Gooding, P. 2013. Supported Decision Making- A Rights-Based Disability Concept and its Implications for Mental Health Law. *Psychiatry Psychology and Law* 20(3) 431-451
- Goodley, D. 'Who is Disabled? Exploring the Scope of the Social Model of Disability' in Swain, S., French, S., Barnes, C. and Thomas, C. (Eds) 2004, *Disabling Barriers-Enabling Environments* 2nd Ed London: Sage
- Goodley, D. 2012 Dis/entangling Critical Disability Studies *Disability & Society* 28(5) 631-644
- Gostin, L. 1975. *A Human Condition 1*. London: National Association for Mental Health
- Gostin, L. 1977. *A Human Condition 2*. London: National Association for Mental Health
- Gostin, L. 1983. Contemporary Social Historical Perspectives on Mental Health Reforms. *Journal of Law and Society* 10 47-70
- Hall, M.I. 2012. Mental Capacity in the (Civil) Law: Capacity, Autonomy and Vulnerability *McGill Law Journal* 58(1) 1-35
- Hankivsky, O. 2004. *Social Policy and the Ethic of Care*. Vancouver: UBC Press
- Harding, R. 2012. Legal Constructions of dementia: discourses of autonomy at the margins of capacity *Journal of Social Welfare and Family Law* 34(4) 425-442
- Harding, R. and Peel, E. 2011. Dementia Project News: Findings Summary 1' available at http://www.dementiaproject.net/assets/user/files/1330689267_d2claysummary1a_august2011.pdf
- Hardwig, J. 1997. Is there a duty to die? *Hastings Centre Report* 27
- Hargreaves, R. 2010. *Briefing Paper 1-Deprivation of Liberty Safeguards: An initial review of implementation*. London: Mental Health Alliance. Available at http://www.mentalhealthalliance.org.uk/resources/DoLS_report_July2010.pdf
- Harnacke, C. 2013. Disability and Capability: Exploring the Usefulness of Martha Nussbaum's Capabilities Approach for the UN Disability Rights Convention. *The Journal of Law, Medicine and Ethics* 41(4) 768-780
- Health and Social Care Information Centre, 2014. *Mental Capacity Act 2005, Deprivation of Liberty Safeguards (England) Quarter 1 Return, 2014-1*
- Held, V. 2006 *The Ethics of Care: Personal, Political and Global*. Oxford, OUP
- Held, V. 2010. Can the ethics of care handle violence? *Ethics and Social Welfare* 4(2) 115-129
- Herring, J. 2007. Where are the carers in healthcare law and ethics? *Legal Studies* 27(1) 51-73
- Herring, J. 2008. Caregivers In Medical Law and Ethics, *Journal of Contemporary Health Law & Policy* 25 1-37
- Herring, J. 2008b. Entering the Fog: On the Borderlines of Mental Capacity. *Indiana Law Journal* 83(4) 1619-1649
- Herring, J. 2009. Losing it ? Losing what? The law and dementia. *Child and Family Law Quarterly* 21(1) 3-29
- Herring, J. 2010. The Legal Duties of Carers. *Medical Law Review* 18(2) 248-255
- Herring, J. 2011. Legal Issues Surrounding Dementia. *Elder Law Journal* 1 182
- Herring, J. 2012. Mental Disability and Capacity to Consent to Sex: A Local Authority v H [2010] EWHC 49 (CoP). *Journal of Social Welfare and Family Law* 34 471-478
- Herring, J. 2013a. *Caring and the Law*. Oxford: Hart Publishing

- Herring, J. 2013b. Forging a Relational Approach: Best Interests or Human Rights? *Medical Law International*, 13(1) 32-54
- Herring, J. 2014. The Disability Critique of Care *Elder Law Review* 8 1-15
- Herring, J. and Foster, C. 2012. Welfare means relationally, virtue and altruism *Legal Studies* 32(3) 480-498
- Herring, J. and Wall, J. 2014. Capacity to Consent to Sex *Medical Law Review* (advance access)
- Hewitt, D. 2009. Not just in the Mental Capacity Act: Using the Law to Protect Vulnerable Adults. *Journal of Adult Protection* 11(2) 25-31
- Hewitt, D. 2012. Objection, Purpose and Normality; Three ways in which the courts have inhibited safeguarding. *Journal of Adult Protection* 14(6) 280-286
- Hingsburger, D. 1995. Just Say Know!- Understanding and Reducing the Risk of Sexual Victimization of People with Developmental Disabilities. Ontario: Diverse City Press
- HM Government, 2008. *Carers at the Heart of 21st-Century Families and Communities* London: The Stationery Office
- Ho, A. 2008. Relational Autonomy or Undue Pressure? Family's role in medical decision making *Scandinavian Journal of Caring Science* 22 128-135
- Hollomotz, A. 2011. *Learning Difficulties and Sexual Vulnerability: A Social Approach*. London: Jessica Kingsley
- Hollomotz, A. 2014. Are We Valuing People's Choices Now? Restrictions to Mundane Choices Made by Adults with Learning Difficulties. *British Journal of Social Work* 44(2) 234-251
- Hollomotz, A. and The Speakup Committee, 2008. May We Please Have Sex Tonight? People With Learning Difficulties Pursuing Privacy in Residential Group Settings *British Journal of Learning Disabilities* 37(2) 91-97
- Holstein, M. Parks, J. and Waymack, M. 2011. *Ethics, Aging and Society: The Critical Turn*. New York: Springer Publishing
- Home Office, 2000. *Setting the Boundaries: Reforming the law on sexual offences*. London: TSO
- House of Commons Health Select Committee, 2013, *Post Legislative Scrutiny of the Mental Health Act 2007*, London: TSO
- House of Lords Select Committee on the Mental Capacity Act 2005, 2014, Report of Session 2013-14, *Mental Capacity Act 2005 Post Legislative Scrutiny*, London: TSO
- Hughes, B., McKie, L., Hopkins, D. and Watson, N. 2005 Love's Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care *Sociology* 39(2) 259-275
- Jackson, E. 2009. *Medical Law: Text, Cases and Materials* 2nd Ed Oxford: Oxford University Press
- Jahoda, A. and Pownall, J. 2014. Sexual understanding, sources of information and social networks; the reports of young people with intellectual disabilities and their non-disabled peers. *Journal of Intellectual Disability Research* 58(5) 430-441
- Jones, J. and Marks, L.A.B (Eds) 1999. *Disability, Diversity and Legal Change*. The Hague, Kluwer Law International
- Kanter, A. 2011 'The Law: What's Disability Studies got to do with it? Or, An Introduction to Disability Legal Studies' (*Columbia Human Rights Law Review* 42(2) 404-479
- Kayess, R. and French, P. 2008. Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review* 8(1) 1-34
- Kelly, F. 2005. Conceptualising the child through an 'ethic of care': lessons for family law *International Journal of Law in Context* 1(4) 375-396

- Keywood, K. Sterilising the Woman with Learning Difficulties - In Her Best Interests? in Bridgeman, J. and Millns, S. (Eds.) 1995. *Law and Body Politics: Regulating the Female Body*. Dartmouth: Aldershot
- Keywood, K. 2001. "I'd Rather Keep Him Chaste" Retelling the Story of Sterilisation, Learning Disability and (Non)Sexed Embodiment. *Feminist Legal Studies* 9(2) 185-194
- Keywood, K. 2003a. Gatekeepers, Proxies, Advocates: The evolving role of carers under mental health and mental incapacity law reforms. *Journal of Social Welfare and Family Law* 25(4) 355-368
- Keywood, K. 2003b. Supported to be Sexual? Developing Sexual Rights for People with Learning Disabilities. *Tizard Learning Disability Review* 8(3) 30-36
- Keywood, K. 2010. Vulnerable Adults, Mental Capacity and Social Care Refusal. *Medical Law Review* 18(1) 103-110
- Keywood, K. 2011. Commentary: Safeguarding Reproductive Health? The Inherent Jurisdiction, Contraception and Mental Incapacity. *A Local Authority v A* [2010] EWHC 1549 (Fam). *Medical Law Review* 19(2) 326-333
- Keywood, K and Flynn, M. 2006. Healthcare Decision Making by Adults with Learning disabilities; Ongoing Agendas, Future Challenges. *Psychiatry* 5(10) 260-262
- King, J. 2012. *Judging Social Rights*. Oxford: OUP
- Kittay, E. F. 1999. *Love's Labor: Essays on Women, Equality and Dependency* New York: Routledge
- Kittay, E.F. and Carlson, L (Eds) 2010. *Cognitive Disability and its Challenge to Moral Philosophy* New York: Wiley Blackwell
- Kittay, E.F. and Feder, E. K. (Eds) 2002. *The Subject of Care: Feminist Perspectives on Dependency* Maryland: Rowman & Littlefield
- Kittay, E. F. and Meyers, D. T. 1987. *Women and Moral Theory*. New Jersey Rowman and Littlefield:
- Knight, A. 2014. Disability as Vulnerability: Redistributing Precariousness in Democratic Ways. *The Journal of Politics* 76(1) 15-26
- Koehn, D. 1998. *Rethinking Feminist Ethics: Care, Trust and Empathy* . New York Routledge
- Koggel, C. (Ed) 2006. *Moral Issues In Global Perspective*. 2nd Ed, Ontario: Broadview Press
- Kristiansen, K. Vehmas, S. and Shakespeare, T. (Eds) 2009. *Arguing about Disability: Philosophical Perspectives*. London: Routledge
- Lacey, N. 1993. Theory into Practice? Pornography and the Public/Private Dichotomy. *Journal of Law and Society* 20 93-113
- Lacey, N. 1998. *Unspeakable Subjects: Feminist essays in legal and social theory*. Oxford: Hart
- Law Commission, 1995. *Mental Incapacity*. London: HMSO
- Lawson, A. and Flynn E. 2013. Disability and Access to Justice in the European Union: Implications of the United Nations Convention on the Rights of Persons with Disabilities. *Yearbook of European Disability*. 47-44
- Lindemann Nelson, H. and Lindemann Nelson, J. 1995. *The Patient in the Family* New York: Routledge
- Lord, J. and Brown, R. The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities in Rioux, M., Basser, L. and Jones, M (Eds) 2011. *Critical Perspectives on Human Rights and Disability Law*. UK: Martinus Nijhoff.
- Lord, J., Suozzi, D. and Taylor, A. 2010. Lessons from the experience of the United Nations Convention on the Rights of Persons with Disabilities: Addressing the Democratic

