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Dignity in elderly care: meaning and legal protection

PhD

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Abstract

We are living increasingly longer in a society that is struggling to define how to treat the very old, particularly those in care homes. The concept of dignity can guide how an older individual in care ought to be treated. In this dissertation I argue for an understanding of dignity that is built around the views of the persons cared for, and for the introduction of laws and policies aimed at creating conditions amenable to its realisation. Dignity must be viewed as rooted in our concrete autonomy, one that sees us embodied and embedded in the connections we make with others throughout our lives. Dignity, understood according to the views of the individual cared for, is aligned with this relational view of autonomy, one that prompts us to understand the individual through dialogical engagement. In order to realise the kind of dignity that matters to elderly individuals in care, it is essential to address a number of negative factors, including through law and policies. Addressing these factors means taking concrete steps towards converting potential dignity into actual dignity. One of these ‘conversion factors’ of dignity is vulnerability. In order for this personal conversion factor to be conducive to dignity, vulnerability ought to be conceptualised as inherent, universal and relational. Another conversion factor, this time environmental, is the regulatory system that controls care homes: for dignity to flourish, those affected by this system must be involved in its elaboration and monitoring. On a social level exists the conversion factor of ageism. Generational rapprochement is one way in which to help reduce it. This dissertation examines whether and how legal means responsive to these conversion factors help or hinder the creation of conditions amenable to dignity in long term aged care.

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged

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Introduction

The appeal to dignity, more strongly, the insistent claim to dignity, points to something in us which is genuinely transcendent, something which reflects our freedom to call into question all social roles, to say out loud that I am something more than my frailty or my performances or my buying power. At that moment the passive victim rises up to say “You can’t treat me this way”. The moment we speak these words, dialogue becomes possible and advocacy becomes inevitable.¹

When it comes to growing old, we are relatively lucky. We live in a part of the world where our life expectancy is higher than ever before. According to the Office for National Statistics the life expectancy at birth in the UK was calculated to be 83 based on data for 2014.² Unimaginably even a few years ago, female life expectancy in England has been projected to be 100 by 2064.³ We are lucky because we live in a country that makes welfare provisions for when we stop working and our bodies get old. When we retire we can expect a state pension,⁴ free healthcare delivered by the National Health Service,⁵ and social care organised by local authorities to help us through old age when we can no longer look after ourselves.⁶

Legislation governing the provision of social care for older adults has recently been overhauled with the enactment of the Care Act 2014. This statute is the result of a comprehensive review of the law concerning adult social care by the Law Commission, a first of its kind since the days of the National Assistance Act 1948.⁷ The Law Commission’s report was motivated by a need to streamline the ‘disparate

¹ Moody H.R., ‘Why Dignity in Old Age Matters’ (1998) 29 Issue 2-3 Journal of Gerontology 13, 37

² Office for National Statistics, ‘Past and projected data from the period and cohort life tables: 2014-based, UK, 1981 to 2064’ (11th December 2015)
<<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/pastandprojecteddatafromtheperiodandcohortlifetables/2014baseduk1981to2064>> Accessed 25th August 2017

³ Ibid

⁴ Old-Age Pensions Act 1908

⁵ National Health Service Act 1946

⁶ National Assistance Act 1948

⁷ Law Commission, ‘Adult Social Care’ Law Com 326 (The Stationary Office, 2011)

<https://s3-eu-west-2.amazonaws.com/lawcom-prod-storage-11jxou24uy7q/uploads/2015/03/lc326_adult_social_care.pdf> Accessed 14th January 2018

range of legislative provisions’ adult social care law consisted of, held ‘piecemeal and tortuous’ by the courts, and which still included provisions that were ‘outdated and difficult to justify in modern times’.⁸ Still rooted in part in the old Poor Law, section 47 of the 1948 Act allowed the removal of people who lived in ‘insanitary conditions’ to ‘suitable premises of persons in need of care and attention’, whilst defining under section 29 the aim of the Act as ‘the welfare arrangements for blind, deaf, dumb and crippled persons’.⁹ The report noted that these legislative provisions were incompatible with the Human Rights Act 1998 and ought to be changed.¹⁰

Following a period of consultation, the Law Commission recommended, *inter alia*, the setting of statutory principles, ‘to give legislative expression to the underlying purpose of the statute’.¹¹ Dignity in care was one of the general concepts put forward by the Law Commission in its consultation paper as a potential basis for such statutory principles.¹² The response on this topic divided the opinions:

[a] large majority of consultees who expressed a view argued there should be a principle in the statute based on dignity in care. Some consultees went further and argued this should be the primary principle of the statute. However, others were concerned by the imprecise nature of dignity and argued there might be unnecessary overlap with the choice and control principle.¹³

The Law Commission concluded that a concept such as dignity was ‘too imprecise to be expressed as statutory principles’, and that whereas the courts were well versed in constructing a legal structure ‘conducive to dignity’, it was ‘difficult to build a legal structure on the imprecise notion of dignity’.¹⁴ Instead, the Law Commission recommended the setting out of ‘a single overarching principle that adult social care must promote or contribute to the well-being of the individual’.¹⁵

⁸ Ibid [1.2]

⁹ Ibid [1.1]

¹⁰ Ibid [1.2]

¹¹ Ibid [4.1]

¹² Ibid [4.3]

¹³ Ibid [4.11]

¹⁴ Ibid [4.35]

¹⁵ Ibid [4.37]

The promotion of personal dignity is therefore found under the Care Act 2014 as part of a wider public duty by local authorities to promote individuals' wellbeing in the delivery of care services.¹⁶ Personal dignity is listed in the Act as one of the definitional elements of wellbeing, a definition that also includes physical and mental health, the protection from abuse or social and economic wellbeing.¹⁷ The promotion of wellbeing hinges on the presumption that 'the individual is best placed to judge' his or her own wellbeing, and therefore services ought to be led by the wishes and preferences of the person cared for.¹⁸ It could be argued that if the definition of wellbeing ought to be understood from the perspective of the adult who receives care, then that of dignity could be understood under the same premise.

Without deploying a meaning of dignity within those legislative provisions on adult social care, how can elderly individuals' dignity in care be effectively protected? How should it be defined and by whom? From these basic questions came my conviction that in order to protect dignity, it was essential to understand it from the perspective of those whose care was in the hands of others. The two main aims of this dissertation are therefore to establish the meaning of dignity as an experienced concept, and then to set out whether and how it can be upheld in care homes, through laws or other means. Before I do so, I believe it is useful to delve into the origins of the meaning of dignity.

1) Dignity: origins and evolution

The meaning of dignity has evolved over time and has been used in a variety of contexts. During Roman times dignity appears to have had two meanings.¹⁹ One was that of 'dignitas hominis' or 'status', accompanied by the 'honour and respect' one would inspire from holding a particular position in society.²⁰ The other meaning of dignity can be found in the writings of Cicero, and where this time 'dignitas' was

¹⁶ Care Act 2014 s.1(a)

¹⁷ Care Act 2014 s.1(2)

¹⁸ Care Act 2014 s.3

¹⁹ McCrudden C., 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19(4) European Journal of International Law 655

²⁰ Ibid 656-657

meant as the dignity of all humans, irrelevant of their status.²¹ In the period of the Middle Ages a link was made between God, humankind and dignity. Only humans had dignity, as only they were made in the image of God, endowing them of a special divine gift no other sentient beings possessed.²² It was not long before the humanists of the Renaissance period, amongst whom Pico della Mirandola was a figurehead,²³ identified this gift as that of reason, the ability to decide one's path.²⁴ Kant then famously dissected the concept of dignity during the Enlightenment period.²⁵ Far from the theological interpretation of dignity that valued humankind for being the image of God on earth, and bucking the utilitarian ideals that negate the intrinsic value of the individual, Kant remains associated with the idea that humans should be treated as ends in themselves and not means.²⁶

Besides philosophy, the concept of dignity has also been used in the context of law. The French Revolution led to the Declaration of the Rights of Man and of the Citizen where under Article 6, 'dignities', as understood as those positions so far reserved for the aristocracy, were now declared to belong to all.²⁷ As Dupré notes, 'while the Declaration did not refer to dignity in the modern sense of this term, the spirit of dignity as equality arguably underpins the whole text'.²⁸ Dignity is also central to the constitution of Germany under the first Article of the Basic Law for the Federal Republic of Germany, stating that 'human dignity shall be inviolable. To respect and protect it shall be the duty of the state authority'.²⁹ It is also prominent in the constitutional text of South Africa where the Bill of Rights 'enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom'.³⁰ The legal codification of dignity understood as the 'dignity of man' can be traced back to 1948, where it took centre stage in the Universal Declaration of

²¹ Ibid 657

²² Ibid 658

²³ Pico della Mirandola, *On the Dignity of Man* (Trans. C. Glenn Wallis, Hackett Publishing Company, 1965)

²⁴ Ibid 259

²⁵ Ibid

²⁶ Kant I., *Groundwork of the Metaphysics of Morals* (trans. Mary J. Gregor) *Practical Philosophy* (Cambridge University Press, 1996) 429

²⁷ Dupré C., *The Age of Dignity: Human Rights and Constitutionalism in Europe* (Hart Publishing, 2015), 39-40

²⁸ Ibid 40

²⁹ <https://www.gesetze-im-internet.de/englisch_gg/> Accessed 22nd August 2017

³⁰ <<http://www.constitutionalcourt.org.za/site/constitution/english-web/ch2.html>> Accessed 22nd August 2017

Human Rights (UDHR), following on from the atrocities committed against mankind in the Second World War. The recognition of the ‘inherent dignity ... of all members of the human family’ was held in the Preamble as the ‘foundation of freedom justice and peace in the world’.³¹

The UDHR recognises ‘the equal and inalienable rights of all members of the human family’, declaring that ‘the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom’.³² The International Covenant of Civil and Political Rights (ICCPR) specifically declares that rights ‘derive from the inherent dignity of the human person’.³³ Human rights embrace the idea that certain duties are owed to human beings in order for their dignity to flourish. They suggest that ‘all people have some core entitlements just by virtue of their humanity, and that it is a basic duty of society to respect and support these entitlements’.³⁴

The meaning of dignity could therefore be garnered from human right texts. By understanding what dignity requires, one could extrapolate as to the meaning of conditions necessary for dignity. For instance, the European Convention on Human Rights depicts dignity as requiring life (Article 2, Right to life), respect for body and mental integrity (Article 3, Prohibition of torture), freedom (Article 4, Prohibition of slavery and forced labour; Article 5, Right to liberty and security), justice (Article 6, Right to a fair trial; Article 7, No punishment without law). Moody may call this a ‘minimalist approach to dignity’, a conceptualization of dignity seen as an appeal to an ‘ethical floor’.³⁵ But is such an understanding of dignity really enough for those who depend on the care of others for their wellbeing?

The multiplication of international human rights instruments for the disabled (the Convention on the Rights of Persons with Disability), children (Convention for the

³¹ Universal Declaration of human Rights, Preamble

³² Ibid

³³ International Covenant on Civil and Political Rights, Preamble

³⁴ Nussbaum M. C., *Creating Capabilities: The Human Development Approach* (Harvard University Press, 2013) 62

³⁵ Moody (n1) 15

Rights of the Child) and women (Convention of the Elimination of All Forms of Discrimination Against Women) may be taken to suggest that basic human rights as enshrined in the ICCPR or the European Convention on Human Rights (ECHR), are insufficient for individuals who are considered to be in an inferior position to the 'norm'. This evolution can also be interpreted as a reflection of our increasingly sophisticated understanding of the human condition. Dupré sees dignity as a 'heuristic' concept,³⁶ one 'whose meaning-content can be increasingly grasped with successive acts of knowing, but where further significant discovery always remains possible.'³⁷ This substantive 'malleability' does not mean that human dignity is an empty shell.³⁸ On the contrary, it is its ability to be fashioned by current human concerns that makes it a relevant and indispensable value that can inform law responsible to uphold it. This is due to the fact that dignity is primarily a moral concept. Moral concepts, as Waltzer suggests, 'have minimal and maximum meanings', or may be given 'thick and thin accounts'.³⁹ The thick meaning of dignity has been described as a 'whole moral view'.⁴⁰ Spiegelberg implies that, unless they are thick, conceptions of dignity may not be very helpful: 'the search for grounds of human dignity presupposes a full pledged philosophical anthropology, showing man's essential nature, its ingredients, its structure and its place in the cosmos, but also his values, rights and responsibilities'.⁴¹ It stands to reason that the search for an understanding of dignity that can recommend normative implications for the elderly requires us to commit to a thicker, rather than thinner, conception of dignity. But proceeding along the lines suggested by Spiegelberg is only one way of thickening the concept of dignity. An alternative route, which I favour in this dissertation, and which I will defend at greater length later, proceeds from the perspective of the dignity-bearing individual.

³⁶ Dupré (n27)16

³⁷ Hughes G, 'The Concept of Dignity in the Universal Declaration of Human Rights' (2011) 29 *Journal of Religious Ethics* 1, 8

³⁸ Dupré (n27) 17

³⁹ Waltzer M., *Thick and Thin: Moral Argument at Home and Abroad* (Notre Dame Press, 1994), 2

⁴⁰ Schultziner D., 'Human Dignity: Functions and Meanings' (2003) 3(3) *Global Jurist Topic* 1, 4

⁴¹ Spiegelberg H., 'Human Dignity: A Challenge to Contemporary Philosophy' in R. Gotesky and E. Laszlo (Eds) *Human Dignity: This Century and the Next* (Gordon and Breach, 1970), 61

2) Dignity: a disputed concept

Dignity is also a concept whose value has long been disputed.⁴² A review of the literature on the subject highlights the many reasons why dignity has been rejected as a worthwhile idea. Rosen brings six main charges against dignity.⁴³ The first one is that ‘dignity is a humbug’, meaning that although dignity attracts ideas of ‘grandeur and elevated status’, it is in fact only ‘an empty space’.⁴⁴ Humbug is defined in the Oxford dictionary as ‘deceptive or false talk or behaviour’.⁴⁵ Claims to dignity can hide the harsh reality of poor human treatment, making dignity similar to ‘a deceptive façade’.⁴⁶ His second claim against dignity is that conferring dignity to all human beings is only a social convention, and that its universality weakens its value.⁴⁷ Thirdly, Rosen argues that even if we conceded that dignity was this ‘inner transcendental kernel’ that Kant refers to as humanity’s capacity for morality, it fails to give any indication as to how one ought to be treated.⁴⁸ Indeed, if this kernel is a given that cannot be taken away, then its immutable presence does not depend on any particular conduct from others; it exists regardless. To all these three criticisms I would reply that although we may indeed all possess this kernel, it lays dormant unless conditions for its flourishing exist. As Nussbaum writes, dignity remains but a ‘promissory note’.⁴⁹

His fourth charge against dignity is that under its religious understanding, similar to that of Kant’s intrinsic value, dignity can undermine equality.⁵⁰ The ‘eternal truths of natural law’ that inform the religious conception of dignity, demand the ‘need for a properly ordered and respectful hierarchy in society’, therefore going against the idea of equality of rights to all.⁵¹ Fifthly, Rosen objects to claims to dignity on the ground

⁴² McCrudden C. (Ed.) *Understanding Human Dignity* (Oxford University Press, 2013)

⁴³ Rosen M., ‘Dignity: The Case Against’ in C. McCrudden, *Understanding Human Dignity* (Oxford University Press, 2013), 143-153

⁴⁴ *Ibid* 143

⁴⁵ < <https://en.oxforddictionaries.com/definition/humbug> > Accessed 2nd January 2018

⁴⁶ Rosen (n43)

⁴⁷ *Ibid* 145

⁴⁸ *Ibid* 146

⁴⁹ Nussbaum (n34) 30

⁵⁰ Rosen (n43) 148

⁵¹ *Ibid*

that although it has been held by the court to ground respect for autonomy,⁵² it has also been used to attack autonomy.⁵³ A value that can mean something and its contrary can be argued to be nonsensical indeed. Lastly, Rosen argues that courts use dignity to undermine legitimate and democratically made laws.⁵⁴ According to him, calls to respect for dignity have not only allowed the courts to override the will of the legislature, but have also been ignored in cases where dignity had been plainly abused.⁵⁵ Dignity, by remaining unclear, can be the vessel of many a meaning, and be used to impose the will of those in power.

The common thread to this latter set of objections in Rosen's argument against dignity is that dignity is devoid of substantial meaning and so can be manipulated to serve the ends of those who refer to it. Dignity used to impose the will of the powerful over that of the individual through its application as an objective but opaque idea is indeed a dangerous prospect. Only a 'well defined core meaning' of dignity would help guide ethical behaviour and decision making, averting the risk of dignity being filled with whatever meaning suits the priorities of those using it to justify their actions.⁵⁶

Gearty also argues 'against justiciable dignity'.⁵⁷ Indeed, he is of the opinion that 'the relatively subsidiary role played by dignity even in cases in which the dignity of each of the claimants is so obviously engaged, is the right approach for the judges to have taken'.⁵⁸ His point of view is sustained by two arguments. Firstly, he believes that, unlike human rights, 'dignity cannot afford to be qualified', explaining why 'judges steer clear of the term'.⁵⁹ He gives the example of a case in Germany where the constitutional court had to rule over the compatibility of abortion with the

⁵² *Planned Parenthood v Casey* 505 US 833 (1992) at [851], 'These matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment'

⁵³ *Manuel Wackenheim v France*, Communication No 854/1999, U.N. Doc. CCPR/C/75/D/854/1999 (2002). Although Manuel Wackenheim wished to challenge the ban on 'dwarf tossing' events in France, claiming that it was 'an affront to his dignity', the Council of State sustained the ban arguing that these events were 'an affront to dignity', illustrating the dual interpretation of dignity of empowerment and protection.

⁵⁴ Rosen (n43) 152

⁵⁵ *Ibid* 153

⁵⁶ *Ibid*

⁵⁷ Gearty C., 'Socio-Economic Rights, Basic Needs and Human Dignity: A Perspective from Law's front line' in C. McCrudden (Ed.), *Understanding Human Dignity* (Oxford University Press, 2013)

⁵⁸ *Ibid* 154

⁵⁹ *Ibid* 163

constitutional requirement to respect dignity.⁶⁰ Here, the court decided that it could not balance the protection of the life of the foetus with that of the woman's right to self-determination in such cases and so used the protection of human dignity as a lens through which to consider both interests; this unavoidably led them to conclude that the right to life of the foetus overrode that of the woman's right to decide for herself.⁶¹

The second reason Gearty argues against the justiciability of dignity is that its multiple meanings cannot be reconciled.⁶² Gearty also objects to dignity as a justifiable legal category. His concerns are primarily with dignity turning into a counter-majoritarian tool in the hands of judges, who may use it to unsettle the will of the people and Parliament. He believes it is primarily the job of lawmakers to attend to dignity-related concerns and that they should do so through specific, targeted legislative provisions that do not hand over to judges the task of filling dignity with meaning. It is not my intention to enter into a debate about whether judges or legislators are better at understanding the requirements of dignity. I agree that 'what dignity is thought to require' necessitates, as Gearty points out, political debate.⁶³ But the logic of this argument also calls for giving, in those debates, a central place to the views of dignity-bearing individuals whose dignity is at stake in such debates. Thus, if the debate is about dignity in elderly care, we have a special responsibility to attend to the views of elderly individuals cared for.

Möllers also argues against the use of dignity in 'a legal order that respects individuals rights'.⁶⁴ His argument is similar to those expounded above that the meaning of dignity is too controversial. He suggests that part of the root of the problem can be situated in the fact that different conceptions of the self underpin different and potentially incompatible conceptions of differences. In answer to these conflicting views of the human being, Möllers replies by asserting that 'lawyers should ignore the underlying fundamental issue in favour of the concrete problem'.⁶⁵

⁶⁰ Basic Law of the Federal Republic of Germany, Article 1

⁶¹ BVerfGE 39, 1 at 43

⁶² Gearty (n57) 163

⁶³ Ibid 171

⁶⁴ Möllers C. 'The Triple Dilemma of Human Dignity: A Case Study' in C. McCrudden (Ed.), *Understanding Human Dignity* (Oxford University Press, 2013), 173

⁶⁵ Ibid

This seems to assume that attending to the concrete problem while bracketing one's underlying view of dignity and the self will generate some sort of consensus on how to resolve it. It remains to be seen, however, if this is indeed so: it seems just as likely that it is impossible to tackle concrete problems without at least implicit or unconscious appeal to intuitions about broader moral principles such as dignity and broader questions such as the nature of the self. This is why I believe it is imperative to interrogate human dignity and to address heads-on the underlying issue of the conception of human being that underpins it; without doing so, we will always generate various and possibly conflicting resolutions to concrete problems, resulting from various and conflicting views of dignity and personhood. In this dissertation I will discuss the question of the conceptualisation of the self, as it is of great significance for working out the meaning of dignity.

Macklin rejects the usefulness of dignity on the ground that it adds nothing to how individuals are treated.⁶⁶ Unlike Rosen she does not reject its failure to guide conduct on the ground that it is inviolable and inherent and so impervious to the treatment of others. Her argument is that other terms can replace it without any problem. In the domain of medical ethics, she argues that dignity has no meaning beyond that of 'the need to obtain voluntary, informed consent; the requirement to protect vulnerability; and the need to avoid discrimination and abusive practice'.⁶⁷ It may indeed be the case that in medical ethics this is the way that dignity may be translated. The important point that Macklin seems to allude to but dismisses, is that it is because of calls to human dignity that these forms of treatment have been devised. Dignity is a cry that demands attention and the setting out of conditions that can give rise to it. Dignity is a useful discourse in medical treatment to focus the mind about the nature of human beings and the type of care they require to flourish in specific environments, especially those where they are vulnerable. Indeed, in such circumstances, dignity may be translated into the need for voluntary consent, the protection of vulnerability through non-discriminatory practice and the prohibition of abuse.

Bagaric and Allan's critique of dignity is grounded in their assertion that 'as a legal or philosophical concept it is without bounds and ultimately is one incapable of

⁶⁶ Macklin R., 'Dignity is a useless concept' (20th December 2003) 327 *British Medical Journal* 1419

⁶⁷ *Ibid* 1419

explaining or justifying any narrower interests'.⁶⁸ Their argument against dignity springs from their belief that it is an ill-founded justification for rights. According to them, dignity cannot fulfil this role as it is itself a vacuous concept, one that 'is used by academics, judges and legislators when rational justifications have been exhausted'.⁶⁹ Despite the widespread use of the concept of dignity in legal and philosophical texts, they argue that the 'lack of convergence regarding the meaning of, and foundations for, a normative concept' shows that 'something is amiss', putting in doubt the very existence of the concept of dignity.⁷⁰ Similarly to those criticisms cited above, they put in doubt usefulness of the concept of dignity further by the fact that it can be used as an argument for and against the same issue.⁷¹ This can be illustrated by the debate around euthanasia, where dignity can be advanced as an argument for as well as against its practice. Once again, dignity is shown as problematic because it is 'an empowering notion' as well as 'a sort of constraint on action'.⁷² This is a recurring contention raised against dignity.⁷³

As Grover writes in response, 'the essential point is that whether pro or anti-assisted suicide, both sides claim to achieve human dignity for the afflicted and both acknowledge the centrality of dignity in the human psyche. In this regard, the concept of 'human dignity' can be analogised to the notion of 'justice'.⁷⁴ Few people would claim appeals to justice are empty simply because the concept lends itself to different interpretations. Furthermore, the very reason that Bagaric and Allan use to defend the usefulness of rights can be applied to dignity. They contend that 'rights claims can be politically effective' and are 'to many people intuitively appealing', because 'the generally absolutist and forceful manner in which they are expressed (...) carry more emotive punch than related claims grounded in the languages of duties'.⁷⁵ I would endow dignity with the same capacity to raise attention and command action, to ask for justice. Its meaning may be contended and unclear, to the point of attaching itself

⁶⁸ Bagaric M. and Allan J., 'The Vacuous Concept of Dignity' (2006) 5 *Journal of Human Rights* 257, 260

⁶⁹ *Ibid*

⁷⁰ *Ibid* 265

⁷¹ *Ibid* 266

⁷² *Ibid* 267

⁷³ Beyleveld B. and Brownsword R., *Human Dignity in Bioethics and Biolaw* (Oxford University Press, 2001)

⁷⁴ Grover S., 'A Response to Bagaric and Allan's 'The Vacuous Concept of Dignity'' (September 2009) 13(4) *The International Journal of Human Rights* 615, 619

⁷⁵ *Ibid* 260

to oxymoronic values, but dignity has the merit of stirring debates and questioning the very notion of being in the world and the type of conditions it necessitates to thrive.

Pinker also criticises the indeterminate meaning of dignity and writes that ‘the problem is that “dignity” is a squishy, subjective notion, hardly up to the heavyweight moral demands assigned to it’.⁷⁶ He argues that dignity has three features that prevent it from being defined clearly. Firstly, he argues that it is ‘relative’; ‘ascription of dignity vary radically with the time, place, and beholder’.⁷⁷ It is certainly true that certain conduct that in the past attracted indignity would not nowadays raise a single eyebrow (Pinker gives the example of showing the glimpse of a stocking). Certain persons will consider certain actions below their dignity, whereas others will see no harm in them at all. Subjectivity does prevail when it comes to dignity, and it is context specific. A one-fit-all definition is bound to compromise someone’s dignity. The fact that it is so ought not make of the concept a defunct one. On the contrary, it has the quality of specificity and adaptability; it manages to represent the custom and tradition of individuals at a certain time in history. Its definition ought to be contextualised.

Secondly, Pinker qualifies dignity as being ‘fungible’, that is to say a value we compromise for the sake of others; Pinker notes that we would rather relinquish our dignity than our ‘life, health and safety’.⁷⁸ He illustrates this by giving many examples of situations where we would rather behave in an undignified way (‘getting out of a small car... having sex... doffing your belt and spread-eagling to allow a security guard to slide a wand up your crotch.... undergoing a pelvic or rectal examination’) than jeopardize other values we hold dear. It could be argued that the ability to choose which value to prioritise is itself an intrinsic element of dignity. Indeed, as we will see, conditions fruitful to dignity imply the idea of autonomy. In any case, trade-offs between important values or interests are the rule, not the exception, in human lives. Just because one value or interest is given up at any one time – and generally for a limited period of time – does not mean it ceases to have significance.

⁷⁶ Pinker S., ‘The Stupidity of Dignity’ (28th May 2008) The New Republic
< <https://newrepublic.com/article/64674/the-stupidity-dignity>> Accessed 10th January 2018

⁷⁷ Ibid

⁷⁸ Ibid

Similarly to Rosen above, Pinker also believes that ‘dignity can be harmful’.⁷⁹ Dignity can indeed lose its positive appeal if it is imposed on by a third party as a justification to poor treatment; but that is not dignity, that is the hijacking of a concept for personal gain or the infliction of harm, and so must be rejected off hand. Other sentiments such as love or welfare can also be invoked to justify actions or behaviours that ultimately harm or manipulate others under cover of good intentions. It does not mean that these words mean nothing and ought to be rejected. Dignity ought not be defined by some to be imposed on others, but be understood through the experienced lives of individuals. As Kass writes, ‘what we need is a defence of the dignity of what Tolstoy called ‘real life’, like as ordinarily lived, everyday life in its concreteness’.⁸⁰

3) Methodology

The methodology that I have chosen to fulfil my aims in this dissertation is socio-legal, underpinned by feminist legal theory. The British Library defines socio-legal studies as ‘an interdisciplinary approach to analysing law, legal phenomena, and relationship between these and wider society. Both theoretical and empirical work is included, and perspectives and methodologies are drawn from the humanities as well as the social sciences’.⁸¹ The part of my dissertation that has drawn from the social sciences is found in my definition of dignity. I formulated this definition on the basis of an extant of qualitative social science studies conducted specifically to gather and understand older people’s views about dignity in order to form a definition of it. My approach has been to use empirical findings to understand dignity from the point of view of those who live and are cared for in elderly care institutions. In the dissertation I use this definition of dignity to inform the duty of local authorities to take dignity into account under the Care Act. I have then used this definition of dignity to establish whether and how the laws that shape the lives of individuals who live in long-term aged care are creating conditions responsive to its flourishing.

⁷⁹ Ibid

⁸⁰ Kass L. ‘Defending Human Dignity’ in E. Pellegrino, A. Schulman and T. Merrill (Eds), *Human Dignity and Bioethics* (University of Notre Dame Press), 313-314

⁸¹ British Library, ‘Help for Researchers’

<<http://www.bl.uk/reshelp/findhelpsubject/busmanlaw/legalstudies/soclegal/sociolegal.html>> Accessed 14th August 2017

My criterion in selecting the particular sample of studies I used to establish a definition of dignity was relevance to my topic of research. My aim was never to compile a comprehensive study of them all. Nor was it to find the most detailed definition of dignity – rather a workable definition. My aim was to illustrate the point that when you ask individuals for their participation in the definition of a particular value, main themes emerge that can form the basis of a framework to work from. The interesting thing about this exercise was that studies revealed that although different things mattered to different people (privacy; being talked to like an adult, not a child; being well-dressed), all converged to the same kind of discourse. No one answer stuck wildly out of the others to give an unusual or alternative meaning to dignity. The point is that while each individual experienced dignity differently because everyone is unique, there were sufficient similarities and points of convergence to construct a general understanding of dignity in elderly care. This sensitivity to particulars, coupled with an aptitude for yielding synthetic generalisations, is at the very essence of dignity. It is a universal value that speaks of the uniqueness of each human being, and in order to enable it, knowing what it means for the individual is essential.

The feminist legal theory aspect of the methodology I used in this dissertation justifies theoretically my social approach to dignity. Feminist legal theory espouses an idea of autonomy rooted in the concrete nature of the human being that explains the need to approach dignity in a social, dialogical and empirical way. Feminist scholars that I refer to throughout this paper have all in their own way and within their own theories about vulnerability, capabilities, the self and relational autonomy, set out the fact that we are all concrete, feeling, biological, interconnected and interdependent finite beings who need particular conditions to thrive. I refer to some of their texts in this introduction. Taking responsibility for the care of a person, requires dialogical exchanges and communication in order to understand, rather than assume, what truly matters to that person.

Kant asserts that ‘autonomy is (...) the ground of the dignity of human nature’,⁸² and that autonomy is ‘the capacity to adopt principles that can be universally adopted,

⁸² Kant (n26) 84-85, AK 4:436

because they are law-like, and more significantly the rejection of principles that cannot be universally adopted'.⁸³ Autonomy here is attached to an idea of personhood that is extracted from all human traits. If, on the contrary, we assume that a person only becomes autonomous via the process of relating to others, then dignity can only be apprehended through knowing the concrete other. Feminist legal scholars' perception of what it means to be a human being has helped me understand why I thought dignity could only ever be understood through a relational ethic, one that demands that we ask to know the person in front of us.

4) Dissertation Structure

This dissertation is split into six main chapters. The first one will set out the theoretical underpinnings of a definition of dignity obtained through dialogue. Here, I will delve into the Kantian realm of dignity and expose why this particular understanding of it, although absolutely relevant, cannot guide ethical conduct in the context of people in need of care because of the kind of being it is attached to. Turning my attention to the communitarian view of human autonomy, I will end up aligning my thoughts to that of feminists. Autonomy is not here understood as 'the property the will has of being a law unto itself (independently of every property belonging to the objects of volition',⁸⁴ but rather as the result of our interconnectedness. The notion of the stand-alone man that underpins a Kantian view of autonomy is rejected by the feminist reconceptualization of autonomy, to be replaced by a view of the human being that is more fragile, that does not live in a vacuum and is embedded in human relationships.⁸⁵ This particular view of autonomy is relational, rooted in our interconnectedness.⁸⁶ From this starting point, I will establish the kind of ethical model that I believe is needed to understand dignity, a model rooted in the relational autonomy of human beings. I suggest that the meaning of dignity needs to be found in communication and dialogue, without which it would

⁸³ O'Neill O., *Bounds of Justice* (Cambridge University Press, 1996) 43

⁸⁴ Kant (n26) 47, AK 4:441

⁸⁵ Mackenzie C. and Stoljar N., *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford University Press, 2000)

⁸⁶ Nedelsky J., *Law's relations: a relational theory of self, autonomy, and law* (Oxford University Press, 2012)

be impossible to know the ‘concrete other’, a paradigm devised by Benhabib.⁸⁷ My approach to dignity is phenomenological, that is, grounded in individuals’ subjective experiences.

In the second chapter, I have used a sample of qualitative social sciences studies realised in the context of healthcare that have questioned older people about their perception of dignity. I have teased out from them the main areas of dignity for those individuals who need to be cared for because of their advanced chronological age. It transpires that identity formation, self-determination and respect for the individual’s humanity are essential for the possibility of dignity. I do not claim that the definition of dignity these studies generate is definite and immutable. It is only there to suggest that for the creation of care environments amenable to dignity, our understanding of dignity must be done in partnership with the individuals concerned, through a dialogical exchange.

Dignity understood under this ethical framework resonates with Nussbaum’s work on human capabilities, where she believes that certain human capabilities are essential for human dignity, a promissory note that requires certain conditions to actually flourish.⁸⁸ I suggest that for dignity in institutional care to be realised (identity, self-determination and respect for humanity), certain conditions are necessary. These conditions rest on certain factors to be addressed that regard the person cared for, the environment they live in, and the wider social environment. Following the capability theory, I call these factors ‘conversion factors’, where conversion points to the ways in which these factors mediate between potential and actual dignity, *converting* the former into the latter.⁸⁹ The next few chapters are devoted to examining these factors.

The third and fourth chapters examine the vulnerability of the older person in care. Vulnerability is identified here as a personal conversion factor to dignity. The first of these chapters discusses the meaning of vulnerability and how to understand it so that it can be amenable to the flourishing of dignity. I argue in this chapter that in order to

⁸⁷ Benhabib S., *Situating the Self: Gender, Community and Postmodernism in Contemporary Ethics* (Polity Press, 1992)

⁸⁸ Nussbaum (n34)

⁸⁹ Robeyns I., ‘The Capability Approach: a theoretical survey’ (March 2005) 6(1) *Journal of Human Development* 93

achieve this aim, vulnerability has to be conceptualised in a way that will trigger protection from the state but prevent over paternalistic interventions that could undermine a person's dignity. The second half of this chapter examines criminal and human rights laws currently in place to protect individuals from the effects of vulnerability. I will examine here how the Crown Prosecution Services approach crimes against older individuals and the reach of criminal laws into vulnerability protection. I will then review the role of human rights law on the protection of vulnerability in care. In the last part of this chapter I will focus my attention on the important case of *McDonald*, which not only discusses the role of Article 8 in the protection of dignity in the context of care, but also reveals the impact courts can have, in their judicial review capacity, on the conceptualisation of dignity.⁹⁰

The fourth chapter examines the more interventionist laws aimed at protecting individuals from the consequences of vulnerability, namely laws relating to safeguarding, capacity and deprivation of liberty. In this chapter I will examine whether these rules, aimed at protecting the individual's vulnerability, are compatible with the aim of dignity realisation. I will review the problem posed by the tension between capacity and autonomy, wondering how best to protect the most vulnerable in a way that can be amenable to dignity.