- Deficit in Global Health Governance. *Journal of Law, Medicine and Ethics* 38(3) 564-579
- Louhiala, P. 2009. 'Philosophy Meets Disability' *Journal of Medical Ethics* 35(9)570-572
- MacIntyre, A. The Virtues, the Unity of a Human Life and the Concept of a Tradition in Sandel, M. 1984. *Liberalism and its Critics*. New York: New York University Press
- Mackay, D. 2006/7. The United Nations Convention on the Rights of Persons with Disabilities. *Syracuse Journal of International Law and Commerce* 34(2) 323
- Mackenzie, C., Rogers, W. and Dodds, S. 2014. *Vulnerability: New Essays in Ethics and Feminist Philosophy* Oxford: Oxford University Press
- McCarthy, M. 1999. *Sexuality and Women with Learning Disabilities* London: Jessica Kingsley
- McCarthy, M. 2003. Drawing a line between consented and abusive sexual experiences: The complexities for women with learning disabilities. *The Journal of Adult Protection* 5(3) 34-40
- McCarthy, M. 2014. Women with intellectual disability: Their sexual lives in the 21st century. *Journal of Intellectual and Developmental Disability* 39(2) 1124-131
- McLean, S. and Williamson, L. 2007. *Impairment and Disability Law and Ethics at the Beginning and End of Life*. Oxon: Routledge Cavendish
- McNicoll, A. 2014. 'Half of Deprivation of Liberty Safeguards Cases Breaching Legal Timescales' *Community Care* <http://www.communitycare.co.uk/2014/10/01/50-deprivation-liberty-safeguards-cases-breaching-legal-timescales>
- McSherry, B. and Weller, P. 2010. *Rethinking Rights Based Mental Health Law*. Oxford: Hart
- Meckled- Garcia, S. and Cali, B. 2006. *The Legalization of Human Rights-Multidisciplinary Perspectives on Human Rights and Human Rights Law* Oxon: Routledge
- Mencap 2001. *Behind Closed Doors* London: Mencap
- Mental Health Alliance, 2012. *The Mental Health Act 2007: A Review of its Implementation* London: Mental Health Alliance. available at http://www.mentalhealthalliance.org.uk/news/MHA_May2012_FINAL.pdf
- Meyers, D. 'Choice and Control in Feminist Bioethics' in Mackenzie, C. and Stoljar, N. 2000 *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* Oxford: OUP
- Miles, M. 2011 'The Social Model of Disability Met a Narrative of (In)credulity: A Review' *Disability, CBR and Inclusive Development* 22(1) 5-15
- Minow, M. 1990. *Making All the Difference: Inclusions, Exclusion and American Law* Ithica: Cornell University Press
- Montgomery, J. 2006. Law and the Demoralisation of Medicine *Legal Studies*. 26 185-210
- Morris, J. 1991. *Pride Against Prejudice: Transforming Attitudes To Disability*. University of California: New Society
- Morris, J. 1996. *Encounters with Strangers: Feminism and Disability*. University of Michigan: Women's Press
- Muir, K. and Goldblatt, B. 2011. Complementing or Conflicting Human Rights Conventions? Realising an inclusive approach to families with a young person with a disability and challenging behaviour. *Disability & Society* 26(5) 629-642
- Munro, N, 2014. Taking wishes and feelings seriously: the views of people lacking capacity in Court of Protection decision-making *Journal of Social Welfare and Family Law*. 36(1), 59-75

- Murphy, J. and Oliver, T. 2013. The use of Talking Mats to support people with dementia and their carers to make decisions together *Health and Social Care in the Community* 21(2) 171-180
- Naffine, N. The Body Bag in Naffine, N. and Owens, R. (Eds) 1997. *Sexing the Subject of Law* Sydney: Sweet & Maxwell,
- Nedelsky, J. 1989. Reconceiving autonomy: Sources, thoughts and possibilities. *Yale Journal of Law and Feminism* 1(7) 7-36
- Nedelsky, J. 1990. Law, Boundaries and the Bounded Self. *Representations: Special Issue: Law and the Order of Culture* 30 162-189
- Nedelsky, J., 2006. Reconceiving Rights as Relationship. In: Koggel, C. Ed. *Moral Issues in Global Perspective*. 2nd ed. Peterborough: Broadview
- Nedelsky, J. 2012. *Laws Relations: A Relational Theory of Self, Autonomy and the Law* Oxford: OUP
- NHS Information Centre, 2010. *Survey of Carers in Households 2009-10*
- Noddings, N. 1984. *Caring: A Feminine Approach to Ethics*. Berkeley: University of California Press
- Noddings, N. 2002. *Starting at Home: Caring and Social Policy*. California: University of California Press
- Norrie, A. 1993. *Crime, Reason and History: A Critical Introduction to Criminal Law*. Cambridge: Cambridge University Press
- Nussbaum, M. 1997. Capabilities and Human Rights. *Fordham Law Review* 66(2) 293-294
- Nussbaum, M. 2003. Capabilities as Fundamental Entitlements: Sen and Social Justice. *Feminist Economics* 9(2) 33-59
- Nussbaum, M. 2004. *Beyond the Social Contract: Toward Global Justice* (The Tanner Lectures on Human Values) Utah: University of Utah Press
- Nussbaum, M. 2006. *Frontiers of Justice: Disability, Nationality, Species Membership* (The Tanner Lectures on Human Values). Harvard: Belknap Press of Harvard University Press
- Nussbaum, M. 2011 *Creating Capabilities: The Human Development Approach* Belknap Press, Harvard University Press
- Nussbaum, M. and Sen, A. (Eds) 1993 *The Quality of Life (Wider Studies in Development Economics)* Oxford, Oxford University Press
- O'Cinneide, C. Legal accountability and social justice in Leyland, P. and Bamforth, N. (Eds.) 2013. *Accountability in the contemporary constitution*. Oxford: OUP
- O'Donovan, K. and Gilbar, R. 2003. The Loved Ones: Families, Intimates and Patient Autonomy *Legal Studies* 23(2) 332-358
- Office of the Public Guardian, 2009. *Making Decisions: A Guide for family, friends and other unpaid carers* 4th Ed available at <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf>
- Oliver, M. 1990 *The Politics of Disablement*, London: Palgrave Macmillan
- Oliver, M. 1996, *Understanding Disability: From Theory to Practice*. London: Palgrave Macmillan
- O'Mahony, C. 2012. Legal Capacity and Detention: Implications of the UN Disability Convention for the Inspection Standards of Human Rights Monitoring Bodies. *International Journal of Human Rights* 16(6) 883-901
- Ortoleva, S. 2011. Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System. *ILSA Journal of International and Comparative Law* 17(2) 281-317
- Owens, F. and Griffiths, D. (Eds) 2009. *Challenges to the Human Rights of People with Intellectual Disabilities*. London: Jessica Kingsley

- Palmer, E. 2007. *Judicial Review, Socio-economic Rights and the Human Rights Act*. Oxford: Hart
- Pettersen, T. 2011. The Ethics of Care: Normative Structures and Empirical Implications *Health Care Analysis* 19 51-64
- Pickard, S. Jacobs, S. Kirk, S. 2003. Challenging Professional Roles: Lay Carers' Involvement in Health Care in the Community *Social Policy and Administration* 37(1) 82-96
- Pilgrim, D. 2012. Lessons from the Mental Health Act Commission for England and Wales: The Limitations of Legalism-Plus-Safeguards. *Journal of Social Policy* 40(1) 61-81
- Quigley, M. 2008. Best Interests, the Power of the Medical Profession, and the Power of the Judiciary *Health Care Analysis*. 16 233-239
- Quinn, G. 2010. *Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD* Harvard Law School
- Quinn, G. 2011. *Rethinking Personhood: New Directions in Legal Capacity Law and Policy: Or, how to put the Shift back into Paradigm Shift*, available at http://cic.arts.ubc.ca/fileadmin/user_upload/CIC/July_2011/Gerard_Quinn_s_Keynote_-_April_29__2011.pdf
- Quinn, G. and Degener, T. (Eds) 2002. *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*. Office of the United Nations Commissioner for Human Rights: Geneva
- Richardson, D. 2000. Constructing Sexual Citizenship: Theorising sexual rights. *Critical Social Policy* 20 105-135
- Richardson, G. 2012. Mental Disabilities and the Law: from Substitute to Supported Decision-Making? *Current Legal Problems* 65(1) 1-22
- Richardson, G. 2013. Mental Capacity in the Shadow of Suicide: What can the law do? *International Journal of Law in Context* 9(1) 87-105
- Rioux, M. and Valentine, F. Does Theory Matter? Exploring the nexus between disability, human rights and public policy in Pothier, D. (Ed) 2005. *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* Vancouver: UBC
- Robinson, F. 1999. *Globalizing Care: Ethics, Feminist Theory and International Relations*. Boulder: Westview Press
- Rose, N. 1985. Unreasonable Rights: Mental Illness and the Limits of the Law. *Journal of Law and Society* 12(2) 199-218
- Rothman, J. 2010. The Challenge of Disability and Access: Reconceptualizing the Role of the Medical Model. *Journal of Social Work in Disability and Rehabilitation* 9(2) 194-222
- Ruddick, S. 1989. *Maternal Feminism: Toward a Politics of Peace*. Boston: Beacon Press
- Ruger, J. 2012. *Health and Social Justice* Oxford: Oxford University Press
- Rummery, K.. 2011. A Comparative Analysis of Personalisation: Balancing an Ethic of Care with User Empowerment *Ethics and Social Welfare* 5(2) 138-152
- Samaha, A. 2007. What good is the social model of disability? *University of Chicago Law Review* 74(4) 1251
- Samanta J. 2009. Lasting Powers of Attorney for Healthcare under the Mental Capacity Act 2005: Enhanced Prospective Self-Determination for Future Incapacity or a Simulacrum? *Medical Law Review* 17(3) 377-409
- Saunders, C. 2010. Making it count: sexual offences, evidential sufficiency, and the mentally disordered complainant. *Liverpool Law Review* 31(2) 177-206
- Sandel, M. 1984. *Liberalism and its Critics*. New York: New York University Press
- Sandel, M. 1998. *Liberalism and the Limits of Justice* 2nd Ed Cambridge: Cambridge University Press

- Sandland, R. 1995. Between “Trust” and “Difference”: Poststructuralism, Law and the Power of Feminism *Feminist Legal Studies*. 3(1) 3-47
- Saxe, A. and Flanagan, T. 2014. Factors that impact on support workers’ perceptions of the sexuality of adults with developmental disabilities: A quantitative analysis. *Sexuality and Disability* 32 45-63
- Secker, B. 1999. Labelling Patient (In)Competence: A Feminist Analysis of Medico-Legal Discourse. *Journal of Social Philosophy* 30(2) 295-314
- Sen, A. 2001 *Development as Freedom* Oxford: OUP
- Sen, A. 2010 *The Idea of Justice*, 2nd ed: London: Penguin
- Series, L. 2014. Comparing Old and New Paradigms of Legal Capacity *Elder Law Journal* 1 62
- Series, L., Arstein-Kerslake, A., Flynn, E. and Gooding, P. 2014. Mental Capacity Law Discussion Paper-The Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and the Convention on the Rights of Persons with Disabilities: The Basics. 39 Essex Street Newsletter, available at http://www.39essex.com/docs/newsletters/crpd_discussion_paper_series_et_al.pdf
- Sevenhuijsen, S. 1998. *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics* London: Routledge
- Sevenhuijsen, S. 2003. The Place of Care: The Relevance of the feminist Ethic of Care for Social Policy *Feminist Theory* 4(2) 179-197
- Shakespeare, T. 2006. *Disability Rights and Wrongs*. London: Routledge
- Shakespeare, T. and Watson, N. 2002 ‘The Social Model of Disability: An Outdated Ideology?’ *Research in Social Science and Disability* 2 9-28
- Shanley, M. 1998. ‘Unencumbered Individuals and Embedded Selves: Reasons to Resist Dichotomous Thinking in Family Law’ in A. Allen and M. Regan, *Debating Democracy’s Discontent: Essays on American Politics, Law and Public Philosophy* Oxford: Oxford University Press
- Sherwood Johnson, F. 2013. ‘Constructions of Vulnerability in Comparative Perspective: Scottish Protection Policies and the Trouble with ‘Adults at Risk’’ *Disability and Society* 28(7) 908-921
- Shogren, K. 2013. Considering Context: An Integrative Concept for Promoting Outcomes in the Intellectual Disability Field *Intellectual and Developmental Disabilities* 51(2) 132-137
- Skaerbaek, E. 2011. Navigating in the Landscape of Care: A Critical Reflection on Theory and Practise of Care and Ethics, *Health Care Analysis* 19(1) 41-50
- Spring, J. 2011. On the Rescuing of Rights in Feminist Ethics: A Critical Assessment of Virginia Held’s Transformative Strategy *Praxis* 3(1) 66-83
- Spring, J. 2013. Justice, Rights and Capabilities (University of Western Ontario- Electronic Thesis and Dissertation Repository) Paper 1447
- Stanley, N. and Manthorpe, N. 2009. Small Acts of Care: Exploring the Potential Impact of the Mental Capacity Act 2005 on Day-to-Day Support *Social Policy and Society* 8(1) 37-48
- Surtees, D. What can elder law learn from disability law? in Doron, I. (Ed.) 2009. *Theories on Law and Ageing*. Berlin: Springer
- Swain, S., French, S., Barnes, C. and Thomas, C. (Eds) 2004, *Disabling Barriers- Enabling Environments* 2nd Ed London: Sage
- Swift, P. et al, 2013. What Happens When People with Disabilities Need Advice about the Law? Bristol: University of Bristol: Norah Fry Research Centre
- Syrett, K. 2007. *Law, Legitimacy and the Rationing of Healthcare: A Contextual and Comparative Perspective*. Cambridge: Cambridge University Press