In the fifth chapter I broaden my field of enquiry to examine the living environment of the care home. Nursing homes, as Agich remarks, are institutions that can 'isolate, control and reconstitute the daily lives of their residents'.⁹¹ Here, I consider the regulatory framework care homes are under as an environmental conversion factor to dignity. Starting with the wider aims of regulations, I will then examine in details those in place for care homes and assess whether they can create conditions amenable to dignity as defined in this dissertation. Aided by Braithwaite's practical expertise in the regulatory system of care institutions across continents, I will discuss the possibly to create a regulatory model that goes beyond safety concerns and embraces the

⁹⁰ *R (On the Application of Elaine McDonald) v Royal Borough of Kensington and Chelsea* [2011] UKSC 33, 6 July 2011 and *McDonald v The United Kingdom*, Application 4231/12, [2014] ECHR 492, 20th May 2014

⁹¹ Agich, G. J., *Dependence and Autonomy in Old Age: An ethical framework for long-term care* (Cambridge University Press, 2003), 5

possibility of dignity.⁹² My argument will be that regulations need to include the participation of those they regulate. Imposing rules on individuals for the sake of their best interest and protection may not necessarily allow the dignity of the individual to flourish. I will argue that individuals in care must have a say in the regulatory framework that controls the environment they live in, and be part of its monitoring process.

The final chapter widens the net of inquiry to look at an important societal conversion factor, that of ageism. In this part of my paper I discuss the various theories that have tried to explain our complicated relationship with old age. Whether because older individuals remind us of our own mortality, because through our evolution we prefer to keep the weakest in society at arms' length, or because we have over the years severed the ties that used to bind us to our elders, the reasons why we treat older people less well than others are complex and multi-faceted. I will discuss here the detrimental effects of ageism on dignity. Finally, I will mention the current anti-discrimination laws that exist to mitigate its negative effects and the kind of initiatives that may help bolster their aim.

I believe it is also important to mention here the impact of the economic system a country adopts on its welfare policies, and as such on the potential creation of conditions for dignity in care. Although for the purpose of this thesis I will not be able to delve into this topic, it is worth mentioning here that it is axiomatic that the realisation of dignity is shaped by the commitments states make to their public resources redistribution policies. It can be argued that neoliberalism, the economic system currently adopted by the UK, influences the possibility of dignity in long-term aged care by suppressing the flow of public resources to the sector, but most importantly by redefining the value and meaning of public services.⁹³ According to Harvey, the brand neoliberalism we live under is

⁹² Braithwaite J., Makkai T. and Braithwaite V., *Regulating Aged Care: Ritualism and the New Pyramid* (Edward Elgar Publishing, 2007)

⁹³ For an in depth analysis of the relationship between economics, welfare and rights, see amongst others; Esping-Andersen G. (Ed.) *Why We Need a New Welfare State* (Oxford University Press, 2002); Marshall T.H., *Citizenship and Social Class* (Pluto Classics, 1987); Polanyi K., *The Great Transformation* (Beacon Press, 1957)

[a] theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills, within an institutional framework characterised by strong private property rights, free markets and free trade. The role of the State is to create and preserve an institutional framework appropriate to such practices. ... State interventions in markets (once created) must be kept to a bare minimum.⁹⁴

Commodification is key to promote these aims, transforming an ever-increasing array of goods, activities, and relationships as market commodities.⁹⁵ Even ‘sexuality, culture, history, heritage and nature’ are now being traded for a price, although they were never originally ‘produced as commodities’.⁹⁶ Polanyi, commenting on the commodification of labour, has written that ‘in disposing of a man’s labour power the system would, incidentally, dispose of the physical, psychological and moral entity ‘man’ attached to that tag.’⁹⁷ The commodification of care could have similar consequences to that of labour, and so have some important bearing on the conceptualisation of dignity in care settings. Although Britain still has not ventured fully down the path of complete welfare marketization, it is slowly opening the doors to private markets for the provision of care. Estes and Philippon point to the fact that ‘elder care has already been identified by the Coalition of Service Industries as a service area to be included in a comprehensive GATS agreement’.⁹⁸

Neoliberalism also promotes the idea that welfare can have a de-incentivizing effect on people to work, and instead assumes that the solution to social good can be reached through the virtues of equal individual responsibility.⁹⁹ Pursuing the marketization of care is meant to promote empowerment through choice, and a rise of high quality low cost care through efficiency brought on by competition.¹⁰⁰ Neoliberal ideals are therefore defining the way in which vulnerability is perceived and the

⁹⁴ Harvey, D., *A Brief History of Neoliberalism* (Oxford University Press, 2005), 2

⁹⁵ *Ibid* 288

⁹⁶ *Ibid* 166

⁹⁷ Polanyi K., *The Great Transformation: The Political and Economic Origins of Our Time* (2nd Ed., Beacon Press, 2001), 76

⁹⁸ Estes C. L. and Philippon C., ‘The Globalization of Capital, the Welfare State, and Old Age Policy’ (2002) 33(2) *International Journal of Health Services* 279, 288

⁹⁹ McGregor S., ‘Neoliberalism and Health care’ (2001) 25(2) *International Journal of Consumer Studies* 822

¹⁰⁰ *Ibid*

response it warrants from the state's redistributive policies. Navarro has written that 'deregulation of international capital flows and trade has considerably narrowed the scope of governments to pursue expansionist and redistributive policies, forcing all governments to cut public social expenditures and deregulate labour markets in order to make their countries more competitive'.¹⁰¹ Under neoliberalism the trend has been to reduce public welfare programmes, but to facilitate global markets.¹⁰²

For these reasons and many more that cannot be examined here, the economic context of a country should also be considered a conversion factor to dignity in care, one that shapes the public services landscape, and so the way in which individuals are treated by institutions and public authorities when in receipt of welfare. However dignity in care may be conceptualised by social care policies, its realisation cannot but be influenced by the economic ideology that governs a state's redistributive policies.

¹⁰¹ Navarro V., Schmitt J. and Astudillo A., 'Is Globalization Undermining the Welfare State? The Evolution of the Welfare State in Developed Capitalist Countries during the 1990s' in V. Navarro (Ed.) *Neoliberalism, Globalization and Inequalities, Consequences for Health and Quality of Life* (Baywood Publishing Company, 2007), 27

¹⁰² Estes C.L. and Phillipson C., 'The Globalization of Capital, The Welfare State, And Old Age Policy' (2002) 32(2) *International Journal of Health Services* 279

Chapter I

Theoretical framework

1) Introduction

In England and Wales, local authorities are the public bodies responsible for organising and sometimes dispensing care in the community. Their duties are defined under the Care Act 2014. The Care Act demands the promotion of individual wellbeing, and dignity is referred to as a component part of that wellbeing.¹ The Act then specifies that individual wellbeing is best understood from the perspective of the individual concerned.² As wellbeing is defined as comprising personal dignity, it can be assumed that dignity ought to also be understood in a similar way. There is no clear indication within the Act as to how local authorities need to proceed in taking the person's dignity into account as part of this wellbeing duty, but I will argue here that the best way forward would be to ask the individuals concerned what dignity means to them. In this chapter, I will explain the theoretical justification for this particular choice.

Leget argues that there are three types of dignity, one subjectively experienced, one social or relational and one that is intrinsic.³ I will argue here that in order to give rise to dignity in care, it is insufficient to limit our understanding of dignity to the idea of intrinsic dignity; rather, the subjective and relational perspectives of dignity are also crucial to the context of care. Although intrinsic dignity is the basis upon which the claim to a minimum treatment of older individuals in care stems from,⁴ it fails to give any indication as to the nature of that treatment. I believe that a subjectively experienced understanding of dignity, justified by our relational and social nature, is the key to appreciating how to treat a person dependent on care. As Nussbaum writes, 'some living conditions deliver to people a life that is worthy of the human dignity

¹ Care Act 2014 s.1(a)

² Care Act 2014 s.3

³ Leget C., 'Analyzing dignity: a perspective from the ethics of care' (2013) 16 *Med Health Care and Philos* 945

⁴ Moody H.R., 'Why Dignity in Old Age Matters' (1998) 29 *Issue 2-3 Journal of Gerontology* 13, 37

that they possess, and others do not. In the latter circumstances, they retain dignity, but it is like a promissory note whose claims have not been met'.⁵ Indeed, the way to create those conditions is firstly to understand dignity. My claim here is that a more concrete view of personhood has considerable potential for informing political theory about the conditions necessary for dignity in care institutions for the elderly. I will be adopting here an approach to personhood underpinned by the feminist ethics of care.⁶

In this chapter, I argue that the adoption of a strictly Kantian view of dignity, based on the revolutionary idea that all individuals possess inviolable and intrinsic worth, is insufficiently concrete to specify the conditions necessary to the realisation of dignity. I propose that although Kant brings an essential and ground-breaking understanding of dignity as the inherent value of every human being independently of any other, it is rooted in an abstract view of autonomous rational agency, and that this abstraction hides from view the complex biological, relational and finite nature of individuals' autonomy, concrete characteristics that must be taken into account when setting out those conditions for dignity in elderly care. Kant's understanding of dignity would also, interpreted strictly, limit the reach of human rights guarantees in the realisation of dignity.

Most specifically, this chapter will proceed along the following lines. Firstly, I will briefly expound Kant's definition of intrinsic human dignity and show how it rests on an underlying abstract conception of autonomy. Secondly, I will suggest that such an abstract understanding of dignity requires no more than the presence of conditions of negative freedom and cannot be used to inform ethical conduct. This in turn implies that human rights have a limited role to play and that they are not promising tools to promote the dignity of dependent vulnerable people. Thirdly, I will use Grear's account of human rights and the 'vulnerable embodied' idea of humanity it embraces, to highlight the necessity to engage with the concreteness of our beings and autonomy in order to understand and therefore enable dignity for all.⁷ Fourthly, I will discuss

⁵ Nussbaum M. *Creating Capabilities* (Harvard University Press, 2011), 30

⁶ Gilligan C., *Psychological Theory and Women's Development* (Harvard University Press, 1982); Noddings N., *Caring: A Feminine Approach to Ethics and Moral Education* (University of California Press, 1984); Held V., *The Ethics of Care: Personal, Political and Global* (Oxford University Press, 2006)

⁷ Grear A., *Redirecting Human Rights: Facing the Challenge of Corporate Legal Humanity* (Palgrave Macmillan, 2010)

alternative conceptions of autonomy, and conclude that relational and concrete autonomy is a more relevant ground into which to anchor our understanding of dignity in care. Concrete autonomy is based on the importance of the individual's environment, history and relationships, and adopts a conceptualisation of the individual rooted in care ethics. Finally, I will contend that a concrete and relational understanding of autonomy demands a discursive ethical framework to give rise to a subjective and experiential understanding of dignity – one which is better suited to frame care policies, and more relevant to them.

2) Kantian dignity

Although the concept of dignity has only relatively recently entered the legal domain,⁸ its legal protection by law is traditionally considered to be the preserve of human rights instruments. The legal codification of dignity is most famously found in the Preamble of the Universal Declaration of Human rights (UDHR). The UDHR recognises the 'inherent dignity' and 'the equal and inalienable rights of all members of the human family', declaring that 'the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom'.⁹ The International Covenant on Civil and Political Rights specifically declares that rights 'derive from the inherent dignity of the human person'.¹⁰ Human rights embrace the idea that certain duties are owed to humans in order for their dignity to be respected. They suggest that 'all people have some core entitlements just by virtue of their humanity, and that it is a basic duty of society to respect and support these entitlements'.¹¹

⁸ For a summary of the history of dignity see McCrudden C., 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19(4) EJIL 655, 656-663

⁹ Universal Declaration of Human Rights, Preamble

¹⁰ International Covenant on Civil and Political Rights, Preamble

¹¹ Nussbaum M.C., *Creating Capabilities* (Harvard University Press, 2011) 62

This statement implies a certain idea of dignity, one that can be attributed to Kant. Rosen, who has written extensively on the subject of dignity, refers to Kant as ‘the thinker on whose giant shoulders the modern theory of human rights largely rests’.¹² The Kantian understanding of dignity is far removed from the theological interpretation of dignity that valued mankind for being the image of God on earth, and bucks the utilitarian ideals that negated the intrinsic value of the individual for the sake of optimizing the overall happiness of all,¹³ Kant’s depiction of dignity is as a special value (*Würde*) bestowed upon human beings because of their unique capacity for ‘acting morally and feeling the force of morality’s claims’.¹⁴ Kant shows individuals as intrinsically valuable, independently of religion and other human beings.

On this anti-utilitarian basis Kant defines the inviolability of dignity by declaring that a man cannot be used ‘merely as a means’ by any man, but must always be ‘regarded ... at the same time as an end.’¹⁵ Although it may be clear to us how using a man as a mere instrument or object for a particular purpose may indeed violate his dignity, it is less clear how a man may be treated as an end.¹⁶ Kant indicates that ‘morality is the condition under which alone a rational being can be an end in itself’,¹⁷ but this statement only takes us so far.

According to Korsgaard’s interpretation of Kant, the Kantian’s notion of humanity as an end in itself refers to human beings’ ‘power of rational choice’, ‘the power to (...) make something an end by conferring the status of goodness on it, and pursue it by rational means’.¹⁸ This, Rosen argues ‘draws the boundaries of personhood quite narrowly: it restricts it to those human beings who are actively capable of exercising rational agency’.¹⁹ It appears to exclude those whose age has rendered them dependent on others for their sheer survival.

¹² Rosen M., *Dignity: Its history and meaning* (Harvard University Press, 2012), 19

¹³ For an overview of the meaning of dignity through the ages, see Rosen M., *Dignity: Its History and Meaning* (2012, Harvard University Press)

¹⁴ Rosen (n12) 24

¹⁵ Kant I., *Groundwork of the Metaphysics of Morals* (trans. Mary J. Gregor) *Practical Philosophy* (Cambridge University Press, 1997), 37 AK 4:429

¹⁶ Rosen (n12) 85-90

¹⁷ *Ibid* 21

¹⁸ Korsgaard C., *Creating the Kingdom of Ends* (Cambridge University Press, 1996) 124

¹⁹ Rosen (n12) 93

The concept of personhood under Kant seems restricted even further if we follow his proposition that ‘autonomy is therefore the ground of the dignity of human nature and of every rational nature’.²⁰ As Rosen points out, this does not mean that dignity and autonomy are one of the same things.²¹ Kantian’s autonomy, as the ground to dignity, has been interpreted as ‘the capacity to adopt principles that can be universally adopted, because they are law-like, and more significantly the rejection of principles that cannot be universally adopted’.²² Kant’s autonomy hereby rests on the idea that ‘the moral law which we must acknowledge as binding upon us is “self-given”’.²³ It is ‘the dignity of the moral law that makes human beings –its embodiment- worthy of respect’.²⁴ That is to say to the extent that they are capable of endorsing the moral view.

This particular conception of autonomy has attracted much criticism because of the conception of the self that it adopts. Kant’s analysis sees negative freedom as meaning to work ‘independently of alien causes determining it’, and positive freedom as a rational way of using negative freedom,²⁵ or the capacity for autonomy (namely, for identifying and pursuing universally valid values). In this context negative freedom is a pre-requisite of positive freedom or autonomy. But negative freedom here is not mere absence of material constraints. Rather, it is also a freedom from ‘preferences, desires, inclinations’,²⁶ or any other human emotion that may interfere with our appreciation and pursuit of the moral law. Thus understood, negative freedom assumes a ‘noumenal self’, an entity that bears no resemblance to any empirically definable agent.²⁷ It assumes a version of personhood that is able to suspend any human trait or emotion in order to assume autonomy, and appears therefore even further removed from reality.²⁸

²⁰ Kant (n15) 43 AK 4:436

²¹ Rosen (n12) 25

²² O’Neill O., *Bounds of Justice* (Cambridge University Press, 1996), 43

²³ Rosen (n12) 25

²⁴ *Ibid* 30

²⁵ Kant (n15) 52 4:446

²⁶ O’Neill (22) 44

²⁷ Sandel M. J., *Liberalism and the Limits of Justice* (Cambridge University Press, 1982)

²⁸ O’Neill (n22) 57 O’Neill’s response to this criticism of Kant’s account of the ‘noumenal self’ advances that Kant does not reject ‘an empiricist approach to human action’, but rather demands its juxtaposition to the ‘theoretical standpoint’. She concludes by affirming that according to Kant’s perspective ‘if we try to eliminate our own agency by viewing the theoretical stand-point and its

Kant's definition of autonomy has not always been seen as 'this metaphysically ambitious'; elsewhere it has also been interpreted as 'a capacity to understand moral reasons and be motivated by them'.²⁹ Even this 'toned down' version of autonomy, however, requires rational thought and so also suggests a conception of personhood that excludes certain groups, amongst them the cognitively impaired elderly.

A Kantian articulation of dignity marks an important shift away from its Christian ethos of 'sacred worth of the human person in the sight of God'.³⁰ It also underpins a conception of morality founded on 'absolute principles' such as rights and justice, and departs from a consequentialist model that favours utility outcomes, and where mankind is but a homogenous grouping whose overall happiness maximisation overrides individual dignity.³¹ Kantian dignity certainly marks a departure from the idea that it is acceptable to treat some lives with impunity for the sake of increased levels of overall happiness for the greatest number. Nevertheless, it still seems inept at including people whose autonomy has been compromised because of age, and whose lives are led in institutions. As Nussbaum writes, although 'dignity is an intuitive notion', it 'needs to be given content by placing it in a network of related notions'.³² Kantian dignity espouses a view of personhood that is anchored in the notion of abstract autonomy and hence at first sight, appears to generate principles that may not consider the dignity of the non-autonomous elderly in care settings. It also fails to inform as to the type of conditions necessary to allow dignity to flourish in concrete situations.

3) Conditions for Kantian dignity

A strict reading of Kantian dignity predicated on the notion of abstract autonomy appears to require a strictly liberal arrangement of society. Hill has set out that 'the

cognitive stance as comprehensive, we shall undercut the possibility not only of morality but of knowledge'. For other interpretations of Kant's approach to autonomy see also Hill T. E., *Human Welfare and Moral Worth: Kantian Principles* (Oxford University Press, 2002)

²⁹ Murphy J.G., *Punishment and the Moral Emotions: Essays in Law, Morality and Religion* (Oxford University Press, 2012), 260

³⁰ Gushee D. P., 'A Christian Theological Account of Human Worth' in C. McCrudden (Ed.) *Understanding Human Dignity* (Oxford University Press, 2013), 275

³¹ Murphy (n29) 258

³² Nussbaum (n11) 29,30

dignity principle must be applied not merely to relations between individuals isolated from others but, first and crucially to a system of laws that can provide the framework for moral relations amongst individuals'.³³ He explains that in setting out the 'implication of the dignity principle for laws, one should take the point of view of the legislators in the 'kingdom of ends', that is, fully rational and autonomous persons, each with 'private ends' but abstracting from personal differences' and making only universal laws'.³⁴ This point of view, he explains, is embraced by Kant and Rawls when they assert that 'the first principle of justice adopted would be that the system of laws should try to ensure to each person viewed in advance of particular contingencies an equal and full opportunity to live out his or her life within the constraints of those laws'.³⁵ Hill continues by stating that 'one of the most significant consequences of placing a special value on human beings' capacity to set and rationally pursue ends is that there is a strong prima facie case for allowing individuals freedom to form and pursue their own life plans subject only to the constraints that others be allowed a similar freedom'.³⁶ According to Rawls, under the veil of ignorance and in the original position of complete impartial rationality as espoused by Kant, individuals would choose the same universal principles of justice based on freedom and equal rights.³⁷ Agich has argued that

liberal theory is not in itself the problem, but the extension of what is primarily a political and legal theory into ethics levels the complex landscape of moral life. We need not reject liberal theory, but can confine it within its proper borders and we can supplement its contribution to ethical analysis and practice by offering a fuller and more adequate view of what it means to be an autonomous agent.³⁸

Applying the notion of abstract liberal autonomy as the foundational value of dignity would restrict quite dramatically its ability to help shape the societal conditions needed for the realization of dignity in institutions.

³³ Hill T. E., *Dignity and Practical Reason* (Cornell University Press, 1992), 208

³⁴ *Ibid* 209

³⁵ *Ibid*

³⁶ *Ibid* 53

³⁷ Rawls J., *A Theory of Justice* (Revised Edition, Harvard University Press, 1971), 221-227

³⁸ Agich. G. J., *Dependence and Autonomy in Old Age: An ethical framework for long-term care* (Cambridge University Press, 2003), 13

In the context of a strict liberal notion of autonomy, human rights would be used to forbid the interference of the state with the individual by for instance, prohibiting the use of torture, preventing the state from interfering in a person's private life, or forbidding arbitrary detention, and also preventing individuals from interfering with another in unwarranted (e.g. harmful) ways. This particular political conception of rights promotes the 'negative liberty' of the individual or the 'freedom to be left alone'.³⁹ A system of human rights mostly anchored in negative freedom embraces a conception of personhood that is attached to a liberal view of autonomy.⁴⁰ Autonomy understood in this way demands that the state refrains from interfering so that individuals may pursue their own version of a good life. In turn, this assumes certain individual qualities such as 'self-assertion, critical reflection, and knowledge of one's interest qualities'.⁴¹ This particular conception of personhood, as Agich suggests, is political in nature, but translates with difficulty as an adequate ethical model upon which to build a framework to protect the dignity of those who become acutely dependent due to age.⁴²

Rights intervene paradigmatically when the individual needs to assert a claim against authority. Hence rights do have a place in institutions when conflicts arise between the individual and the care professionals in charge.⁴³ In fact the Care Act 2014 makes explicit that care providers fall under section 6(3)(b) of the Human Rights Act 1998 as exercising a 'function of a public nature' in providing care arranged by local authorities, and so are required to abide by human rights laws.⁴⁴ Rights are a useful counterweight to the power of the institution to enforce certain rules imposed on the individual that may conflict with her right to a private life, her right to refuse or consent to treatment, but say little as to the sustainability of dignity pre-conflict.⁴⁵ Agich writes that

³⁹ Berlin I., *Four Essays on Liberty* (Oxford University Press, 1969)

⁴⁰ Agich (n38)

⁴¹ Dworkin G., *The Theory and Practice of Autonomy* (Cambridge University Press, 1988)

⁴² Agich (n38) 20

⁴³ Ibid 39

⁴⁴ Care Act 2014 s.73

⁴⁵ Agich (n38) 39

[A] preoccupation with personal entitlements can divert concern from collective responsibilities. Rights rhetoric too often channels individuals' aspirations into demands for their own share of protected opportunities and fails to address more fundamental issues about what ought to be protected. Such an individualistic framework ill serves the values of cooperation and empathy that feminists find lacking in our current legal culture.⁴⁶

Whether Kant's concept of dignity rests on rational agency, or a metaphysical version of the self, unperturbed by its connection to the outside world and immune to its physicality, it is not easily reconcilable with an idea of dignity that includes all people, even those whose autonomy has been compromised by ageing. Dignity in this context, as Waldron remarks, may be the '*legal ground* of the rights' set out in human rights instruments, but not the *telos* or goal of human rights.⁴⁷ Griffin considers that 'the sort of dignity relevant to human rights, is that of a highly prized status: that we are normative agents',⁴⁸ once more anchoring dignity within an autonomy-based discourse. He also concedes that 'there are several acceptable uses of 'dignity' not relevant to human rights: for example, the dignity that quite properly should be accorded to a person deep in dementia'.⁴⁹ Dignity based on abstract and Kantian ideals of autonomy and rational agency may indeed be the ground of human rights, but this would limit the meaning of dignity and certainly evade those who no longer possess these characteristics.

Douzinas concurs when he writes, in respect of the universality of rights, that '(o)nce the slightest empirical or historical material is introduced into abstract human nature, once we move from the declarations onto the concrete embodied person, with gender, race, class and age, human nature with its equality and dignity retreats rapidly'.⁵⁰ Rights have been accused of framing the individual as 'represented without significant reference to their own developmental history, personal values, or relationships with others'.⁵¹ The ethical debate, if unduly focused on rights thus

⁴⁶ Rhode D., 'Feminist Critical Theories' (1990) 42 Stanford Law Review 617

⁴⁷ Waldron J., 'Dignity, Rank, and Rights' (21-23 April 2009), The Tanner Lectures on Human Values, Delivered at the University of California, Berkeley

⁴⁸ Griffin J., *On Human Rights* (Oxford University Press, 2008) 152

⁴⁹ *Ibid* 151

⁵⁰ Douzinas C., *The End of Human Rights* (Hart, 2000), 96

⁵¹ *Ibid* 40

understood, would be limited to the balancing of rights and omit to consider the person as a social and complex evolving and biological entity. Our vulnerability, inherent to our physiological selves,⁵² would then be addressed by healthcare provisions whenever it became an obstacle to our pursuit of a worthwhile life, but would not be catered for when it were or became a permanent state. A strict interpretation of Kantian dignity entails a strict liberal political ideology, which would on the face of it, disregard the dignity of the partially functioning by focusing too heavily on the importance of negative liberty.

It is unquestionable that in order for dignity to flourish, certain rights not to be interfered with are fundamental, but as I have argued, a strict liberal interpretation of autonomy rooted in negative liberty would jeopardize the universality of dignity as a human value. Fortunately, the reality of human rights as they are currently interpreted and operationalised is far more complex than what is suggested by the Kantian view of fully autonomous individuals protected by rights grounding duties which are primarily ones of non-interference. The panoply of human rights obligations currently adhered to by our government, whether nationally, regionally or internationally, manifests a far more concrete view of persons and autonomy, and a far more inclusive meaning of dignity. Human rights protect far more than an ideal of dignity borne out of abstract autonomy, and are nowadays very much representative of our complex and finite human nature.

In the next part of this chapter I will examine the underlying nature of the person that is revealed by human rights, and how they reflect a more concrete and flawed human nature than that espoused by Kant's dignity. As I will argue, the development of economic, social and cultural rights more particularly reflects the need for certain conditions for dignity for all, and the concrete and embodied nature of people. By committing to the upholding of these human rights, the state is also under a positive obligation to provide certain resources and conditions for dignity to be realized, acknowledging that the self is vulnerable and not an autonomous entity in the strict liberal sense of the term.

⁵² Fineman M.A., *The Autonomy Myth: A Theory of Dependency* (The New Press, 2005)

4) Human rights and the embodied self

In her work looking at corporate human rights, Grear has argued that the conception of the self underpinning legal human rights ought to be understood as one of ‘embodied vulnerability’, instead of one of ‘quasi-disembodiement’ rooted in male autonomous rationality.⁵³ She presents this ‘quasi-disembodiement’ as borne out of Western rationality and entrenched in liberal laws and the legal subject.⁵⁴ Indeed, she traces its Western world origins in Kantian’s morality, rooted in reason and able to ‘transcend embodied particularities’,⁵⁵ and ‘premised on the decontextualisation of the subject from the world of objects, including the body’.⁵⁶ As law is ‘a discourse of reason’, it ‘functions as both product and producer of this disembodied rationalism’.⁵⁷

According to Grear, liberal laws, distinguished by rationality and positivity, have indeed functioned as a ‘rationalising enterprise’, eclipsing the importance of the human biological nature by a system of rational and positive laws.⁵⁸ She traces this phenomenon back to the emergence of capitalism in the nineteenth century, and the important role the state played during this period in facilitating its development through legal positivism.⁵⁹ According to her account, the ensuing ‘rationalistic jurisprudence’ these laws produced was to serve the interests of the property owners, but also cut out from its ambit the disorderliness and complexity of the social sphere.⁶⁰ She notes that this created a dichotomy between the ‘thin’ and caricature-like conception of the legal subject, capable of engaging in rational and consensual social relationships, and the actual human being who evolves in a complicated and confrontational web of social interactions.⁶¹

⁵³ Grear (n7)

⁵⁴ Ibid 96

⁵⁵ Ibid 42

⁵⁶ Halewood P., ‘Law’s Bodies: Disembodiment and the Structure of Liberal Property Rights’ (1996)

⁸¹ Iowa Law Review 1331, 1340

⁵⁷ Grear (n7) 42

⁵⁸ Ibid 41

⁵⁹ Ibid 78

⁶⁰ Ibid

⁶¹ Ibid 81

Despite the fact that the origins of the human rights movement are often found in times of social crisis and as a response to actual human suffering (the French Revolution and the Second World War being prime examples of such phenomena), Grear notices that even in international human rights instruments, human beings, who are ‘ontologically vulnerable’, are ‘conceptualised as quasi-disembodied legal subject’.⁶² She points out that the UDHR has assimilated the social contractarians’ abstract construct of the ‘natural man’ and his ‘natural rights’, as found under the French Declaration of the Right of Man and Citizen, into the abstract construct of ‘human beings’.⁶³ Feminist commentators have echoed this view where they have criticized international human rights law as being set out under the male ‘standard’, one that dictates how the ‘other’, the female, ought to be protected to reach the same equal status.⁶⁴ According to some, even CEDAW’s portrayal of discrimination is based on the flawed idea of discrimination that ‘male and female are the same’.⁶⁵ This particular articulation of international human rights instruments shows it as a paradox of exclusions under the guise of universality, because founded on one gendered abstract model, a similar construct to that of Kantian dignity.

Grear’s account of disembodiment then focuses on the genealogy of human rights law, ‘the paradigmatic jural site for the convergence of humanity, law and the legal subject’.⁶⁶ However, if we track the *evolution* of human rights, the ever-increasing particularization of contemporary rights in recent decades may be interpreted as an attempt to rectify the excessive abstraction that characterized the origins of the human rights tradition. Thus, the relatively recent recognition of the rights of ‘the girl child, migrant labour, indigenous peoples, gay and lesbians (...), prisoners, and those in institutional regimes, refugees, and asylum-seekers children’,⁶⁷ denotes the recognition of the suffering of those bodies that are excluded by the abstract model of quasi-disembodiment, and the paramount importance of the recognition of their ‘embodied difference’.⁶⁸ This development can be applied to the dependent elderly.

⁶² Ibid 103

⁶³ Ibid 103

⁶⁴ Charlesworth H., Chinkin C. and Wright S., ‘Feminist Approaches to International Law’ (1991) 85 International Journal of International Law 613

⁶⁵ Ibid 631

⁶⁶ Ibid 97

⁶⁷ Baxi U., *The Future of Human Rights* (Oxford University Press, 2002), 32

⁶⁸ Grear (n7) 112

Grear hence continues by exposing the ‘centrality of embodiment’ to argue for a shift in the focus of human rights. She bases her argument on the writings of Merleau-Ponty,⁶⁹ a western philosopher whose work provides ‘a phenomenological account of perception as being embodied experience’. The importance of his account resides in the importance of the ‘perspectival nature of perception’, which translates more simply in saying that our embodiment conditions how we conceive the world around us, but how it is also borne out of that very world we inhabit.⁷⁰ Grear also quotes the work of Johnson and Lakoff,⁷¹ whose cognitive scientific work has concentrated on showing that ‘the mind is inherently embodied. Thought is mostly unconscious. Abstract concepts are largely metaphorical’.⁷² This perspective is in contrast with Kant’s ‘noumenal self’, free of all human biological and neurological realities. Grear therefore concludes that ‘it cannot be stressed enough that the centrality of human embodied vulnerability is a crucial insight for the theory of human rights’,⁷³ and that the impossibility of legal disembodiment results in a gap between legal subjectivity and human beings’.⁷⁴

This gap Grear mentions between abstract legal subjectivity and concrete situated human beings is similar to the one I referred to above between different understandings of dignity. Autonomy needs not be rejected as the normative basis of dignity. What ought to change is how autonomy is defined so as to better reflect the embodied and finite nature of individuals. This shift in the understanding of autonomy and dignity helps us move towards a more concrete and phenomenological approach to human rights, closing the gap between abstraction and reality, and better able to provide the conditions necessary for dignity to thrive. In the next part of this chapter I will therefore examine the nature of concrete autonomy. I will begin by reviewing the communitarian critique against the Kantian ideal of autonomy. Inspired by their belief in the inextricable link between the person and her environment, I will then explore more concrete accounts of autonomy founded on a version of the self that is social

⁶⁹ Ibid 116

⁷⁰ Ibid 117

⁷¹ Lakoff G. and Johnson M., *Philosophy in the Flesh: The Embodied Mind and its Challenge to Western Thought* (Basic Books, 1999)

⁷² Ibid 3

⁷³ Grear (n7) 131

⁷⁴ Ibid 162

and biological in nature. These concrete views of autonomy will provide a framework within which to understand and reformulate not only dignity, but the kind of human rights needed to promote its possibility.

5) Concrete Autonomy

a) Communitarian critique of liberal autonomy

Communitarians, the main critics of liberal autonomy and the individualistic view of the person it presupposes, have stressed the fundamental importance of the world individuals inhabit as part of the conceptualization of the self.⁷⁵ Their ethical standpoint privileges ‘the formation of character rather than the possession of rights and obligations’.⁷⁶ They understand autonomy as bounded by and relative to particular traditions. They also consequently challenge the primacy of individual rights and the place of liberal autonomy.

In contrast to the high levels of abstraction and universalism used by liberal theories such as Rawls, communitarians believe that individuals cannot be disconnected from the tradition they belong to; not only do individuals see the world through this tradition, but their tradition is constitutive of their very subjectivity.⁷⁷ Indeed, communitarians reject Rawls’ justification of the original position that ‘the self is prior to the ends which are affirmed by it’.⁷⁸ In other words, there is no self that logically precedes the ends chosen by it; the self and the ends available to it are constituted within the same tradition.

Taylor adopts an Aristotelian conception of the person where ‘[m]an is a social animal, indeed a political animal, because he is not self-sufficient alone, and in an important sense is not self-sufficient outside the polis’.⁷⁹ Taylor suggests that

⁷⁵ See for instance Avineri S., and de-Shalit, A. (Eds), *Communitarianism and Individualism* (Clarendon Press, 1992)

⁷⁶ Agich (n38) 31

⁷⁷ See Taylor C., *Philosophy and the Human Sciences: Philosophical Papers 2* (Cambridge University Press, 1985); MacIntyre A., *Against the Self-Images of the Age* (University of Notre Dame Press, 1978)

⁷⁸ Rawls (n37) 491

⁷⁹ Taylor (n77) 189

liberalism portrays an atomistic view of the self that somehow manages to exist independently of any social context, whilst at the same time resting on the paradoxically non-liberal premise that those individuals belong to a society founded on freedom and self-fulfillment.⁸⁰ Taylor therefore proposes a ‘politics of difference’, one that recognizes the specific identity of groups and individuals, rather than one based on universalism, where all individuals are presumed to possess the same rights and the same worth.⁸¹ It goes against the discriminatory and detrimental effect of the homogenizing model of liberal identity, and instead argues for the consideration of the specificities and characteristics of those groups, particularly those vulnerable groups, that do not fit its profile.