- Szerletics, A. 2011. *Best interests decision-making under the Mental Capacity Act Essex Autonomy Project Green Paper Report*. University of Essex: Essex Autonomy Project
- Szerletics, A. and O'Shea, T. 2011. *The Deprivation of Liberty Safeguards*. Essex Autonomy Project Briefing. University of Essex.
- Szmukler, G., Daw, R. and Callard, F. 2013. Mental health law and the UN Convention on the rights of persons with disabilities. *International Journal of Law and Psychiatry*, 17(3) 245–252.
- Tarzia, L., Fetherstonhaugh, D. and Bauer, M. 2012. Dementia, Sexuality and Consent in Residential Aged Care Facilities. *Journal of Medical Ethics* 38 609-613
- Taylor, A. 2013. 'Lives Worth Living' Theorizing Moral Status and Expressions of Human Life *Disability Studies Quarterly* 33(4) (online access only)
- Terzi, L. 2004. 'The Social Model of Disability: A Philosophical Critique' *Journal of Applied Philosophy* 21(2) 141-157
- Terzi, L. 2008. *Justice and Equality in Education: A Capability Perspective on Disability and Special Educational Needs* London: Continuum
- Thompson, S.A. 2003. Subversive political praxis: Supporting choice, power and control for people with learning difficulties *Disability & Society* 18(6) 719-736
- Tollefsen, C. 'Disability and Social Justice' in Ralston, D. and Ho, J (Eds) 2010. *Philosophical Reflections on Disability* Springer: New York
- Tremain, S. (Ed), 2005. *Foucault and the Government of Disability*, University of Michigan: University of Michigan Press
- Tronto, J. 1987. Beyond Gender Difference to a Theory of Care *Signs* 12(4) 644-663
- Tronto, J. 1993. *Moral Boundaries: A Political Argument for an Ethic of Care* New York: Routledge
- UN Committee on the Rights of Persons with Disabilities, 2014. General Comment (Number 1) on Art 12: Equal Recognition before the Law.
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>
- University of Warwick Centre for Human Rights in Practice, *The Human Rights and Equality Impact Assessments of Public Spending Cuts - A Resource Database* available at <http://www2.warwick.ac.uk/fac/soc/law/chrp/projects/spendingcuts/resources/databases/>
- Unsworth, C. 1987. *The Politics of Mental Health Legislation*. Oxford: Clarendon Press
- Vehmas, S. 2004. 'Ethical Analysis of the Concept of Disability' *Mental Retardation* 42(3) 209-222
- Vehmas, S. and Makela, P. 'The Ontology of Disability and Impairment: A Discussion of the Natural and Social Features' in Kristiansen, K. Vehmas, S. and Shakespeare, T. (Eds) 2009. *Arguing about Disability: Philosophical Perspectives*. London: Routledge
- Venkatapuram, S. 2014. Mental Disability, Human Rights and the Capabilities Approach: Searching for the Foundations. *International Journal of Psychiatry* 26(4) 408-414
- Verkerk, M. 1999. A Care Perspective on Coercion and Autonomy. *Bioethics* 13 3658-368
- Wall, J. and Herring, J. 2013. Capacity to Cohabit: Hoping Everything Turns out well in the end- *PC v City of York. Child and Family Law Quarterly* 25(4) 474-483
- Wallbank, J. and Herring, J. 2014. *Vulnerabilities, Care and Family Law* London: Routledge
- Ward, A. 2014. Abolition of all Guardianship and Mental Health Laws? *Elder Law Journal* 1 5-11
- Ward, N. 2011. Care Ethics and Carers With Learning Disabilities: A challenge to dependence and paternalism *Ethics and Social Welfare* 5(2) 168-180
- Watson, J. 2011. Supported Decision Making for People with Severe to Profound Intellectual Disability: We're All In This Together Aren't we? in Bigby, C. and Fyffe, C. Eds

- Services and Families Working Together to Support Adults with Intellectual Disability* (6th Annual Roundtable on Intellectual Disability Policy) Living and Disability Group, La Trobe University, Victoria
- Watson, N., McKie, L., Hopkins, D. and Gregory, S. 2004. (Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theories to Develop an Emancipatory Model *Sociology* 38 331-350
- Weber, M. 2011. Disability Rights, Welfare Law *Cardozo Law Review* 32(6) 2483-2531
- Wendell, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability* New York: Routledge
- West, R. 1997. *Caring for Justice* New York: New York University Press
- Williams, F. 2001 'In and Beyond New Labour: Towards a Political Ethics of Care' *Critical Social Policy* 21(4) 467-493
- Williams, J. 2002. Public Law Protection of Vulnerable Adults: The Debate Continues, So Does the Abuse. *Journal of Social Work* 2 293-316
- Wong, S. Duties of Justice to Citizens with Cognitive Disabilities. in Kittay, E. F., and Carlson, L. (Eds) 2010 *Cognitive Disability and its Challenge to Moral Philosophy* Malden, Wiley-Blackwell
- Yannamani, N. Zia, A. and Khalil, N. 2009. Family Carers of People with Learning Disabilities: Common Themes Across Caring' *Psychiatry* 8(11) 441-444
- Yeates, V. 2007. Ambivalence, Contradiction and Symbiosis: Carers' and Mental Health Users' Rights *Law and Policy* 29(4) 435-459
- Young, I.M. 1990. *Justice and the Politics of Difference* Princeton: Princeton University Press

APPENDIX

Published Papers

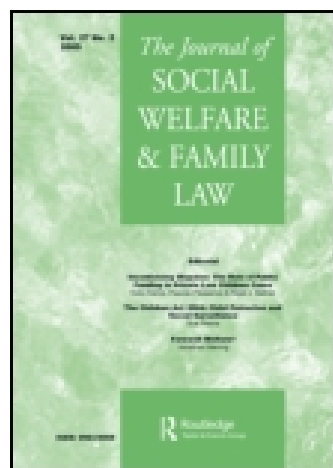
1. B. Clough, 'What About Us? A case for legal recognition of interdependence in informal care relationships', (2014) 36(2) *Journal of Social Welfare and Family Law*, 129-148.
2. B. Clough, 'People Like That': Realising the Social Model in Mental Capacity Jurisprudence' (2015) 23(1) *Medical Law Review* 53-80.
3. B. Clough, 'Vulnerability and capacity to consent to sex – asking the right questions?' (2014) 4 *Child and Family Law Quarterly* 371-396

This article was downloaded by: [University of Liverpool]

On: 25 September 2014, At: 03:05

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Journal of Social Welfare and Family Law

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/rjsf20>

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

Beverley Clough^a

^a Centre for Social Ethics and Policy, School of Law, University of Manchester, UK

Published online: 28 May 2014.

To cite this article: Beverley Clough (2014) What about us? A case for legal recognition of interdependence in informal care relationships, *Journal of Social Welfare and Family Law*, 36:2, 129-148, DOI: [10.1080/09649069.2014.916081](https://doi.org/10.1080/09649069.2014.916081)

To link to this article: <http://dx.doi.org/10.1080/09649069.2014.916081>

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the "Content") contained in the publications on our platform. However, Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Any opinions and views expressed in this publication are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor and Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Terms & Conditions of access and use can be found at <http://www.tandfonline.com/page/terms-and-conditions>

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

Beverley Clough*

Centre for Social Ethics and Policy, School of Law, University of Manchester, UK

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

*Email: Beverley.clough@manchester.ac.uk

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,

[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 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.¹ 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).² 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 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.

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 care-giver is overlooked and 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 Myelodysplastic 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, 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' (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.³ 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).⁴ 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 (Nedelsky, 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.⁵ 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).⁶ 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.⁷ 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.⁸

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).

References

- Allen, A., & Regan, M. (1998). *Debating democracy's discontent: Essays on American politics, law and public philosophy*. Oxford: Oxford University Press.
- Arksey, H., & Glendinning, C. (2007). Choice in the context of informal care giving. *Health and Social Care in the Community*, 15, 165–175.
- Barnes, M., & Brannelly, T. (2008). Achieving care and social justice for people with dementia. *Nursing Ethics*, 15, 394–395.
- Benhabib, S. (1992). *Situating the self: Gender, community and postmodernism in contemporary ethics*. New York, NY: Routledge.
- Berger, J., DeRenzo, E., & Schwartz, J. (2008). Surrogate decision making: Reconciling ethical theory and clinical practice. *Annals of Internal Medicine*, 149, 48–53.
- Brazier, M. (2006). Do no harm – do patients have responsibilities too? *Cambridge Law Journal*, 65, 397–422.
- Brennan, S. (1999). Reconciling feminist politics and feminist ethics on the issue of rights. *Journal of Social Philosophy*, 30, 260–275.
- Bridgeman, J. (2007). Accountability, support or relationship? conceptions of parental responsibility. *Northern Ireland Legal Quarterly*, 58, 307–324.
- British Institute of Human Rights. (2012). Your human rights: A pocket guide for carers. Retrieved from <http://www.bihhr.org.uk/sites/default/files/BIHR%20Pocket%20Guide%20for%20Carers.pdf>
- British Institute for Human Rights and Age UK. (2011). *Older people and human rights: A guide for professionals working with older people* (2nd ed.). London: Age UK and BIHR.
- Buckner, L., & Yeandle, S. (2011). *Valuing carers*. Leeds: University of Leeds.
- Butler, F. (2006). *Rights for real: Older people, human rights and the CEHR*. London: Age Concern.
- Case, P. (2003). Confidence matters: The rise and fall of informational autonomy. *Medical Law Review*, 11, 208–236.
- Clement, G. (1996). *Care, autonomy and justice*. Boulder, CO: Westview.
- Chan, H. M. (2004). Informed consent Hong Kong Style: An instance of moderate familism. *Journal of Medicine and Philosophy*, 29, 195–206.
- Coggon, J. (2007). Varied and principled understandings of autonomy in English law: Justifiable inconsistency or blinkered moralism? *Health Care Analysis*, 15, 235–255.
- Coggon, J. (2008a). Harmful rights doing? The perceived problem of liberal paradigms in public health. *Journal of Medical Ethics*, 34, 798–801.
- Coggon, J. (2008b). Best interests, public interests and the power of the medical profession. *Health Care Analysis*, 16, 219–232.
- Cong, Y. (2004). Doctor–patient–family relationship: The Chinese paradigm of informed consent. *Journal of Medicine and Philosophy*, 29, 149–178.
- Deber, R., Kraetschmer, N., Urowitz, S., & Sharpe, N. (2007). Do people want to be autonomous patients? Preferred roles in treatment decision making in several patient populations. *Health Expectations*, 10, 248–258.
- Department for Constitutional Affairs. (2007). *Mental Capacity Act 2005 Code of Practice*. London: The Stationery Office.

- Department of Health. (2009). *National dementia strategy: Living well with dementia*. London: The Stationery Office.
- Department of Health. (2010). *Recognised, valued and supported: Next steps for the carer's strategy*. London: The Stationery Office.
- Department of Health. (2012). *Draft care and support bill*. London: The Stationery Office.
- Dodds, S. (2007). Depending on care: Recognition of vulnerability and the social contribution of care provision. *Bioethics*, 21, 500–510.
- Donnelly, M. (2009). Best interests, patient participation and the Mental Capacity Act 2005. *Medical Law Review*, 17, 1–29.
- Donnelly, M. (2010). *Health care decision making and the law: Autonomy, capacity and the limits of liberalism*. Cambridge: Cambridge University Press.
- Donnelly, M. (2011). Commentary; determining best Interests under the Mental Capacity Act 2005: In the Matter of G(TJ) [2010] EWHC 3005 (COP). *Medical Law Review*, 19, 304–313.
- Dunn, M., Clare, I., & Holland, A. (2010). Living 'a life like ours': Support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 54, 144–160.
- Engster, D. (2004). Care ethics and natural law theory: Toward an institutional political theory of caring. *Journal of Politics*, 66, 113–135.
- Engster, D. (2007). *The heart of justice: Care ethics and political theory*. Oxford: Oxford University Press.
- Fan, R., & Tao, J. (2004). Consent to medical treatment: The complex interplay of patients, families, and physicians. *Journal of Medicine and Philosophy*, 29, 139–148.
- Fineman, M. (2000). Cracking the foundational myths: Independence, autonomy and self-sufficiency. *Gender, Work & Family Project Inaugural Feminist Legal Theory Lecture*, 13–29.
- Fineman, M. (2004). *The autonomy myth: A theory of dependency*. New York, NY: New Press.
- Fletcher, R., Fox, M., & McCandless, J. (2008). Legal embodiment: Analysing the body of health care law. *Medical Law Review*, 16, 321–345.
- Fox, M., & Thomson, M. (2013). Realising social justice in public health law. *Medical Law Review*, 21, 278–309.
- FP v HM and A Health Board* [2011] EWHC 2778.
- G v E, A Local Authority & F* [2010] EWHC 621 (Fam).
- Gilbar, R. (2011). Family involvement, independence and patient autonomy. *Medical Law Review*, 19, 192–234.
- Gilligan, C. (1982). *In a different voice*. Cambridge: Harvard University Press.
- Glover, N., & Brazier, M. (1996). Ethical aspects of the Law Commission Report on Mental Incapacity. *Reviews in Clinical Gerontology*, 6, 365–370.
- Hankivsky, O. (2004). *Social policy and the ethic of care*. Vancouver: UBC Press.
- Harding, R. (2012). Legal constructions of dementia: discourses of autonomy at the margins of capacity. *Journal of Social Welfare and Family Law*, 34, 425–442.
- Harding, R., & Peel, E. (2011). *Dementia project news: Findings summary 1*. Retrieved from http://www.dementiaproject.net/assets/user/files/1330689267_d2claysummary1a_august2011.pdf
- Hardwig, J. (1990). What about the family? The role of family interests in medical decision making. Hastings Centre Report 5–10.
- Hardwig, J. (1997). Is there a duty to die? Hastings Centre Report 27.
- HBCC v LG, JG and SG* [2010] EWHC 1527 (Fam).
- Held, V. (1993). *Feminist morality: transforming culture, society and politics*. Chicago: Chicago University Press.
- Herring, J. (2007). Where are the carers in healthcare law and ethics? *Legal Studies*, 27, 51–73.
- Herring, J. (2008). Caregivers in medical law and ethics. *Journal of Contemporary Health Law & Policy*, 25, 1–37.
- Herring, J. (2012). *Caring and the law*. Oxford: Hart Publishing.
- Herring, J., & Foster, C. (2012). Welfare means relationally, virtue and altruism. *Legal Studies*, 32, 480–498.
- Ho, A. (2008). Relational autonomy or undue pressure? Family's role in medical decision making. *Scandinavian Journal of Caring Science*, 22, 128–135.
- Holstein, M., Parks, J., & Waymack, M. (2011). *Ethics, aging and society: The critical turn*. New York, NY: Springer.

- Kelly, F. (2005). Conceptualising the child through an 'ethic of care': Lessons for family law. *International Journal of Law in Context*, 1, 375–396.
- Keywood, K. (2003). Gatekeepers, proxies, advocates: The evolving role of carers under mental health and mental incapacity law reforms. *Journal of Social Welfare and Family Law*, 25, 355–368.
- Keywood, K., & Flynn, M. (2006). Healthcare decision making by adults with learning disabilities: Ongoing agendas, future challenges. *Psychiatry*, 5, 260–262.
- Kittay, E. F. (1999). *Love's labor: Essays on women, equality and dependency*. New York, NY: Routledge.
- Kittay, E. F., & Feder, E. K. (Eds.). (2002). *The subject of care: Feminist perspectives on dependency*. Lanham, MY: Rowman & Littlefield.
- Kittay, E. F., & Meyers, D. T. (1987). *Women and moral theory*. Totowa, NJ: Rowman & Littlefield.
- Koehn, D. (1998). *Rethinking feminist ethics: Care, trust and empathy*. New York, NY: Routledge.
- Lacey, N. (1998). *Unspeakable subjects: Feminist essays in legal and social theory*. Oxford: Hart.
- Law Commission. (1995). *Mental incapacity*. London: HMSO.
- Lindemann Nelson, H., & Lindemann Nelson, J. (1995). *The patient in the family*. New York, NY: Routledge.
- MacIntyre, A. (1984). *After Virtue* (2nd ed.). Notre Dame: Notre Dame Press.
- Minow, M. (1990). *Making all the difference: Inclusions, exclusion and American law*. Ithaca, NY: Cornell University Press.
- Montgomery, J. (2006). Law and the demoralisation of medicine. *Legal Studies*, 26, 185–210.
- Murphy, J., & Oliver, T. (2013). The use of talking mats to support people with dementia and their carers to make decisions together. *Health and Social Care in the Community*, 21, 171–180.
- Naffine, N. (1997). The body bag. In N. Naffine & R. Owens (Eds.), *Sexing the subject of law*. Sydney: Sweet & Maxwell.
- Nedelsky, J. (1990). Law, boundaries and the bounded self representations. *Law and the Order of Culture*, 30, 162–189.
- Nedelsky, J. (2006). Reconceiving rights as relationship. In C. Koggel (Ed.), *Moral issues in global perspective* (2nd ed., pp. 95–106). Peterborough: Broadview.
- NHS Information Centre. (2010). *Survey of carers in households 2009–10*. Leeds: The Health and Social Care Information Centre.
- Noddings, N. (1984). *Caring: A feminine approach to ethics*. Berkeley, CA: University of California Press.
- Noddings, N. (2002). *Starting at home: Caring and social policy*. Oakland: University of California Press.
- Norrie, A. (1993). *Crime, reason and history: A critical introduction to criminal law*. Cambridge: Cambridge University Press.
- O'Donovan, K. (1997). With sense, consent or just a con? Legal subjects in the discourse of autonomy. In N. Naffine & R. Owens (Eds.), *Sexing the subject of law* (pp. 47–64). London: Sweet & Maxwell.
- O'Donovan, K., & Gilbar, R. (2003). The loved ones: Families, intimates and patient autonomy. *Legal Studies*, 23, 332–358.
- Office of the Public Guardian. (2009). *Making decisions: A guide for family, friends and other unpaid carers* (4th ed.). Retrieved from <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf>
- Pettersen, T. (2011). The ethics of care: Normative structures and empirical implications. *Health Care Analysis*, 19, 51–64.
- Pickard, S., Jacobs, S., & Kirk, S. (2003). Challenging professional roles: Lay carers' involvement in health care in the community. *Social Policy and Administration*, 37, 82–96.
- Princess Royal Trust for Carers. (2011). *Always on call, always connected: A survey of the experiences of older carers*. Essex: The Princess Royal Trust for Carers.
- Quigley, M. (2008). Best interests, the power of the medical profession, and the power of the judiciary. *Health Care Analysis*, 16, 233–239.
- Quinn, G. (2011). *Rethinking personhood: New directions in legal capacity law and policy: Or, how to put the shift back into paradigm shift*. Retrieved from http://cic.arts.ubc.ca/fileadmin/user_upload/CIC/July_2011/Gerard_Quinn_s_Keynote_-_April_29_2011.pdf
- R (A and B, X and Y) v East Sussex County Council and Disability Rights Commission* [2003] EWHC 167.