This conceptualization of the self as embedded in its tradition and community shifts the ethical focus off individual rights. MacIntyre for instance returns to the Aristotelian vision of virtues,⁸² where ‘virtues are human qualities, the possession of which enables it to achieve the goods, which are intrinsic to social practices’.⁸³ This entails the adoption of ‘an enacted narrative’ in order to ‘avoid conflicts between different virtues’, so as to ‘have an account of the good for the whole of human life conceived as a unity’.⁸⁴ Waltzer also rejects the universality of rights and claims that ‘actual men and women (...) claim justice, and resist tyranny, by insisting on the meaning of social goods amongst themselves. Justice is rooted in the distinct understanding of places, honors, jobs, things of all sorts that constitute a shared way of life. To override those understanding is to act unjustly’.⁸⁵

Many commentators have argued against the communitarian critique of liberalism and its individualistic atomized vision of agents. Some have insisted that liberalism could include a vision for common good within the bounds of autonomy.⁸⁶ Feinberg for instance has argued that “‘common good’ is hardly alien to the pluralistic liberal tradition. One of its great enemies is the intolerant predominant sub-community that

⁸⁰ Ibid 200

⁸¹ Taylor C., ‘The Politics of Recognition’ in Gutmann A. (Ed) *Multiculturalism* (Princeton University Press, 1994)

⁸² MacIntyre A., *After Virtues: A Study in Moral Theory* (University of Notre Dame Press, 1981)

⁸³ Nino C., *The Ethics of Human Rights* (Clarendon Press, 1993), 88-89

⁸⁴ Ibid

⁸⁵ Waltzer M., *Spheres of Justice: A Defense of Pluralism and Equality* (Basic Books, 1983), 314

⁸⁶ See Raz, J., *The Morality of Freedom* (Clarendon Press, 1986) and Kymlicka W., *Liberalism, Community and Culture* (Clarendon Press, 1989)

chokes off or absorbs weaker sub-communities and soon identifies its own parochial values and traditions with those of the comprehensive national community⁸⁷. Indeed, Agich has written that the communitarians' appeal to tradition may be their downfall.⁸⁸ He, as Feinberg, sees tradition in the concrete world as something people disagree about, and so necessitate a certain overarching authority 'to impose orthodoxy' and 'foreclose further discussion and debates'.⁸⁹ Ultimately, this appeal to higher authorities could result in 'tyranny, not community'.⁹⁰ In fact, Scanlon remarks that 'victims (of human rights violations) would rarely concede that, because such behavior is common in their country, their tormentors are acting quite properly'.⁹¹ From this point of view, human rights may be seen as one of the essential elements to provide the conditions necessary for an autonomy-based dignity, even as we recognize that autonomy cannot and should not be conceived entirely separately from the value and specificities of cultural and historical traditions. Mindful of this, rejecting liberalism completely on the count of its abstract view of the autonomous self, extricated from its community and tradition, is to my mind unnecessary. Some liberals embrace a conception of personhood anchored in communities and tradition, whilst still acknowledging the central place of autonomy. In a liberal landscape, the 'social nature of man' can be accommodated by 'recognising the bedrock importance of community to human nature and well-being'.⁹²

In any case, the basic point remains that communitarians arguments expose the concrete, socially embedded nature of autonomy; as such, these arguments are a useful starting point in the quest for a fuller conception of autonomy, one that fleshes out the bare abstract bones of the liberal ideal of autonomy. In order to include the dependent elderly in a conceptualization of dignity sensitive to the conditions that enable the realization of dignity, it is necessary to ground it precisely in such a concrete view of autonomy and personhood. In this next section, I will explore how more concrete and embodied conceptions of autonomy may lead to a different approach to dignity. I will shift my attention from considering conception of

⁸⁷ Feinberg J., 'Liberalism, Community, and Tradition' (1988) 3(3) *Tikkun* 39

⁸⁸ Agich (n38) 33

⁸⁹ *Ibid*

⁹⁰ *Ibid*

⁹¹ Scanlon T., *The Difficulty of Tolerance: Essays in Political Philosophy* (Cambridge University Press, 2003) 119

⁹² Feinberg (n87) 39

autonomy as self-ruling rationality, to that adopted by feminist writers as entrenched in the relational self, and our ‘embodied vulnerability’.⁹³ I will conclude that a concrete view of autonomy can give rise to a subject-specific understanding of dignity, giving rise to a more phenomenological approach to rights as defended by Grear above.

b) Evolutional Autonomy

For Haworth, whose work on autonomy cuts across the social sciences, autonomy is evolutionary.⁹⁴ According to his account of autonomy, the individual can only become autonomous through a process of ‘internalization’ of her community’s values and habits that will enable her to ‘acquire a certain amount of competence in the world, to achieve the results she wants, so that she can interpose herself between domination by others and domination by say, those of her physically based desires with which she does not identify’.⁹⁵ This view of autonomy insists on the embodiment of individuals, and on the idea that we do not possess the same capacity for autonomy throughout the course of our lives. Autonomy is learnt, and presumes a fluctuating level of dependency on others.

Without wishing to assimilate the issues faced by elderly people in care to those of children, parallels can nonetheless be drawn up with the theoretical ideas that have underpinned the debates regarding children’s rights. The particularization of rights for children reveals the need to respect their autonomy in face of parental authority, but also to limit that autonomy for their own protection. Indeed, Eekelaar reminds us that ‘children often lack the information or ability to appreciate what will serve them best’.⁹⁶ Some writers have defined children’s ‘autonomy interest’ as their claim to lead a life of their choosing, free from adult authority.⁹⁷ Freeman has explained that uncritically giving heed to such interest could prevent children from reaching ‘a rationally autonomous adulthood’ where they would be ‘capable of deciding on (their)

⁹³ Grear (n7)

⁹⁴ Haworth L., *Autonomy: An Essay in Philosophical and Ethics* (Yale University Press, 1986)

⁹⁵ Moore M., *Foundations of Liberalism* (Oxford University Press, 1993), 185

⁹⁶ Eekelaar J., *The Emergence of Children’s Rights* (1986) 6(2) *Oxford Journal of Legal Studies* 161, 170

⁹⁷ Holt J., *Escape from Childhood* (Dutton, 1974)

own system of ends as free and rational beings'.⁹⁸ Eekelaar therefore advances the view that a child's 'autonomy interest' could not only conflict with 'his developmental interest', but also his 'basic interest', that of 'general physical, emotional and intellectual care within the social capabilities of his or her immediate caregivers'.⁹⁹

It could be argued here that although the 'developmental interest' of children no longer applies to the dependent elderly, their 'basic interest' may sometimes need to take priority over their 'autonomy interest'. It is unavoidable therefore to raise the problematic notion of paternalism, the 'bête noire' of liberal autonomy, especially for those whose 'developmental interest' cannot be invoked as a reason to compromise their autonomy. Agich writes that there is a tendency to see a necessary conflict between autonomy and 'acting in the best interests of another' under the premise of beneficence.¹⁰⁰ O'Neill does point out that in the case of medical treatment, beneficence should not be the only concern of medical practice, as it would involve treating 'patients as persons only if beneficence so required', regardless of their level of autonomy.¹⁰¹ This dichotomy is only problematic under the guise of liberal autonomy and the negative concept of paternalism as something that imposes a particular idea of wellbeing onto the individual. In fact, autonomy is not necessarily relinquished when someone acts in the best interest of another if that best interest includes safeguarding their 'personal independence and judgment'.¹⁰² VanDeVeer refers to this kind of beneficence as 'autonomy-respecting paternalism',¹⁰³ whilst Agich refers to it as 'parentalism', or 'the term used for a wide range of relationships that foster human development'.¹⁰⁴

In fact, O'Neill remarks that it is false to assume that only people dependent on the care of others, such as children or the very elderly for instance, suffer from constraints

⁹⁸ Freeman M.D.A. *The Rights and Wrongs of Children* (Continuum International Publishing, 1983), 57

⁹⁹ Eekelaar (n96) 170

¹⁰⁰ Agich (n38) 47

¹⁰¹ O'Neill O., 'Paternalism and partial autonomy' (1984) 10 *Journal of Medical Ethics* 173, 173

¹⁰² Thomasma D. C. 'Competency, dependency, and the care of the very old' (1984) 32 *Journal of the American Geriatrics Society* 906, 911

¹⁰³ VanDeVeer D., *Paternalistic Intervention: The Moral Bounds of Benevolence* (Princeton University Press, 1986)

¹⁰⁴ Agich (n38) 46

on their autonomy: rather, ‘all human capacities for autonomous action are limited’.¹⁰⁵ This can be explained if we adopt a conception of the individual that is inherently vulnerable. In this context, she resorts to an ethical theory that does not rely on ‘idealised autonomy’, but on that of ‘actual human autonomy’.¹⁰⁶ O’Neill does not recommend giving up on Kantian action-oriented ethics, (based on the primacy of agency and hence autonomy), for result-oriented ethics, which is based on wellbeing outcomes only, as a basis for an ethical framework in the domain of medical treatment.¹⁰⁷ She does, however, recommend adapting or modifying Kantian action-oriented ethics. O’Neill insists that in order for action-oriented ethics to work in the context of diminished autonomy, it is essential not to ‘rely on an abstract, ‘idealising’ account of autonomy’ that would ‘rule out all paternalism’, but to ‘take account of the partial character of human autonomy’, so as to ‘sketch patterns of reasoning which draw boundaries in given contexts between permissible and impermissible forms of paternalism’.¹⁰⁸

An action-oriented ethical framework where autonomy remains intrinsically valuable must be based on actual autonomy rather than idealised autonomy, so as to define the correct level of paternalism necessary for a life worth living, a life worthy of dignity. This ethical framework, as O’Neill concludes, complicates medical (or care) treatment, by forcing ‘patterns of reasoning’ that deliver individual outcomes for those cared for, rather than a simpler ‘boundary-line’ approach to paternalism.¹⁰⁹ In practice this means having a personal knowledge of the patient’s circumstances to be able to define at which point and for what purpose their autonomy ought to be curtailed by paternalistic interventions. An evolutionary account of autonomy highlights its temporal and individual character. Human beings’ capacity for autonomy fluctuates throughout their lives, and for that reason requires the intervention of others. In the case of the elderly in long-term care, reduced autonomy should not mean that beneficence alone should become the ethical guidance de rigueur.

¹⁰⁵ O’Neill (n101)

¹⁰⁶ Ibid

¹⁰⁷ Ibid

¹⁰⁸ Ibid 177

¹⁰⁹ Ibid

In order for the evolutionary characteristic of autonomy to be respected, care is necessary. It needs not replace autonomy but must facilitate it within an individualized approach. A formulation of dignity based on concrete autonomy must encompass this element of care or paternalism as argued by O'Neill, in order to give rise to the conditions necessary to its flourishing. I will delve into the notion of vulnerability and the state response it should trigger to enable dignity in Chapters III and IV. The communitarian critique of liberal autonomy and evolutionary definitions of autonomy all presuppose that individuals, whatever their age or actual capacity for autonomy, are relational creatures, and that autonomy must also be defined as such.

c) Relational Autonomy

As I have explained above, an abstract notion of autonomy as the source of dignity assumes a strict liberal system where legal rights promote negative liberty. I have also engaged with the communitarian critique of the autonomous liberal self to reveal the importance of communities and tradition in the construction of the self. Dworkin concurs that 'all individuals have a history', that 'they develop socially and psychologically in a given environment with a set of biological endowments', and that 'they mature slowly and are, therefore, heavily influenced by parents, peers, and culture'.¹¹⁰ He therefore defines autonomy as a

second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values. By exercising such a capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are.¹¹¹

This definition supposes a person very much more concrete than the 'noumenal' self of Kantian autonomy, free from all human impulses and sentiments. It sets out a vision of autonomy that is enmeshed with the individuals' environment and history.

¹¹⁰ Dworkin (n41)

¹¹¹ Ibid 20

Nonetheless, historical accounts of autonomy such as that espoused by Dworkin above, but also by Christman, are not without their problems.¹¹² Christman insists on the necessity of the person to possess ‘processes of critical reflection’ which themselves must be ‘procedurally independent’.¹¹³ This means that the person is only truly autonomous when she is able to reflect on the influences of the world she inhabits, and then analyze and reject if necessary, those that prevent her from critical self-reflection. True autonomy, under this particular conception, appears utopian. Nobody is fully able to identify and segregate those social influences in order to become ‘self-transparent’.¹¹⁴

Some feminist writers have challenged Kantian autonomy because of its repressive effect on women. Cole has argued for instance that it represents a masculine obsession with self-sufficiency and self-realization to the detriment of human interconnectedness and dependency.¹¹⁵ Feminists have argued that social embeddedness is not necessarily an obstacle to autonomy, but a factor that may diminish it without necessarily negating it.¹¹⁶ Meyers argues that autonomy is a competency that can only be realized ‘in the context of social relationships, practices, and institutions’.¹¹⁷ She takes the example of women to argue that the skills required for autonomy competency can be fostered or stunted depending on the social context the individual lives in. According to this account, autonomy is similar to ‘self-realisation’ and so implies that

since individuals differ so significantly in their talents, capacities, character traits, values, desires, beliefs and emotional attitudes (...), there can be no blueprint for what constitutes an autonomous life. Rather autonomy can be secured only through the exercise of autonomy competency, or a coordinated repertoire of skills and capacities that enable each individual to fully realize

¹¹² Christman J., ‘Autonomy: A Defence of the Split-level Self’ (1987) 25 *Southern Journal of Philosophy* 281

¹¹³ Mackenzie C. and Stoljar N., *Relational Autonomy* (Oxford University Press, 2000), 16

¹¹⁴ *Ibid*

¹¹⁵ See for instance Friedman M., ‘Autonomy, social disruption, and women’ in C. Mackenzie and N. Stoljar (Eds.) *Relational Autonomy* (Oxford University Press, 2000) and Code L., *What Can She Know?* (Cornell University Press, 1991)

¹¹⁶ Meyers D.T., *Self, Society and Personal Choice* (Columbia University Press, 1989)

¹¹⁷ MacKenzie and Stoljar (n113) 17

himself or herself, whatever self-realization amounts to for each particular individual.¹¹⁸

Meyers' view of autonomy is linked to the individuals' identity within their social context, and confirms the fluctuating character of autonomy. In her account, autonomy is a dynamic norm that allows for self-realization, shaped positively or negatively by social context.¹¹⁹ She mentions the case of women, and how 'traditional gender socialization' may compromise their competence to reach full autonomy; on one side it facilitates skills useful for 'self-discovery' such as 'emotional receptivity and receptiveness', whilst it also hinders their ability to develop skills for 'self-definition', skills that men will more easily develop in this context.¹²⁰ Autonomy as competence hence reveals the effect of the wider social context in the ability of persons to reach higher level of autonomy. It is arguably similar for elderly people, whose skills for autonomy competence will be greatly influenced by the social meaning of age. The social context the very elderly inhabit will have an impact on their ability to be autonomous.

Meyers' exposition of autonomy sits within a relational account of autonomy because it situates it within the definitional bounds of society, but also the very personal perception of self-realization it results in. In the same relational perspective, Nedelsky argues that autonomy is made possible by 'constructive relationships - including intimate, cultural, institutional, national, global, and ecological forms of relationships, all of which interact'.¹²¹ She states that 'a relational conception of autonomy turns our attention to the kinds of relations that undermine or enhance autonomy, and the forces that structure those relations - from institutional design to gendered division of labor to beliefs about entitlement. Examining institutional practices, and the law that shapes them, can, in turn, shed lights on what fosters autonomy'.¹²² The concept of relational autonomy reflects and pulls together the characteristics of autonomy highlighted in other conceptions of autonomy examined above: autonomy is an individual competence, shaped and informed by the individual's community and tradition, the

¹¹⁸ Ibid

¹¹⁹ Ibid

¹²⁰ Ibid 18

¹²¹ Nedelsky J., *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford University Press, 2012), 118

¹²² Ibid 119

care of others, societal norms and the institutional framework. The network of all these relationships, whether public or intimate, develops within individuals the capacity for autonomy. Rooting dignity in concrete autonomy, instead of that underscored by Kant, results in a better understanding of the conditions necessary to its flourishing in care.

6) Dignity rooted in relational autonomy

a) Care ethics

Adopting a relational view of autonomy grounds dignity in an ‘embodied’ view of the person, evolving through the lifecourse.¹²³ Relational autonomy underscores the paramount importance of care and care ethics. The origins of the ethic of care school of thought are generally attributed to Gilligan who developed it in the context of feminist critical theories.¹²⁴ Her path to the formulation of an ethic of care started as a critique to the conclusion of Kohlberg’s stages of moral development that women were less morally developed than men.¹²⁵ According to him, moral maturity was reached at the post-conventional morality stage, where individuals’ judgments were no longer based on the rules adopted by the group they belonged to (the conventional morality stage), but fashioned on universal principles such as justice and human rights. Kohlberg noted that women tended to make decisions predominantly in accordance with the people they were responsible for, and therefore did not attain this last stage of moral development associated with moral maturity.¹²⁶

Gilligan questioned this association of moral maturity and use of universal principles and held that women approached moral reasoning differently, with a greater emphasis on the relationships and emotional connections they formed, and the context they were in. It was not the case that their moral reasoning was weaker, but it was the case that it was rooted in a different value system. The place of care, this link that binds

¹²³ Grear (n7)

¹²⁴ Gilligan C., *In a Different Voice* (Harvard University Press, 1982)

¹²⁵ Kohlberg L., *The Philosophy of Moral Development: Moral Stages and the Idea of Justice, Essays on Moral Development, Volume 1* (Harper Collins, 1981)

¹²⁶ Herring J., *Caring and the Law* (Hart Publishing, 2013), 47

people together at some point in their lives, becomes paramount in moral reasoning. As Sevenhuijsen summarises, the ethic of care means that ‘individuals can exist only because they are members of various networks of care and responsibility (and that) the self can exist only through and with others and vice versa’.¹²⁷ Elderly individuals who can no longer live independently must still be considered as intrinsic parts of a web of relationships, and not as burdens on society that need to be removed from it.

Caring is the stuff of life, and feminist views on the topic have influenced welfare.¹²⁸ As well as being essential to our survival, it can be the source of much ill if absent or badly performed. Care within an ethic of care is defined as fundamentally human, and whether being cared for, caring for others or both, we are always part of a caring dynamics.¹²⁹ Derived directly from caring, the idea of dependency is also pivotal to an ethic of care. Herring has written that ‘a relational life is inevitable’.¹³⁰ Instead of conceiving individuals as separate entities, the ‘relational self’ reflects the fact that ‘our identities and values are found not in ourselves but in our relationships’.¹³¹ People considered under an ethic of care are not looked at individually, but as part of a web of relations.¹³² As they place value in their relations with others, they seek to improve these in order to improve their own selves.¹³³ Put differently, the self is not ever autonomous and free from ties, but the result of connections with others. This vision of the self means that we are all dependent on each other for our sense of self. The idea that people are stand-alone individuals perfectly content without the interference of others is actually a fallacy that Held sees as ‘modelled on the experience of men in public life and in the market place’.¹³⁴

¹²⁷ Sevenhuijsen S., ‘A third way? Moralities, ethics and families. An approach through the ethic of care’ in A. Carling, S. Duncan and R. Edwards (Eds.) *Analysing Families, Morality and rationality in policy and practice* (Routledge, 2002), 131

¹²⁸ Williams F., ‘The Presence of Feminism in the Future of Welfare’ (2002) 31 *Economy and Society* 502

¹²⁹ Sevenhuijsen (n127) 49

¹³⁰ Herring J., ‘Rational autonomy and family law’ in J. Wallbank, S. Choudury and J. Herring (Eds.), *Rights, Gender and Family Law* (Routledge, 2010), 267

¹³¹ Sevenhuijsen (n127)

¹³² *Ibid* 59

¹³³ *Ibid*

¹³⁴ Held V., *The Ethics of Care* (Oxford University Press, 2006), 23-24

At most stages of our lives, our relational self forms part of interdependent relations, but at others, only dependence remains. As Kittay writes, perfect autonomy is fictitious, especially in old age;

The frail elderly person ... may herself have been involved in a series of interdependent relations. But at some point there is a dependency that is not yet, nor longer an interdependency. By excluding this dependency from social and political concerns, we have been able to fashion the pretence that we are independent, that the cooperation between persons that some insist is interdependence is simply the mutual cooperation between essentially independent persons'.¹³⁵

The last pillar of an ethic of care is the notion of responsibility. Care and dependency demand and create relations of responsibility. The default position of an ethic of care is the effective fulfilment of the responsibility we have towards those we care for.¹³⁶ Sevenhuijsen suggests that 'because the ethic of care starts from a relational ontology, it focuses primarily on the question of what politics could mean for the safeguarding of responsibility and relationship in human practice and interaction.'¹³⁷

Applying an ethic of care to social care policies, so that our responsibilities to the dependent elderly can be fulfilled, demands that we inquire into the meaning of dignity for those who are dependent on the care of others. It is only through this willingness to discover what the other person needs (or does not want) in order to experience dignity that we can begin to create those conditions amenable to it. As Sevenhuijsen remarks, 'the ability and willingness to place oneself in the perceptions and viewpoints of others is indispensable in practicing care and responsibility'.¹³⁸ It is important to be aware of the 'asymmetrical reciprocity' that caring relationships can create.¹³⁹ Indeed, assuming to know the other and taking responsibility for them can

¹³⁵ Kittay E. F., *Love's Labour: Essays on Women, Equality and Dependency* (Routledge, 1999), xii

¹³⁶ Noddings N., *A Feminine Approach to Ethics and Moral Education* (University of California Press, 2003) 86

¹³⁷ Sevenhuijsen (n127) 132

¹³⁸ Sevenhuijsen S., 'The place of care: The relevance of the feminist ethic of care for social policy' (2003) 4(2) *Feminist Theory* 179, 186

¹³⁹ Young I. M., *Intersecting Voices: Dilemmas of Gender, Political Philosophy and Policy* (Princeton University Press, 1997)

lead to oppression and paternalism. It is, as Sevenhuijsen reminds us, quite impossible to see ‘through someone else’s eyes’, as it is to ‘stand in someone else’s shoes’.¹⁴⁰ It is therefore essential to have ‘the willingness to be open to everyone’s unique, embodied subjectivity: the idea that everyone is positioned differently and leads an existence that cannot be reduced to that of others’.¹⁴¹ In order to find out about this other, communication is key, and so it is in finding out about the other’s dignity.

b) Dignity as subjectively experienced

Benhabib’s feminist critique of the nature of the self under the Rawlsian veil of ignorance also leads her to adopt a relational view of the self.¹⁴² Benhabib writes that ‘according to Kohlberg and Rawls, moral reciprocity involves the capacity to take the standpoint of the other, to put oneself imaginatively in the place of the other, but under conditions of the ‘veil of ignorance’, the other as different from the self disappears’.¹⁴³ Rawlsian subjects under the veil of ignorance are rational but ‘do not know their conception of the good’.¹⁴⁴ Similarly to the beholder of Kantian autonomy, this being is dis-embodied, fictitious and un-human like. In her account of ‘the other’ Benhabib criticises the moral perspective view of the ‘generalised other’, a standpoint epitomised by Rawl’s theory of justice that ‘requires us to view each and every individual as a rational being entitled to the same rights and duties we would want to ascribe to ourselves.’¹⁴⁵ She posits this version of the ‘self-other’ relationship model to that of the ‘concrete other’, a standpoint that ‘requires us to view each and every rational being as an individual with a concrete history, identity and affective-emotional constitution’.¹⁴⁶

Benhabib concludes that ‘from a meta-ethical and normative standpoint, I would argue for the validity of a moral theory that allows us to recognize the dignity of the generalised other through an acknowledgement of the moral identity of the concrete

¹⁴⁰ Sevenhuijsen (n138) 186

¹⁴¹ Ibid

¹⁴² Benhabib S., ‘The Generalized and the Concrete Other: The Kohlberg-Gilligan Controversy and Feminist Theory’ in S. Benhabib and D. Cornell (Eds.) *Feminism as Critique* (Polity Press, 1987)

¹⁴³ Ibid 283

¹⁴⁴ Rawls J. (n37) 123

¹⁴⁵ Benhabib (n142) 280

¹⁴⁶ Ibid 281

other'.¹⁴⁷ In order to put this moral order in practice, and combine both ethics of justice and ethics of care, she suggests 'a model of communicative need interpretations',¹⁴⁸ based on the idea that in order to create acceptable living conditions, it is not sufficient to assume the wishes and wants of this generalized other, but rather do so by trying to 'learn, discursively or 'dialogically' what the 'otherness' of other people consists in'.¹⁴⁹ She explains that

[N]either can the concreteness nor the otherness of the 'concrete other' can be known in the absence of the voice of the other. The viewpoint of the concrete emerges as a distinct one only as a result of self-definition. It is the other who makes us aware both of her concreteness and her otherness. Without engagement, confrontation, dialogue and even a "struggle for recognition" in the Hegelian sense, we tend to constitute the otherness of the other by projection and fantasy or ignore it in indifference.¹⁵⁰

Autonomy under the 'generalized other' Kantian sense, as the root to human beings' dignity, can be read as excluding a large number of individuals at the periphery of its normative framework. Just as the 'sphere of justice' once eclipsed women and relegated them to the 'realm of nature' and the domestic activities of 'nurture, reproduction, love and care', so it can be argued that abstract autonomy has pushed to the shadows those who no longer fit the Kantian autonomous mold. Their dignity is not necessarily realized, because the conditions needed for its realisation do not appear to correspond to the strict model of justice rooted in Kantian autonomy.¹⁵¹

I agree with Behabib that this does not mean that both ethical concerns of justice and care cannot be accommodated within our social order. There already exists, as I discussed above, a recognition of the embodiment of the self within the discourse of rights. A discursive approach to dignity reflects the intensely personal and relational character of autonomy and the concrete other, and offers a far more promising ground

¹⁴⁷ Ibid 287

¹⁴⁸ Ibid 288

¹⁴⁹ Ibid 268

¹⁵⁰ Benhabib S., *Situating the Self: Gender, Community and Postmodernism in Contemporary Ethics* (Polity Press, 1992), 168

¹⁵¹ For a detailed account of the limits of the contractarian model of justice see Nussbaum M., *The Frontiers of Justice: Disability, Nationality, Species Membership* (Harvard University Press, 2006)

upon which to create those conditions necessary to its realization. This is what has led me to examining qualitative studies about the meaning of dignity for elderly people in institutional care. The role law may play to foster dignity-enabling conditions depends on the adoption of a correct ethical framework. The kind of ‘communicative needs interpretation’ suggested by Benhabib offers such a framework. I will refer to this ethical model as discursive. Because our autonomy is relational and we are the product of caring relationships, we have a responsibility to understand dignity from the standpoint of the concrete other through dialogue.

In adopting such an ethical model for dignity, particularly in institutional settings where people’s concrete autonomy has been deteriorated by age, the person’s own idea of dignity becomes the foundational value. This ethical framework makes dignity the heuristic concept I referred to in my introduction, one that can mean something quite specific to each and every human being, hence embracing individual particularism, whilst at the same time remaining universal in the sense that everyone has dignity. The meaning of dignity hinges on the person it refers to, and must be arrived at through the means of discourse. It should then be the role of the policy makers to create laws that enable the conditions fertile for dignity to flourish. It is evident that this model raises many problems. One of them would be the practical aspect of gathering the information needed from the people concerned. If the person is not able to communicate, other means would have to be deployed, and family members or close relatives may need to step in and reveal what they believe to be the meaning of dignity for that person. One of the main problems is that if dignity has as many meanings as there are people, it is going to be impossible to create the conditions necessary for its realization. But this needs not be the case. As I will show in the next chapter, although the meaning of dignity may be different from person to person, it will also be formed of many common elements. The extraction of common features to the meaning of dignity as produced through a model of discursive ethics can be used as a guiding frame onto which to hook the more detailed dialogical exchange that ought to take place with each individual in care.

7) Conclusion

This chapter has set out the theoretical framework that supports the rest of this dissertation's idea, which is that the understanding and enabling of dignity in care ought to be informed by the subjective views of individuals in care. I started by exploring the classic concept of Kantian dignity. Kantian dignity is ground breaking in its approach because it defines the intrinsic value of individuals independently of religion and a God-like conception of the human. It also sets out the importance and value of each and every individual, to be treated as ends and not means, in contrast to the utilitarian idea that endless sacrifices may be imposed on individuals so long as they promote the greatest happiness for the greatest number. The basis of dignity as defined by Kant is upheld by an abstract view of autonomy and rational agency that may be interpreted as excluding individuals whose autonomy has been compromised because of age. A strict interpretation of this particular conception of the self would lead to a system of rights intent on the protection of negative freedom as a prevalent political goal, leaving unfulfilled the creation of conditions necessary for the dignity of those who are considered dependent. Evidently, this is not the case in reality, as many human rights, especially those that are cultural, social and economic in nature, recognize our embodied and finite nature, and the fact that we need a certain environment for dignity to flourish.

The second part of this chapter has therefore focused on exploring a more concrete concept of autonomy, in order to come up with a definition of dignity that could guide public bodies to fulfil their duty to take it into account in the delivery of their social care services. I first looked at the communitarian critique of theories of justice incorporating a Kantian view of mankind, and concluded that, although tradition and history do play a part in creating who we are, a communitarian political theory did not warrant the dismissal of liberalism. Instead, communitarian critique opened the debate on the nature of autonomy, one that is shaped by its history, surroundings and culture. This account of autonomy then led me to explore other concrete accounts of autonomy, for the most part developed by feminist writers. In conclusion, it appears that autonomy is not only anchored in our history and tradition, but it is also evolutionary, and ultimately relational. Our autonomy is an individual value that is transient, and based paradoxically on interdependence and interconnectivity.

I have argued that embracing the notion of relational autonomy provides a far more inclusive basis for dignity for all. It fits within an ethical framework of care that recognises the relational embeddedness of individuals. Understanding dignity grounded in relational autonomy suggests that the state has a responsibility to safeguard those relationships people depend on. A discursive approach demands to take into account people's concrete autonomy, and therefore offers a practical mean to apprehend experienced and subjective dignity. This in turn would facilitate setting out the conditions necessary for dignity to flourish. The next step of my enquiry is therefore the application of the theory described here and the search of a definition of dignity based on qualitative and empirical studies that have asked the older individuals what dignity means to them.

Chapter II

Meaning of Dignity

1) Introduction

I suggested in the last chapter that dignity ‘à la Kant’ was rooted in a kind of autonomy that was not relatable to all human beings, especially those whose rational agency had been eroded by age. Instead, I introduced and endorsed a feminist view of autonomy, one entrenched in the concrete self. I have linked relational autonomy to its source, namely the ethics of care, an approach to morality centred round our need to care and be cared for. Sevenhuijsen, quoted in the last chapter, reminds us that this is an ethics that is relational by definition, because it ‘focuses primarily on the question of what politics could mean for the safeguarding of responsibility and relationships in human practice and interaction’.¹ This question relies on knowing ‘the concrete other’, a process that cannot derive from pretending to be the other, but rather only happens when we engage in dialogue.²

I believe that in order to refine the meaning of dignity in the context of elderly care, asking the people concerned is essential. A number of academics working in social sciences disciplines have conducted such empirical studies through the methodology of qualitative research, based on a mix of in-depth or semi-structured interviews and focus groups. Most of these studies have been run in the context of social and healthcare research, in response to a large body of policies focused on promoting dignity as a new paradigm for care.³ These policies in turn are a political reaction to

¹ Sevenhuijsen S., ‘A third way? Moralities, ethics and families. An approach through the ethic of care’ A. Carling, S. Duncan and R. Edwards (Eds) *Analysing Families, Morality and rationality in policy and practice* (Routledge, 2002), 132

² Benhabib S., ‘The Generalized and the Concrete Other: The Kohlberg-Gilligan Controversy and Feminist Theory’ in S. Benhabib and D. Cornell (Eds.) *Feminism as Critique* (Polity Press, 1987)

³ See for instance Department of Health, ‘Treating patients and service users with respect, dignity and compassion’ (March 2013)

<<https://www.gov.uk/government/policies/treating-patients-and-service-users-with-respect-dignity-and-compassion>> Accessed 17th December 2014

Or Care Quality Commission, ‘Time to Listen In Care Homes, Dignity and Nutrition Inspection Programme 2012’ (March 2013)

some of the Care Quality Commission reports on inadequate care practices, and on the need for reform in the care industry.⁴ Although many of these documents hail dignity as the value to be promoted, few explore directly the meaning of dignity from the perspective of the people receiving care.⁵ For the reasons already stated, however, it is of crucial importance to gather the views of those whose lives are affected by these policies about the meaning of dignity and its importance in their daily lives. Studies that engage with the views of these constituencies are an invaluable source of information for the purpose of my argument, as they offer the possibility to critically assess whether dignity as understood by those concerned is a concept currently legally protected, or capable of legal protection.

In this chapter, I will review studies conducted to this effect and published in nursing, healthcare and ageing study journals. In order to locate them, I performed a systematic search of the words ‘dignity’, ‘elderly’ and ‘care’ on the social sciences databases Assia (Applied Social Sciences index and Abstracts), BHI (British Humanities Index), and Web of Science. I limited this search to material from the last ten years to keep the results as relevant and up to date as possible. I chose those studies that were the most closely matched to my inquiry’s objective, the discovery of the meaning of dignity for elderly people in care homes.

Two studies came back as a direct match to my area of inquiry. They could have been the sole basis of my inquiry, but I preferred to expand my data pool and put some extra flesh on the bare bones of the definition of dignity that was emerging, without, however, including findings that were too far removed from the topic at hand. I selected an additional 10 studies through this process. As Mason explains, the

<http://www.cqc.org.uk/sites/default/files/documents/time_to_listen_-_care_homes_main_report_tag.pdf> Accessed 26th January 2015

Or Northern Ireland Human Rights Commission, ‘In Defence of Dignity, The Human Rights of Older People in Nursing Homes’ (March 2012)

<<http://www.nihrc.org/documents/research-and-investigations/older-people/in-defence-of-dignity-investigation-report-March-2012.pdf>> Accessed 26th January 2015

⁴ See for example Care Quality Commission, ‘The State of Health Care and Adult Social Care in England 2013/14’ (October 2014) <<http://www.cqc.org.uk/sites/default/files/state-of-care-201314-full-report-1.1.pdf>> Accessed 17th December 2014

⁵ For an example of dignity defined from the perspective of the service user see Social Care Institute for Excellence (SCIE), Cass E., Robbins D. and Richardson A., ‘Dignity in care’ (March 2009)

<http://www.hscbusiness.hscni.net/pdf/SCIE-_Dignity_in_care_March_2009_pdf.pdf> Accessed 14th January 2018

quantity of data analysed in qualitative studies does not equate to quality of outcome.⁶ Indeed data saturation means that eventually, extra data will not add any information of value to the original dataset used. In this instance, I felt that adding any more qualitative studies to the 12 already analysed in this review would not improve the quality of the emerging definition of dignity: the focus of this enquiry must remain on the meaning of dignity for a particular segment of the population in particular circumstances.

The findings of these studies are presented in this chapter in a thematic form following the coding of the material collected, which enabled me to get a clearer understanding of dignity and gauge the recurrent motifs and disparities in results. I have organised all findings under themes and sub-themes I believe best capture the meaning of all the data examined. My goal in this particular chapter has been to remain as descriptive as possible, following the themes already identified by those undertaking the studies I discuss, in order to let the voices of the research participants speak as much as possible.

The studies I have focused upon are as follows; I have used the findings of the Dignity and the Older European Project, a long term study spanning the years between 2001 and 2004, aimed at forming a better understanding of dignity as a basis for 'better quality of life and healthcare' through 'policy development and service provision for older people throughout Europe'.⁷ I have chosen to relate the results found for the United Kingdom,⁸ but also the overall summarised findings for the six participating European countries (France, Ireland, Slovakia, Spain, Sweden and the United Kingdom).⁹ I have also chosen to use another paper grounded on this original

⁶ Mason M., 'Sample Size and Saturation in PhD Studies Using Qualitative interviews' (2010) 11(3) Forum Qualitative Social Research Art.8

⁷ Tadd W., 'Editorial: Dignity and Older Europeans' (2005) Vol. 6(1), Quality in Ageing 2, 3

⁸ Woolhead G., Calnan M., Dieppe P., Tadd W. 'Dignity in older age: what do older people in the United Kingdom think?' (2004) 33(2) Age and Ageing 165

The qualitative research conducted here was based on fifteen focus groups and two individual interviews and was set in South West England and South Wales between April and October 2002. The 72 participants came from 12 different settings, were all aged over 65 years old and purposely selected in order to represent a cross section of socio-economic backgrounds, ethnicity, gender and level of physical fitness. Six of the individuals chosen for the study were nursing home residents.

⁹ Bayer T., Tadd W. and Krajcik S., 'Dignity: The voice of older people' (2005) Vol 6(1), Quality in Ageing 22

'This paper reports on the findings of 89 focus groups and 18 individual interviews (involving 391 older people in 6 European countries between April and October 2002). The participants were

research but used as the basis for an enquiry into the similarities between findings extracted from interviews and theories written about dignity.¹⁰ When possible, I have only taken into account the responses offered by those interviewees who lived in care homes, although some of the findings related are also mixed with perceptions of dignity of older people who are not in residential care.

Another study held in North Wales asked the question ‘What one change today could make a difference to you tomorrow?’ and was aimed at older people who used care services.¹¹ This study does not specifically target people in nursing homes, but it referred to the perception of dignity for people in the context of the provision of care services, where vulnerability and dependency occur. It is also the only study conducted in the form of a survey where people’s answers were more succinct, more numerous and anonymous.

Other studies I have taken into account explore exclusively the meaning of dignity for elderly people in situation of care dependency, but do so with an end of life focus. One such paper aims at comparing the meaning of dignity for care home residents with that of cancer patients in the latter stages of the disease,¹² whereas another explores dignity in care homes as an extension to the application of palliative care practices,¹³ or a basis upon which to ameliorate end of life care.¹⁴

purposely selected to represent a cross section of ‘educational, social and economic backgrounds’, 23. 25% of the people interviewed were 80 years old and over and 17% were care and nursing home residents.

¹⁰ Calnan M., Badcott D. and Woolhead G., ‘Dignity Under Threat? A study of the Experience of Older People in the United Kingdom’ (2006) 36(2) *International Journal of Health Services* 355

¹¹ Morgan G., ‘Dignity in Care Survey in North Wales’ (2012) 16(4) *Working with Older People* 175
The survey was organized by the North Wales Dignity in Care Forum and involved the National Health Service and local authorities organisations. 499 responses were received, but there is no data recording the demographic statistics of the people who answered.

¹² Hall S., Longhurst S. and Higginson I., ‘Living and dying with dignity: a qualitative study of the view of people in nursing homes’ (2009) 38 *Age and Ageing* 411
This study is based on the interviews of 18 selected nursing home residents aged 75 and over in one of two care homes in London.

¹³ Franklin L-L., Ternstedt B-M. and Nordenfelt L., ‘Views on Dignity of Elderly Nursing Home Residents’ (2006) 13 *Nursing Ethics* 130

This study is based on the multiple interviews (39 in total) of 12 selected residents (10 women and 2 men) aged 85 and over in two nursing homes in Sweden. It was compiled following a hermeneutic approach over a period of 18 months during 2002 and 2003.

¹⁴ Pleschberger S., ‘Dignity and the challenge of dying in nursing homes: the residents’ view’ (2007) 36 *Age and Ageing*, 197

The work conducted here was conducted between November 2001 and February 2003 and is based on interviews with 20 residents aged between 63 and 93 years old, 15 women and 5 men in six different nursing homes. Participants were selected to represent a range of age, gender, care needs and nursing

One study held in Holland has addressed the issue of dignity in care homes in the context of illness and its impact on dignity.¹⁵ In that country, elderly people with disabilities and on-going medical conditions are placed specifically in nursing homes rather than residential homes. This particular study was conducted in such nursing homes and therefore gave the specific viewpoints of the most frail and vulnerable elderly individuals in care, and the impact poor health had on their dignity. Following on from this study, the same researchers went on to conduct a longitudinal analysis of the changes in the personal dignity of the same residents, giving a particular insight into whether the notion of dignity evolved as time went on.¹⁶

Another research paper published their findings on the meaning of dignity in care homes in the UK following the interviews of all those involved in the care of elderly people, including home managers, care assistants, care home nurses, community nurses, care home residents and some of their family members.¹⁷ Once again, in this chapter I only report the responses obtained from the nursing home residents.

I have also included in the research material a study focused on the meaning of dignity for residents with dementia.¹⁸ A large majority of people in care homes suffer

homes were chosen for their varied organizational characteristics. Three further focus group discussions involving 30 participants were used to validate the original findings.

¹⁵ Oosterveld M.G., Vlug, H., Roeline, W. Pasman, van Gennip I.E., Muller M., Dick L. Onwuteaka-Philipsen W. and B.D. 'Dignity and the factors that influence it according to nursing home residents: a qualitative interview study' (2013) 70(1) *Journal of Advance Nursing* 97

This study relied on in-depth interviews conducted between May 2010 and June 2011 with 30 recently admitted residents recruited from four nursing homes in Holland. They were aged between 49 and 102 with a majority suffering from diminished bodily functions due to old age.

¹⁶ Oosterveld M.G., Vlug, H., Roeline, W. Pasman, van Gennip I.E., Muller M., Dick L. Onwuteaka-Philipsen W. and B.D. 'Changes in the Personal Dignity of Nursing Home Residents: A Longitudinal Qualitative Interview Study' (2013) 8(9) *Plos ONE*

Twenty-two participants from the study described under n10 were interviewed multiple times over a period ranging from May 2010 to December 2012 to find out how their perception of dignity changed over time post admission to a nursing home.

¹⁷ Hall S., Dodd R.H., Higginson I.J., 'Maintaining dignity for residents of care homes: A qualitative study of the views of care home staff, community nurses, residents and their families' (2014) 35(1) *Geriatric Nursing* 55

16 residents, 11 women and 5 men whose median age was 80.5 years old and living in one of 8 care homes in two areas of London were interviewed as part of this particular study.

¹⁸ Goodman C, Amador S., Elmore N., Machena I. and Mathie E., 'Preferences and priorities for ongoing and end of life care: A qualitative study of older people with dementia resident in care homes' (2013) 50 *International Journal of Nursing Studies* 1639

The findings used here are part of a larger 'four year longitudinal mixed method study entitled "Evidence Based Interventions for Dementia End-of-Life"' (at 1640). The data collected in this

from some form of the disease.¹⁹ Although the particular paper used here does not make a direct reference to dignity in its title, it explores the meaning of a worthwhile life for the residents with dementia, and so offers some information akin to that found in dignity-led discussions.

Finally, I have chosen to take into account a study exploring the opinions on dignity of older people from different ethnic backgrounds.²⁰ This particular study focused on the opinion of women, but as for most of the research work carried out in this field, women tend to be overrepresented because of their naturally longer lifespan.²¹

The questions ‘what does dignity means to you personally?’, ‘what would treating you with dignity involve?’, ‘can you describe an example of how you or anyone you know has been treated in a (un)dignified way?’, or ‘what do you think supports a resident’s sense of dignity?’,²² were the kind of questions most people were asked to answer as a starting point of the interviews conducted. Generally the people interviewed found it easier to give examples of threats to dignity than give a positive description of dignity. Despite this, it is also true that some were able to highlight those good practices in health and care practice that fostered their sense of dignity. However the answers were formulated, they were all interpreted and coded to fit a dignity-defining framework.

instance are based on the semi-structured interviews of 18 participants across 6 care homes (13 female and 5 male). Their median age was 84.7 years, ranging from 68.7 to 93 years old.

¹⁹ According to the Alzheimer’s Society website, ‘80 per cent of people living in care homes have a form of dementia or severe memory problems’ < <http://www.alzheimers.org.uk/statistics>> Accessed 17th December 2014

²⁰ Saltus R. and Pithara C., ‘A sense of dignity in later life: a qualitative study on the views of older women migrants from minoritised backgrounds’ (2014) 15(1) *Quality in Ageing* 22

For this research, 32 older women from Caribbean, Chinese, Bangladeshi and Indian origins living in Wales took part in semi-structured interviews in their mother tongue. This study asks about the interviewees’ perception of dignity in later life, care, and the meaning of dignity in care.

²¹ Office for National Statistics, ‘Life Expectancy at Birth and at age 65 by Local Areas in England and Wales: 2011 to 13’ <<http://www.ons.gov.uk/ons/rel/subnational-health4/life-expectancy-at-birth-and-at-age-65-by-local-areas-in-england-and-wales/2011-13/stb-life-expectancy-at-birth-2011-13.html#tab-National-life-expectancy>> Accessed 26th December 2014n‘Life expectancy at birth in England and Wales (combined) increased between the periods 2007–09 and 2011–13, from 78.1 to 79.3 years for males and 82.2 to 83.0 years for females. Life expectancy increased at a faster pace for males than females, causing the gap between the sexes to narrow from 4.1 years in 2007–09 to 3.7 years in 2011–13’.

²² Woolhead et al (n8), Bayer et al (n9) and Oosterveld-Vlug (n15)

The limitations of these studies must be acknowledged and some methodological clarifications made. Firstly, although some of the research used here was conducted in the United Kingdom, some relate findings submitted in other countries such as Germany, Holland, Sweden and others mentioned above. Following the pan-European work undertaken by the Dignity and Older European Consortium, I treat the findings of these different studies as commensurable, because of the similar socio-economic, religious and cultural backgrounds these countries broadly share, as well as their comparable attitudes and policies concerning ageing populations.²³

Secondly, all research except the one surveying older people in Wales,²⁴ purposely sampled their participants so as to give a more rounded answer to the questions asked. Some tried to select people with a variety of educational, social, and religious backgrounds as well as different level of fitness and age. In most cases researchers recognized that there was an inevitable female gender bias to their sample groups. It must also be appreciated that most participants were selected by the care home professionals in charge of their care because they were able to give informed consent and were judged by them to be mentally and physically able to contribute to the study at hand.

Thirdly, only one study used here purposely reported on the views of people with dementia and only one focused on the impact of the ethnicity of the participants on the notion of dignity. As the Social Care Institute for Excellence remarks, gaps in research still exist about the views of people suffering from dementia or other impairment limiting their ability to communicate; studies tend to underrepresent the viewpoint of men; and there is limited research on the opinions of some marginalised groups such as gay and lesbian older people.²⁵

The themes identified by Woolhead et al to classify their findings were chosen as my initial framework upon which to organise the data from all other research papers.²⁶ Woolhead's study is closely related to my area of enquiry and the themes she chose

²³ Tadd (n7), Woolhead et al (n8) and Bayer et al (n9)

²⁴ Morgan (n11)

²⁵ < <http://www.scie.org.uk/publications/guides/guide15/selectedresearch/gapsintheresearch.asp>>

Accessed 23rd December 2014

²⁶ Woolhead et al (n8)

are clear and simple: dignity of identity, human rights and autonomy.²⁷ With slight modifications, I found that Woolhead's themes were able to provide a useful analytical framework for discussing the findings of the other studies I discuss. Thus 'dignity of identity' became 'identity', and human rights evolved into 'humanity'. Autonomy remained the same as it stood out as an important and recurring theme in all studies.

2) Identity

a) Introduction

Identity here is understood as a sense of self. It is intimately related to define the perception of one's own emotional and physical being. It has transpired from reading these studies that the emotional fulfilment of a sense of self depended heavily on the interactions a person had. These could be those interactions they had with themselves, in the form of self-respect, but also those they experienced with others and which made up part of who they were. In the specific case of vulnerable elderly people, interactions with health and care professionals were regarded as essential to a sense of identity, as well as those with other groups in the wider society.²⁸ These particular relationships appear to fulfil the emotional self by defining the person's place in the world, giving them a certain weight and sense of worth. The quality of each of these relationships was described as having a real impact on a person's sense of dignity overall. An essential hallmark of that quality was found in the type of communication people in care had with their carers.

People interviewed also claimed participation was an important mean to sustain their identity. Being involved and having a voice were aspects of participation people referred to as important to feeling dignified. Some of the people interviewed also talked about their physical selves as an important part of their identity. Identity was indeed also perceived as intrinsically linked to the functionality of people's bodies, essential to their wellbeing. Coping with a less able ageing body was regarded in

²⁷ Ibid

²⁸ Woolhead et al (n8) 167

some studies as a threat to dignity. The loss of privacy, inescapable when the body fails to sustain autonomy, was cited time and again as undignified. These multiple challenges to identity were made all the more difficult by the emotional aftermath of loss many residents had lived through (including, but not limited to, their partner, friends, or home). The dimension of identity can be usefully broken down into a number of sub-themes.

b) Self-respect

Although self-respect was viewed as a quality people possessed within themselves, it was reported important to keep up with physical appearances and look after oneself well in order to maintain a sense of pride.²⁹ Some people thought that if you could no longer look after yourself, it was essential to be kept looking ‘respectable’ and that care staff should enable people to do so in order to keep hold of a sense of dignity.³⁰ It was considered undignified for people to be left clothed badly or dressed up by staff as if they were dolls.³¹ People who resisted help and stopped looking after themselves through either a lack of will or resources were thought to be less likely to be respected by others.³² External appearances connoted the status and state of mind of the person and for that reason were important to keep up with.³³

Mentally, the ability to react pragmatically to ageing and its negative societal image was considered by some to be a proof of dignity.³⁴ Being strong-minded was therefore one way of coping with the indignity ageing could bring, but how self-respect was sustained varied depending on the person asked. Some held that the actions of others were interlinked with their own sense of self-respect (i.e. the effect that had on the preservation of their privacy), whereas some said that their sense of pride was within them, intimate and unchangeable by others and for that reason managed to remain strong in the face of ageing and frailty.³⁵ Some took pride in the achievements they

²⁹ Hall et al (n17) 59

³⁰ Ibid

³¹ Ibid

³² Calnan et al (n10) 364

³³ Ibid

³⁴ Bayer et al (n9) 24

³⁵ Hall et al (n12) 414

had accumulated throughout their lives,³⁶ some found their self-respect rooted in their family,³⁷ whilst others maintained a strong sense of self by standing up for themselves and questioning the care practices they did not agree with.³⁸ People who had religious beliefs found that their faith enabled them to preserve their dignity.³⁹

Maintaining self-respect in the face of ageing and dependency was not always possible or easy. One resident who was ill felt that her sense of self had been completely and irrevocably altered by the physical and personality changes brought on by her condition.⁴⁰ Being unable to recognize oneself because of the changes ill health provoked was felt as a threat to identity and dignity.

Participants defined self-respect as an inner quality that made up the immutable core and strength of their being. Physical appearance could reflect it and so dictated that looking presentable mattered. It was also bolstered by remaining strong mentally, a feat many achieved by believing in themselves, their achievements, or their faith. This internal component part of people's identity was defined in the context of many external factors that also played a role in their overall perception of dignity.

c) Relationships

Relationships participants had with others around them were mentioned time and again in all studies as very much intertwined with how people perceived their own sense of identity. Pleschberger related the results of her study by separating dignity into an interpersonal and a relational concept.⁴¹ For her, 'dignity (was) socially constructed by the act of recognition and therefore require(d) recognition'.⁴² Whether with the people who cared for them, their family members, friends or the wider community, relationships had an important bearing on the dignity of people in care homes, as they gave them a sense of who they were.

³⁶ Oosterveld-Vlug et al (n15) 101

³⁷ Saltus and Pithara (n20) 28

³⁸ Ibid

³⁹ Ibid

⁴⁰ Ibid

⁴¹ Pleschberger (n14) 199

⁴² Ibid

The relationships of dependence people had with health and care workers were essential to their sense of dignity because they influenced many aspects of their daily lives. Firstly, they had an impact on the privacy of the participants, a component part of their dignity.⁴³ One resident explained that being shielded from others when being cared for or dressed was essential to her dignity.⁴⁴ For people who had experienced a hospital stay or a time when they needed care, respect for their privacy was vital. Mixed sex wards, the exposure of the naked body and the interference of others in the conducting of very intimate care were all portrayed as infringements of their privacy and sense of identity.⁴⁵ On the other hand, some people who lived in nursing homes seemed to have accepted the daily intrusions of others on their privacy, and only wished to be kept clean and presentable.⁴⁶ It appears that although these participants' sense of identity had been changed beyond recognition through the ageing process, remaining dignified was still made possible by their acceptance of that change, the acknowledgment that they needed help, and the adaptation of their expectations to their new condition.

Secondly, the relationships people had with care staff contributed to giving them a sense of worth, another element important to a sense of dignity. Someone related that being ignored by staff made them feel as if 'they were blockheads just because they were old', and that it made them feel like they were seen as a chore rather than an individual.⁴⁷ Some reported that care professionals who listened, took time to talk and fostered relationships based on mutual respect were key to their dignity.⁴⁸ In one survey mutual respect within relationship in general was prized as one of the most important element for dignity to flourish.⁴⁹ Others felt that staff members were often too busy, or not interested to have any meaningful relationships with them.⁵⁰ Some thought that they ought not to upset staff by complaining because they depended on them too much and so were vulnerable to possible retributions.⁵¹ It was also reported

⁴³ Hall et al (n17) 57

⁴⁴ Ibid

⁴⁵ Woolhead et al (n8) 167, Franklin et al (n13) 138, Oosterveld-Vlug et al (n15) 102

⁴⁶ Woolhead et al (n8) 168

⁴⁷ Franklin et al (n13) 139

⁴⁸ Calnan et al (n10) 368, Oosterveld-Vlug et al (n15) 102

⁴⁹ Morgan (n11)

⁵⁰ Franklin et al (n13) 139; Pleschberger (n14) 199; Goodman (n15) 1643

⁵¹ Woolhead (n4) 167

that the lack of resources meant a high turnover of temporary staff, which did not allow for the building of meaningful relationships.⁵² Time pressures carers were under to get the job done as quickly and efficiently as possible were experienced by those cared for as an affront to their dignity.⁵³ It was as if they were not individuals anymore, but an item on a list of jobs to complete. The more people needed help with every day tasks, the more they relied on care staff for their wellbeing and appreciated the care they received.⁵⁴ It can therefore be assumed from these findings that in the case of people in nursing homes, where daily life is defined and ruled by care staff, the quality of the relationships formed with them is all the more relevant to their sense of identity.

Relationships with family members and friends were also cited as essential to a sense of worth.⁵⁵ One participant, whose sense of dignity had worsened because of her loss of mobility and poor health since her admission in a nursing home, said that she only felt dignified when she received visitors, because ‘they at least knew who she was’.⁵⁶ The person interviewed felt that because of her illness and new circumstances, she could no longer be truly herself in her new surroundings. The fact that these visitors were few and far between because ‘they were not so many left’ meant that her sense of dignity was fragile and in jeopardy when the visits stopped.⁵⁷ Some felt that the place of older people within their own family unit was not as important as it should be, reflecting the general depreciation of the value older people held in society today, even in those ethnic communities where tradition used to dictate respect for the elderly.⁵⁸ Some people noticed that although they had had quite a few visits when they had first arrived at the care home, this tended to diminish as time went on.⁵⁹ One person commented that this kind of abandonment made them feel like they were ‘alive, but not really living anymore’.⁶⁰ A study remarked on how some residents were no longer visited by their family and hence relied on the interactions they had

⁵² Oosterveld-Vlug (n12) 103

⁵³ Ibid

⁵⁴ Goodman et al (n18) 1643

⁵⁵ Franklin et al (n13) 140; Oosterveld-Vlug et al (n16) 102

⁵⁶ Oosterveld-Vlug et al (n16) 4

⁵⁷ Ibid

⁵⁸ Bayer et al (n9) 24; Saltus and Pithara (n20) 28

⁵⁹ Oosterveld-Vlug et al (n16) 6

⁶⁰ Ibid

with their carers to fulfil their need of acknowledgement and exchange.⁶¹ Some older women from ethnic minorities associated dignity in later life with the status conferred to them in their family, one of particular importance that reflected their experience and ability to advise and counsel family members.⁶²

Relationships with other people from the nursing home were resented by some and interpreted as forced upon them, making it difficult to have some time alone.⁶³ Most of the people asked in one particular study where people suffered from ill health found that the presence of others was on the contrary reassuring, and that they took comfort in the knowledge that they could help each other out if needed.⁶⁴ One person interviewed a while after admission to a nursing home remarked that her dignity had been enhanced by her getting to know other residents.⁶⁵

Relationships interviewees had with other groups in society also influenced their sense of identity. People felt their dignity threatened when pejorative terms were used to describe them as a sub-group. Words such as ‘wrinklies’ or ‘bed blockers’ used to describe older people had a damaging effect on their overall sense of dignity. The negative feeling brought on by being seen as a group rather than an individual was also a threat to dignity found in other studies.⁶⁶ It exposed the direct impact of ageism on the sense of dignity older people had. Ageism is expressed in the grouping of older people, a group that is supposed to share the same defining characteristics.⁶⁷ This idea that a person is only seen as a part of a group rather than as an individual has insidious consequences. For instance, some older people felt that they should avoid complaining because they would be reinforcing the negative image society already had of them.⁶⁸ Some felt a lack of collective respect for older people transpired in today’s world.⁶⁹ Others felt that it was a shame to be viewed as a group with no use

⁶¹ Franklin et al (13) 139

⁶² Saltus and Pithara (n20) 27

⁶³ Oosterveld-Vlug et al (n15) 102

⁶⁴ Ibid

⁶⁵ Oosterveld-Vlug et al (n16) 4

⁶⁶ Mann J., ‘Dignity and Health: the UDHR’s Revolutionary First Article’ (1998) Vol. 3 (2) Fiftieth Anniversary of the Universal Declaration of Human Rights 30

⁶⁷ Calnan et al (n10) 365

⁶⁸ Calanan et al (n10) 368 For example, people did not complain to care staff that they did not like being called by their first names because they thought they would appear too ‘stuffy’.

⁶⁹ Saltus and Pithara (n20) 29

and that their experience and knowledge were too quickly dismissed by younger generations who could benefit from them.⁷⁰

On the positive side, one study showed that although people could feel the weight of negative stigma and stereotype prior to their admission in care, it seemed less relevant as time went by.⁷¹ In fact, the environment of the care home felt to some like a protective barrier between them and the outside world where people were ‘really quick to look down on you’.⁷² Those with disabilities liked the fact that they were amongst others similar to themselves and that their common understanding of how this was like was far preferable to the disrespectful look society sometimes had on them.⁷³

Relationships, whether with carers, friends, family members, care home residents, or the wider community were all extremely important in forming a person’s sense of identity. These interactions were essential to a sense of self and influenced greatly how the transition to life in a care home was experienced. How positively or negatively these relationships influenced people’s perception of themselves often was linked to the quality of the communication involved.

d) Communication

Communication with people around them affected some residents’ sense of identity, as it reinforced their sense of self through the possibility of verbal interaction and the expression of their personal preferences and desires. Communication was one of the main five issues raised as having a bearing on dignity in the survey carried out in North Wales.⁷⁴ One aspect of communication that was cited as undignifying was excessive familiarity and the automatic use of a person’s Christian name by health and care staff. Most people found that being addressed by patronizing terms such as

⁷⁰ Bayer et al (n9) 25; Saltus and Pithara (n20) 28

⁷¹ Oosterveld-Vlug et al (n16) 6

⁷² Ibid

⁷³ Ibid

⁷⁴ Morgan (n11)

‘dear’ or ‘love’ was also detrimental to their perception of identity.⁷⁵ Ten per cent of those surveyed in North Wales by the health board expressed a wish to see the casual way people were greeted changed to a more formal and respectful one.⁷⁶ Being addressed in the wrong manner was one example where communication had a negative bearing on a person’s identity and indicates that respect for people’s individuality, their status and background is very much linked to their identity.

The situation of being talked about but not talked to was reported by one interviewee as having the same adverse effect on her dignity.⁷⁷ Some relayed the same concern when they said they were ‘seen but not heard’, talked to as if children, or taken out of conversations altogether about their own care choices.⁷⁸ Being excluded from conversation on the assumption that old people are less able to understand what is said reinforces the generational divide and the idea that a person’s identity is compromised once they reach a certain stage in life.

The quality of the communication people in care homes had with those who cared for them was also mentioned as having consequences on their dignity.⁷⁹ Some people revealed that the silence of care staff during the course of their care made them feel invisible, which in turn impacted negatively on their sense of dignity.⁸⁰ In fact, one study exposed that the emotional unavailability of care staff was detrimental to the quality of every day life of the residents.⁸¹ Social exclusion and isolation in old age in general is well documented, and people in care homes, even though surrounded by other people, are not immune from it.⁸² People being cared for often avoided communicating their complaints against undignified care because they felt in a real position of vulnerability in the hands of the staff looking after them.⁸³ In order to sustain autonomy even when frailty set in, it was felt by some participants that the

⁷⁵ Woolhead et al (n8) 167

⁷⁶ Morgan (n11) 176

⁷⁷ Hall et al (n17) 59

⁷⁸ Franklin et al (n13) 139

⁷⁹ See also Woolhead G., Tadd W., Boix-Ferrer J. A., Krajcik S., Schmid-Pfahler S., Spjuth B., Stratton D. and Dieppe P., “‘Tu’ or ‘Vous’ ? A European qualitative study of dignity and communication with older people in health and social care settings’ (2006) 61 *Patient Education and Counseling* 363

⁸⁰ Calnan et al (n10) 368

⁸¹ Franklin et al (n13) 140

⁸² See the campaign ‘Help end loneliness’ on their website <<http://www.ageuk.org.uk/get-involved/loneliness/>> Accessed 01/12/2014

⁸³ Ibid

ability to ‘negotiate’ with professionals was primordial, so as to obtain the best treatment possible.⁸⁴ Ultimately people who were dependent on care wished they were asked what their wishes and preferences were, and valued being listened to by a kind ear.⁸⁵

More positively, some stated that health care staff who asked for permission before carrying out an examination demonstrated respect for their dignity.⁸⁶ On the contrary, communicating by adopting a superior tone, giving non-negotiable instructions or using disrespectful or hurtful language, was regarded as damaging to dignity.⁸⁷ Those who developed a relationship with their carers over time found that they were listened to more willingly, and hence were more able to influence their care.⁸⁸ The study focused on the views of residents with dementia showed that although a person with the disease may express herself in a seemingly confused way, her wishes could be understood if listened to carefully and patiently, and not dismissed as nonsense and symptomatic of the condition.⁸⁹

Communicating with others formed an important part of how some participants saw themselves. People’s sense of identity was affected by how they were spoken to, by whether they felt included in conversations generally, and by the opportunity they had to have a say in the direction of their own lives. As well as relationships and communication, taking part in activities and having a sense of purpose also mattered to some participants and had consequences for their sense of dignity.

e) Participation

Participation appeared on multiple occasions as an area essential to the fulfilment of a person’s sense of self. It is closely linked to communication and the idea that inclusion is intrinsic to a sense of self. Taking part in activities made some people feel worthwhile and was regarded as enhancing their dignity by providing them with an

⁸⁴ Franklin et al (n13) 139

⁸⁵ Bayer et al (n9) 27

⁸⁶ Calnan et al (n10) 368

⁸⁷ Oosterveld-Vlug et al (n15) 102, Hall et al (n17) 58

⁸⁸ Oosterveld-Vlug et al (n16) 5

⁸⁹ Goodman et al (n18) 1643

opportunity to interact with others and contribute to something.⁹⁰ After feeling isolated and homesick upon admission to a nursing home, one resident claimed that taking part in the various organised activities in place there made her life far more enjoyable, and allowed her to build a social circle within her new environment.⁹¹ A sense of purpose was also found through helping others,⁹² although the lack of physical ability to do so was problematic to some.⁹³

Participation could also be defined in a less practical sense, but rather as the feeling of being a part of something bigger than oneself. For instance, some people seemed to take strength from a 'sense of coherence' given to them by the place they still occupied within their family unit.⁹⁴ Being surrounded by photographs and memorabilia consolidated this sense of worth through belonging.⁹⁵

Some people interviewed felt that they still would have liked to participate in the wider society, that their life experience and accumulated skills could be put to good use in educating younger generations or serving their community.⁹⁶ Some felt that unfortunately retirement usually meant the beginning of exclusion from participation in society.⁹⁷ Dignity was also promoted when people felt they were being asked their opinion about policies and issues that concerned them directly.⁹⁸ Older women from different ethnic origins felt that their participation resided in the transferring of their culture through the generations.⁹⁹

Throughout these studies, participation was linked to a sense of worth and purpose in life, on whatever scale, and seemed paramount to a sense of identity and ultimately dignity. Permeating all these criteria that fostered dignity, the physical changes people were faced with meant new challenges to their identity too.

⁹⁰ Franklin et al (n13) 140

⁹¹ Oosterveld-Vlug et al (n16) 4

⁹² Franklin et al (n13) 140

⁹³ Goodman et al (n18) 1644

⁹⁴ Franklin et al (n13) 140

⁹⁵ Ibid

⁹⁶ Calnan et al (n10) 365; Bayer et al (n9) 25

⁹⁷ Bayer et al (n9) 25

⁹⁸ Ibid

⁹⁹ Saltus and Pithara (n20) 27

f) Physical Changes

Physical changes resulting from ageing also played a part in the sense of identity elderly people interviewed had about themselves. The ‘unrecognisable body’ emerged as a theme in the study conducted by Franklin et al and included the feelings of being let down by one’s body through the inability to perform basic functions once taken for granted.¹⁰⁰ Although people did not feel that their dignity was jeopardized directly by their failing bodies, a phenomenon they recognised as the natural process of ageing,¹⁰¹ it was the shift in their identity resulting from their increasing dependence on others that was strongly felt as a threat to dignity. Indeed, People resented their bodies for not allowing them to fulfil their basic needs.¹⁰² Physical deterioration meant the loss of privacy because of the need for others to interfere in daily personal care, and this forced exposure of the body to the eyes of others was felt as shameful and undignified.¹⁰³ Incontinence was mentioned as a real problem, bringing shame and embarrassment to many, and so the need to be kept clean was cited as essential for dignity.¹⁰⁴ A study reported that especially for women, the wish to keep looking ‘well groomed’ was important for oneself but also for the image one gave to others.¹⁰⁵

The repercussions of an outwardly frail body were extensive. It was mentioned that the loss of bodily functions often led to people being ignored in conversations, as if it conveyed to others that they were also mentally impaired and could no longer understand what was being said to them.¹⁰⁶ More generally some felt that the outward signs of ageing bred disrespect from younger generations and so threatened dignity by once again demarcating older individuals physically as a different group.¹⁰⁷

Conversely, an interesting point worth noting is that older people in care homes did not view old age as an illness.¹⁰⁸ In a study aimed at evaluating whether the dignity

¹⁰⁰ Franklin et al (n13) 138

¹⁰¹ Oosterveld-Vlug et al (n15) 101

¹⁰² Ibid

¹⁰³ Woolhead et al (n8) 167

¹⁰⁴ Ibid

¹⁰⁵ Oosterveld-Vlug et al (n15) 103

¹⁰⁶ Ibid

¹⁰⁷ Woolhead et al (n8) 167

¹⁰⁸ Hall et al (n12) 414

model compiled by Chochinov for terminally ill cancer patients could be adapted to elderly people in nursing homes, it was found that the latter viewed their decreasing abilities and deteriorating health as a natural part of the ageing process.¹⁰⁹ It was reported that the effective management of health related concerns such as ‘pain, breathlessness, loss of appetite, vomiting, digestive problems and sensory losses’ was actually a source of hopefulness to the older individuals.¹¹⁰ Contrary to terminally ill patients, none of the elderly healthy people interviewed in this particular study ever felt that death was the only outcome to their physical suffering.¹¹¹

On the contrary, another study focused on the opinions of people in nursing homes who were ill found that physical suffering made their lives meaningless and that they hoped to die soon.¹¹² This is an important point because it shows that although dignity is not synonymous to good health, the sense of dignity is strengthened by it. The medical control of symptoms helped people aspire to a better every day and improved their sense of dignity,¹¹³ but it was never considered the only role nursing homes should play in a dignity-centred caring ethos. Some have questioned the over medicalization of later life.¹¹⁴ Being kept alive at all cost has been pitted against the optimization of quality of life, where effective symptoms and pain management at the end of life are favoured to allow the person to continue living life to the fullest of their abilities.¹¹⁵ Some residents were indeed of the opinion that quality of life was essential and that when it was ‘time to go’ there was no need to sustain life at all costs.¹¹⁶ Most people defined a dignified death as one that was pain free, and agreed with the possibility of leaving a living will to prevent the unnecessary and artificial maintenance of life.¹¹⁷ These discussions are important because the median period between admission to the care home and death is only fifteen months,¹¹⁸ a fact some have taken into account by recommending that the type of care offered to home

¹⁰⁹ Chochinov H.M., Hack T., McClement S., Kristjanson L. and Harlos M., ‘Dignity in the terminally ill: a developing empirical model’ (2002) 54 *Social Science & Medicine* 433

¹¹⁰ Hall et al (n12) 413

¹¹¹ Ibid

¹¹² Oosterveld-Vlug et al (n15) 101

¹¹³ Oosterveld-Vlug et al (n16) 4

¹¹⁴ Gawande A., *Being Mortal: Illness, Medicine and What Matters in the End* (Profile Books Ltd, 2014)

¹¹⁵ Ibid

¹¹⁶ Calnan et al (n10) 370

¹¹⁷ Wollhead et al (n8) 167

¹¹⁸ Forder J. and Fernandez J-L., ‘Length of Stay in care homes’ (2011) PSSRU Discussion Papers, London School of Economics and Political Science

residents should be included within the realm of dignity issues encountered in palliative care practices.¹¹⁹

The loss of functions an ageing body brought about resulted in a different sense of identity, one where others had to be included in everyday tasks. This shift meant a compulsory interference by others into the realm of privacy and the difficult acceptance of the loss of independence. This failing body often meant the need for pain management, an essential aspect to dignity for some people felt was paramount especially when close to dying. This loss of physical dexterity and aptitude was part of a larger theme of loss.

g) Loss

Loss in more general terms was another aspect of people's lives that affected their sense of identity and therefore their sense of dignity. It is a sub-theme more difficult to fit in any particular category, but the interviews showed that loss affected a person's perception of who they were and redefined the world they lived in, so I have included it here as part of the dimension of 'Identity'. As well as the experience of physical pain experienced because of the natural decline of the body, a study revealed that older people in care homes also suffered the emotional pain of loss.¹²⁰ The fact that they had lived through the loss of people they had been close to all their life caused them a great deal of distress. The combined losses of familiar surroundings and personal belongings were hard to overcome, although some found their sense of dignity improve over time once they had familiarised themselves with their new environment and way of life.¹²¹

The repercussions of loss were therefore a subject to be addressed in a dignity-centred model of care.¹²² The new physical environment of the nursing home was perceived as a necessity because the residents were aware that they needed care, but it was

¹¹⁹ See Pleschberger (n14) for such an example

¹²⁰ Hall et al (n12) 414, Goodman et al (n18) 1644

¹²¹ Oosterveld-Vlug et al (n16) 5

¹²² Ibid

rarely described as a new home per se.¹²³ Although some wished they had not had to leave their home, others were thankful that care homes existed at all to fulfil their needs, and thought that to be left to cope alone at home was undignified.¹²⁴

The loss of what had been before, the people and the places that once mattered, was portrayed by some as traumatic. This sense of loss generally accompanied them into their new life chapter, in a different place, surrounded by different people. Loss must therefore be acknowledged as one of the significant factors shaping the dignity of elderly people in care.