- R (Hughes) v Liverpool City Council* [2005] EWHC 428 (Admin).
- Re A (Medical Treatment: Male Sterilisation)* (2000) 1 FLR 549.
- Re F (Mental Patient: Sterilisation)* [1989] 2 WLR 1025.
- Re MM (An Adult)* [2007] EWHC 2003 (Fam).
- Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 645.
- Re VW; NK v VW* (2011) COP 27/10/10 11744555.
- Re Y (Mental Incapacity: Bone Marrow Transplant)* [1997] 2 FCR 172.
- Richardson, G. (2012). Mental disabilities and the law: From substitute to supported decision-making? *Current Legal Problems*, 65, 1–22.
- Ruddick, S. (1989). *Maternal feminism: Toward a politics of peace*. Boston, MA: Beacon.
- Rummery, K. (2011). A comparative analysis of personalisation: balancing an ethic of care with user empowerment. *Ethics and Social Welfare*, 5, 138–152.
- Sandel, M. (1984). *Liberalism and its critics*. New York, NY: New York University Press.
- Sandel, M. (1998). *Liberalism and the limits of justice* (2nd ed.). Cambridge: Cambridge University Press.
- Sandland, R. (1995). Between 'trust' and 'Difference': Poststructuralism, law and the power of feminism. *Feminist Legal Studies*, 3, 3–47.
- Sevenhuijsen, S. (1998). *Citizenship and the ethics of care: Feminist considerations on justice, morality and politics*. London: Routledge.
- Sevenhuijsen, S. (2003). The place of care: The relevance of the feminist ethic of care for social policy. *Feminist Theory*, 4, 179–197.
- Shanley, M. (1998). Unencumbered individuals and embedded selves: Reasons to resist dichotomous thinking in family law. In A. Allen & M. Regan (Eds.), *Debating democracy's discontent: Essays on American politics, law and public philosophy* (pp. 229–248). Oxford: Oxford University Press.
- Skaerbaek, E. (2011). Navigating in the landscape of care: A critical reflection on theory and practise of care and ethics. *Health Care Analysis*, 19, 41–50.
- Spring, J. (2011). On the rescuing of rights in feminist ethics: A critical assessment of Virginia Held's transformative strategy. *Praxis*, 3, 66–83.
- Stanley, N., & Manthorpe, N. (2009). Small acts of care: Exploring the potential impact of the Mental Capacity Act 2005 on day-to-day support. *Social Policy and Society*, 8, 37–48.
- Szerletics, A. Best interests decision-making under the Mental Capacity Act. Essex Autonomy Project Green Paper Report. University of Essex: Essex Autonomy Project (2011). Retrieved from <http://autonomy.essex.ac.uk/best-interests-decision-making-under-the-mental-capacity-act>
- Tronto, J. (1987). Beyond gender difference to a theory of care. *Signs*, 12, 644–663.
- Tronto, J. (1993). *Moral boundaries: A political argument for an ethic of care*. New York, NY: Routledge.
- Ward, N. (2011). Care ethics and carers with learning disabilities: A challenge to dependence and paternalism. *Ethics and Social Welfare*, 5, 168–180.
- Watson, J. (2011). 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.), *Services and families working together to support adults with intellectual disability (6th Annual Roundtable on Intellectual Disability Policy)*. Victoria: Living and Disability Group, La Trobe University.
- West, R. (1997). *Caring for justice*. New York, NY: New York University Press.
- Yannamani, N., Zia, A., & Khalil, N. (2009). Family carers of people with learning disabilities: Common themes across caring. *Psychiatry*, 8, 441–444.
- Yeates, V. (2007). Ambivalence, contradiction and symbiosis: Carers' and mental health users' rights. *Law and Policy*, 29, 435–459.



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

B. CLOUGH*

Centre for Social Ethics and Policy, School of Law, University of Manchester, Oxford Road, Manchester M13 9PL, UK
*beverley.clough@manchester.ac.uk

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

1 G Quinn, ‘Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD’ (Harvard Project on Disability: Harvard, 20 February 2010).

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 Court³; 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

2 *Cheshire West and Chester Council v P* [2011] EWCA Civ 1257.

3 *P v Cheshire West and Chester Council and P and Q v Surrey County Council* [2014] UKSC 19.

4 *ibid.*

5 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

6 J Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy and Law* (Oxford University Press, Oxford 2012).

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’.⁷ 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 state⁸ 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.⁹ 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.¹⁰ Disability, viewed from this perspective, is simply an ‘unfortunate state of functioning and being’¹¹ 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’.¹² 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.¹³ Due in part to the foregrounding of a medical diagnosis and a reliance on medical experts, it is not surprising, and perhaps understandable,

7 C Unsworth, *The Politics of Mental Health Legislation* (Clarendon Press, Oxford 1987) 5.

8 MA Fineman, ‘The Vulnerable Subject and the Responsive State’ (2011) 60 *Emory LJ*—(Symposium Issue on ‘The New Deal’).

9 G Quinn and T Degener (eds), *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (Office of the United Nations Commissioner for Human Rights, Geneva 2002).

10 C Barnes and G Mercer, *Implementing the Social Model of Disability: Theory and Research* (The Disability Press, Leeds 2004) 2.

11 Nedelsky, above, n 6, 209.

12 K Shogren, ‘Considering Context: An Integrative Concept for Promoting Outcomes in the Intellectual Disability Field’ (2013) 51 (2) *Intellect Dev Disabil* 133.

13 P Bartlett, ‘Judging Disability: The Problem of Ableism’ (1997) 2 (3) *HRL Rev* 2; P Beresford and others, *Towards a Social Model of Madness and Distress? Exploring What Service Users Say* (Joseph Rowntree Foundation 2010); P Bartlett, ‘The United Nations Convention on the Rights of Persons with Disability and Mental Health Law’ (2012) 75(5) *Med LR* 752–78.

that there is a high level of recourse in law to a medical model.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.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’.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.¹⁷ Non-compliance with such responses is ‘perceived as an unacceptable act of deviance’.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.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’.²⁰

The Mental Capacity Act 2005 similarly foregrounds the existence of an impairment of, or disturbance in, the functioning of the mind or brain²¹—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.²² A recent worrying

14 The Mental Health Act 1983 (Amended 2007) ss 2 and 3.

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.

16 JK Burns, ‘Mental Health and Inequity: A Human Rights Approach to Inequality’ (2007) 11(2) *Health & Hum Rts* 21.

17 Mental Health Act 1983, Part IV.

18 P Bartlett and R Sandland, *Mental Health Law: Policy and Practice* (3rd edn Oxford University Press, Oxford 2007) 9.

19 See cases such as *B v Croydon Health Authority* [1995] 1 ALL ER 683 (CA) and *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 *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 *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.

20 P Beresford and others, above, n 13, 13.

21 Mental Capacity Act 2005 s 2(1).

22 The Mental Capacity Act 2005, s 3(1). See, for example, *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.’

example of this can be seen in *Re AA*,²³ 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 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.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

23 [2012] EWHC 4378 (COP) (In Private).

24 *ibid.* Transcript of Proceedings, 11.

25 See *Re C* [1994] 1 WLR 290 and, more recently *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 (COP).

26 J Bellhouse and others, ‘Decision Making Capacity in Adults: It’s Assessment in Clinical Practice’ (2001) 7 *Adv Psychiatr Treat* 296.

27 A Taylor, ‘“Lives Worth Living:” Theorizing Moral Status and Expressions of Human Life’ (2013) 33(4) *Disab Stud Q*, available online only at <<http://dsq-sds.org/article/view/3875/3404>> last accessed 8 July 2014.

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’.²⁹ 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.³⁰

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.³¹ This was reflected in the Select Committee’s conclusions, where it was highlighted that clinical judgements or resource-led decision-making predominate.³² 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’.³³ Furthermore, through this narrow lens, ‘patients become understood in terms of physical, mental or emotional frailty and dysfunction’³⁴ 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.³⁵

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

29 B Secker, ‘Labelling Patient (In)Competence: A Feminist Analysis of Medico-Legal Discourse’ (1999) 30 (2) *J Soc Phil* 296.

30 NF Banner, ‘Can Procedural and Substantive Elements of Decision Making be Reconciled with Assessments of Mental Capacity?’ (2013) 9 (1) *Int JLC* 84.

31 The Select Committee on the Mental Capacity Act, Revised transcript of evidence, 15 October 2013, per Baroness Barker Q164, p 26 [available at <<http://www.parliament.uk/documents/Mental-Capacity-Act-2005/cMCA151013ev8%20-%20Final.pdf>>].

32 House of Lords Select Committee on the Mental Capacity Act 2005, ‘Mental Capacity Act 2005: Post-Legislative Scrutiny’ (The Stationery Office, London, 13th March 2014).

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).

34 K Keywood, ‘“I’d Rather Keep Him Chaste” Retelling the Story of Sterilisation, Learning Disability and (Non)Sexed Embodiment’ (2001) 9 *Fem LS* 190.

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: Boundaried 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 judgment 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

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.

39 The DoLS have attracted significant criticism since their commencement in April 2009: A Szerletics and T O'Shea, *The Deprivation of Liberty Safeguards* (Essex Autonomy Project Briefing 2011); also see CQC, *Monitoring the use of the Mental Capacity Act 2005 Deprivation of Liberty Safeguards 2011/12*, available at <<http://www.cqc.org.uk/public/reports-surveys-and-reviews/reports/deprivation-liberty-safeguards-2011/12>>; R Hargreaves, *Briefing Paper 1-Deprivation of Liberty Safeguards: An initial review of implementation*, (Mental Health Alliance, London 2010) available at <http://www.mentalhealthalliance.org.uk/resources/DoLS_report_July2010.pdf>; Mental Health Alliance, *The Mental Health Act 2007: A Review of its Implementation* (Mental Health Alliance, London 2012) available at <http://www.mentalhealthalliance.org.uk/news/MHA_May2012_FINAL.pdf>. Concerns about the practical effects of the DoLS, and the Mental Capacity Act 2005 more generally were expanded upon in the evidence submitted to the House of Lords Select Committee on the Mental Capacity Act 2005, in which DoLS featured heavily. <<http://www.parliament.uk/business/committees/committees-a-z/lords-select/mental-capacity-act-2005/>>. Reporting deadline 28 February 2014. The Select Committee have recommended a comprehensive review of the Deprivation of Liberty Safeguards and their replacement. See above, n 32.

40 D Hewitt, 'Objection, Purpose and Normality; Three Ways in which the Courts Have Inhibited Safeguarding' (2012) 14 (6) *J Adult Prot* 280–6.

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',⁴¹ and that instead the task should be to 'identify what it is that we are comparing X's concrete situation with'.⁴² 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',⁴³ 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'.⁴⁴ 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'.⁴⁵ 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 body,⁴⁷ 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 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 community⁴⁹ and the framing of individual responses based on this. An approach predicated on 'false universalising'⁵⁰ prevents 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 individual 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 cognitive 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 Inspection Standards of Human Rights Monitoring Bodies' (2012) 16 (6) Int J Hum Rts 884.

50 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 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'; T Shakespeare and N Watson, 'The Social Model of Disability: An Outdated Ideology?' (2002) 2 Res Soc Sci & Disabil 9–29, 30.

51 C Baylies, 'Disability and the Notion of Human Development: Questions of Rights and Capabilities' (2002) 17(7) Disabil Soc 728.

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 accommodations 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

52 See, for example, *Ashingdane v UK* Series A no 93, judgment of 28 May 1985; *HL v UK* [2004] ECHR 471; *Storck v Germany* [2005] 43 EHRR 96; *Stanev v Bulgaria* (2012) ECHR 46; *DD v Lithuania* [2012] ECHR 254; *Austin v UK* (2012) ECHR 459; *Kedzior v Poland* [2012] ECHR 1809.

53 Hewitt, above, n 40, 284.

54 *P v Cheshire West and Chester Council and P and Q v Surrey County Council* [2014] UKSC 19.

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,

59 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

60 Para 45, per Lady Hale.

61 Quinn and Degener, above, n 9.

62 Para 47.

63 Para 45.

64 McLean and Williamson, above, n 35; P Fennell, ‘Best Interests and Treatment for Mental Disorder’ (2008) 16 Health Care Anal 255–67.

65 See, for example, para 41.

66 *Re J (Wardship: Medical Treatment)* [1991] Fam 33; *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1881.

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.⁷⁰ 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.⁷¹ In essence, the core of the social model, in its original formulation, is that societal structures and institutions, rather than impairments, cause disability.⁷² 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.⁷³ Commentators have emphasised the need to bring individual experiences back into social approaches to disability⁷⁴ 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.⁷⁵ 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'.⁷⁶

70 Para 81.

71 S Goering, 'Revisiting the Relevance of the Social Model of Disability' (2010) 10 (1) *Am J Bioeth* 54.

72 M Oliver, *The Politics of Disablement* (Palgrave Macmillan 1990); M Oliver, *Understanding Disability: From Theory to Practice* (Palgrave Macmillan 1996).