In sum, identity has been defined as those elements that make up a person sense of self. The challenges brought on by the increasing reliance on others, the deterioration of the ageing body and the loss of a life once familiar, all contribute to a shift in identity. Furthermore, a person's identity must be placed in context. As the next theme will expose, it is how people are able to express that identity that matters, the choices they make for themselves and their place in the world that also make up their dignity.

3) Self-determination

a) Introduction

Self-determination, (often also referred to in studies as autonomy) is a strong theme emerging from all studies. For most of the participants, autonomy was a significant aspect of their dignity and was to be kept for as long as possible. One interviewee described a 'good death' as one where one could be 'active to the very last', illustrating the importance attached to autonomy and the ability to carry on without the help of others.¹²⁵ Although most people interviewed were pragmatic about their evolving situation, it did not mean that they did not worry about the loss of basic functions such as 'being unable to walk, go out alone, take medication, bath, dress, eat

¹²³ Franklin et al (n13) 138; Goodman et al (n18) 1643

¹²⁴ Oosterveld-Vlug et al (n15) 101; Oosterveld-Vlug et al (n16) 4

¹²⁵ Peschberger (n14) 200

and enjoy hobbies'.¹²⁶ One interviewee reported that she would rather die than becoming more and more dependent now that she had to be helped with washing and using a commode.¹²⁷ One study reported that nine out of fifteen respondents (or 60%) viewed independence, autonomy and choice as the most important aspects of dignity.¹²⁸ Interestingly, district nurses explained that they thought that 'providing comfort and care' were the most relevant elements they could provide for dignity to flourish, and that residents' choices were always vetoed according to what care staff thought were the safer choices or those better for their health.¹²⁹ This discrepancy of opinions about the meaning of dignity between cared for and carers suggests a real risk that the choices of the people cared for are not always duly considered by those who care for them.

b) Independence

Independence, the ability to remain 'free from outside control',¹³⁰ was very much seen as essential to dignity. Twenty seven per cent of all responses sent back to the health board in the 'Dignity in care survey in North Wales' were concerned with keeping independence.¹³¹ People felt that initiatives to promote independent living were good (as in day centres and help at home), but they regarded the need for help due to ageing as a threat to their independence and hence dignity.¹³² Some felt that family members and healthcare staff often over-protected them and were therefore a hindrance to the maintenance of their independence.¹³³

The fear of losing one's independence was aggravated by the idea that one could become a burden to others, physically or financially.¹³⁴ Some residents from a nursing home mentioned that they were reticent to ask for assistance from the nurses because

¹²⁶ Hall et al (n12) 413

¹²⁷ Ibid

¹²⁸ Hall et al (n17) 57

¹²⁹ Ibid

¹³⁰ Oxford Dictionary <<http://www.oxforddictionaries.com/definition/english/independent>> Accessed 8th January 2015

¹³¹ Morgan (n11) 176

¹³² Bayer et al (n9) 26

¹³³ Calnan et al (n10) 369

¹³⁴ Calnan et al (n10) 369; Pleschberger (n14) 199; Oosterveld-Vlug et al (n15) 103

they felt they were a burden to them.¹³⁵ Many of the people interviewed had once been expected to look after their own parents, and they were keen not to be a charge to their own children.¹³⁶

The loss of freedom of movement was a threat to dignity. Some participants whose health had deteriorated so much that they were physically bound to their bed or a wheelchair expressed that their sense of dignity was much lower than before their dependent state, with some even wishing their lives were over.¹³⁷ The availability of care, in those instances of physical disability, was key to the residents' ability to sustain their independence and feel more dignified.¹³⁸ For example, having to wait for staff when called for help was often mentioned as undignified, especially when one needed to go to the toilet and risked not making it in time because of the delay.¹³⁹

The ability to remain physically but also mentally independent was very much associated with keeping one's dignity intact. This was particularly highlighted when people interviewed expressed their concern about being affected by dementia. Many considered that the illness rendered people so dependent that it stripped them of their dignity.¹⁴⁰ One person asked whether dignity could still exist despite such a disease answered that it was possible if you were kept clean, talked with and not 'left alone so much'.¹⁴¹ It transpires that even when all independence is lost, the contribution of carers and human contact is invaluable for dignity to flourish.

Independence appeared to be one characteristic people were very keen to keep for as long as possible, physically and mentally. Many regarded their need to rely on others or the extinction of their aptitude to think for themselves as a threat to their very reason to live, only mitigated by good quality of care. Holding on to independence often meant keeping control, helped or hindered by others.

¹³⁵ Oosterveld-Vlug et al (n15) 102

¹³⁶ Ibid

¹³⁷ Oosterveld-Vlug et al (n16) 4

¹³⁸ Hall et al (n17) 58

¹³⁹ Oosterveld-Vlug et al (n16) 5

¹⁴⁰ Bayer et al (n9) 26

¹⁴¹ Pleschberger (n14) 200

c) Control

Control over one's body and mind was seen as essential to dignity.¹⁴² Many compared losing control over their body to reverting back to infancy, and found accepting this new condition difficult.¹⁴³ One resident reported feeling embarrassed because of her loss of bladder control but described how the reassuring attitude of staff was helpful in maintaining her dignity, dealing with the incidents as if they were nothing to be worried about.¹⁴⁴ In another study the notion of privacy was again linked to that of control, in the sense that people were still keen to make their own choices within their personal space.¹⁴⁵ Although the nursing home did not belong to the residents who lived there, it was considered good practice by staff to knock on their bedroom door, a sign that they were entering their home, a private space they still had some control over.¹⁴⁶ Control over one's movements was also deemed important for a sense of dignity to prevail. One resident found that being in a wheelchair made her feel 'worthless' because she had had to relinquish all control over her daily life to others.¹⁴⁷

Control over one's treatment or care was also mentioned as consequential to a sense of dignity.¹⁴⁸ Generally, people interviewed felt that having a set routine imposed on oneself in care homes was synonymous with the curtailment of freedom and the loss of control.¹⁴⁹ Having to go to the toilets at certain times only was an example given of such set practice that threatened a person's dignity.¹⁵⁰ In contrast with those who anticipated dependency as a degradation of dignity, those who were able to adjust to circumstances beyond their control seemed better able to preserve their identity.¹⁵¹

In essence, the restriction of people's control over their actions, their privacy, their movements, or the type of care they preferred was deemed an infringement of their

¹⁴² Franklin et al (n13) 138

¹⁴³ Ibid

¹⁴⁴ Oosterveld-Vlug et al (n16) 4

¹⁴⁵ Hall et al (n17) 57

¹⁴⁶ Ibid

¹⁴⁷ Ibid

¹⁴⁸ Bayer et al (n9) 26

¹⁴⁹ Woolhead et al (n8) 168

¹⁵⁰ Bayer et al (n9) 27

¹⁵¹ Woolhead et al (n8) 168

dignity. Many wished they still had control over certain aspects of their lives that ageing had deprived them of. The capacity for self-control is intertwined with freedom of choice.

d) Freedom of choice

Freedom of choice also appeared an important sub-category of autonomy. Some people interviewed resented that choice was limited in the daily life of care homes, with a regimented routine replacing the freedom once enjoyed at home.¹⁵² Even some of the participants with dementia desired to express their preferences for future care or the kind of activity they would enjoy, despite knowing that their condition meant a loss of memory.¹⁵³ One resident commented that although she understood why limits were put on her whereabouts, she still thought it unreasonable to forbid her a walk in the grounds.¹⁵⁴ One participant saw her dignity bolstered by the freedom of choice an electric wheelchair gave her, allowing her independent movement.¹⁵⁵ Despite their loss of mental capacity and their physical frailty, people still wished they could be the ones making some choices in their daily lives.

Others mentioned that freedom of choice about their care was removed from them and that professionals imposed their own choice as an alternative.¹⁵⁶ This theme was also found under the previous findings about identity and the importance older people attached to being listened to and participate in decisions about their life choices. In some discussions freedom of choice was balanced against the need for intervention when a person could no longer look after herself. People found dignity in the ability to make choices about one's life course when faced with the consequences of ageing. Whether people chose to cope alone despite the disapproval of society, or chose to accept help gracefully, participants felt that people's life choices ought to be respected.¹⁵⁷

¹⁵² Oosterveld-Vlug et al (n15) 101

¹⁵³ Goodman et al (n18) 1643

¹⁵⁴ Ibid

¹⁵⁵ Oosterveld-Vlug et al (n16) 4

¹⁵⁶ Woolhead et al (n8) 168

¹⁵⁷ Calnan et al (n10) 371

Freedom of choice was also mentioned in the context of discussions about the inadequacy of resources spent for the elderly such as pensions, and the level of poverty older people suffered from. Without a sufficient level of income, it was thought that freedom of choice was reduced, which in turn affected one's self image and sense of dignity.¹⁵⁸

Finally, freedom of choice was found to be an important ingredient of what some people referred to as a 'good death'.¹⁵⁹ The ability to choose freely how to live one's life but also how to die was very much in the mind of some of the people who took part in the research.¹⁶⁰ Some considered the artificial prolongation of life to be against their sense of dignity and valued instead the freedom to choose to be 'allowed to die'.¹⁶¹

The capacity to choose for oneself loomed large in the list of criteria essential for dignity. In life or in death, most participants wished they were left some freedom to decide for themselves, even in the confines of institutional livings and even when in the throes of illness. They also wished they were given the means to do so. It has been shown that autonomy has many interrelated facets. Its loss was difficult for many and perceived as an affront to dignity, but could be mitigated by accepting its inevitability.

e) Acceptance

Acceptance of one's inability to be as autonomous as was previously possible often coincided with a better and more dignified life for some nursing homes residents.¹⁶² Those who fought the inevitable changes brought on by ageing by refusing help were regarded by others as behaving in an undignified manner.¹⁶³ The acceptance of the more regimented style of living offered by some institutions seemed to many respondents essential to maintaining some dignity. It appears that the strict routine of daily life imposed by institutional living stopped being perceived as an affront to

¹⁵⁸ Bayer et al (n9) 24-25

¹⁵⁹ Pleschberger (n14) 200

¹⁶⁰ Woolhead (n8) 168

¹⁶¹ Woolhead (n8) 168; Pleschberger (n14) 200

¹⁶² Oosterveld-Vlug et al (n15) 101

¹⁶³ Woolhead et al (n8) 168

dignity when it was accepted out of free will as an inevitable consequence of a loss of autonomy.¹⁶⁴

Adjustment to this new life was not always immediate and straightforward. A study has shown that people needed time to get used to their new routine and that accepting it was not always immediate.¹⁶⁵ Overall, acceptance and the ability to adapt to change seemed to be a key attribute one should possess in order to maintain dignity in the face of the loss of autonomy. A study has indeed related that despite the narrowing of possibilities people may encounter because of ageing, those who possessed ‘inner strength’ could find meaning in every day life through their family, their memories or their appreciation of the moment, and for that reason seemed better able to hold on to a sense of dignity.¹⁶⁶ People who could put their situation in perspective and focus on their abilities, rather than their inabilities, seemed also more able to accept their new living arrangements.¹⁶⁷ Even though some thought that dignity could not possibly prevail once one became ‘demented’, others viewed their loss of cognitive ability as an unavoidable consequence of old age, had made peace with it, and were therefore better equipped to hold on to their dignity.¹⁶⁸ No study has yet revealed whether acceptance was an internal quality people already possessed as a personality trait, or because of the values they held dear, or whether acceptance could be reached through external interventions such as medical help, better care practices or other features of care home living.¹⁶⁹

The theme of autonomy appeared significantly in many studies. Being relatively free to decide on the path of one’s life is something most of us will have had the privilege to enjoy. Unsurprisingly, the sudden interference of others with our free will and personal choices because of old age translates into a threat to our dignity. The next theme is less straightforward than autonomy, but is certainly a dimension of dignity that many mentioned when they tried to define its meaning.

¹⁶⁴ Ibid

¹⁶⁵ Oosterveld-Vlug et al (n16) 5

¹⁶⁶ Franklin et al (n13) 140

¹⁶⁷ Oosterveld-Vlug et al (n16) 5

¹⁶⁸ Oosterveld-Vlug et al (n15) 101-102

¹⁶⁹ Oosterveld-Vlug et al (n16) 5

4) Humanity

a) Introduction

Most studies have reported on the comments of people who recognised that their dignity was an internal quality that was theirs for the sole reason that they were human beings. I have devised the theme of humanity to include the themes of ‘human worth, human rights and equality’.¹⁷⁰ It is difficult to describe humanity thus understood succinctly, but it includes these particular traits that make a person human and differentiate that person from other living organisms. Respondents referred to their human condition alone as reason enough for dignified care. Equality of treatment was also spoken about under various guises, but surprisingly, human rights, understood as legal tools to protect from undignified treatment, were only mentioned in the study conducted in the UK by Woolhead et al.¹⁷¹

b) Intrinsic worth

Intrinsic worth in this context can be compared to the Kantian’s concept of inherent dignity, the notion that all humans must be treated as an end in themselves, and that human dignity cannot be extinguished.¹⁷² Some people interviewed felt they deserved to be ‘treated as individuals’ on the sole basis of their human nature and inherent human dignity.¹⁷³ Sentences such as ‘every human being has dignity’ or everyone should be treated as an individual’ reflects this sense of intrinsic human dignity some of the people interviewed felt they possessed.¹⁷⁴ A study revealed that being treated as a human, and not a ‘job to be done’, was an intrinsic part of dignity.¹⁷⁵

Being treated as a human being meant that there should be no difference of treatment between an older person and other people, hence the importance of equality as part of dignity.

¹⁷⁰ Woolhead et al (n8) 167-168

¹⁷¹ Woolhead et al (n8) and Calnan et al (n10)

¹⁷² Kant I., *Groundwork of the Metaphysics of Morals* (trans. Mary J. Gregor) *Practical Philosophy* (Cambridge University Press, 1997)

¹⁷³ Woolhead et al (n8) 167

¹⁷⁴ Ibid

¹⁷⁵ Hall et al (n17) 58

c) Equality

Equality of treatment and the idea that all people deserved dignity were felt strongly by participants. Someone commented that older people were in a position of inferiority when they were in hospital because they were in a far more vulnerable state than the knowledgeable, younger and stronger staff in charge of their care.¹⁷⁶ Some related that they felt that they were excluded from society and that once you were old 'you no longer counted', reflecting this idea that older people are less important than the young.¹⁷⁷

Inequality was also felt in a financial way. The lack of resources allocated through public funding and pension provisions for older people were branded woefully inadequate and unable to meet care needs, creating societal inequality but also personal suffering.¹⁷⁸ It has been reported that a total of 13% of pensioners or 1.6 million people live in poverty, with incomes of less than £224 a week after housing costs.¹⁷⁹ Out of this total 900,000 are considered to be in a state of material deprivation.¹⁸⁰ Lower standards of living mean less choice in the care provided. Whereas the cost of private care remains prohibitively expensive,¹⁸¹ locally funded care has been described as too task oriented and of inadequately short duration due to

¹⁷⁶ Woolhead et al (n8) 168

¹⁷⁷ Oosterveld-Vlug et al (n15) 103

¹⁷⁸ Woolhead et al (n8) 168

¹⁷⁹ Department for Work and Pensions, 'Households Below Average Income'. An Analysis of the income distribution 1994/95-2012/13' (July 2014), Chapter 6
<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/325416/households-below-average-income-1994-1995-2012-2013.pdf> Accessed 20th December 2014

¹⁸⁰ Ibid. Those considered in material deprivation score over 20 on a series of 15 questions, each weighting a certain amount of points cumulating to a total of 100. These questions can be found in Department for Work and Pension 'Households Below Average Income (HBAI) Quality and Methodology- Information Report- 21012/21013' (July 2014), 17
<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/325492/households-below-average-income-quality-methodology-2012-2013.pdf> Accessed 22nd December 2014
People are questioned on varied subjects such as their ability to have 'at least one filling meal a day' or 'replace the cooker if broken down' or 'have their hair cut regularly'.

¹⁸¹ According to Laing and Buisson, a specialist healthcare market research consultancy 'average care home fees across the UK for the financial year 2013/2014 are £728 per week for nursing care and £550 per week for residential care (figures combine for profit, voluntary and public sector beds)'.
<<http://www.laingbuisson.co.uk/MediaCentre/PressReleases/CareofOlderPeople26thedition.aspx>>
Accessed 22nd December 2014

restricted budgets and staff shortages.¹⁸² The low level of state pensions also translates into the poorer segment of the population being portrayed as a burden on public resources.¹⁸³ This state of affairs reinforces the stereotype that the elderly constitutes an inferior class of citizens.¹⁸⁴ The income gap between those who earn and those who do not made some older people feel that they were second class citizens whose opinions were not valued.¹⁸⁵ Similarly some felt that their needs for medical treatment were not viewed as essential and urgent as those of other patients, and that they were treated unequally in the provision of healthcare.¹⁸⁶

Some older people felt that societal perceptions tended to readily assimilate them into a group whose status was perceived as inferior to others. This inequality was confirmed to some by how they were treated by others, especially in the health care sector. Although people mentioned equality, they did not extend its reach to that of a right to non-discrimination. In fact, human rights figured little in the discussions people had about dignity.

d) Human rights

Human rights were not mentioned directly by those interviewed as a mode of defence against undignified treatment. They were mentioned as ‘the right to choose how they

¹⁸² See the UKHCA (UK Home Care Association) Commissioning Survey 2012, ‘Care is not a commodity’ July 2012 <<http://www.ukhca.co.uk/pdfs/UKHCACommissioningSurvey2012.pdf>> Accessed 28th December 2014

¹⁸³ The current maximum rate of state pension is £113.10 per week.

<<https://www.gov.uk/state-pension/overview>> Accessed 22nd December 2014

According to AgeUK, 1 in 6 pensioners in the UK live in poverty, defined as 60% and below of median income after housing costs.

<<http://www.ageuk.org.uk/money-matters/income-and-tax/living-on-a-low-income-in-later-life/>> Accessed 22nd December 2014

¹⁸⁴ The old age dependency ratio, which ‘gives the number of people of State Pension Age (SPA) and over for every 1000 people of working age (between 16 and SPA). Without the changes to SPA, making all working people work longer, the ratio would have increased from 300, a stable number between the mid-70s and 2006, to 310 in 2008, 376 by 2021 and 495 by 2051. With the changes planned for SPA, the projected ratio only reaches 343 by 2051. This is only possible due to longer working lives. Office for National Statistics, ‘Pension Trends. Chapter 2: Population change’ (9th April 2010), 2-3

<www.ons.gov.uk/ons/rel/...2.../chapter-2--population-change-.pdf> Accessed 22nd December 2014

¹⁸⁵ Bayer et al (n9) 25

¹⁸⁶ Ibid 26

lived'.¹⁸⁷ The word 'right' was also brought up in conversation in the context of the right to live or die according to one's wishes, or the right to be treated equally. These correspond to the human rights to freedom/private life and the right to non-discrimination, but they were not referred to as human rights. Other studies into older people and their perception of human rights have tended to bolster these findings.¹⁸⁸ Human rights were recognized as other people's concerns in war torn countries and did not concern them directly. It remains to be seen whether this attitude will evolve. Those who have lived all of their adult lives in a society imbued by a human rights discourse might be more eager and able to invoke them in later life should their treatment in care homes affect their dignity. Although it could have been expected that a dialogue focused on the meaning of dignity would lead to conversations about human rights, these did not feature prominently at all. The participants' education, culture and age could explain this absence.

As I mentioned in the introduction of this chapter, it must be noted here that although dignity defined from the perspective of the person cared for is rare in policy and governmental research papers on this topic, it is not an entirely novel idea. Defining dignity from the perspective of the individual cared and those involved in that care was at the heart of a report published by the Social Care Institute for Excellence in 2009 about dignity in care.¹⁸⁹ There, the concept of dignity was gathered from the perspectives of care providers, representatives of care users, carers and individuals cared for.¹⁹⁰ Dignity was defined as a set of expectations that individuals in care ought to have with regard to the services they received. In order to respect dignity, services were to

1. Have a zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family
3. Treat each person as an individual by offering a personalised service

¹⁸⁷ Woolhead et al (n8) 168

¹⁸⁸ 'Rights for Real: Older People, Human Rights and the CEHR' (May 2006), 63
<<http://www.edf.org.uk/news/0406%20Rights%20for%20Real%20Report.pdf>> Accessed 01/12/2014

¹⁸⁹ Social Care Institute for Excellence (n5)

¹⁹⁰ Ibid 9

4. Enable people to maintain the maximum possible level of independence, choice and control
5. Listen and support people to express their needs and wants
6. Respect people's right to privacy
7. Ensure people feel able to complain without fear of retribution
8. Engage with family members and carers as care partners
9. Assist people to maintain confidence and a positive self-esteem
10. Act to alleviate people's loneliness and isolation.¹⁹¹

The report then examines each of these areas individually, giving examples of best practice from various Primary Care Trusts. Although this conception of dignity is the result of a larger variety of individuals' opinions in a broader spectrum of care settings, it is comparable to that used in this dissertation reached focused on the responses of older individuals. This definition of dignity is also interesting in two respects. The first one is that it stems from a similarly subjective approach to the conceptualisation of dignity as that adopted in this dissertation, and the second is that it intimates that dignity requires positive action when individuals are in a vulnerable state. In the area of care dignity ought to be understood from the perspective of the person cared for, and that certain conditions need to be present for dignity so defined to flourish.

5) Conditions for dignity based on concrete autonomy

a) Setting capabilities for dignity in care

In this section, I will argue for the use of the capability theory of rights as a framework upon which to hang this discursive ethical approach to dignity, as understood and applied in the contemporary world. As I have written above, human rights do acknowledge our embodiment and finite nature, and the need we have for certain minimum conditions to exist in order for life to be worth living. I have also elaborated on the complex, relational and personal concept of autonomy, and that has led me to conclude that dignity is best understood through a discursive approach. Nussbaum writes that 'the basic idea (behind the capabilities approach) is that some

¹⁹¹ Ibid 10

living conditions deliver to people a life that is worthy of the human dignity that they possess, and others do not. In the latter circumstances, they retain dignity, but it is like a promissory note whose claims have not been met'.¹⁹² Whether or not the conditions necessary for this promissory note of dignity to be delivered for elderly people in institutional care settings are met depends heavily, amongst other things, on the meaning of dignity that is adopted by care policies and legislation. I will argue here that understanding elderly individuals' own idea of what dignity means to them would enable policy and lawmakers to fashion laws and policies conducive to those conditions needed for dignity in long term care institutions.

In order to create the conditions necessary for dignity in this context, the language of human rights as traditionally framed appears too limiting. In fact, traditional conceptions of human rights fail to address the very fact that dignity is personal and contextual, and that conditions needed for its realisation are very much environment and person dependent. They are claims to certain capabilities, but they fail to engage on a deeper level as to whether an individual can ever possess that capability. Nussbaum believes that the capabilities approach 'is a good idea because we then understand that what is involved in securing a right to people is usually a lot more than simply putting it down on paper'.¹⁹³ The language of capabilities 'gives us a benchmark in thinking about what it is really to secure a right to someone'.¹⁹⁴

Arguably, the particularisation of human rights under international instruments such as for instance the Convention on the Elimination of All Discrimination Against Women (CEDAW), the Convention on the Rights of the Child (CRC), the Convention on the International Convention on the Elimination of all forms of Racial Discrimination (ICERD), or the Convention on the Rights of Persons with Disabilities (CRPD), all show that it is necessary to go beyond the universal character of rights and acknowledge that for some groups, the conditions necessary to their dignity need added protection. Some have made a case for the implementation of a convention for the rights and dignity of older people.¹⁹⁵ If we want rights to give rise to conditions

¹⁹² Nussbaum M. *Creating Capabilities* (Harvard University Press, 2011) 30

¹⁹³ Nussbaum M., 'Capabilities and Human Rights' (1997) 66(2) *Fordham Law Review* 293

¹⁹⁴ *Ibid* 294

¹⁹⁵ General Assembly, Seventieth Session, Agenda item 72(b), 'Measures to enhance the Promotion and Protection of the Human Rights and Dignity of Older Persons' (18th November 2015)

amenable to dignity to flourish, then we must take into account the wide variety of individuals they concern, and so tailor rights to their particular situations. The capability theory can be viewed as a phenomenological approach to rights that is especially concerned with particular cases and the nature of the self in relation to its social situation.

Robeyns defines the capability approach as ‘a broad normative framework for the evaluation and assessment of individual well-being and social arrangements, the design of policies, and the proposals about social changes in society’.¹⁹⁶ As its founding theorists, the philosopher-economist Amartya Sen,¹⁹⁷ and the philosopher Martha Nussbaum,¹⁹⁸ have written extensively about the capability approach albeit according to different perspectives. Whereas Sen has used the capability approach in an economic context to address a human development agenda,¹⁹⁹ Nussbaum has concentrated her efforts on using it as the basis of a partial theory of justice that critically responds to Rawls’ contractarian theory of justice as fairness.²⁰⁰

The capability approach has been defined by Nussbaum as ‘an approach to comparative quality-of-life assessment and to theorizing about basic social justice’.²⁰¹ The capability theory is anchored in the liberal tradition, based on the belief that individual freedom is essential to the pursuit of a life worth living.²⁰² Sen has criticized traditional economic enquiries that have focused on assessing whether a life is worth living by measuring utility,²⁰³ (or a person’s ability to fulfil their interest), in the form of happiness under classic utilitarianism,²⁰⁴ or desire-fulfilment under the

< <http://www.ifa-fiv.org/wp-content/uploads/2015/11/General-Assembly-Convention.pdf>> Accessed 26th July 2016

¹⁹⁶ Robeyns I, ‘The Capability Approach: a theoretical survey’ (March 2005) *Journal of Human Development* 6(1) 93, 94

¹⁹⁷ See for instance Sen A. ‘Equality of What?’ in S. McMurrin (Eds), *The Tanner Lectures on Human Values*, Volume I, 1980 (Cambridge University Press, 2011); ‘Rights and Capabilities’ in *Resources, Values and Development* (Harvard University Press, 1984); *Commodities and Capabilities* (North-Holland, 1985); ‘Well-being, agency and freedom’ (1985) *The Journal of Philosophy* 82(4) 169

¹⁹⁸ See for instance Nussbaum M., ‘Nature, functioning and capacity: Aristotle on political distribution’ (1988) *Oxford Studies of Ancient Philosophy*, Supplementary Volume 152; ‘Human Functioning and social justice. In defense of Aristotelian essentialism’ (1992) *Political Theory* 20(2) 202

¹⁹⁹ Sen A., *Development as Freedom* (Knopf, 1999)

²⁰⁰ Nussbaum (n192)

²⁰¹ *Ibid* 18

²⁰² Robeyns (n196) 95

²⁰³ Bentham J., *An introduction to the principles of morals and legislation* (Payne, 1789)

²⁰⁴ Hare R.M. *Moral thinking: Its levels, methods and point* (Clarendon Press, 1981)

modern strand of the tradition.²⁰⁵ In contrast, the capability approach focuses on the actual opportunities people have in ‘beings and doings’, which Sen calls ‘functionings’ and which together ‘constitute what makes life valuable’.²⁰⁶ This theory concentrates on how policies can achieve certain functionings (i.e. being healthy, working, being educated), and capabilities, which provide the ‘substantive opportunities’ or ‘freedoms’ to choose to do and be what matters to individuals.²⁰⁷

The benefit of the capability theory as a framework for the conditions necessary to dignity is that it encourages an in-depth analysis of the journey a person would have to undertake to possess those capabilities in the world they live in. For instance, the capability approach has been useful in highlighting the plight of disadvantaged groups such as women. Nussbaum gives the example of women who, despite their legal right to seek employment, may be prevented from doing so de facto, because of the threat of violence they may face in doing so.²⁰⁸

The main value of the capability approach, for the purpose of my analysis, however, is that it forces us to look into the obstacles a person may face in order to have the actual possibility of those functionings. This is a particularly helpful exercise to carry out for the dignity in care of older individuals, because they are part of a group hidden from society and whose concrete autonomy has been depleted by age. Accordingly, having set out the meaning of dignity from the perspective of elderly people in care, the next goal of this dissertation is to evaluate whether the conditions necessary for the realisation of dignity exist. Are elderly people in care actually capable of functioning in a way that accords with *their* understanding of what it means to lead a dignified life? To answer this question I will need to identify which main obstacles there are, and whether and how current laws help overcome them.

²⁰⁵ Sen A., *Commodities and Capabilities* (Oxford University Press, 1999) 2

²⁰⁶ Robeyns (n196) 95

²⁰⁷ Ibid

²⁰⁸ Nussbaum (n192) 293

b) Conversion factors and practical implications

In order to assess whether and how the law could play a part in upholding or creating the conditions necessary for dignity, it is important to consider a variety of internal and external influences. Under his focus on human development, Sen has put forward the idea that the impact of means onto a functioning will be different depending on a variety of factors.²⁰⁹ Particular resources will allow for the possibility of a functioning for certain people but not others. An able bodied person who has learned to ride a bike will get far more out of the bike as a means of transport than a disabled person who has never been taught to ride.²¹⁰ These are personal factors that will influence whether certain goods and services, but also institutional arrangements can transform into a particular functioning. The capability theory is useful in that it recognises different challenges faced by differently situated people, and that one particular mean to a capability cannot always translate into a functioning. For example, state benefit to fund care cannot always mean good care if the person has no information as to the best care for them, or no access to it within their preferred locality near family and friends.

The possibility an individual will have to transform capabilities into actual functionings therefore depends on personal, social and environmental factors. Robeyns has cited ‘metabolism, physical condition, sex, reading skills or intelligence’ as examples of personal conversion factors, ‘public policies, social norms, discrimination practices gender roles societal hierarchies and power relations’ as examples of social conversion factors, and ‘climate, or geographical location’ as examples of environmental conversion factors.²¹¹ Inspired by the concept of conversion factors as an evaluative framework, I will analyse here the factors that I believe are most influential in the ability of the elderly dependent person to achieve the functionings implied by the idea of dignity as understood by that person.

On a personal level, the vulnerability of the person in care is the prominent obstacle to the possibility of dignity. Care homes are an environmental factor to dignity,

²⁰⁹ Sen A., *Inequality Re-examined* (Clarendon Press, 1992)

²¹⁰ Robeyns (n196) 98, 99

²¹¹ Ibid 99

regulating the lives of the individuals who live there. On a wider societal level, ageism can also be identified as a conversion factor to dignity, making its flourishing more difficult. In the next chapters my analysis will focus on how the law is engaging with those conversion factors, and whether it is able to shape them in a way that may allow the possibility of dignity in elderly care.

6) Conclusion

The legal meaning of dignity tends to be gathered from historical or jurisprudential analysis, rather than based on empirical social research.²¹² Here I have used social studies to identify three major themes that define dignity for elderly people in care homes, namely identity, self-determination and humanity. In order of importance it appears that identity is the subject most mentioned by the participants of the research carried out, followed by self-determination and humanity. The various elements that make up a person's sense of identity are numerous and depend for the most part on external influences. Many themes are recurrent, although not always approached or perceived in the same manner by those interviewed. Some themes are found in some studies but not in others, which explains the different amount of data for each category.

From the research examined, self-respect, relationships, privacy, communication, participation and loss, all affect a person's identity within the environment of a care home. Self-respect is the one element described as internal or intimate to those questioned and varies from person to person. Some have an inner sense of self they feel others could reach and change, others find their self-respect through religious beliefs, assertiveness or the positive image they have of themselves. External influences on the identity a person holds are numerous. The relationships people have with others deeply influence many aspects of their lives, which ultimately reflect on their sense of dignity. The quantity and quality of the relationships people have with care staff, family and friends shape their perception of self, their place in the world

²¹² See for instance the eminent work about dignity by McCrudden C., 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19(4) *European Journal of International Law* 655 or Dupré C., *The Age of Dignity: Human Rights and Constitutionalism in Europe* (Hart Publishing, 2015)

and their sense of worth. How carers interact with people in need can either sustain or deteriorate their sense of dignity. Upholding privacy, listening carefully, speaking respectfully and openly, and taking the time to treat residents as individuals are all features of care relationships that bolster dignity.

Keeping a link to the life once led outside the care home with family and friends is also cherished and helps people hold on to the whole of their personhood, not only the person they have become in the care home, but also the person they were throughout their life. Being able to communicate, or the ability to be heard and put one's point across, also supports a person in feeling dignified and worthy. Participation was mentioned time and again as an ingredient of identity and was derived from a sense of belonging and a sense of purpose. The many physical changes people go through in old age, those that ultimately force them to live in a place that can cater for their dependency, make up a large part of their new identity and so have a large influence on how they perceive themselves. Finally, loss is expressed as redefining identity. Whether the loss is one of a lifelong partner, friends or a home, it means a break from the anchorage to the familiar and is experienced by many as a fracture of the self.

Self-determination is the next theme linked with dignity. This combines independence, control, freedom of choice and acceptance. Self-determination may mean many things and can be associated with the notion of freedom to do or be whatever one chooses. Although people in care homes are realistic about the kind of autonomy they can enjoy, they still wish to be allowed to make some decisions. The aim to protect frail elderly people can have the undesired consequence of impinging on their ability to make their own choices. Elderly people's will for autonomy also stems from the fear of being a burden on their carers, relatives and the wider society. This is why retaining control is considered important to retain dignity. The loss of the ability to control movements or thoughts is depicted as the loss of independence and therefore the loss of dignity. This is balanced nonetheless by the capacity to accept one's reduced autonomy because of ageing or even dementia, and to redefine dignity according to these parameters. In those situations it appears that dignity is able to remain and flourish, even when independence has been lost.

Humanity is the last theme that makes up dignity for older people in care. It is in fact the category least populated by the data gathered from the various interviews used. This could be explained by the fact that some sub themes are closely linked to others in other categories and, although they could have been treated under the heading of humanity were discussed elsewhere. For example human dignity or that inner quality some people refer to, is often assimilated to self-respect, which has been here categorised under the theme of identity. Humanity is the hardest aspect of dignity to define. It is that intrinsic quality that defines our human status and differentiates us from other living creatures. It implies we should all be treated equally and paradoxically as individuals. Within humanity, human rights are the least mentioned subject in relation to dignity. This could be explained by the age of the people who took part in the various studies. Most of the people interviewed are from a generation that is not used to the language of human rights, especially as a legal concept that could vindicate undignified treatment.

On a practical level, it is essential to protect dignity because ‘a fractured sense of dignity has been found to be associated with depression, hopelessness and a desire for death’.²¹³ In order to assess whether conditions exist that can foster a person’s dignity as understood here, and inspired by the capability theory, I am going to review each of the conversion factors to dignity that I have identified above. These are vulnerability (Chapter III and IV), care home regulations (Chapter V), and ageism (Chapter VI). I will examine under each of those areas the impact laws have on the possibility of dignity as presented in this chapter.

²¹³ Chochinov HM, Hack T, Hassard T, Kritsjanson LJ, McClement S and Harlos M, ‘Dignity and the terminally ill: a cross-sectional, cohort study’ (2002) 360 (9350) *Lancet* 2026

Chapter III

Personal Conversion Factor: Vulnerability I

1) Introduction

In the previous chapter I set out the theoretical framework upholding the use of a discursive ethical model to understand the meaning of dignity for the dependent elderly in long-term care. I suggested that dignity ought to be understood in this way (that is, from the perspective of elderly people in care) because it is grounded in concrete autonomy, and concluded that it necessitated certain conditions to become a possibility. In the last chapter, I also mentioned the use of the capability theory as an evaluative tool to assess ‘policies according to their impact on people’s capabilities as well as their actual functioning’.¹ Evaluating the impact laws have on the realisation of dignity as understood in this dissertation means looking at how they help or hinder a person in care to actually experience dignity. As we have seen under the capability approach, Robeyns elaborates on the notion of conversion factors: these can be personal, social and environmental.² Conversion factors determine ‘how much functioning one can get out of a good or service’.³ In other words, those factors affect how a person transforms the possibility of a capability into a functioning.

Inspired by this evaluative framework, I will examine in the following chapters how current laws affect the conditions necessary for dignity. Some laws will contribute favourably to the realisation of dignity by, for example, setting out a regulatory framework for care homes that enables identity creation, promotes opportunities for participation in their social environment and allows respectful treatment of the person. Other laws will have an impact on the amount of resources available to the social care sector, and so influence the recruiting of staff and quality of care. I will argue that

¹ Crocker D. A. and Robeyns I., ‘Capability and Agency’ in C. W. Morris (Ed.) *Amartya Sen* (Cambridge University Press, 2010) 64

² Robeyns I., ‘The Capability Approach: A Theoretical Survey’ (2005) 6(1) *Journal of Human Development* 93, 98

³ Stanford Encyclopedia of Philosophy, The Capability Approach (14th April 2011)
< <http://plato.stanford.edu/entries/capability-approach/#ConFac> > Accessed 6th September 2016

new laws may help certain dignity-enabling conditions to come about, but that other such conditions may remain unaffected by legislative initiatives, and require deeper cultural changes.

In the next two chapters, I will focus on the *personal* conversion factor affecting elderly people in care homes, that of vulnerability. In order for care services to deliver the kind of conditions needed for dignity, it is essential for policy makers to understand who the individuals in long-term care are. In this instance, it is crucial to take into account the physical and mental frailty of those in such circumstances. Figures from the National Institute for health Research show that the care home population is made up of a majority of women over the age of 85, is steadily getting older and has a high prevalence rate of ‘cognitive impairment (conditions such as dementia), co-morbidity (people who have more than one illness) and poly-pharmacy (people who take several prescribed drugs)’.⁴

Mitigating the effects of vulnerability in long-term care is a pre-requisite element to any possibility of dignity realisation as understood under a discursive ethic. Care policies must be alive to the fact that the realisation of dignity as understood here as resting on conditions amenable to identity, self-determination and humanity, can be compromised if they do not adequately mitigate the effects of physical and mental vulnerability induced by ageing on the person’s ability to access those conditions. Institutional care is set out to respond to heightened levels of vulnerability brought on by the physiological effects of ageing. As Hall remarks, ‘a coherent social response to the vulnerabilities of old age requires and rests on a coherent understanding of old age as a way of being in the world; meaningful response is impossible without first understanding the nature of the phenomenon to which that response is intended to be useful or ameliorate’.⁵

In this particular chapter I will firstly explore various theoretical conceptions of vulnerability and examine which one is most compatible with the realisation of dignity under a discursive model. I will conclude that in order for vulnerability to be

⁴ National Institute for Health Research ‘Understanding Care Homes’
< <http://enrich.nihr.ac.uk/page/understanding-care-homes>> Accessed 12th December 2016

⁵ Hall M. I., “‘Old Age’ (Or do we need a critical theory of law and aging?)” (2014) 35 Windsor Review of Legal and Social Issues 1, 2

conducive to dignity, it ought to be apprehended as a universal principle, rooted in, rather than opposed to, autonomy in a relational sense. Secondly, I will look at how laws set to protect vulnerability through the prohibition of certain conducts - such as criminal and human rights laws - respond to the vulnerability of those in long-term care. I will review whether such laws are conducive to the realisation of dignity. Finally, I will analyse the case of *McDonald*, pertinent here not only because of the discussions it elicited about Article 8 in the context of dignity in care services, but also because it illustrates the importance of courts' role in the conceptualisation of dignity through their judicial reviewing functions.⁶

2) Vulnerability meaning

a) Three conceptions of vulnerability

The manner in which vulnerability in long-term care is understood will influence social care policies and so the possibility of dignity. In order to formulate a conception of vulnerability that will be conducive to dignity, it will need to allow individuals in care to hold on to a sense of identity, self-determination and humanity. Measures put in place to alleviate or compensate for vulnerability cannot frustrate these other parameters: I will argue, in other words, that interventions set out for the protection of vulnerability must not come at the complete expense of identity, humanity and self-determination. Dunn et al have highlighted that the law constructs vulnerability from two different standpoints.⁷ One is that of inherent vulnerability, pertaining to 'a person's particular characteristics', such as amongst others, 'age, gender, or the presence of a particular illness or disability'.⁸ Inherent vulnerability is attached to certain traits. This particular approach to vulnerability can be illustrated by Munby J's declaration in the case of *ReSA* that 'I would treat as a vulnerable adult someone who, whether or not mentally incapacitated, and whether or not suffering from any mental illness, or mental disorder, is or may be unable to take care of himself or herself, or unable to protect him or herself against significant harm or

⁶ *R (On the Application of Elaine McDonald) v Royal Borough of Kensington and Chelsea* [2011] UKSC 33, 6 July 2011 and *McDonald v The United Kingdom*, Application 4231/12, [2014] ECHR 492, 20th May 2014

⁷ Dunn M., Clare I. and Holland J., 'To empower or to protect? Constructing the 'vulnerable adult' in English law and public policy' (2008) *Legal Studies* 28(2) 234

⁸ *Ibid* 239

exploitation, or who is deaf, blind or dumb, or who is substantially handicapped by illness, injury or congenial deformity. (This) is not intended to be a definition. It is prescriptive, not definitive'.⁹

Classifying someone as vulnerable allows the law some targeted interventions.¹⁰ Children are considered vulnerable and to that effect are protected from death or serious injury in the context of home life by statutes such as the Domestic Violence, Crime and Victims Act 2004 (DVCVA).¹¹ They are also afforded specific protection in the context of sexual offences¹² and offences against the person.¹³ Adults deemed vulnerable are also protected by a particular legal regime according to the same DVCVA, the Mental Health Act 1983 and the Mental Capacity Act 2005. In conjunction with the coming into force of the Human Rights Act in 2000, the government published guidance for those policies intent on protecting vulnerable adults.¹⁴ Under the 'No Secrets' guidelines a vulnerable adult was defined as someone 'who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of himself, or unable to protect him or herself against significant harm or exploitation'.¹⁵ Other measures have been taken on the basis of protecting gender vulnerability, such as the regulation of abortion rights for women in the United States.¹⁶

I argue that a conceptualisation of vulnerability based on such pre-defined characteristics may not be conducive to dignity as it can reinforce ageist stereotypes and hence distort a person's sense of identity, particularly by giving the impression of homogenised inferiority. Under a discursive ethical model, and according to the studies used in Chapter II, the capacity to maintain a sense of identity free from

⁹ *Re SA (Vulnerable Adult with Capacity: Marriage)* [2006] 1 FLR 867 at [82]

¹⁰ *Ibid* 23-27

¹¹ Domestic Violence Crime and Victims Act 2004 s.5

¹² Sexual Offences Act 2003 s.5 to s.8

¹³ Children and Young Persons Act 1993 s.1 recognises as an offence the 'willful assault, ill treatment, neglect, abandon or exposure to suffering or injury to health' to persons under sixteen.

¹⁴ Home Office and Department of Health, 'No Secrets: Guidance on developing and implementing multi-agency policies and procedure to protect vulnerable adults from abuse' (20th May 2000)

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/194272/No_secrets_guidance_on_developing_and_implementing_multi-agency_policies_and_procedures_to_protect_vulnerable_adults_from_abuse.pdf> Accessed 28th October 2016

¹⁵ *Ibid* 8-9

¹⁶ See for instance Siegel R.B., 'Dignity and the Politics of Protection: Abortion Restrictions Under Casey/Carhart' (2007-2008) 117 *Yale Law Journal* 1694

stereotypes that subsume the individual to a group emerged as an essential element to dignity. Conceptualising vulnerability as inherent in old age is problematic because vulnerability is traditionally associated with ‘victimhood, deprivation, dependency, or pathology’,¹⁷ and ideologically understood as diametrically opposed to autonomy in the liberal sense of the term. In the case of old age, Hall writes that ‘legal theory focusing on personal vulnerability increases social vulnerability (...) to the extent that it reinforces ageist presumptions of weakness and incapacity’.¹⁸ Self-image may become warped through the discriminatory eyes of society and influence negatively how elderly people in care perceive themselves. For instance, it transpired through the studies used in Chapter II that individuals resented the fact that they were, or understood themselves to be a burden to others.

Attaching vulnerability to certain individuals also ‘seems to locate the cause of the abuse with the victim, rather than placing responsibility with the actions and omissions of others’.¹⁹ It reinforces inequality by supposing that some individuals are in some way deficient in relation to a yardstick that is fully autonomous and self-supporting. It implies that the group in question is dysfunctional in comparison to the golden standard of the autonomous legal individual. Code defines this individual as

Self-sufficient, independent, and self-reliant, a self-realizing individual who directs his efforts towards maximizing his personal gains. His independence is under constant threat from other individuals: hence he devises rules to protect himself from intrusion. Talk of rights, rational self-interest, expediency, and efficiency permeates his moral, social and political discourse.²⁰

Vulnerability understood in this way may therefore be considered as a defect, something for the state to fix in order for the vulnerable to remain functionally self-

¹⁷ Fineman M.A., ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (2008) 20(1) *Yale Journal of Law and Feminism*, 8

¹⁸ Hall M.I., ‘Equity Theory: Responding to the Material Exploitation of the Vulnerable but Capable’ in I. Doron (Ed.) *Theories on law and Ageing* (Springer, 2009), Preface viii

¹⁹ The Association of Directors of Social Services (ADSS) ‘Safeguarding Adults’ (October 2005), 4 <<https://www.adass.org.uk/adassmedia/stories/publications/guidance/safeguarding.pdf>> Accessed 28th October 2016

²⁰ Code L., *What Can She Know? Feminist Theory and the Construction of Knowledge* (Cornell University Press, 1991), 77-78

sufficient under the liberal order.²¹ It challenges the possibility of dignity by not only compromising substantial equality and so a person's sense of humanity, but by possibly curtailing a person's free choice through rehabilitative interventions that negate individual choice.

A more refined view of vulnerability is that based on intersectionality. Following Meyers

the idea of intersectional identity is premised on the general philosophical thesis that who one is depends on one's social experience. However, the intersectional conception is specific to societies that exhibit certain kinds of social stratification, for it derives from a social-psychological view about how individuals internalize gender, sexual orientation, race, class and ethnicity in sexist, homophobic, racist, classist and xenophobic societies.²²

Intersectionality emerged as a response to the criticism that the feminist critique of the patriarchal order was only reflecting the perspective of the white heterosexual woman,²³ and that other aspects of a person's identity such as race and sexuality ought to be taken into account simultaneously.²⁴ Intersectionality offers a more sophisticated lens through which to understand social oppression by examining the cumulative effects of confluent identity markers. For instance, Crenshaw has highlighted the fact that 'although racism and sexism readily intersect in the lives of real people, they seldom do in feminist and antiracist practices.'²⁵ By omitting to take into account that a person is often at the intersection of multiple identities, policies fail to adequately respond to oppression or unequal treatment.²⁶ Importantly for my purposes, the intersectional view on vulnerability conceives of it not as inherent in

²¹ Fineman M.A., *Autonomy Myth: A Theory of Dependency* (The New Press, 2005)

²² Meyers D. T., 'Intersectional Identity and the Authentic Self? Opposite attract!' in N. Stoljar and C. Mackenzie (Eds.) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press, 2000), 153

²³ Crenshaw K., 'Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics' (1989) 1, Article 8 *University of Chicago Legal Forum*

²⁴ *Ibid* 620

²⁵ Crenshaw K., 'Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color' (June 1991) 43(6) *Stanford Law Review* 1241, 1242

²⁶ *Ibid* 1246

certain individuals, but as the end result of the convergence of different practices of subordination or axes of social disadvantage.

A third view on vulnerability is proposed by Fineman who has argued that focusing on a narrow view of equality, one that rests on prohibiting the discrimination of certain pre-defined identity characteristics, fails to address the ‘persistent forms of subordination and domination’,²⁷ and the ‘structural disadvantages and debilitating institutional and societal arrangements’ that are part of the problem of persisting inequality.²⁸ I have argued above how unequal treatment and stereotypes can be pernicious to the realisation of dignity by damaging a person’s sense of identity. Fineman’s perception of vulnerability, Kohn argues, ‘suggests that it can replace group identity (e.g. race, gender, poverty) as a basis for targeting social policy’.²⁹ Rejecting even the idea of ‘intersectionality and multiplicities of identities’, Fineman’s theory aims at moving ‘away from the fragmentation of the legal subject to the creation of a vigorous universal conception’.³⁰

According to Fineman, relying on identities, or even intersectionality, ‘will tend to direct critical attention to discrimination by and against individuals or, at best, individual institutions, and not to the failure, distortions or corruption of societal structures more systematically’.³¹ According to her, equality as ‘sameness-of-treatment’ focuses too heavily on individuals, leaving out of the law’s reach those arrangements that produce ‘material, cultural and societal imbalances’.³² Instead, she proposes that ‘a legal subject with which to replace the abstract liberal subject ... must be based on an appreciation of the human condition’, and as ‘the liberal subject is a universal construct, ... so must be its alternative’.³³ Fineman therefore suggests that vulnerability is universal and inescapable, anchored in our embodied self.³⁴

²⁷ Ibid 1737

²⁸ Ibid 1739

²⁹ Kohn N. A., ‘Vulnerability Theory and the Role of Government’ (2014) 26(1) Yale Journal of Law and Feminism 1

³⁰ Fineman M.A., ‘Feminism, Masculinities and Multiple Identities’ (2013) 13(101) Nevada Law Journal 619, 636

³¹ Ibid 635

³² Ibid 636

³³ Ibid 620

³⁴ Fineman M.A., *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Routledge, 2016), 20

From the premise that vulnerability forms an intrinsic part of our life journey, and is not a deficiency that needs to be fixed, it would generate a more subtle and cooperative approach to social policies that could prove far more beneficial to the possibility of dignity under a discursive ethical approach. Fineman returns us to the idea of inherent vulnerability, but her version of inherent vulnerability is much more attractive than the one that limits inherent vulnerability to specific groups of people. Fineman's approach shares with intersectional vulnerability a substantive rather than formal approach to equality; but one way in which it may have the edge over intersectional vulnerability is that it rejects the traditional idea that only certain individuals or groups are vulnerable and need help.³⁵ It would put a stop to the over simplification of people's identities according to particular features,³⁶ which risks creating and perpetuating stigma, but instead would underpin all policies with the idea that all human beings need, at some time in their lives, support due to their vulnerability.

b) Universal vulnerability and dignity

Fineman is clear on one point: inherent universal vulnerability ought to be guiding a responsive state in its quest to social justice and substantive equality.³⁷ Nevertheless, drafting effective social welfare policies that will be compatible with the possibility of dignity based on a universal principle of vulnerability raises some objections. In fact, state intervention in responding to vulnerability may result in paternalistic policies that encroach on the autonomy of the individual, and so have the very effect Fineman reproaches current anti-vulnerable policies to have.³⁸ Oddly, Fineman has herself suggested intrusive social policies in the case of the elderly, prioritising their safety and security over their self-determination.³⁹ In doing so, she not only espoused the stigmatising effect of vulnerability she so adamantly rejects, but also compromised

³⁵ Ibid 3

³⁶ Fineman M.A. and Gear A., 'Introduction: Vulnerability as Heuristic. An Invitation to Future Exploration' in 'M. A. Fineman and A. Gear (Eds) *Gender in Law, Culture and Society: Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Routledge, 2013)

³⁷ Fineman (n34)

³⁸ Kohn (n29) 14-21

³⁹ Fineman M. A., "'Elderly" as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility' (2012-2013) 20 *Elder Law Journal* 71

the possibility of dignity. Her approach may be explained in part by her theoretical model of the Mother-Child relationship she adopts.⁴⁰ Applying to ‘all forms of inevitable dependency’⁴¹ policies based on this carer/cared for paradigm may result in a kind of beneficent protectionism that would suit children but not the older dependent adults.

This paternalistic outcome can also be explained by Fineman’s understanding of autonomy as a liberal paradigm that advocates freedom from state intervention to promote the ability of the individual to organise her life trajectory unburdened.⁴² Fineman presents the rhetoric of autonomy as a justification for the abdication of the state in its social welfare duties, exposing it as an obstacle to substantial equality and social justice.⁴³ Kohn, however, contends that ‘the fact that the language of autonomy can be used rhetorically to justify the avoidance of (state) responsibilities does not mean that valuing autonomy must be sacrificed to enhance resilience to vulnerability’.⁴⁴ Denying individual autonomy in order to address vulnerability may actually hinder the possibility of dignity and be harmful to the individual.⁴⁵ Conditions favourable for dignity require the dual and seemingly contradictory goals of respect for autonomy and protection for vulnerability.

The key to a conception of vulnerability that is amenable to dignity is one that fosters rather than denies autonomy. In order to achieve such a goal, autonomy has to be understood within the context of relational autonomy rather than as autonomy in the political liberal sense.⁴⁶ Established under Chapter I as the ground of dignity and the justification for a discursive ethical framework upon which to understand it within care policies, relational autonomy must also be embraced within a conceptualisation of vulnerability for it to enable dignity. Mackenzie argues that ‘responding to

⁴⁰ Fineman M.A. *The Neutered Mother, the Sexual Family and Other Twentieth Century Tragedies* (Routledge, 1995)

⁴¹ *Ibid* 235

⁴² Mackenzie C., ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C. Mackenzie, W. Rogers and S. Dodd (Eds.) *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2013), 41

⁴³ Fineman (n17)

⁴⁴ Kohn (n29) 22

⁴⁵ Kohn (n29) 15

⁴⁶ Mackenzie (n42)

vulnerability by promoting autonomy is a matter of social justice'.⁴⁷ Vulnerability and autonomy cannot be considered as mutually exclusive without fettering the possibility of dignity. Relational autonomy rests on the basic proposition that in order for individuals to develop and retain their capacity to self-determine, essential to their thriving, they need the support of social, emotional and institutional relationships, and that the state's role is to set out such policies and laws that not only facilitate these links, but also prevent their frustration because of oppression, disadvantages and social control.⁴⁸

Arguably then, policies aimed at tackling universal vulnerability ought to bear relational autonomy in mind in order to allow the possibility of dignity. It means that they have to respect the fact that individuals 'form, sustain and revise (their) self identities in relational connections to specific others, and we negotiate our sense of individual selfhood in a specific geographical, historical and political context in relation to intersecting social determinants, such as gender, race, ethnicity, ability and class'.⁴⁹ Just as Fineman advocates a state responsive to universal vulnerability, relational theorists advocate that the state must have a central role in the setting out of conditions that promote the relationships at the core of autonomy competencies.⁵⁰

c) Refining universal vulnerability

Collins argues that creating policies responsive to a universal approach to vulnerability is impractical as 'it sets a very low standard for vulnerability' that fails to 'be an illuminating argument' for intervention, as everyone is vulnerable by virtue of being human.⁵¹ According to her, vulnerability should be defined as a 'real-life concept' to warrant appropriate legal responses.⁵² Fineman-type vulnerability may be used as a focus for attention, but then the reasons behind vulnerability ought to be

⁴⁷ Ibid 34

⁴⁸ Ibid 42

⁴⁹ Ibid 43

⁵⁰ Ben-Ishai E., *Fostering Autonomy: A Theory of Citizenship, the State and Social Services Delivery* (Pennsylvania State University Press, 2012)

⁵¹ Collins J., 'The Contours of Vulnerability' in J. Herring and J. Wallbank (Eds.) *Vulnerabilities, Care and Family Law* (Routledge, 2013) 27, 28

⁵² Ibid 29

examined to offer pertinent solutions. Defining vulnerability as a ‘real-life concept’ would mean making ‘evaluative judgments’.⁵³ Mackenzie concurs that Fineman ‘gives too much weight to unavoidable ontological vulnerabilities arising from biological processes’, giving less importance to the compounding effect of ‘physical, human, social and environmental’ resources on vulnerability.⁵⁴ A universal conception of vulnerability based solely on our biological nature will also hinder the efficient allocation of finite public resources to effectively alleviate it,⁵⁵ which, as we saw, was the strength of intersectional views on vulnerability. Setting out a threshold for intervention requires us to refine the universal and inherent view of vulnerability espoused by Fineman.

As to the conceptualization issue, Mackenzie suggests that vulnerability should be analysed according to three different dimensions. The first type of vulnerability she refers to is *inherent*, the type of vulnerability that is, as Fineman conceives it, ‘ineradicable’, and for which the state’s response ought to be the mitigation of its disproportional effect on the disadvantaged.⁵⁶ This means amongst others the provision of adequate welfare and health care. Hall’s conceptualisation of old age is particularly pertinent here because it offers a simple but useful lens through which to understand the specificity of inherent vulnerability in elderly individuals in long-term care.⁵⁷ She explains that ‘old age is a distinct quality of embodiment, and therefore of vulnerability, experienced on both the corporeal and social level’.⁵⁸ Old age is depicted as a phenomenon that takes over the body and ‘dethrones’ self-perception by not only changing how the social world perceives the person, but by how the person perceives herself too. Some have gone as far as advancing that ‘the body ... in deep old age ... becomes the bottom line: socially constructed differences such as race and gender blur and blend into the final triumph of the natural over the social’.⁵⁹

⁵³ Ibid

⁵⁴ Mackenzie (n42) 38-39

⁵⁵ Kohn (n29) 15

⁵⁶ Mackenzie (n42) 38-40

⁵⁷ Hall (n5)

⁵⁸ Ibid 5

⁵⁹ Featherstone M. and Helpworth M., ‘Ageing, the Lifecourse and the Sociology of Embodiment’ in G. Scambler and P. Higgs (Eds.) *Modernity, Medicine and Health* (Routledge, 1998), 148

The stranglehold of embodiment on the identity of those who rely on care is at the source of their vulnerability. The inherent vulnerability of old age so conceptualised resides in the process of ‘increased and intensified embodiment despite whatever one “is” on the inside’.⁶⁰ The specific biological vulnerability spoken of here should alert policy makers of the need for a high degree of intervention to facilitate everyday living tasks, and protect from increased risk from harm. Nevertheless, such intervention ought not to be at the complete expense of those conditions necessary for dignity. Policy makers should always consider the impact they will have on them, so as to minimise their interference as much as possible. Mitigating the effects of ‘extreme embodiment’ should not be the only target of care policies.

Secondly, Mackenzie identifies *situational* vulnerability, vulnerability that is ‘context specific’ and so influenced by ‘social, political, economic or environmental factors’.⁶¹ Situational vulnerability for the elderly arises specifically out of the relationship between the individual and the care home environment. Kohn believes that situational vulnerability is the only possible practical application of universal vulnerability in a prescriptive context.⁶² Dunn et al, however, warn that ‘the incorporation of situational vulnerability into the construction of the ‘vulnerable adult’ draws upon an understanding of the vulnerability as universal’, and that under the premise of situational vulnerability, ‘vulnerability becomes a concept tied to the personal, social, economic and cultural circumstances within which individuals find themselves at different points in their lives’; this could lead to ‘interventions that are infinite in scope and application’.⁶³ It is therefore important once again that this appreciation of vulnerability be restricted to justifying only interventions that sit within the confines of relational autonomy.

Thirdly and lastly, Mackenzie refers to *pathogenic* vulnerability,⁶⁴ borne out of ‘prejudice or abuse in interpersonal relationships and from social domination, oppression, or political violence’.⁶⁵ It is far more complex to mitigate this kind of vulnerability, as its roots are often cultural and pervasive. Furthermore, actions taken

⁶⁰ Ibid 8

⁶¹ Ibid 39

⁶² Kohn (n29) 23

⁶³ Dunn et al (n7) 241

⁶⁴ Mackenzie (n42) 39

⁶⁵ Ibid

in good faith to ameliorate the negative impact of inherent or situational vulnerability may actually engender pathogenic vulnerability.⁶⁶ For example, a measure taken to protect care home residents from abuse, based on their situational vulnerability, may increase the stigma attached to the old that they are victims and weak. Pathogenic vulnerability may be likened to a sophisticated intersectional approach to identity, where vulnerability is situated at the confluence of various identity categories that are at the source of prejudice and inferior treatment.⁶⁷ It is paramount for the care sector to address pathogenic vulnerability and offer services that are sensitive and alive to the possibility of prejudice and abuse towards the people they care for. This may come from abusive interpersonal relationships (within family members, relatives, friends or care staff), or from wider social negative bias towards particular characteristics (age, gender, sexuality or ethnicity for instance).

It may be contended that this segmented approach to vulnerability harks back to one based on certain characteristics and is far from universal. I would respond that this multi-dimensional approach to vulnerability for policy purposes does not contradict but rather sits within a universal conception of vulnerability, one that justifies a responsive state and acknowledges that ‘our vulnerabilities range in magnitude and potential at the individual level’.⁶⁸ Vulnerability so understood is a fluctuating and individually experienced phenomenon, but one that touches us all and so sustains the proposition that over a life course, ‘no individual can avoid vulnerability entirely’, and that we ought to ‘look to societal institutions to mediate, compensate and lessen’ its effect.⁶⁹ I will now turn to policies currently in place to protect individuals in care homes, and discuss whether they do so on the basis of an appropriate understanding of vulnerability as universal vulnerability, and whether they allow for dignity by anchoring them in relational autonomy.

⁶⁶ Ibid

⁶⁷ Crenshaw K., ‘Mapping the Margins: Intersectionality, Identity Politic, and Violence Against Women of Color’ (1991) 43 Stanford Law Review 1241

⁶⁸ Fineman (n34) 10

⁶⁹ Ibid

3) Protection of vulnerability

a) Criminal law

A state responsive to universal vulnerability must set out laws that forbid and punish the infliction of harm. It is the task of the responsive state to fashion policies that will effectively protect vulnerability as understood above, without encroaching on the possibility of dignity anchored in relational autonomy. In order to evaluate whether this is achieved I am going to review laws set out for the purpose of protecting the multi-dimensional vulnerability of the elderly in long term care homes, and see whether they create conditions favourable to the three components of dignity in elderly care: identity, self-will and respect for humanity. In the specific context of care homes, the criminal law acts to punish those who harm those in their care, either by their action or by their omission. Individuals in care homes are dependent on the care of others for their physical and psychological wellbeing, and so are particularly prone to being harmed by the withdrawal of that care.

The Social Care institute for Excellence (SCIE) has published a list of ‘types of abuse’ under their adult safeguarding section.⁷⁰ Physical abuse includes the physical harm inflicted by a person to another (assault, hitting, punching, kicking...), the unlawful use of restraint, the purposeful withdrawal of care, the forcible feeding or withholding of food, the misuse of medication or the imposition of physical isolation. To this list can be added the harm caused by sexual assaults, a harm that may be both physical and psychological. Psychological abuse is defined by the SCIE as encompassing social isolation, verbal abuse in the form of intimidating, patronizing or humiliating language, lack of opportunity to express one’s religious beliefs or take part in meaningful activities, lack of privacy or lack of opportunity to express oneself and have choices. Some of these types of abuse have been addressed by the criminal law, and I will address each one in turn.

Physical harm inflicted on an elderly person is not specifically designated as ‘elder

⁷⁰ Social Care Institute for Excellence, ‘Adult Safeguarding: Types and indicators of abuse’ (January 2015)

<<http://www.scie.org.uk/publications/ataglance/69-adults-safeguarding-types-and-indicators-of-abuse.asp>> Accessed 5th September 2016

crime'. The criminal system is intent on avoiding stigmatizing older people and so has not defined crime against the elderly as a discreet category of offence. The Crown Prosecution Services (CPS) guidance states that 'whatever the age of a victim or witness, their needs and case management issues should be assessed on an individual basis. Reliance should not be placed on pre-conceived or stereotypical notions and norms about older people in general'.⁷¹ Crimes against older people do not attract the statutory sentencing uplift set out under sections 145 and 146 of the Criminal Justice Act 2003 that can be applied to racist, religious, homophobic or transphobic crimes, or hate crimes against disability.⁷² Despite this statutory disparity, 'sentencing guidelines do however invite the court to increase the sentence for offences against older people on the basis that their perceived vulnerability is an aggravating factor increasing the seriousness of the crime'.⁷³ Unlike crimes motivated by racism or religion (for instance the racially or religiously aggravated offences listed under the Crime and Disorder Act 1998),⁷⁴ there is no statutory aggravated offence for crimes committed against an older person, although the CPS qualifies any crime motivated by hostility towards older people as a hate crime, amounting to an aggravating factor.⁷⁵ Once more, this reflects the concern expressed by the CPS to avoid ageist stereotypes that assume that vulnerability occurs de facto past a certain age, whilst sending the message that this type of prejudice is reproachable.

Although the use of restraints is not prohibited in care homes, their improper use can lead to criminal charges. I will examine this issue in more details in the next chapter as one example of the difficulties faced by policy makers intending to protect the person whilst enabling dignity. Although the CPS mentions the use of restraints as a potential crime, there is no specific offence that addresses the issue. Rather, the CPS holds that 'when considering matters such as whether a criminal offence has been committed or whether the public interest requires a prosecution, prosecutors may find

⁷¹ CPS, 'Prosecuting Crimes against Older People'
<http://www.cps.gov.uk/legal/p_to_r/prosecuting_crimes_against_older_people/#abuse> Accessed 11th January 2017

⁷² CPS, 'Hate Crime report, 2014/2015 and 2015/16' (July 2016)
<http://www.cps.gov.uk/publications/docs/cps_hate_crime_report_2016.pdf> Accessed 8th September 2016, 37

⁷³ Ibid

⁷⁴ Amended by the Anti-terrorism, Crime and Security Act 2001 and Part 11 of Schedule 9 of the Protection of Freedoms Act 2012

⁷⁵ CPS (n72) 37

these Regulations and guidance helpful in assessing whether the use of restraint was appropriate and proportionate'.⁷⁶ The purposeful withdrawal or force-feeding of food could amount to ill treatment. Indeed, under sections 20 and 21 of the Criminal Justice and Courts Act 2015 the ill treatment and willful neglect of a person by a care worker or a care provider are now criminal offences. The Act recognizes the need to protect those who, by the nature of the services they use, are not only inherently but also situationally vulnerable, and so at higher risk of harm.⁷⁷ The misuse of medication can be dealt with by the Medicines Act 1968, whilst sexual assault is covered under the Sexual Offences Act 2003.

Other criminal offences more specifically address psychological abuse. The CPS lists 'humiliation, intimidation, emotional blackmail, verbal abuse, being shouted or sworn at' as offences punishable under the Public Order Act 1986, the Protection from Harassment Act 1997, or the Theft Act 1968.⁷⁸ This list shows that the criminal law falls short of protecting all categories of psychological abuse as defined by the SCIE. In particular, it offers no protection against being patronized, lacking privacy and being isolated. The kind of harm that may result from such treatment may have a profound effect on a person's dignity because it goes to the heart of a person's sense of identity, self-determination and humanity. Institutional support is essential to the sustaining of the relational autonomy of the person in care who has been displaced from her environment and cut off from those inter-subjective and social relationships that had previously defined and sustained it. Nonetheless I would argue that the criminal law may not be the appropriate tool to protect every type of indignity committed against the person in care homes. This may be better addressed, as I will examine in chapter V, by the regulatory framework governing care provisions, or may originate from deeper changes in societal behaviours.

The conclusion to draw from this panoply of criminal offences is twofold. Firstly, the

⁷⁶ Ibid

⁷⁷ Neglect was previously only criminalized in cases where the person cared for lacked capacity (s.44 Mental Capacity Act 2005), died as a consequence of it in domestic settings (s.4 Domestic Violence Crime and Victims Act 2004), or was cared for under the Mental Health Act regime (s.127 Mental Health Act 1983)

⁷⁸ Fear of violence, (Public Order Act 1986 s.4 (POA); Intentional harassment, alarm or distress (POA 1986 s.4A), Harassment, alarm or distress (POA 1986 s.5); Course of conduct amounting to harassment/causing another to fear (Protection from Harassment Act 1997 s.1 and s.4; Protection from blackmail (Theft Act 1968 s.21)

type of protection offered by the criminal law reveals that there is a focus on situational vulnerability, by setting out offences linked to a particular environment, in this instance that of healthcare settings where individuals go to when they require the help of others. This contributes to the positive message that elderly people are not a homogeneously vulnerable sub-group but that it is the situation they are in that heightens the risk of harm they may face. I discussed in Chapter II the fact that the image elderly people have of themselves is often influenced by the idea society has of them, and this in turn has an impact on their identity, a founding block of dignity. It must also be noted that some important elements to dignity that may result in psychological abuse are not protected by the criminal law. As I argued, this is not necessarily inappropriate – certain forms of damaging behaviour, may be better addressed by other means and a change in cultural environment. I will address this particular aspect in the chapter examining ageism.

Secondly, the very need for criminal law to be involved in protecting those who use healthcare settings specifically ought to be questioned. Understanding the reasons why these types of offences occur is complex. Abusing frail dependent elderly people may be caused by a wide variety of factors, some of them personal to the caregiver, others linked to the conditions of work experienced in the care home, including the challenging behaviour of some residents. Individuals in care homes need to be free from physical and psychological abuse for dignity to flourish. Although the criminal law appears to be responsive to this need by forbidding and punishing physical abuse, the root causes of that abuse also need to be assessed in order to offer the possibility of conditions amenable to dignity. Preventing situational vulnerability ought to be part of the same policies that seek to protect it. Some of these issues will be explored in the next chapter under the regulatory framework and staffing issues that prevail in the care industry.

b) Human rights

Protection from physical and psychological abuse is also found under national and international human rights laws. Domestically, the articles engaged in the protection of physical and psychological integrity are Article 3 of the Human Rights Act 1998 (HRA), the absolute right ‘not to be subjected to torture or to inhuman or degrading treatment or punishment’,⁷⁹ as well as Article 8, the right to respect for private life, and Article 5, the right not to be deprived of one’s liberty. These rights are particularly potent for the protection of vulnerability of the older person in care homes. Despite this fact, there exist three potential problems against the effective protection offered by human rights in this context.

Firstly, the scope of protection against personal integrity is limited by the fact that only public bodies are caught under the obligations of the Human Rights Act.⁸⁰ Under the Care Act 2014, any care provider who is delivering care that is arranged, or paid for (directly or indirectly, in whole or in part) by a local authority, will be deemed to be exercising a function of a public nature.⁸¹ Any provider of care that is organised and paid for privately is not legally required to comply with the Human Rights Act.