73 M Miles, 'The Social Model of Disability Met a Narrative of (In)credulity: A Review' (2011) 22 (1) *Disab CBR Inclusive Dev* 5–15; C Barnes and G Mercer, 'Breaking the Mould' in C Barnes and G Mercer (eds), *Doing Disability Research* (The Disability Press, Leeds 2006) 1–14; T Shakespeare, *Disability Rights and Wrongs* (Routledge, London 2006); S McLean and L Williamson, Ch1 'Conceptualising Disability' in McLean and Williamson, above n 35, 11–36.

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 models⁸²; 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

77 J Gilliard and others, 'Dementia Care in England and the Social Model of Disability: Lessons and Issues' (2005) 4 *Dementia* 573.

78 J Gilliard and others, *ibid.*, 571–86; P Dorenlot, 'Applying the Social Model of Disability to Dementia; Present Day Challenges' (2005) 4 *Dementia* 459–61; L Terzi, 'The Social Model of Disability: A Philosophical Critique' (2004) 21 (2) *J Appl Philos* 141–57; S Vehmas, 'Ethical Analysis of the Concept of Disability' (2004) 42 (3) *Ment Retard* 209–22; EF Kittay and L Carlson (eds), *Cognitive Disability and its Challenge to Moral Philosophy* (Wiley Blackwell, New York 2010); K Shogren, 'Considering Context: An Integrative Concept for Promoting Outcomes in the Intellectual Disability Field' (2013) 51 (2) *Intellect Dev Disabil* 132–7; D Goodley, 'Who is Disabled? Exploring the Scope of the Social Model of Disability' in J Swain, S French, C Barnes and C Thomas (eds), *Disabling Barriers—Enabling Environments* (2nd edn Sage, London 2004) 118–24; A Chappell, D Goodley, and R Lawthorn, 'Making Connections: The Relevance of the Social Model of Disability for People with Learning Difficulties' (2001) 29 *Brit J Learn Disabil* 45–50.

79 Beresford and others, *above*, n 13.

80 J Rothman, 'The Challenge of Disability and Access: Reconceptualizing the Role of the Medical Model' (2010) 9 (2) *J Soc Work Disabil Rehabil* 205.

81 Rothman, *ibid.*; McLean and Williamson, *above*, n 35; P Louhiala, 'Philosophy Meets Disability' (2009) 35 *J Med Ethics* 570; S Vehmas and P Makela, 'The Ontology of Disability and Impairment: A Discussion of the Natural and Social Features' in K Kristiansen, S Vehmas, and T Shakespeare (eds), *Arguing about Disability: Philosophical Perspectives* (Routledge, London 2009) 42–56; D Goodley, 'Dis/entangling Critical Disability Studies' (2013) 28 (5) *Disabil Soc* 631–45.

82 P Louhiala, *ibid.*

83 D Goodley, *above*, n 81.

claims . . . but promised improvements all too often fail to materialise'.⁸⁵ 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.⁸⁶ 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.⁸⁷ 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. 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.⁸⁸ The sense is that the resulting legal framework has simply created 'medical freedom with the appearance of legal control',⁸⁹ with the ethos informing Gostin's original work being 'lost in translation into domestic law'.⁹⁰ 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

84 T Burchardt, 'Capabilities and Disability: the Capabilities Framework and the Social Model of Disability' (2004) 19 (7) *Disabil Soc* 735; Also see A Samaha, 'What Good Is the Social Model of Disability?' (2007) 74 (4) *U Chi L Rev* 1251–308.

85 C Barnes, G Mercer, and T Shakespeare, *Exploring Disability: A Sociological Introduction* (Polity, Cambridge 1999) 227.

86 Nedelsky, above, n 6.

87 L Gostin, *A Human Condition 1* (National Association for Mental Health, London 1975); L Gostin, *A Human Condition 2* (National Association for Mental Health, London 1977); L Gostin, 'Contemporary Social Historical Perspectives on Mental Health Reforms' (1983) 10 *J L & Soc'y* 47–70.

88 P Fennell, 'Institutionalising the Community' in B McSherry and P Weller (eds), *Rethinking Rights Based Mental Health Law* (Hart Publishing, Oxford 2010) 17; P Gooding 'Supported Decision Making—A Rights-Based Disability Concept and its Implications for Mental Health Law' (2013) 20 (3) *Psychiatry Psychol & L* 430.

89 Bartlett and Sandland, above, n 18, 347.

90 P Weller, 'Lost in Translation: Human Rights and Mental Health Law', in McSherry and Weller, above, n 88, 54.

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'⁹⁶ 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.

92 E Palmer *Judicial Review, Socio-economic Rights and the Human Rights Act* (Hart, Oxford 2007) 24.

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.

94 D Pilgrim, 'Lessons from the Mental Health Act Commission for England and Wales: The Limitations of Legalism-Plus-Safeguards' (2012) 40 (1) *J Soc Pol'y* 78.

95 AS Kanter, 'The Law: What's Disability Studies Got to do with it, or an Introduction to Disability Legal Studies' (2011) 42 (2) *Colum Hum Rts L Rev* 32.

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'¹⁰⁰ 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 recognised¹⁰¹ 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'.¹⁰² 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 Sen¹⁰³ and Martha Nussbaum.¹⁰⁴ 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'.¹⁰⁵ This approach instead scrutinises 'what people are actually able to do and be',¹⁰⁶ 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'.¹⁰⁷ The capabilities approach requires a focus on wider contextual aspects of a given

100 G Quinn and T Degener, 'Expanding the System: The Debate about a Disability-Specific Convention' in Quinn and Degener, above, n 9.

101 N Rose, 'Unreasonable Rights: Mental Illness and the Limits of the Law' (1985) 12 (2) *JL & Soc'y* 199–218.

102 C O'Cinneide, 'Legal Accountability and Social Justice' in P Leyland and N Bamforth (eds), *Accountability in the Contemporary Constitution* (Oxford University Press, Oxford 2013). See also J King, *Judging Social Rights* (Oxford University Press, Oxford 2012).

103 A Sen, 'Equality of What?' *Tanner Lecture* (Stanford University 1979); A Sen, *The Idea of Justice* (Penguin 2010).

104 M Nussbaum and A Sen, *The Quality of Life* (Oxford University Press, Oxford 1993); M Nussbaum, 'Capabilities and Human Rights' (1997) 66 (2) *Fordham L Rev* 293–4; M Nussbaum, 'Capabilities as Fundamental Entitlements: Sen and Social Justice' (2003) 9 (2) *Feminist Econ* 33–59.

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.¹⁰⁸ This shared affinity and complementarity between the social model of disability and capabilities approaches has been noted by authors such as Burchardt¹⁰⁹ and Terzi.¹¹⁰ 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’.¹¹¹ 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,¹¹² 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’.¹¹³ 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.¹¹⁴ 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’.¹¹⁵ 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

107 C Arjona and others, ‘Senses of Sen: Reflections on Amartya Sen’s Ideas of Justice’ (2012) 8 (1) *Int JLC* 159.

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’.

109 T Burchardt, ‘Capabilities and Disability: The Capabilities Framework and the Social Model of Disability’ (2004) 19 (7) *Disabil Soc* 735–51.

110 L Terzi, ‘The Social Model of Disability: A Philosophical Critique’ (2004) 21 (2) *J Applied Phil* 141–57.

111 C Tollefsen, ‘Disability and Social Justice’ in D Ralston and J Ho (eds), *Philosophical Reflections on Disability* (Springer, New York 2010) 211–27.

112 A Sen, *The Idea of Justice* (2nd edn Penguin, London 2010) 246.

113 S Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (Routledge, New York 1996) 71.

114 *ibid*, 37.

115 M Nussbaum, *The Frontiers of Justice* (Harvard University Press, Belknap Press, Cambridge, MA 2006) 54.

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'.¹¹⁶ From the informational focus on a person's actual ability to achieve certain basic capabilities,¹¹⁷ 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'.¹¹⁸ 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.¹¹⁹ 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'¹²⁰ based on an understanding that given appropriate and adequate enabling conditions, individuals with intellectual disabilities can become fully cooperating members of society.¹²¹

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'.¹²² 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.

118 M Nussbaum, 'Beyond the Social Contract: Toward Global Justice' in *The Tanner Lectures on Human Values* (University of Utah Press 2004) 458.

119 J Ruger, *Health and Social Justice* (Oxford University Press, Oxford 2012) 1076.

120 Ibid, 729. See also Samaha, above, n 84, 1303; M Fox and M Thomson, 'Realising Social Justice in Public Health Law' (2013) 21 Med LR 288 and 304.

121 S Wong, 'Duties of Justice to Citizens with Cognitive Disabilities' in EF Kittay and L Carlson (eds), *Cognitive Disability and its Challenge to Moral Philosophy* (Wiley-Blackwell, Malden 2010) 127–46. This is not a new idea—Carson earlier spoke of 'utilizing positively valued services and ideas in order to enhance expectations of and dignity for the people concerned'. D Carson, 'Disabling Progress: The Law Commission's Proposals on Mentally Incapacitated Adults Decision Making' (1993) 15 (5) JSWFL 305.

empowering people with disabilities. Indeed, the Preamble and Articles of the Convention are infused with the language of the social model and capabilities approaches,¹²³ 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.¹²⁴

One of the key concepts of the UNCRPD is that of reasonable accommodation. This obligation is enshrined in the Convention in Articles 2¹²⁵ 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'¹²⁶ 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.¹²⁷ Denial of reasonable accommodation under the Convention forms a basis upon which a claim for discrimination can be made,¹²⁸ 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.¹²⁹ This demonstrates vital recognition of the relational and situational impacts upon an

122 F Owens and D Griffiths, *Challenges to the Human Rights of People with Intellectual Disabilities* (Jessica Kingsley, London 2009) 35.

123 O'Mahony, above, n 49; Samaha, above, n 84.

124 United Nations Convention on the Rights of Persons with Disability 2006, Preamble.

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.'

126 J Lord and R Brown, 'The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities' in M Rioux, L Basser, and M Jones (eds), *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhoff, UK 2011) 277.

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'.

129 A Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?' (2006–2007) 34 *Syracuse J Int'l L & Com* 429; Gooding, above, n 88.

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.

131 See for example Bartlett (2012) above, n 13; D Mackay, 'The United Nations Convention on the Rights of Persons with Disabilities' (2006/7) 34 *Syracuse J Int'l L & Com* 323–32; A Dhanda, 'Constructing a New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities' (2008) 5 (8) *IJHR* 43.

132 CR Kayess and P French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 (1) *HRL Rev* 1–34.

133 E Flynn, 'Making Human Rights Meaningful for People with Disabilities: Advocacy, Access to Justice and Equality Before the Law' (2013) 17 (4) *IJHR* 497; Owen and Griffiths, above, n 122.

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.

136 Office of the High Commissioner for Human Rights, 'Committee on the Rights of Persons with Disability General Comment No 1: Article 12 Equal Recognition Before the Law' (Eleventh Session, 31st March–11th April 2014) para 7, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en> last accessed 2 April 2014.