Secondly, the scope of the protection offered by each article is not absolute, hinging on judicial interpretation, and public interest qualifications. Article 3 protection depends on the definition of the terms ‘inhuman or degrading treatment’ and the level of harm reached. This must be deemed sufficient for the protection of the right to be engaged. According to the jurisprudence of the European Court of Human Rights, treatment has been held to be ‘inhuman because, *inter alia*, it was premeditated, was applied for hours at a stretch, and caused either actual bodily injury or intense physical and mental suffering’, whereas ‘degrading treatment is that which is said to arouse in its victims feelings of fear, anguish and inferiority, capable of humiliating

⁷⁹ British Institute of Human Rights (BIHR), ‘Older People and Human Rights’ (Age UK March 2009, updated March 2011 by Age UK’s Equalities and Human Rights Team), <http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Equality-and-human-rights/Older_People_Human_Rights_Expert_series_pro.pdf?dtrk=true> Accessed 24th October 2016

⁸⁰ Human Rights Act 1998 s. 6 (1) ‘It is unlawful for a public authority to act in a way which is incompatible with a Convention right’

⁸¹ Care Act 2014 s.73

and debasing them'.⁸² The case of *Ireland v UK* has clarified that the minimum level of severity was dependent on the situation and that 'the sex, age and state of health of the victim' should be taken into account.⁸³ This caveat recognizes the element of vulnerability under the protection of Article 3. AgeUK gives the following example of a potential Article 3 abuse:

Mrs S, aged 102, felt isolated, disrespected and neglected while she was in hospital. Despite being blind, her meals and drinks were left on a trolley – in most cases without even letting her know they were there. For the most part, staff also did not offer any assistance with eating or drinking. As a result, many of the meals were removed untouched. Mrs S also suffered a great indignity when she asked for a commode, but was told by a nurse that she could use her incontinence pad.⁸⁴

The protection against abuse that is offered by Article 3 demands a certain threshold of harm (apparently a relatively high one, as the example above may suggest) and so does not cover all abusive behaviour. It may leave out again the harm that results from lacking privacy or being talked to in an infantilizing way, which may nonetheless contribute to a feeling of indignity.

Article 8 has also been interpreted as including the right to physical and psychological integrity, in cases where the interference was of a lesser degree than those under Article 3.⁸⁵ Although the court has held that measures against integrity must be 'substantial' before Article 8 is engaged,⁸⁶ it has also declared that only minor interference could be regarded a breach of Article 8 'if carried out against the individual's will'.⁸⁷ Article 8 protection is also limited by the caveat that 'there shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests

⁸² Council of Europe, 'A guide to the implementation of Article 3 of the ECHR' Human Rights handbook No. 6, 16
< [http://www.echr.coe.int/LibraryDocs/DG2/HRHAND/DG2-EN-HRHAND-06\(2003\).pdf](http://www.echr.coe.int/LibraryDocs/DG2/HRHAND/DG2-EN-HRHAND-06(2003).pdf)> Accessed 26th June 2014

⁸³ *Ireland v UK* Application no. 5310/71, 18th January 1978, [162]

⁸⁴ BIHR (n79) 21

⁸⁵ *Bensaid v United Kingdom*, Application no. 44599/98, 6th February 2001, [46]

⁸⁶ *Ibid* [48]

⁸⁷ *Storck v Germany*, Application no. 61603/00, 16th June 2005, [143]

of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others'.⁸⁸ Although the threshold of harm is lower than for Article 3, the engagement of Article 8 is limited by the state's margin of appreciation. I will discuss the application of Article 8 in care situations in the next part of this chapter when I discuss the case of Ms McDonald.

The third obstacle to the effectiveness of the protection of human rights legislation against abuse is the attitude of those it aims to help, a topic I touched on under the theme of humanity in Chapter II. A sample panel study conducted by AgeUK revealed that older people thought that 'the HRA is about political correctness, not older people's treatment; human rights are in issue in dictatorships, not Britain; people shouldn't have to use legal rights to get action; using the Act will not make any difference, and there is a lack of information and system navigations skills.'⁸⁹

As to the perceived 'political correctness' of the HRA the people interviewed thought it was a mechanism to legitimise bad behaviour ('It means you can get away with murder, literally, it means the victims don't get a say').⁹⁰ Human rights were also confused with democratic rights and considered mostly suitable for use in countries where a change of ruling regime is needed ('Its why they got rid of Saddam').⁹¹ It was apparent to those interviewed that having to legalise human rights meant that society was deteriorating ('It's sad that we need them').⁹² Although people were reluctant to 'make a fuss' and use the courts to enforce their rights, they were far more prepared to do so for a relative.⁹³ According to this study, it appears that should care providers act in a way that is incompatible with their human rights obligations, the older people concerned may not use the mechanisms in place to challenge them. Despite recent initiatives to break down the psychological barriers that are preventing people from

⁸⁸ <<http://www.legislation.gov.uk/ukpga/1998/42/schedule/1/part/1/chapter/7>> Accessed 24th October 2016

⁸⁹ A sample of 28 older people were interviewed in the report compiled by Frances Butler, 'Rights for Real: Older People, Human Rights and the CEHR (Age Concern, May 2006), 63

<<http://www.edf.org.uk/news/0406%20Rights%20for%20Real%20Report.pdf>> Accessed 25th October 2016

⁹⁰ Ibid

⁹¹ Ibid 64

⁹² Ibid 65

⁹³ Ibid 66

using the protection of the HRA in cases of abuse,⁹⁴ it seems that the language of human rights does not sit well with current generations of older people who regard them with a certain ‘antipathy’ and suspiciousness, a reaction that is not conducive to their enforcement.⁹⁵ This may change with future generations of individuals in care who are more familiar with the human rights discourse.

International human rights instruments are even more removed from the grasp of those in institutional care settings who may wish to invoke them to combat abuse. Article 7 of the International Covenant on Civil and Political Rights,⁹⁶ as well as the Convention Against Torture and other Cruel, inhuman or Degrading Treatment or Punishment,⁹⁷ or Article 15 of the Convention on the Rights of Persons with Disabilities,⁹⁸ offer individuals freedom from serious harm. Individual complaints procedures exist, but they can only be used once all domestic remedies have been exhausted.⁹⁹ It is easy to imagine that individuals who do not rely or trust in the use of national human rights laws will be even more reluctant to use the even more removed mechanism of international complaints procedures. Another difficulty with international human rights law in this context arises in connection with the responsibility of states to report on their implementation of International Covenants. States may report less well so on the subject of the elderly in care system if there is no international human right treaty specifically elaborated for the protection of the rights of the older person. I will discuss this possibility further in chapter VI under the topic of ageism.

To conclude, using human rights laws for the specific goal of protecting the vulnerability of those elderly individuals who are cared for in institutions is not the most efficient of legal tools. The protection they offer requires a certain level of harm and can be qualified by wider public concerns. The human rights discourse is also – at

⁹⁴ BIHR (n79) Chapter 4

⁹⁵ Ibid

⁹⁶ ‘No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.’ <<http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>> Accessed 25th October 2016

⁹⁷ <<http://www.ohchr.org/en/ProfessionalInterest/pages/cat.aspx>> Accessed 25th October 2016

⁹⁸ <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>> Accessed 12th January 2017

⁹⁹ Human Rights Treaty Bodies- Individual Communications

<<http://www.ohchr.org/EN/HRBodies/TBPetitions/Pages/IndividualCommunications.aspx#proceduregenerale>> Accessed 19th January 2017

least for current generations of elderly people – considered irrelevant and too removed from those they seek to protect. It may be that with time and the right campaigning strategy, the use of human rights may become more prominent in the fight against all forms of abuse against personal integrity in care homes.

It must be remembered, however, that human rights laws are not just about providing victims with an avenue for redress when their human rights are violated. They are also there to guide public bodies in the exercise of their functions. Public bodies are under a positive obligation, mainly under Article 3 and 8, to safeguard, in the exercise of their public functions, those adults at higher risk of abuse. Care homes, under the Care Act 2014, are considered to assume the functions of a public body, unless the care is organized and/or paid for privately.¹⁰⁰ Safeguarding measures are devised to protect the person's vulnerability, but they may also represent an intrusion on the person's self-determination, specifically in those cases where the level of vulnerability is such that the law requires intervention. I will examine those measures set out to safeguard individuals in care in the next chapter, and consider whether they manage to do so without compromising the possibility of dignity. Before I do so, it is important to examine the case of *McDonald*, a case that has explored in greater details the use of Article 8 in the context of dignity in social care.¹⁰¹

4) The case of McDonald

The case of *McDonald* is interesting because it deals directly with the issue of dignity in care, and the way in which the courts interpret social care and human rights laws.¹⁰² This case shows the significance of the courts' interpretation of legal rules on the conceptualisation of dignity in care. I am going to explore how although Ms McDonald argued that her dignity was hers to define, the courts suggested otherwise. Ms McDonald had suffered a stroke and subsequent falls, which had affected her mobility quite severely. As a result, she needed to urinate often during the night, relying on the help of a carer to get to the commode. As a consequence of budget

¹⁰⁰ Care Act 2014, s.73(3)

¹⁰¹ *R (On the Application of Elaine McDonald) v London Borough of Kensington and Chelsea* [2009] EWHC 1582 (Admin)

¹⁰² *Ibid*

tightening, the borough of Kensington and Chelsea decided to withdraw the night time help the applicant had been receiving, offering her in lieu of a carer some incontinence pads. The applicant challenged the legality of the decision taken by the local authority on the ground that her needs had not changed and so did not justify her care to be changed, and that the new care package proposed was not compatible with Article 8, the right to respect for private and family life, due to the indignity it would cause her.¹⁰³

The High Court refused to grant permission to bring judicial review, determining that the need in question was to be interpreted as one of safety and that the council was entitled to meet that need ‘in the most economic manner’.¹⁰⁴ Having considered the ground of Article 8 to be ‘parasitic’ upon this issue, it was not discussed any further.¹⁰⁵ The case went to the Court of Appeal before reaching the Supreme Court.¹⁰⁶ For the purpose of this dissertation, I will concentrate my analysis on the main grounds of appeal, that emanating from the statutory duties public authorities are under in their social care functions, and that of their welfare obligations arising out of Article 8. The appeal to the Supreme Court was rejected by a majority of four to one, Lady Hale dissenting. It was argued that the public authority had followed due process in the assessment of Ms McDonald’s needs, and that Article 8, if engaged at all, was justifiably curtailed on the ground of the economic wellbeing of the wider public. I will concentrate here on reviewing the grounds of appeal of Article 8 breach and failure to follow statutory duties for care assessment, leaving aside those relying on breaches of the Disability Discrimination Act 1995.

a) Article 8 ground

Lord Brown accepted that Article 8 demanded a positive obligation from the state to respect a person’s private life, stating that

¹⁰³ Ibid [2]

¹⁰⁴ Ibid [36]

¹⁰⁵ Ibid [37]

¹⁰⁶ *R (On the Application of Elaine McDonald) v Royal Borough of Kensington and Chelsea* [2011] UKSC 33, 6 July 2011

[t]here is no dispute that in principle it can impose a positive obligation on a state to take measures to provide support and no dispute either that the provision of home-based community care falls within the scope of the article provided the applicant can establish both (i) “a direct and immediate link between the measures sought by an applicant and the latter’s private life” – *Botta v Italy* (1998) 26 EHRR 241, paras 34 and 35 – and (ii) “a special link between the situation complained of and the particular needs of [the applicant’s] private life”: *Sentges v The Netherlands* (2003) 7 CCLR 400, 405.¹⁰⁷

Lord Brown went on to note that even if such links were established in the present case, case law showed that the triggering of Article 8 to demand positive state welfare was very high, quoting the case of *Anufrijeva v Southwark London Borough Council* where the court had held that ‘[w]e find it hard to conceive . . . of a situation in which the predicament of an individual will be such that article 8 requires him to be provided with welfare support, where his predicament is not sufficiently severe to engage article 3’.¹⁰⁸ There the court sets a very low threshold for the council’s positive duty of welfare to be discharged.

In fact, the court settled the Article 8 question more on the procedural aspect of this positive obligation than its substance. The court held that the council had ‘gone to great lengths both to consult the appellant (...) about the appellant’s needs and the possible way of meeting them’.¹⁰⁹ Doing so, in the court’s view, ‘respected (her) human dignity and autonomy, allowing her to choose the details of her care package within their overall assessment of her needs’.¹¹⁰ Here, Ms McDonald invoked dignity as an argument against using pads, whereas the council and the court invoked dignity as an argument in favour of using them. As I noted in Chapter I, critiques have identified the problem that dignity, if left undefined, can be used for and against the same argument, putting the usefulness of the concept in doubt. This case illustrates that very problem.

The court then referred to the state’s legitimate interference with Article 8. Lord Brown cited the Strasbourg jurisprudence as establishing a wide margin of

¹⁰⁷ Ibid [15]

¹⁰⁸ [2004] QB 1124, [43]

¹⁰⁹ McDonald (n106) [19]

¹¹⁰ Ibid

appreciation, allowing to strike ‘a fair balance between the competing interests of the individual and the community as a whole’, especially in situations such as this one, when ‘the issues involve an assessment of the priorities in the context of the allocation of limited state resources’.¹¹¹ He argued that even if the court established that an interference with Article 8 had taken place, it would be justified under Article 8(2), as necessary in a democratic society in the interest of the economic wellbeing of the country.¹¹² Furthermore the interference would have been found to be proportionate to the appellant’s needs, because ‘it afforded her the maximum protection from injury, greater privacy and independence and resulted in a substantial costs savings’.¹¹³ Once more, the court disregards the wishes of Ms McDonald by imposing its own views as to the kind of outcomes her care ought to provide her with.

The case of *McDonald* then reached the Strasbourg court.¹¹⁴ Quoting the case of *Pretty*,¹¹⁵ the Chamber acknowledged that ‘it was under Article 8 that the notions of the quality of life took on significance because, in an era of growing medical sophistication combined with longer life expectancies, many people were concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflicted with their strongly held ideas of self and personal identity’.¹¹⁶ Here, the court recognized that

[A]lthough the facts of the present case differ significantly from those of *Pretty*, insofar as the present applicant believed that the level of care offered by the local authority would have undignified and distressing consequences, she too was faced with the possibility of living in a manner which “conflicted with [her] strongly held ideas of self and personal identity”. In the Supreme Court, Baroness Hale, in her dissenting opinion, appeared to accept that considerations of human dignity were engaged when someone who could control her bodily functions was obliged to behave as if she could not (...). The Court agrees with this general assessment of the applicant’s situation and it does not exclude that

¹¹¹ Ibid [16]

¹¹² Ibid [19]

¹¹³ Ibid

¹¹⁴ *McDonald v The United Kingdom*, Application 4231/12, [2014] ECHR 492, 20th May 2014

¹¹⁵ *Pretty v The United Kingdom*, Application No 2346/02, [2002] 423, 29th April 2002

¹¹⁶ *McDonald* (n114) [47]

the particular measure complained of by the applicant in the present case was capable of having an impact on her enjoyment of her right to respect for private life as guaranteed under Article 8 § 1 of the Convention. It therefore finds that the contested measure reducing the level of her healthcare falls within the scope of Article 8.¹¹⁷

This statement made by the court is important because it recognises that Article 8 is engaged when measures taken by public bodies are shown to have negative consequences on the healthcare of individuals.¹¹⁸ Beforehand the court had only recognised the engagement of Article 8 in cases when the public authority had refused to provide funding for treatment or equipment.¹¹⁹ This new development could be interpreted as an acceptance by the court that a certain level of care is required to be provided by public authorities in order to be compliant with Article 8.

Although ‘prepared to approach the present case as one involving an interference with the applicant’s right to respect for her private life’, the court did so ‘without discussing whether or not Article 8 s.1 imposes a positive obligation on the Contracting States to put a level of entitlement to care equivalent to that claimed by the applicant’.¹²⁰ The court did not discuss which level of entitlement was required to be compatible with Article 8. It avoided making dignity the yardstick of compliance, and instead concentrated on the process followed by the council, holding that the interference was acceptable as far as it was in accordance with the law, pursued a legitimate aim and was necessary in a democratic society, as per Article 8(2).¹²¹ Breach was found to have occurred only during a short period of time during which the council had failed to formally review Ms McDonald’s care plan despite having made changes to her care, thereby doing so in a manner that was not in accordance with the law.

The decision by the council to cut the amount spent on Ms McDonald’s care package was held to be a proportionate measure balanced against ‘the more general interest of the competent public authority in carrying out its social responsibility of provision of

¹¹⁷ Ibid

¹¹⁸ Ibid

¹¹⁹ Ibid [48]

¹²⁰ Ibid [49]

¹²¹ Ibid [50]

care to the community at large'.¹²² A 'particularly wide margin of appreciation' was afforded to nations 'when the issues involve an assessment of the priorities in the context of the allocation of limited State resources'.¹²³ I agree with Jones that this case was a 'missed opportunity' to 'flesh out the concepts of dignity and autonomy in relation to claims made by older disabled adults'.¹²⁴ The case focused essentially on procedures, avoiding more substantial debates about care, human rights, autonomy and dignity.

Although a note of cautious optimism may follow on from the remarks made by the Strasbourg court linking level of care and Article 8, it may still prove difficult to challenge further care funding decisions on the ground of Article 8. Councils can still breach this obligation by showing that it followed the demands of Article 8(2); the problem posed by a wide margin of appreciation still persists. Using Article 8 to demand that social care services be delivered to a level that will uphold dignity as defined by the person cared for seems therefore unlikely to succeed if it implies demands for additional public resources. In its guide on Article 8, the European Court of Human Rights notes that '[w]hen it comes to access to health care services, the Court has been cautious to extend Article 8 in a manner that would implicate extensive State resources because in view of their familiarity with the demands made on the healthcare system as well as with the funds available to meet those demands, the national authorities are in a better position to carry out this assessment than an international court'.¹²⁵

b) Statutory duties of public authorities

The decision of the council to amend Ms McDonald's care was also challenged on the ground of its legality, more particularly on the ground that the council had illegally changed her care plan although her needs had not been reassessed and remained

¹²² Ibid [57]

¹²³ Ibid [55]

¹²⁴ Pritchard Jones L., 'Night-time care, article 8 and the European court of human rights: a missed opportunity?' (2105) 37(1) *Journal of Social Welfare and Family Law* 108, 110

¹²⁵ The European Court of Human Rights, 'Guide on Article 8 of the Convention on Human Rights' (2017) <https://www.echr.coe.int/Documents/Guide_Art_8_ENG.pdf> Accessed 2nd March 2018

unchanged.¹²⁶ The role of the court in its judicial review capacity was to ascertain the legality of the decision made by the borough in its social care duties. Lord Brown referred to the various statutory obligations public authorities were then under, pre-Care Act 2014. Most particularly he pointed to the requirement laid out by the Community Assessment Directions 2004 issued under section 47(4) of the National Health Service and Community Care Act 1990 for local authority to consult the person and their carer at the time of assessment.¹²⁷ The focus remained on the compliance of the local authority with this duty to consult, but did not engage with how much weight the wishes of Ms McDonald should have in the final decision taken about her care. Part of Ms McDonald's care review was quoted in the Supreme Court case, showing that the overriding concern of the local authority was for her safety. It concluded by stating that 'Ms McDonald's need to be kept safe from falling and injuring herself' and that this aim 'can be met by the provision of equipment (pads and/or absorbent sheets)'.¹²⁸

Although Ms McDonald was adamant that this solution was 'an affront to her dignity', the council held that other service users who had felt the same way and who also had been offered the option of pads had realised that they 'improved quality of life by protecting them from harm and allowing a degree of privacy and independence in circumstances which [were] (...) less than ideal'.¹²⁹

When assessing her needs, the council imposed on Ms McDonald ideas about dignity that were not her own. It is disputable that the fact that other individuals had eventually found some advantages to the use of incontinence pads should have had so much weight in the council's decision about her particular care. Despite this, since there was no statutory requirement to presume that the person receiving care is best placed to know which care services best meet her needs, both the council and the court could conclude that giving these other perspectives priority over Ms McDonald's own was lawful. The majority of the Low Lords in this case agreed that due process had been respected and that the local authority had complied with its statutory duties to assess and provide Ms McDonald with care.

¹²⁶ McDonald (n106) [4]

¹²⁷ Ibid [10]

¹²⁸ Ibid [11]

¹²⁹ Ibid

Lady Hale took a very different view by questioning the rationality of the local authority's interpretation of Ms McDonald's needs under their duty to assess set out by section 47 of the National Health Service and Community Care Act 1990. She noted that the need to get to 'a safe and hygienic place' in which to 'urinate and defecate' was not the same as the need some people have for 'equipment designed to cater for the fact that they cannot avoid performing these natural functions in the wrong place'.¹³⁰ Lady Hale remarked that these two needs were very different indeed. She continued by suggesting that 'the fact that (the local authority) have been trying so hard for so long to persuade (Ms McDonald) to accept their point of view does not mean that it is a rational view or one she is bound to accept'.¹³¹

She therefore allowed the appeal, qualifying as 'Wednesbury irrational' the decision of the council, which had 'characterised the appellant as having a different need from the one she in fact has'.¹³² Lady Hale also drew attention to the respect for dignity obligations set out by health and social care regulations. She reminded the court that 'Regulation 17 of the Health and Social Care Act 2008 (Regulated Activities) (...) requires a registered person, so far as reasonably practicable, to make suitable arrangements to ensure the dignity, privacy and independence of service users'.¹³³ She concluded that 'in the United Kingdom we do not oblige people who can control their bodily functions to behave as if they cannot do so, unless they themselves find this the most convenient course. We are, I believe, a civilized society'.¹³⁴ Her argument failed to convince the majority.

Under the new overarching statutory wellbeing principle guiding the Care Act 2014, which now sets out the duty of care assessments of local authorities, the decision of the majority may have had a different outcome. The guidance accompanying the Care Act 2014 states that 'the core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life'.¹³⁵ The Care Act also sets out

¹³⁰ Ibid [74]

¹³¹ Ibid [76]

¹³² Ibid [78]

¹³³ Ibid

¹³⁴ Ibid [79]

¹³⁵ Department of Health and Social Care, 'Care and support statutory guidance' Updated August 2017, [1.1]

< <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> > Accessed 16th January 2018

that in the exercise of their function, local authorities ‘must have regard’ to ‘the importance of beginning with the assumption that the individual is best-placed to judge the individual’s wellbeing’.¹³⁶ This is an important shift in social care law, one that seeks to respect the wishes of vulnerable individuals; it echoes those principles underpinning the Mental Capacity Act 2005 that presume capacity and place the person at the centre of best interests determination, a topic I will examine in more details in the next chapter.¹³⁷ The wellbeing principle of the Care Act adopts the view that ‘the local authority should assume that the persons themselves know best their own outcomes, goals and wellbeing’, and that on this basis ‘should not make assumptions as to what matters most to the person’.¹³⁸

The case law emerging from the Care Act 2014 will no doubt over time flesh out the meaning of the wellbeing principle, and will hopefully demand that public authorities pay substantial attention to the wishes of the person needing care. The case of *R (On The Application of Luke Davey) v Oxfordshire County Council*,¹³⁹ is one such recent judicial review case in the High Court. The Claimant, a disabled man with extensive care needs, argued that the decision of the council to reduce his care budget was Wednesbury unreasonable, citing *inter alia*, the failure of the council to follow the statutory wellbeing principle established under the Care Act. Morris J agreed that sections 1(1) and (2) of the Care Act ‘imposed a distinct duty upon the Defendant, in each individual case, to promote the individual’s wellbeing, including mental health and emotional wellbeing’ and that section 1(3) contained a separate ‘have regard to’ duty to the items listed under that subsection.¹⁴⁰

One of the items under this ‘have regard to’ duty is the presumption, under section 1(3)(a) that the person cared for is best placed to assess his or her own wellbeing. The claimant in this case held that due to his care funding being decreased, he would be left alone during the day for longer periods of time, causing him anxiety, and so impacting negatively on his wellbeing.¹⁴¹ He also held that in this respect ‘the Defendant was purporting to know the Claimant’s needs better than he knows them

¹³⁶ Care Act 2014 s.1(3)(a)

¹³⁷ See Chapter III for a more detailed discussion on this topic

¹³⁸ Department of Health and Social Care (n136) [1.14]

¹³⁹ [2017] EWCH 354 (Admin)

¹⁴⁰ *Ibid* [19]

¹⁴¹ *Ibid* [116] [117]

himself and in this way the Defendant failed to have regard to the relevant considerations identified in section 1(3)(a).¹⁴² The court did not discuss how much weight the local authority ought to give to the presumption that the person assessed knows best when it comes to his wellbeing. Morris J confirmed that

[t]he duties upon the Defendant in ss.1(3)(a) and (d) are duties to "have regard". These duties are a starting point and did not prevent Ms Lovelock and Ms Collins from taking a different view as to the Claimant's needs, based on their objective professional judgment and experience.¹⁴³

The weight that ought to be given to Mr Davey's own perception about his wellbeing was not discussed here, only that in the end the professional opinion of the social worker as to what amounted to his wellbeing prevailed. Here, 'developing independence' through longer periods of time spent alone was taken to be more important for Mr Davey's wellbeing than avoiding his anxiety to be alone.¹⁴⁴ The procedural aspect of the assessment was held to comply with the wellbeing requirements of the Care Act 2014. The 'having regard to' duty established under section 1(3) of the Care Act could be complied with as long as the council showed it had considered the opinion of the person cared for about wellbeing.

In the case of *R (JF) v London Borough of Merton*, the Claimant who suffered from autism and severe learning difficulties challenged the lawfulness of a decision by the local authority to move him from his current accommodation in a college, to one in a residential care home for adults.¹⁴⁵ The importance of the person's own view about their wellbeing under section 1(3) of the Care Act is not discussed directly here, but the comments made by the judge are interesting:

[i]f the Assessment failed to assess the impact of JF's needs for care and support upon the factors of wellbeing listed in section 1(2) of the Act, then it is an unlawful assessment. Likewise, if it failed to assess the outcomes that JF's wishes to achieve in day-to-day life, and whether, and if so to what extent, the

¹⁴² Ibid [117]

¹⁴³ Ibid [121]

¹⁴⁴ Ibid [122]

¹⁴⁵ [2017] EWHC 1519 (Admin)

provision of care and support could contribute to the achievement of those outcomes, it is unlawful.¹⁴⁶

The judge referred in this latter statement to the importance of the presumption of wellbeing being best understood by the person assessed. She also made this clear when she concluded that '[t]here is a clear statutory theme placing the individual at the heart and centre of the process so that he or she is fully involved in decision making. This is emphasised by the duty to have regard to the wishes and preferences of the individual'.¹⁴⁷ These comments illustrate how the wellbeing principle can be interpreted by the court to give real weight to the wishes of the person cared for.

At the same time, both the cases of *Davey* and *JF* have also quoted authorities that set out the position the court should adopt in reviewing the legality of social care assessments:

Community care assessments are prepared by social workers ordinarily, for the benefit of their employers. The courts have frequently said, as in *R (Ireneschild) v Lambeth Borough Council* [2007] EWCA Civ 234 at [57] and [71] that community care assessments must not be subject to over-zealous textual analysis. It is not for the court to be prescriptive about the detail required in an assessment. Social workers are better placed to assess need than courts so long as they act rationally. It is not the function of the court itself to come to a decision on the merits of the decision. Parliament conferred the powers and duties applicable here to local authorities and the court's function is therefore one of review. There must be a respectful distance between the functions of the decision maker and of the reviewing court.¹⁴⁸

This statement reminds us that the court is only meant to rule on the legality of the council's decisions, in order to respect their democratic legitimacy. It is difficult on the basis of these recent cases to imagine that the application of the principle of wellbeing in the case of McDonald would have changed the outcome regarding the legality of the decision taken by the local authority to change her night-time care

¹⁴⁶ Ibid [47]

¹⁴⁷ Ibid [32]

¹⁴⁸ Ibid [35]

arrangements. Although the court is acknowledging that councils are now under a new duty to ‘have regard to’ the presumption that the person assessed knows best regarding her wellbeing, it discharges the council from this duty on procedural ground, as long as the views of the person have been taken into account. Eventually, however, developments in the Care Act jurisprudence may move towards giving more weight to this presumption in the application of the wellbeing principle. This would reflect the increasingly person-centred approach the courts have been taking when determining best interests under the Mental Capacity Act 2005 discussed in the next chapter.

Clements has commented that ‘the absence of judicial ‘cri de coeur’ concerning the rights of disabled people shows that some judges ‘appear to comprehend dignity on an objective intellectual plane but are unable to express (or perhaps ‘experience’) subjectively the meaning of what it is to suffer indignity’.¹⁴⁹ This may change in time with the statutory interpretation of the wellbeing principle that now underpins the Care Act. It may evolve to become amenable to dignity as understood in this dissertation, by giving real weight to the person’s viewpoint in the provision of social care services. On the other hand, *McDonald* shows that using Article 8 as a ground to enable a person-centred conception of dignity in care is less likely to succeed. Although the Strasbourg court has recognised that Article 8 placed a positive duty on states to provide certain welfare provisions, it has not discussed the question of threshold, and has also justified its curtailment on the ground of the economic wellbeing of the country. It is ironic to note that the term ‘wellbeing’ in the context of social care law could prove an influential principle for the promotion of dignity under a discursive model, whereas the use of ‘wellbeing’ under Article 8(2) may prove a barrier to it.

¹⁴⁹ Clements L., ‘Disability, dignity and cri de coeur’ [2011] 6 European Human Rights Law Review 675, 676

5) Conclusion

In order to be amenable to dignity under a discursive model, social policies have to fulfil two goals. They have to be responsive to the effects of vulnerability, whilst at the same time foster conditions amenable to the person's identity, self-determination and humanity grounded in relational autonomy. Vulnerability used to be comprehended under an etic perspective.¹⁵⁰ This particular approach, which originates from anthropology, means 'describing a phenomenon as viewed by someone outside the experience'.¹⁵¹ An etic approach applied to vulnerability defines it on the basis of certain traits that assign to particular individuals or groups a higher 'probability of health or social problems'. In the case of the elderly, the supposition of their vulnerability is based on their age, and translates into the assumption that they are at higher risk of harm and so need a higher level of intervention.¹⁵²

An etic perspective on vulnerability assumes that it is a 'deficient functioning' in comparison to the social values adopted by society.¹⁵³ The value of autonomy reigns supreme in our western liberal societies, and so the label of vulnerability will be attached to those who fall short of that autonomous functioning. Ferguson has established that the interventions that will follow will also reflect the same value of autonomy and so will have for aim to improve autonomy for the vulnerable individual whilst at the same time avoid imposing limits on the autonomy of others.¹⁵⁴ To avoid paternalistic interventions and respond to human needs means that intervention will be justified 'when endangerment or threat of objective harm can be proved'.¹⁵⁵ This in turn limits the meaning of vulnerability which, assessed by external objective evaluation against societal values, may differ to that experienced by the individual.

In order for the law to be more responsive to dignity as understood in this dissertation, it could benefit from following nursing perspectives on vulnerability, which have

¹⁵⁰ Spiers J., 'New perspectives on vulnerability using emic and etic approach' (March 2000) 31(3) *Journal of Advanced Nursing* 715, 716

¹⁵¹ Ibid

¹⁵² Ibid

¹⁵³ Ibid 717

¹⁵⁴ Ferguson E. J. *Protecting the Vulnerable Adult: A Perspective on Policy and Program Issues in Adult Protective Services* (Institute of Gerontology, University of Michigan State University, 1978)

¹⁵⁵ Ibid

brought to the fore the idea that it can be understood as an experienced phenomenon rather than a label of inferiority attributed to certain groups according to certain criteria. This approach to vulnerability is called ‘emic’, a term used to refer to ‘a description of the phenomena as understood by the person’.¹⁵⁶ Under this perspective, ‘vulnerability is based on the experience of exposure to harm through challenges to one’s integrity’.¹⁵⁷ Under an emic perspective, the main assumption made is that ‘vulnerability exists as lived experience’.¹⁵⁸ In this instance, vulnerability is assessed internally, grounded in the individual’s perception of self, the challenges that self may face and the means with which those challenges can be met.¹⁵⁹ Parse notes therefore that only the person experiencing vulnerability is ever able to define it, similarly to other experienced notions such as wellbeing, now embraced by the Care Act 2014,¹⁶⁰ and that of dignity I argue for here.

This emic version of vulnerability is at the core of Fineman’s approach to vulnerability and refined for policy purposes by Mackenzie. It is grounded in the fact that we are by our very biological nature, inherently and universally vulnerable, but that this vulnerability is experienced at different levels of intensity according to personal, environmental and social circumstances, or as McKenzie labels it, it is a vulnerability that is multi-dimensional; inherent, situational and pathogenic. A responsive state must mitigate this multi-dimensional vulnerability without relying on over paternalistic policies that would compromise a person’s ability to experience dignity, and so must anchor them within the bounds of relational autonomy.

Laws play an important role in protecting vulnerability. In the area of criminal law, the CPS is purposefully refraining from treating elderly crime as a discreet category, whilst still sending the message that those who prey on the vulnerability of elderly people will receive harsher punishment through the flexible sentencing powers of the court. Criminal offences created to protect those who use health and social care services reflect the situational vulnerability of those who depend on these services. The human rights regime on the other hand seems to give direct remedy to those

¹⁵⁶ Spiers (n150)

¹⁵⁷ Ibid 718

¹⁵⁸ Ibid 719

¹⁵⁹ Ibid

¹⁶⁰ Parse R. R., ‘Quality of life for people living with Alzheimer’s disease: the human becoming perspective’ (1996) 9 Nursing Science Quarterly 126

individuals whose vulnerability may have been abused in care. The threshold for human rights protection to be triggered is very high, especially under Article 3. Breaches can be justified under Article 8, as the case of Ms McDonald has shown, under economic considerations – a reminder that economics may, as I mentioned in the introduction, be a conversion factor to dignity. I have also argued that the new statutory paradigm of wellbeing under the Care Act 2014 may prompt a change in how much the council should consider a person’s wishes in their delivery of care provisions. Although Ms McDonald’s idea about what dignity meant to her was not upheld by the courts, future judicial interpretation of the wellbeing principle under the Care Act may promote a more subjective conceptualisation of dignity in care. Cases such as that of *Davey* may so far fail to reassure on the ability of the wellbeing principle to achieve this goal.

Chapter IV

Personal Conversion Factor; Vulnerability II

1) Introduction

Keeping elderly people safe from harm is paramount to the realization of dignity. Elderly individuals in care suffer from multi-dimensional vulnerability. The inherent vulnerability of elderly people in care is heightened by a high degree of embodiment, one that affects physical and psychological faculties and compromises identity. Situational vulnerability exists because of the high level of dependence of these individuals on care services, and pathogenic vulnerability may be due to prejudices and harmful relationships. The role of the responsive state is to intervene to alleviate the affects of vulnerability, without compromising on other aspects of dignity. Indeed, questions of self-determination and autonomy loom large in situations where frail individuals are cared for in institutions.