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.¹³⁷ 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.¹³⁸ 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.¹³⁹ Concerns have been raised about the level of advice being offered when services are sought out¹⁴⁰ alongside recommendations for training for those in the legal professions on good practice.¹⁴¹ The fact remains that those most at risk of abuse, neglect or exploitation, remain the least likely to access advice or representation¹⁴² 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.¹⁴³ 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*¹⁴⁴ 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

137 T Collingbone, 'Administrative Justice? Realising the Right to Independent Living: Power, Systems, Identities' (2013) 35 (4) JSWFL 475–89.

138 S Ortoleva, 'Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System' (2011) 17 (2) ILSA J Int'l & Comp L 281–317.

139 P Swift and others, *What Happens When People with Disabilities Need Advice about the Law?* (University of Bristol: Norah Fry Research Centre 2013).

140 A Lawson and E Flynn, 'Disability and Access to Justice in the European Union: Implications of the United Nations Convention on the Rights of Persons with Disabilities' (2013) 4 Yrbk Eur Disabil 7–44.

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 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 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 WMA*¹⁴⁹ 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.¹⁵⁰ 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.¹⁵¹

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’.¹⁵² 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.¹⁵³

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.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*’,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.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.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.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’.¹⁵⁹ However, scope for doing so may be limited. Cases such as *Aintree v James*¹⁶⁰ and *ACCG v MN*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’.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.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

154 S Meckled-Garcia and B Cali, *The Legalization of Human Rights-Multidisciplinary Perspectives on Human Rights and Human Rights Law* (Routledge, Oxon 2006).

155 Art 2 (emphasis added).

156 Kayess and French, above, n 132, 9.

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.

158 Above, n 32. See also paras 90–91.

159 J Lord, D Suozzi, and A Taylor, ‘Lessons from the Experience of the United Nations Convention on the Rights of Persons with Disabilities: Addressing the Democratic Deficit in Global Health Governance’ (2010) 38 (3) JLM & E 568.

160 [2013] UKSC 67.

161 [2013] EWHC 3859 (COP).

162 *ibid*, para 52 per King J.

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'.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.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.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.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.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 the theoretical debates about justice on a broader level. He sees the Convention as 'the latest

164 *ibid.*

165 Para 73.

166 Above, n 152.

167 J Ruger, *Health and Social Justice* (Oxford University Press, Oxford 2012) 1076.

168 Sen, above, n 103.

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'.¹⁶⁹

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.¹⁷⁰ 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.¹⁷¹ 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.¹⁷²

There are undoubtedly public law concerns to be raised when calls are made for more judicial intervention in such decisions.¹⁷³ This is particularly the case when resources are at stake such as in community care funding assessments, and—less visibly—in the DoLS context.¹⁷⁴ 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 resources¹⁷⁵ and that, instead, the utility of

169 G Quinn, *Rethinking Personhood: New Questions in Legal Capacity Law and Policy* (University of British Columbia, Vancouver 2011) 52.

170 O'Cinneide, above, n 102, J Herring, *Caring and the Law* (Hart, Oxford 2013).

171 H Carr, 'Rational Men and Difficult Women—R (on the application of McDonald) v. Royal Borough of Kensington and Chelsea [2011] UKSC 33' (2012) 34 (2) JSWFL 227.

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.

175 K Syrett, *Law, Legitimacy and the Rationing of Healthcare: A Contextual and Comparative Perspective* (Cambridge University Press, Cambridge 2007).

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.¹⁷⁶ If judges do not engage with such issues, then there is no real and effective route for remedial action. Furthermore, as O'Conneide 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'.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 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'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'.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 disabilities¹⁸⁰ need to be debated and brought to the fore.

176 Herring, above, n 170, 147.

177 O'Conneide, above, n 102.

178 Secker, above, n 29, 304.

179 Bartlett and Sandland, above, n 18, 350.

180 See The University of Warwick Centre for Human Rights in Practice, *The Human Rights and Equality Impact Assessments of Public Spending Cuts—A Resource Database*, available at <<http://www2.warwick.ac.uk/fac/soc/law/chrp/projects/spendingcuts/resources/database/>> last accessed 6 June 2014.

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?

*Beverley Clough**

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,

* Centre for Social Ethics and Policy, School of Law, University of Manchester. The author would like to thank Kirsty Keywood and Simona Giordano for their invaluable comments on earlier drafts of this article. Thanks are also extended to Rosie Harding and the anonymous reviewers for the journal for their constructive suggestions on an earlier draft.

¹ M Fineman and A Gear, *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013).

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.’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.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,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.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.⁶ In adopting such an approach, the judiciary have repeatedly asserted that they are upholding private rights and sexual autonomy,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?’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

² S Dodds, ‘Depending on care: recognition of vulnerability and the social contribution of care provision’ (2007) 21(9) *Bioethics* 500, at p 501.

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.

⁴ See J Herring, ‘Mental disability and capacity to consent to sex: *A Local Authority v H* [2010] EWHC 49 (CoP)’ (2012) 34 *Journal of Social Welfare and Family Law* 471.

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*).

⁶ *D Borough Council v AB* [2011] EWHC 101 (COP), [2012] Fam 36, [2011] 2 FLR 72.

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

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

⁹ Ibid.

¹⁰ L Series, 'Comparing old and new paradigms of legal capacity' (2014) 1 *Elder Law Journal* 62.

¹¹ K Keywood, 'Supported to be sexual? Developing sexual rights for people with learning disabilities' (2003) 8(3) *Tizard Learning Disability Review* 31.

¹² J Wallbank and J Herring, *Vulnerabilities, Care and Family Law* (Routledge, 2014); C Mackenzie, W Rogers and S Dodds, *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014); M Fineman and A Gear, *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013).

¹³ M Fineman, 'The vulnerable subject: anchoring equality in the human condition' (2008) 20(1) *Yale Journal of Law & Feminism* 1.

¹⁴ M Fineman, 'Equality, Autonomy and the Vulnerable Subject in Law and Politics', in M A Fineman and A Gear (eds), *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013), at p 16.

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',

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.

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 J Wallbank and J Herring (eds), *Vulnerabilities, Care and Family Law* (Routledge, 2014), at pp 216–234.

¹⁸ M Fineman, 'The vulnerable subject and the responsive state' (2010) 30 *Emory Law Journal* 266.

¹⁹ See J Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (Routledge, 1993); V Held, *The Ethics of Care* (Oxford University Press, 2006); D Engster, *The Heart of Justice: Care Ethics and Political Theory* (Oxford University Press, 2007); J Herring, *Caring and the Law* (Hart Publishing, 2013).

²⁰ F Sherwood Johnson, 'Constructions of vulnerability in comparative perspective: Scottish protection policies and the trouble with "adults at risk" ' (2013) 28(7) *Disability and Society* 910.

²¹ B Clough, 'What about us? A case for legal recognition of interdependence in informal care relationships' [2014] *Journal of Social Welfare and Family Law* 129.

²² M Fineman and A Grear, *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013), at p 21.

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 Others*³¹ 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.

²⁴ C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’, in C Mackenzie, W Rogers and S Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 46.

²⁵ A Timmer, ‘A Quiet Revolution? Vulnerability in the European Court of Human Rights’, in M Fineman and A Grear (eds), *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013), at p 148.

²⁶ C Mackenzie, W Rogers and S Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 7.

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.

²⁹ *Ibid*, at p 9.

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 cases³⁹ – 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].

³⁷ D Richardson, ‘Constructing sexual citizenship: theorising sexual rights’ (2000) 20 *Critical Social Policy* 105, at p 110.

³⁸ A Hollomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach* (Jessica Kingsley, 2011), at p 54.

³⁹ *D Borough Council v AB* [2011] EWHC 101 (COP), [2012] Fam 36, [2011] 2 FLR 72.

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 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.⁴² 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,⁴³ 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.⁴⁴ This can lead to a high risk of abuse, pregnancies and sexually transmitted infections.⁴⁵ 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.⁴⁶ 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

⁴⁰ A Saxe and T Flanagan, 'Factors that impact on support workers' perceptions of the sexuality of adults with developmental disabilities: a quantitative analysis' (2014) 32 *Sexuality and Disability* 48.

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.

⁴² D Richardson, 'Constructing sexual citizenship: theorising sexual rights' (2000) 20 *Critical Social Policy* 105, at p 110.

⁴³ F Owen and D Griffiths, *Challenges to the Human Rights of People with Intellectual Disabilities* (Jessica Kingsley, 2009), at p 187.

⁴⁴ A Hollomotz and The Speakup Committee, 'May we please have sex tonight? People with learning difficulties pursuing privacy in residential group settings' (2008) 37 *British Journal of Learning Disabilities* 91.

⁴⁵ M McCarthy, 'Women with intellectual disability: their sexual lives in the 21st century' (2014) 39(2) *Journal of Intellectual and Developmental Disability* 125.

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.⁴⁷ This means that staff are inevitably aware of her sexual life, diminishing her control over private matters, with little clear justification.⁴⁸ 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.⁴⁹ 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.⁵⁰ Thompson points to a 'learned helplessness' which is manifested when individuals have to 'fit' into existing services.⁵¹ Here, attention is drawn to the way in which individuals may be too afraid to challenge their violator;⁵² may feel helpless and powerless; or may not think that they have a choice about participation in sexual activity.⁵³ 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.⁵⁴ 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*.⁵⁵ 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'.

⁴⁷ A Hollomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach* (Jessica Kingsley, 2011), at p 61.

⁴⁸ M McCarthy, 'Women with intellectual disability: their sexual lives in the 21st century' (2014) 39(2) *Journal of Intellectual and Developmental Disability* 125.

⁴⁹ CHANGE, *Talking about Sex and Relationships: the views of young people with learning disabilities (2007–2010) final report*.

⁵⁰ M McCarthy, 'Women with intellectual disability: their sexual lives in the 21st century' (2014) 39(2) *Journal of Intellectual and Developmental Disability* 128.

⁵¹ S A Thompson, 'Subversive political praxis: Supporting choice, power and control for people with learning difficulties' (2003) 18(6) *Disability & Society* 730.

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'.

⁵⁵ [2009] UKHL 42, [2009] 1 WLR 1786.

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,

⁵⁶ Section 30(1)(c).

⁵⁷ Section 30(1)(d).

⁵⁸ Section 30(2)(a) and (b).

⁵⁹ *R v Cooper* [2008] EWCA Crim 1155, [2009] 1 Cr App Rep 211, at para [53].

⁶⁰ *R v Cooper* [2009] UKHL 42, [2009] 1 WLR 1786, at para [24], citing *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 290 and *Re MB (Medical Treatment)* [1997] 2 FLR 426.

⁶¹ *Ibid*, at para [25].

⁶² *Ibid*, at para [27].

terrifying position⁶³ 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.'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 *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.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*.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.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'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

⁶³ Ibid, at para [26].

⁶⁴ C Saunders, 'Making it count: sexual offences, evidential sufficiency, and the mentally disordered complainant' (2010) 31(2) *Liverpool Law Review* 189.

⁶⁵ *D County Council v LS* [2010] EWHC 1544 (Fam) (unreported) 15 June 2010, *D Borough Council v AB* [2011] EWHC 101 (COP), [2012] Fam 36.

⁶⁶ *IM v (1) LM (By Her Litigation Friend the Official Solicitor) (2) AB (3) Liverpool City Council* [2014] EWCA Civ 37, [2014] COPLR 246.

⁶⁷ *Re E (An Alleged Patient); Sheffield City Council v E and S* [2004] EWHC 2808 (Fam), [2005] 2 WLR 953, at para [136].

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.’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.⁷⁰ 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’.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 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’.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 *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 ...’⁷³

As such, it is seemingly impossible to apply this functional, decision specific approach which is entailed in the statute.⁷⁴

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].

⁷⁰ Noted by Wood J in *D County Council v LS* [2010] EWHC 1544 (Fam) (unreported) 15 June 2010, at para [42].

⁷¹ *D Borough Council v AB* [2011] EWHC 101 (COP), [2012] Fam 36, at paras [34]–[35].

⁷² M Donnelly, ‘Capacity assessment under the Mental Capacity Act 2005: delivering on the functional approach?’ (2009) 29(3) *Legal Studies* 464.

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.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 *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'.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.

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.⁷⁷ 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.⁷⁸ 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.⁷⁹ 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

⁷⁵ Mental Capacity Act 2005, s 27.

⁷⁶ [2013] EWHC 2322 (COP), [2013] COPLR 477, at para [23].

⁷⁷ M Fineman and A Grear, *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013), at 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, *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 33.

⁷⁹ *Ibid*, at p 35; J Nedelsky, *Laws Relations: A Relational Theory of Self, Autonomy and the Law* (Oxford University Press, 2012).

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

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.

⁸¹ C Mackenzie, ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’, in C Mackenzie, W Rogers and S Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 34.

⁸² M Nussbaum, *The Frontiers of Justice* (Harvard University Press, 2006), at p 54.

⁸³ F Owen and D Griffiths, *Challenges to the Human Rights of People with Intellectual Disabilities* (Jessica Kingsley, 2009), at p 35.

⁸⁴ E Flynn, ‘Making human rights meaningful for people with disabilities: advocacy, access to justice and equality before the law’ (2013) 17 *International Journal of Human Rights* 497.

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

⁸⁷ UN Committee on the Rights of Persons with Disabilities, *General Comment No 1 on Article 12: equal recognition before the Law* (United Nations, 2014) available at <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> (last accessed 15 August 2014).

⁸⁸ *Ibid*, at para 1.

⁸⁹ *Ibid*, at para 8.

⁹⁰ *Ibid*, at paras 13–15.

⁹¹ *Ibid*, at para 14

⁹² See, for example, P Bartlett, ‘The United Nations Convention on the Rights of Persons with Disabilities and mental health law’ (2012) 75(5) *Modern Law Review* 752.

⁹³ C Harnacke, ‘Disability and capability: exploring the usefulness of Martha Nussbaum’s capabilities approach for the UN Disability Rights Convention’ (2014) 41(4) *The Journal of Law, Medicine and Ethics* 769.

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:

⁹⁴ M Bach and L Kerzner, ‘A new paradigm for protecting autonomy and the right to legal capacity’ (2010) Prepared for the Law Commission of Ontario.

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.

⁹⁷ R Kayess and P French, ‘Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8(1) *Human Rights Law Review* 1, at p 10.

⁹⁸ J Bickenbach, ‘Minority Rights or Universal Participation: The Politics of Disablement’, in M Jones and L Basser Mark (eds), *Disability, Diversity-Ability and Legal Change* (Martinus Nijhoff, 1999), at p 101.

⁹⁹ Mencap, *Behind Closed Doors* (Mencap, 2001).

¹⁰⁰ A Hollomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach* (Jessica Kingsley, 2011), at p 34.

'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.'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 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.¹⁰² 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.¹⁰³ 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'.¹⁰⁴ 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.¹⁰⁵ 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'.¹⁰⁶ 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'.¹⁰⁷

¹⁰¹ J Leach Scully, 'Disability and Vulnerability: On Bodies, Dependency and Power', in C Mackenzie, W Rogers and S Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 209.

¹⁰² M Burdhardt, 'Common frailty, constructed oppression: tensions and debates on the subject of vulnerability' (2013) 28(4) *Disability & Society* 559.

¹⁰³ Ibid.

¹⁰⁴ A Hollomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach* (Jessica Kingsley, 2011), at p 41.

¹⁰⁵ K Keywood, 'Commentary: safeguarding reproductive health? The inherent jurisdiction, contraception and mental incapacity. *A Local Authority v A* [2010] EWHC 1549 (Fam)' (2011) 19 *Medical Law Review* 326, at p 329.

¹⁰⁶ Ibid.

¹⁰⁷ J Coggon and J Miola, 'Autonomy, liberty and medical decision making' (2011) 70(3) *Cambridge Law Journal* 524.

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.¹⁰⁸ Tied to this liberal understanding of autonomy is the corollary idea that autonomy increases with the reduction of state interference or restrictions.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.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'.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'.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.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 *A Local Authority v H*,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',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.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

¹⁰⁸ M I Hall, 'Mental capacity in the (civil) law: capacity, autonomy and vulnerability' (2012) 58(1) *McGill Law Journal* 1.

¹⁰⁹ J Anderson and A Honneth, 'Autonomy, Vulnerability, Recognition and Justice', in J Christman and J Anderson (eds), *Autonomy and the Challenges to Liberalism: New Essays* (Cambridge University Press, 2005), at p 128.

¹¹⁰ S Doyle, 'The notion of consent to sexual activity for persons with mental disabilities' (2010) 31 *Liverpool Law Review* 119.

¹¹¹ F Sherwood Johnson, 'Constructions of vulnerability in comparative perspective: Scottish protection policies and the trouble with "adults at risk" ' (2013) 28(7) *Disability & Society* 917.

¹¹² C Mackenzie, W Rogers and S Dodds, *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 16.

¹¹³ D Hewitt, 'Not just in the Mental Capacity Act: using the law to protect vulnerable adults' (2009) 11(2) *Journal of Adult Protection* 25, at p 26.

¹¹⁴ [2012] EWHC 49 (COP), [2012] COPLR 305.

¹¹⁵ *Ibid*, at para [6].

¹¹⁶ *Ibid*, at para [9].

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

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'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'.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,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.¹²⁶ 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 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:

¹²³ J Wall and J Herring, 'Capacity to cohabit: hoping everything turns out well in the end – *PC v City of York*' [2013] CFLQ 471.

¹²⁴ J Wallbank and J Herring, *Vulnerabilities, Care and Family Law* (Routledge, 2014), at p 1.

¹²⁵ *Ibid.*

¹²⁶ M I Hall, 'Mental capacity in the (civil) law: capacity, autonomy and vulnerability' (2012) 58(1) *McGill Law Journal* 1, at p 29.

¹²⁷ P Bartlett and R Sandland, *Mental Health Law Policy and Practice* (Oxford University Press, 2014), at p 182.

¹²⁸ M I Hall, 'Mental capacity in the (civil) law: capacity, autonomy and vulnerability' (2012) 58(1) *McGill Law Journal* 1, at p 33.

'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 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.

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

¹²⁹ C Mackenzie, 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability', in C Mackenzie, W Rogers and S Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 46.

¹³⁰ A Hollomotz, 'Are we valuing people's choices now? Restrictions to mundane choices made by adults with learning difficulties' [2012] *British Journal of Social Work* 1.

¹³¹ D Hingsburger, *Just Say Know! – Understanding and Reducing the Risk of Sexual Victimisation of People with Developmental Disabilities* (Diverse City Press, 1995).

¹³² M McCarthy, 'Drawing a line between consented and abusive sexual experiences: the complexities for women with learning disabilities' (2003) 5(3) *The Journal of Adult Protection* 34.

¹³³ A Hollomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach* (Jessica Kingsley, 2011), at p 47.

¹³⁴ G Quinn and T Degener, 'Human rights and disability: the current use and future potential of United Nations human rights instruments in the context of disability' (United Nations, 2002) available at <http://www.ohchr.org/Documents/Publications/HRDisabilityen.pdf> (last accessed 28 June 2014).

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.

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.

¹³⁸ [2007] EWHC 2003 (Fam), [2009] 1 FLR 443, at para [120].

¹³⁹ Article 16.

¹⁴⁰ Centre for Disability Law and Policy NUI Galway, *Submission on Law Reform Commission Consultation Paper: Sexual offences and capacity to consent* (2011) (CDLP NUI Galway, 2011), at p 7.

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 Council*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 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

¹⁴² C Mackenzie, 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability', in C Mackenzie, W Rogers and S Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 51.

¹⁴³ [2013] EWCA Civ 478, [2013] COPLR 409.

¹⁴⁴ J Wall and J Herring, 'Capacity to cohabit: hoping everything turns out well in the end – *PC v City of York*' [2013] CFLQ 471.

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.

¹⁴⁸ *DL v A Local Authority* [2012] EWCA Civ 253, [2012] COPLR 504.

rather than dictatorial'.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.¹⁵⁰ Parker J in *XCC v AA and Others*¹⁵¹ 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.’¹⁵²

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*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 conceived.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 approach aimed at achieving a capacitous decision, through support and a discussion without undue pressure from her husband.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’.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

¹⁴⁹ *LBL v RYJ and VJ* [2010] EWHC 2665 (COP), [2011] 1 FLR 1279 – Macur J endorsed by McFarlane LJ in *DL*, *ibid*, at para [67].

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).

¹⁵¹ *XCC v AA and Others* [2012] EWHC 2183 (COP), [2012] COPLR 730.

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].

¹⁵⁶ P Bartlett and R Sandland, *Mental Health Law Policy and Practice* (Oxford University Press, 2014), at p 187.

paternalistic and coercive forms of intervention'.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 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 mechanism¹⁵⁸ – 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.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.¹⁶⁰ 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 Act¹⁶¹ – 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.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.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.

¹⁵⁷ C Mackenzie, 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability', in C Mackenzie, W Rogers and S Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), at p 33.

¹⁵⁸ K Keywood, 'Commentary: safeguarding reproductive health? The inherent jurisdiction, contraception and mental incapacity. *A Local Authority v A* [2010] EWHC 1549 (Fam)' (2011) 19 *Medical Law Review* 326.

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.

¹⁶⁰ J Collins, 'The Contours of Vulnerability', in J Wallbank and J Herring (eds), *Vulnerabilities, Care and Family Law* (Routledge, 2014).

¹⁶¹ House of Lords Select Committee on the Mental Capacity Act 2005, Report of Session 2013–14, *Mental Capacity Act 2005: post-legislative scrutiny* (TSO, March 2014).

¹⁶² 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) available at http://cic.arts.ubc.ca/fileadmin/user_upload/CIC/July_2011/Gerard_Quinn_s_Keynote_-_April_29_2011.pdf (last accessed 13 June 2014).

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

¹⁶⁴ M Verkerk, 'A care perspective on coercion and autonomy' (1999) 13 *Bioethics* 363.

¹⁶⁵ J Williams, 'Public law protection of vulnerable adults: the debate continues, so does the abuse' (2002) 2 *Journal of Social Work* 298.

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.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'.¹⁶⁸

¹⁶⁷ G Richardson, 'Mental capacity in the shadow of suicide: what can the law do?' (2013) 9(1) *International Journal of Law in Context* 87, at p 97.

¹⁶⁸ *Ibid*, at p 104.