Human rights obligations placed on care home providers have had the beneficial effect of developing a safeguarding regime for the purpose of protecting individuals' vulnerability through intervention.¹ The protection a person receives because of her vulnerability is often imposed by law but may jar with the possibility of autonomy, a paramount element of dignity. Agich suggests that 'respecting the autonomy of persons in long-term care entails a commitment to identifying and establishing the concrete conditions that encourage individuals to face adversity and threats to self that are the inevitable result of the chronic illnesses and functional deteriorations that bring elders to long-term care in the first place'.² In such situations, it is important to understand autonomy in a relational and phenomenological perspective, looking at elderly people in care 'as concrete agents who exhibit complex experiential relations with the world and others'.³ Setting out measures within a relational grasp of

¹ Care Act 2014 s.73

² Agich G.A., *Dependence and Autonomy in Old Age; An ethical framework for long-term care* (Cambridge University Press, 2003), 123

³ *Ibid* 163

autonomy is essential for these measures to be compatible with and conducive to dignity.

In this second chapter about vulnerability I will therefore focus my attention on the legal measures that are in place to protect vulnerability through intervention. For this purpose, I will consider current safeguarding laws, the rules on capacity determination for decision-making and best interest under the Mental Capacity Act 2005, and those defining the use of restraints. I will examine whether those rules aimed at protecting the person from the effects of vulnerability can do so within the bounds of concrete and relational autonomy, in order to be amenable to dignity as understood here.

2) Safeguarding

Under the Care Act 2014, safeguarding is for the first time a duty of the local authority spelt out under sections 42 to 46, and is clarified by new guidance. In this new format, safeguarding is aimed at any adult who ‘has needs for care and support ... is experiencing, or is at risk of abuse and neglect, and as a result of those care and support needs is unable to protect themselves from either the risk of, or the experience of abuse or neglect’.⁴ Safeguarding is independent of setting and applies to all adults in such situation, whether they have capacity or not.⁵ The adult is no longer referred to as vulnerable based on the characteristic of age. Instead, safeguarding is defined as ‘protecting an adult’s right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the adult’s wellbeing is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action’.⁶ It is the ‘risk to independence and wellbeing’ that is assessed here, giving the state the responsibility to investigate and mitigate the undesirable effects of vulnerability.

⁴ Department of Health ‘Care and support statutory guidance’ Updated October 2016
< <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>> Accessed 25th October 2016

⁵ Ibid 14.6

⁶ Ibid 14.7

The accompanying guidance sets out the aims to protect the person at risk, whilst taking into account her right to self-determination. Safeguarding adults must be done ‘in a way that supports them in making choices and having control about how they want to live’.⁷ It involves making enquiries, the setting up of Safeguarding Adult Boards, arranging for an independent advocate if necessary.⁸ The guidance sets out six principles that underpin adult safeguarding. These are Empowerment, Prevention, Proportionality, Protection, Partnership and Accountability.⁹ These principles are aimed at engaging with the person’s own wishes and identity, to enable them to seek out protection from abuse, whilst minimizing the intrusion of safeguarding on their lives. Safeguarding measures are to be tailor-made to the person concerned, because ‘we all have different preferences, histories, circumstances and life-styles, so it is unhelpful to prescribe a process that must be followed whenever a concern is raised’.¹⁰ I have argued here that interventions are only dignity-enabling if they mitigate vulnerability whilst also taking into consideration a person’s relational autonomy. Safeguarding guidance, in theory at least, appears to adhere to that aim.

Safeguarding rules within the Care Act show that state intervention is rooted in mitigating the effects of vulnerability. It acknowledges the negative effects of inherent and situational vulnerability and moves away from a definition of vulnerability linked to certain identifiable characteristics (disability, age or illness). This is a welcome step towards the creation of conditions amenable to dignity. Under the Care Act vulnerability is now located within the relationship of dependency a person has with others due to their inherent vulnerability. The onus is on the council to protect the person at risk of harm, but it is to be done with the person’s autonomy in mind, an autonomy defined in a relational context. This particular way to mitigate vulnerability is in theory amenable to dignity as defined in this dissertation.

Nonetheless, safeguarding policies have their limits and may be inept at mitigating the effects of pathogenic vulnerability. According to Mackenzie’s definition exposed above, pathogenic vulnerability arises ‘from social domination, oppression or political

⁷ Ibid 14.11

⁸ Ibid 14.10

⁹ Ibid 14.13

¹⁰ Ibid 14.4

violence’, and so can be extremely difficult to identify and alleviate.¹¹ Policies that, in order to avoid the use of blunt and stereotype-inducing identity characteristics, are designed to alleviate vulnerability on a *situational* level may fail to take into consideration the negative effects that social or political oppression can generate. Safeguarding alone remains inefficient to mitigate the intersectional effects of multiple prejudices on an older dependent person (for instance the combination of age and gender, or age and sexual orientation and ethnic origins). Although safeguarding policies offer a short-term solution to protection against harm, they should go hand in hand with other social policies aimed at addressing the wider problems of ageism, racism, or sexism, and their cumulative effects on the vulnerability of dependent old age. Safeguarding policies alone cannot address the insidious effects of pathogenic vulnerability.

Safeguarding measures can be directed at anyone thought to be at risk, but the threshold of capacity is the usual trigger for third party interventions in the name of a person’s welfare. I will now examine how the law defines that threshold, and whether it is conducive to dignity.

3) Capacity

Although the council’s safeguarding duties enable state involvement in any cases of high level of vulnerability, the traditional legal threshold triggering interventions is usually that of capacity. Capacity is defined under the Mental Capacity Act 2005 (MCA). It states that ‘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’.¹² The inability to make a decision is that to ‘understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision, or to communicate that decision’.¹³ Once a person is declared

¹¹ Mackenzie C., ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C. Mackenzie, W. Rogers and S. Dodd (Eds) *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2013), 39

¹² Mental Capacity Act 2005, s.2(1)

¹³ Mental Capacity Act 2005, s.3(1)

to lack capacity regarding a particular issue pertaining to her welfare, decisions can be made on her behalf, following the determination of her best interests.¹⁴ The legal construct of capacity is set out to protect a person's vulnerability due to her cognitive impairment. I will examine here whether capacity setting is compatible with dignity as understood in this dissertation.

a) Capacity and dignity

Before I do so, it is necessary to address the argument that dignity defined under a discursive model cannot be applied to persons without capacity. This is particularly pertinent in care homes where many residents are affected by conditions such as dementia that prevent them from communicating in any meaningful way. Indeed, the Alzheimer's Society has reported that '70 per cent of people in care homes have dementia or severe memory problems', and that there were currently over 850,000 people with dementia in the UK, a figure set to rise to over one million by 2025.¹⁵ As I set out in the introduction and based on the writings of Nussbaum, we all possess dignity, but it may merely be a promissory note if conditions around us are not fertile to its flourishing.¹⁶ A discursive understanding of dignity is one that can guide the creation of those conditions, even when the person concerned is not able to articulate what those conditions ought to be.

We can start to appreciate the reason why we must reject the view that dignity, as defined under a discursive model, cannot be applied to persons without capacity by looking at the case of unconscious individuals – an extreme case of people lacking capacity. Foster defines dignity as 'objective human flourishing', where 'flourishing is primarily about *being*, and only secondarily (although often more spectacularly) about *doing*'.¹⁷ It could be argued that flourishing in the sense of being requires life, requires conscious through. But Foster explains that even in the case of dead or

¹⁴ Mental Capacity Act 2005, s.4

¹⁵ Alzheimer's Society, 'Facts for the media'

<https://www.alzheimers.org.uk/info/20027/news_and_media/541/facts_for_the_media> Accessed 13th December 2017

¹⁶ Nussbaum M., *Creating Capabilities* (Harvard University Press, 2011), 30

¹⁷ Foster C., *Human Dignity in Bioethics and Law* (Hart Publishing Ltd, 2011), 6

unconscious individuals (no longer able to flourishing), their dignity still demands that their bodies be respectfully treated because of several potential reasons:

- 1) Because they still live in the mind of others and for that part of them to flourish their body must be respected.
- 2) Because a wish not to be abused also survives them, and ought to be presumed.
- 3) Because knowing, when they were conscious, that abuse could occur when they became unconscious or died would have interfered with their flourishing.
- 4) Because whoever abuses the body of a person no longer alive or unconscious also compromises his or her dignity by compromising his or her flourishing.
- 5) That rules prohibiting of such abuses have a generally beneficial effect on all individuals' flourishing in society at large.¹⁸

The reasons therefore for acting in a certain way, one that respect the body of the inanimate person, is justified on the ground of the person's own flourishing, but also on the impact it has on the flourishing of others; the individuals who remember the person, the one who abuses the person's body, and the wider society. Foster calls this the 'transactional nature of dignity'.¹⁹ I would agree in as much as dignity is indeed to be understood in the context of the relational nature of our autonomy, discussed in more details in Chapter I. As to determining the conditions necessary for this flourishing, Foster does agree that the answer is empirical and that 'what is good for humans will inform our ethical, and hence legal conclusions'.²⁰

I have put forward here that understanding dignity through direct dialogue can help understand flourishing. Doing so has put to the fore the importance of identity, self-determination and humanity. The more vulnerable a person is, the greater the need to situate her in her relational world in order to give meaning to her identity and enable her self-determination, always bearing in mind the equal status of the person on the ground of her shared humanity. Dignity under a discursive model situates the person at the very centre of its meaning, even when that person is no longer able to communicate. As Donnelly writes, 'respect for will and preferences regardless of

¹⁸ Ibid 7-8

¹⁹ Ibid 8

²⁰ Ibid 11

capacity impairment may be justified on dignity principles'.²¹ When dialogue is no longer possible with the person cared for, identity, self-determination and humanity still ought to guide care, and may need to be determined through communicating with those who know and care for that person.

The courts have discussed the role of dignity in the treatment of individuals without capacity or even consciousness in the case of *Bland*.²² Here the House of Lords discussed the legality of terminating the medical treatment of a person in a Permanent Vegetative State (PVS) that would lead to his death. The matter of the decision making in this instance was rendered ethically complex by the fact that the incapacitated person concerned by the decision had made no previous declaration as to how he would like to be treated should such a situation occurred to him. The Law Lords discussed the main ethical issues at stake, focusing on self-determination, dignity and the sanctity of life. In his evaluation of those principles, Hoffman LJ stated that 'the sanctity of life is only one of a cluster of ethical principles which we apply to decisions about how we should live. Another is respect for the individual human being and in particular for his right to choose how he should live his own life. We call this individual autonomy or the right of self-determination. And another principle, closely connected, is respect for the dignity of the human being: our belief that quite irrespective of what the person concerned may think about it, it is wrong for someone to be humiliated or treated without respect for his value as a person'.²³

Despite the lack of capacity of Mr Bland, Hoffman LJ declared that it was wrong to believe in the argument that 'we have no interests except in those things of which we have conscious experience. (...) It is demeaning to the human spirit to say that, being unconscious, he can have no interest in his personal privacy and dignity, in how he lives or dies'.²⁴ He concluded that in balancing these various ethical principles

the choice which the law makes must reassure people that the courts do have full respect for life, but that they do not pursue the principle to the point at

²¹ Donnelly M., 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (August 2016) 24(3) Medical Law Review 318

²² *Airedale NHS Trust v Bland* [1993] A.C. 789 (HL)

²³ *Ibid* 826

²⁴ *Ibid* 829

which it has become almost empty of any real content and when it involves the sacrifice of other important values such as human dignity and freedom of choice. I think that such reassurance can be provided by a decision, properly explained, to allow Anthony Bland to die.²⁵

The case of *Bland* highlights the importance of dignity in guiding the way in which individuals ought to be treated, even when they are not fully functioning rational beings. As Finnis writes, ‘the fact that Bland could indeed have been subjected to indignities, e.g. by being treated as a sex object or thrown, living, into the hospital rubbish, confirms that he remained a person with some interests’.²⁶

Beyond this, the court also appealed to Mr Bland’s right to self-determination and identity in order to guide its decision. Although Anthony Bland had no way of expressing his wishes, either alone or supported, the court still recognised a need to make a decision on his behalf that respected his interests by taking into account the views of those who knew him best and those who cared for him. Lord Goff of Chieveley identified this important element when he related that ‘(a)fter careful thought his family agreed that the feeding tube should be removed and felt that this was what Mr Bland would have wanted. His father said of his son in evidence: ‘He certainly wouldn’t want to be left like that’.²⁷ The application to the court to lawfully discontinue treatment was made by the NHS Trust ‘with the concurrence of Mr Bland’s family, as well as the consultant in charge of his case and the support of two independent doctors’.²⁸

This case illustrates how even when individuals are unconscious, appeals to dignity help guide their treatment. Here, it is interesting to see how the court gathers from those individuals Mr Bland was connected to some idea as to the way in which he would have liked to be treated should he had been able to decide for himself. The court here accepts the principle that ‘the wishes of the family will be given great weight’,²⁹ although ‘the relatives’ views cannot be determinative of the treatment’.³⁰

²⁵ Ibid 830

²⁶ Finnis J.M., ‘Bland: Crossing the rubicon?’ (1993) 109 Law Quarterly Review 329

²⁷ Ibid 861

²⁸ Ibid

²⁹ *Airedale v Bland* (n22) 871

It appears to embrace the idea of relational autonomy, one that identifies individuals as embedded in a web of relationships. The court takes into account the views of those who knew and cared for Mr Bland as the best way of approximating the ideal of upholding his self-determination.

b) The Mental Capacity Act 2005 and best interests determination

Bland is an extreme case where capacity is not at issue. In many other cases making a decision on behalf of someone hinges on a decision of lack of capacity. Capacity determination is the current legal mechanism used to decide whether an individual can be left to make his or her own decision. The Mental Capacity Act is underpinned by principles that reflect a will to enable independent decision-making and avoid unnecessarily paternalistic interventions.³¹ The model of capacity setting is rooted in welfare and best interest paradigms that dictate that when a person is held to lack capacity, a third party may step in and make a decision on her behalf according to her best interests. This model of decision-making appears at first blush not to take the incapacitated person's view into account, thereby disregarding her self-determination and equal status on ground of shared humanity. It does not seem conducive to conditions amenable to dignity under a discursive ethical framework.

Nonetheless, a closer reading of the principles and related guidelines underscoring the MCA reveals that the Act does strive to embrace a relational view of the person assessed, and to take her views and wishes into account. The first principle is a presumption in favour of capacity, reinforcing the idea that autonomous decision-making is a valuable paradigm, and that one cannot be deemed unable to make autonomous decision merely on the basis of certain characteristics (disability or age for instance).³² The Act reinforces the view that vulnerability should not be associated with particular traits. All individuals must be presumed to have capacity unless proven otherwise. For instance, there cannot be the assumption that because a person

³⁰ Ibid

³¹ Department for Constitutional Affairs, 'Mental Capacity Act 2005 Code of Practice' (The Stationary Office, 2007)

< <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>> Accessed 1st February 2018

³² Mental Capacity Act 2005, s.1(2)

is diagnosed with dementia they lack capacity about all their financial affairs.³³ A case must be made to prove that it is so.

The second principle mentions that, except in emergency medical situations, there must be an attempt to get individuals to make their own decision.³⁴ This principle advocates for the engagement of the person in communication through various means. The guidance suggests that this may be achieved through ‘using a different form of communication, for example non-verbal communication’, ‘providing information in a more accessible form, for example photographs, drawings, or tapes’, or ‘treating a medical condition that may be affecting the person’s capacity’.³⁵ This espouses a dialogical approach to decision-making, one that acknowledges the support individuals gain from inter-subjective relationships to form value judgments.³⁶ Indeed, help from ‘a family member, support worker, interpreter, speech and language therapist or advocate’ is encouraged in helping communicate with the person making the decision.³⁷ This approach also suggests the importance of the legitimacy of the decision arrived at, one that rests on the accountability of the autonomous choice.³⁸ This aspect of the principle gives value to the decision someone makes, because whether good or bad, it can be explained.

Indeed, the third principle states that ‘a person is not to be treated as unable to make a decision merely because he makes an unwise decision’.³⁹ This has been referred to as the authenticity conditions of autonomy, conditions that demand that ‘to count as autonomous, a person’s decisions, values, beliefs and commitments must be her ‘own’ in some relevant sense; that is, she must identify herself with them and they must cohere with her ‘practical identity’, her sense of who she is and what matters to her’.⁴⁰ Dworkin’s work can shed some light on the importance of this particular principle. Dworkin explains that we are indeed often not the best judges of our own

³³ Department for Constitutional Affairs (n31) 21

³⁴ Mental Capacity Act, s.1(3)

³⁵ Department for Constitutional Affairs (n31) 22

³⁶ Mackenzie C. and Rogers W., ‘Autonomy, vulnerability and capacity: a philosophical appraisal of the Mental Capacity Act’ (2013) 9 *International Journal of Law in Context* 37, 45

³⁷ Department of Constitutional Affairs (n31) 29

³⁸ Benson P. ‘Taking Ownership: Authority and Voice in Autonomous Agency’, in J. Christman and J. Anderson (Eds.), *Autonomy and the Challenges to Liberalism*. (Cambridge University Press, 2005) 101–126

³⁹ Mental Capacity Act 2005, s.1(4)

⁴⁰ Mackenzie and Rogers (n36) 43

best interests, making choices that can potentially harm us, and so questioning the validity of the claim that there is a welfare value attached to autonomy.⁴¹ Instead, autonomy is valuable on the basis of ‘the integrity rather than the welfare of the choosing agent’.⁴² It is found in the capacity to ‘express one’s character, values, commitments, convictions, and critical as well as experiential interests, in the life one leads’.⁴³ Experiential interests are those things we do ‘because we like the experience of doing them’, whereas our critical interests are those ‘convictions about what makes a life good on the whole’.⁴⁴

The fourth principle stipulates that ‘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 interest’.⁴⁵ Capacity determination is conducted by ‘the person who is directly concerned with the individual at the time the decision needs to be made’.⁴⁶ Once incapacity has been determined, a third-party decision will be made on behalf of the person following their best interest. This is achieved following ‘the person’s past and present wishes and feelings, the beliefs and values that would be likely to influence his decision if he had capacity, and the other factors that he would be likely to consider if he were able to do so’.⁴⁷ The guidance also states that ‘expressions of pleasure or distress and emotional responses will also be relevant’⁴⁸ showing that the person’s current state of mind is to be taken into account to inform the best interest decision. Part of the best interest procedure demands that those who know and care for the person who lacks capacity be consulted.⁴⁹ The determination of best interest strives to incorporate the views of the person deemed incapacitated by situating them within their relational world.

The fifth principle demands that when an act or decision is made on behalf of the incapacitated person, ‘regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person’s

⁴¹ Dworkin R., *Life’s Dominion: An Argument About Abortion and Euthanasia* (Harper Collins, 1993)

⁴² Ibid 224

⁴³ Ibid

⁴⁴ Ibid

⁴⁵ Department for Constitutional Affairs (n31) 26

⁴⁶ Ibid 53

⁴⁷ Mental Capacity Act 2005, s.4(6)

⁴⁸ Department for Constitutional Affairs (n31) 82

⁴⁹ Mental Capacity Act 2005, s.4(7)

rights and freedom of action'.⁵⁰ When a person is deemed to lack capacity, the decision to act on their behalf must always be questioned before it is taken; the person must always try to take the 'less restrictive alternative' to achieve the purpose of the decision.⁵¹ The guidance gives the example of a man with severe learning disabilities who suffers from a type of epilepsy that can cause him to fall and hurt himself. As he is deemed to lack capacity to decide on the best course of action to avoid this harm, his carers guided by the 'less restrictive alternative' decide that he should wear a protective helmet rather than be closely supervised, an idea he was not in favour of.⁵²

The principles underscoring capacity determination strive to give weight to the views of the cognitively impaired individual, through efforts made in dialogical engagement before, during and after capacity determination, at the time of best interests determination. These principles embrace a relational approach of the individual under the welfare/best interest paradigms that underpin the Mental Capacity Act, and therefore seem compatible with a discursive approach to dignity.⁵³ Following the enactment of the MCA, some proceedings of the Court of Protection have illustrated how best interest determination can be decided with the individual's identity and self-determination at its heart, placing them in the context of their relational autonomy.

A London Authority v JH is a case in point.⁵⁴ The court was asked to rule as to whether the best interest of Mrs H meant placing her in a care home after being discharged from hospital Mrs H was held to lack capacity, but her preferences, that of remaining at home, and the strength of her husband's wish to have her stay at home and look after her, were given real weight in the decision of the court to return Mrs H home with a package of care. In his summary about best interest determination District Judge Eldergill reflected that 'in coming to my decision, (...) [t]he quality of Mrs H's relationship with her husband, the strength of their marriage, and the fundamental importance of that relationship to her happiness and indeed her care, have deserved considerable weight'.⁵⁵

⁵⁰ Mental Capacity Act 2005 s.1(6)

⁵¹ Department for Constitutional Affairs (n31) 27

⁵² Ibid 28

⁵³ Herring J., 'Forging a relational approach: Best interest or human rights?' (2013) 13(1) *Medical Law International* 32

⁵⁴ [2011] EWCOP 2420

⁵⁵ Ibid [14]

The judgement also referred to the unreported case of *Re: GC*.⁵⁶ The court quoted the approach taken by Hedley J in the determination of a person's residence:

I have approached this case on the basis that (GC's) primary need is for emotional warmth, emotional security and the commitment of human relationship. That has been a huge feature of his life to date and one that is not readily to be set aside (...) it seems to me that for the elderly there is often an importance in place which is not generally recognised by others; not only the physical place but also the relational structure that is associated with a place.⁵⁷

This case demonstrates a concern with identity because of the importance placed by the court on the inter-personal networks that sustain it, and also a concern with self-determination because those individuals close to the vulnerable person are consulted to help make a decision that second-guesses, as it were, the preferences of the vulnerable individual.

HH Judge Hazel Marshall QC has also given an eloquent appraisal of the MCA's aim to take the incapacitated person's wishes into account. In the case of *Re: S and S* she declares that

[T]here has been a whole sea change in the attitude of the law to persons whose mental capacity is impaired. The former approach was based on a stark division between those who had capacity to manage their own affairs, and those who did not. The former took their own decisions for better or worse, and the latter fell under a regime in which decisions were made for them, perhaps with a generous, and in some cases patronising, token nod to their feelings by asking them what they wanted, and then deciding what nonetheless was objectively "best" for them. This is no longer appropriate. The statute now embodies the recognition that it is the basic right of any adult to be free to take and implement decisions affecting his own life and living, and that a person who lacks mental

⁵⁶ [2008] EWHC 3402 (Fam)

⁵⁷ Ibid

capacity should not be deprived of that right except insofar as is absolutely necessary in his best interests.⁵⁸

For this reason she concluded that ‘the views and wishes of P in regard to decisions made on his behalf are to carry great weight’,⁵⁹ and that ‘justification for overruling P and “saving him from himself” must, in my judgment be strong and cogent’.⁶⁰ This particular way of giving true weight to the wishes and views of the incapacitated person is conducive to conditions amenable to dignity under a discursive model, as it strives to take into account the identity, self-determination and equal status of the person concerned in best interest determination.

The case of *James* was the first one to reach the Supreme Court after the enactment of the MCA, clarifying the way in which to proceed in complex cases of best interest determination.⁶¹ In giving the judgment of the court, Lady Hale stated that

[i]n considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the wider sense, not just the medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.⁶²

In this particular instance, the importance of the patient’s family life, held by the court to be ‘of the closest and most meaningful kind’, weighed heavily in determining the value of the burdensome medical treatment Mr James was to receive.⁶³

⁵⁸ *Re: S and S, C v V* [2008] EWHC B16 (Fam) [51] to [52]

⁵⁹ *Ibid* [55]

⁶⁰ *Ibid* [58]

⁶¹ *Aintree Hospitals NHS Foundation v James* [2013] UKSC 67

⁶² *Ibid* [40]

⁶³ *Ibid*

Rejecting the objective test of ‘what the reasonable patient would think’ used by the Court of Appeal, Lady Hale emphasised that ‘the purpose of the best interests test is to consider matters from the patient’s point of view. This is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail’.⁶⁴ A more subjective approach is put forward, one where ‘insofar as it is possible to ascertain the patient’s wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being’.⁶⁵ Lady Hale reinforced the importance of the person’s wishes and her empowerment in the context of the duty to protect the Act demands. This case shows how the application of the MCA principles to the welfare practice of best interest determination can be conducive to dignity conditions under a discursive model. This is done by taking into account the incapacitated individual’s place within her relational world to support her identity, and by giving considerable weight to her interest in self-determination, through empathetic decision-making, with a view to treating her with equal respect on the ground of her humanity.

Prior to this ruling cases occurred where the court did not give real weight to the wishes of the incapacitated person. In the case of *Re P*,⁶⁶ Lewison J. pointed out that ‘the Act does not of course say that P’s wishes are to be paramount, nor does it lay down any express presumption in favour of implementing them if they can be ascertained. Indeed the paramount objective is that of P’s best interests’.⁶⁷ For this reason he declared that Judge Marshall QC in the case quoted above ‘may have slightly overstated the importance to be given to P’s wishes’.⁶⁸

Even after *James*, some cases have interpreted best interests in a way that makes it unclear whether any real weight was paid to the incapacitated person’s point of view. In the case of *RB v Brighton and Hove City Council*,⁶⁹ the Court of Appeal held that it was in the best interest of the Appellant to remain in a care home in order to prevent

⁶⁴ Ibid [45]

⁶⁵ Ibid

⁶⁶ [2009] EWCH 163 (Ch)

⁶⁷ Ibid [56]

⁶⁸ Ibid [41]

⁶⁹ [2014] EWCA Civ 561

him from hurting himself,⁷⁰ despite the fact the he wished to live independently.⁷¹ Although Judge Horowitz declared that he had taken the Appellant's wishes into account, there is no detail in his judgment as to how much they contributed to his final decision.

The problem remains that away from the courtroom best interest determination may be poorly implemented in every day care practice. A House of Lords report published in 2014 has confirmed that the application of the MCA in a person centred way is failing to be implemented in social care settings:

The empowering ethos of the Act has not been widely implemented. Our evidence suggests that capacity is not always assumed when it should be. Capacity assessments are not often carried out; when they are, the quality is often poor. Supported decision-making, and the adjustments required to enable it, are not well embedded. The concept of unwise decision-making faces institutional obstruction due to prevailing cultures of risk-aversion and paternalism. Best interest decision-making is often not undertaken in the way set out in the Act: the wishes, thoughts and feelings of P are not routinely prioritised. Instead, clinical judgments or resource-led decision-making predominate. The least restrictive option is not routinely or adequately considered.⁷²

A lack of awareness by professionals, the individuals cared for and their relatives, of the 'rights and responsibilities' that the Act sets out has been blamed for this lack of implementation.⁷³ The report furthermore points to a need for a 'fundamental change of attitudes among professionals (...) from paternalism to enablement'.⁷⁴ The report notes that the presumption of capacity especially 'is widely misunderstood', and that it is 'sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm', or 'misappropriated to avoid taking responsibility for

⁷⁰ Ibid [83]

⁷¹ Ibid [81]

⁷² House of Lords, Select Committee on the Mental Capacity Act 2005, Report of Session 2013-2014, 'Mental Capacity Act 2005: post-legislative scrutiny' (The Stationary Office Limited, 13th March 2014), [104]

⁷³ Ibid [106]

⁷⁴ Ibid [108]

a vulnerable adult'.⁷⁵ This report highlights how without adequate implementation of the principles guiding the MCA to respect the relational autonomy of the individual, a strict mechanism of substituted decision making may hinder the creation of conditions amenable to dignity realisation for the cognitively impaired person.

The application of the MCA has had wide-ranging and deeply personal consequences on the lives of those deemed to lack capacity, denying them the possibility to live where they would like,⁷⁶ removing from them the freedom to have contact with their family,⁷⁷ or denying them the choice of sexual partners.⁷⁸ Free from the person-centred interpretation of best interests determination set out by *James*, the MCA can give the court the power to strictly control the autonomy of the person deemed to lack capacity in the name of protection. These interventions have curtailed the self-determination and identity of the individual, and undermined their equal status on the ground of their humanity, creating conditions where dignity remains, as Nussbaum puts it, 'but a promissory note'.⁷⁹ It is essential therefore, in order to create conditions amenable to a discursive meaning of dignity, that the incapacitated person's wishes be given true weight in the determination of best interest. As Lady Hale reminded the court in the case of *James*, the MCA 'is 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'.⁸⁰

Munby J. has provided a useful checklist to follow in relation to 'the weight and importance to be attached to P's wishes and feelings'.⁸¹ He suggests to take into account

- 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;

⁷⁵ Ibid [105]

⁷⁶ *PH v A Local Authority* [2011] EWCH 1704 (Fam)

⁷⁷ *A Local Authority v FG, AG and HG* [2011] EWHC 3932 (COP)

⁷⁸ *A Local Authority v H* [2012] EWHC 49 (COP)

⁷⁹ Nussbaum M., *Creating Capabilities* (Harvard University Press, 2011), 30

⁸⁰ *Aintree Hospitals NHS Foundation v James* (n61) [18]

⁸¹ *ITW v Z* [2009] EWHC 25254 (Fam), [35]

- d) the extent to which P's wishes and feelings are, or are not, rational, sensible, 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.⁸²

Although this list not prescriptive, it gives a practical example of how the court and care professionals on the ground could make best interests decisions informed by the wishes and feelings of the incapacitated person.

c) The supported decision-making model

The MCA model may also undermine a person's dignity by failing to be responsive to her vulnerability in cases where individuals are on the margins of capacity. Under the current law, once a person is deemed to have capacity, they are deemed able to determine their own fate and make unfettered decisions. In elderly care, many individuals are situated on the edges of capacity. Herring argues for a more sophisticated model of capacity that would be more responsive to those with degenerative conditions such as dementia and Alzheimer's.⁸³ He gives the following hypothetical example:

Andrew has early stages Alzheimer's disease. At night times he has taken to wandering off in the local woods for hours at a time, often without sufficient clothing to keep him warm. Further, it has been discovered that he has been spending substantial sums of money viewing internet pornography. This is despite the fact that previously he had been a devout religious and of conservative moral views who has been carefully saving money for his care in old age. His wife and relatives are concerned for his wellbeing. This is not, they think, how he would have wished to live his life. It is accepted by Andrew's doctors that the

⁸² Ibid

⁸³ Herring J., 'Losing It? Losing What? The Law and Dementia' (2009) *Child and Family Law Quarterly* 21(1)

case is not a straightforward one, but they are persuaded, just, that he has capacity to make decisions about his lifestyle.⁸⁴

Herring argues that ‘not all autonomous decisions carry the same weight’,⁸⁵ and so ‘where a person is on the borderline of incapacity, but who wishes to engage in behaviour which may be harmful to himself, it may be properly said that, even if technically competent, his decision does not reflect a decision based on a higher-order preference’.⁸⁶ Consequently, he concludes that ‘the harm that he is risking with its consequent impact on autonomy later is such that autonomy requires the decision not to be respected’.⁸⁷ Herring is right in arguing that a model based on capacity setting may not be adequate to respond to the needs of those at the edges of capacity, but I believe that his conclusion – limiting current autonomy in the interest of future autonomy – risks letting paternalism back in through the backdoor.⁸⁸

A more flexible way to respond to Andrew’s heightened state of vulnerability without completely impinging on his autonomy could exist in the opportunity of formal support. A model of supported decision-making may be more responsive to individuals’ vulnerability in cases of degenerative cognitive diseases brought on by age than that of strict capacity setting. In the case of Andrew, the support of a trusted third party may be more responsive to his vulnerable state by considering the harm he is likely to suffer, whilst at the same time considering his autonomy and identity. Support would not be there to forbid a person from making decisions they would not have made before they were ill, but it may be more responsive to their vulnerability than a strict application of capacity, which would not offer any support until incapacity was agreed upon.

Supported decision-making is endorsed by Article 12 of the Convention of the Rights of Persons with Disabilities (CRPD) entitled ‘Equal recognition before the law’,

⁸⁴ Ibid 7

⁸⁵ Ibid 10

⁸⁶ Ibid 10

⁸⁷ Ibid 10

⁸⁸ Cf Peleg N. ‘Reconceptualising the Child’s Right to Development: Children and the Capability Approach’ (2013) 21 *International Journal of Children’s Rights* 523 (arguing that children’s exercise of whatever capacity for autonomy they possess should not be unduly subordinated to a concern for the child’s future as a fully autonomous adult).

which seeks to ‘provide access by persons with disabilities to the support they may require in exercising their legal capacity’.⁸⁹ Here legal capacity is a given, not a threshold to be cleared, and support is to be available to give rise to it for those who need it. It is underpinned by a more egalitarian viewpoint that considers that ‘persons with disabilities enjoy legal capacity on an equal basis with others’.⁹⁰ This support may come in various forms and includes the help of trusted persons, peer support, advocacy, or assistance with communication, verbal or non-verbal.⁹¹

The support model has been adopted in various jurisdictions.⁹² In Sweden, a system of Personal Ombudsmen (PO Skåne) has been in force to help support the decision-making process of individuals with mental health problems.⁹³ The website dedicated to this system highlights the ethos behind its existence;

The social model of disability says that the problem is not within the individual, but in the society which does not meet this person in such a way that he can function. This applies also to problems with legal capacity. It’s not a problem inside the individual – which should be met by forced intervention or guardianship – but society must relate in another way to this person, so that his disabilities regarding legal capacity diminishes.

Supported decision-making is an example of this. If some persons find it hard to express and communicate their wishes, the solution is not to put in a guardian, but to develop a relation and ways, which make it possible for this person to express and communicate what he wants.

In our service with personal ombudspersons the most important thing has been to develop ways to work which are adjusted to this special group of persons with mental health problems of the most difficult kind. In other projects it is

⁸⁹ Covenant on the Rights of Persons with Disabilities, Article 12(3)

⁹⁰ Covenant on the Rights of Persons with Disabilities, Article 12(2)

⁹¹ Committee on the Rights of Persons with Disabilities, 11th Session, General Comment No.1, 31March-11 April 2014, [17]

<<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>>
Accessed 21st December 2016

⁹² Goodling P., *A New Era for Mental Health Law and Policy; Supported Decision-Making and the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2017)

⁹³ PO Skåne, Personal Ombudsman in Skåne <<http://po-skane.org/in-foreign-languages/>> Accessed 21st December 2017

usually the clients who have to adjust themselves to a bureaucratic system, but we work in the opposite way. The PO's have to be very flexible and creative and unconventional in finding ways to work with this group.⁹⁴

In Canada the Representation Agreement Act 1996 (RRA) is another example of an application of the support model of decision-making. It provides that 'an adult may authorize his or her representative to help the adult make decisions, or to make decisions on behalf of the adult' in the areas of the person's care, financial affairs, purchases of services and goods, or the obtaining of legal services.⁹⁵ Under the MCA model, it is also possible for a person to give to another Lasting Powers of Attorney (LPA), in order for that person to make for them decisions regarding their welfare, property and affairs.⁹⁶ The person requesting a LPA to be set up must, under the MCA, have capacity to do so.⁹⁷ Furthermore, the person with Lasting Powers of Attorney (the donee) is not authorised to help the person who has appointed her (the donor) until it has been shown that the donor lacks capacity.⁹⁸

The setting up of support under the RRA is not so strict and does not hinge on the determination of capacity, making it more responsive to vulnerability. Section 8 of the RRA specifies that

- (1) An adult may make a representation agreement consisting of one or more of the standard provisions authorized by section 7 even though the adult is incapable of
 - (a) making a contract,
 - (b) managing his or her health care, personal care or legal matters, or
 - (c) the routine management of his or her financial affairs.

⁹⁴ PO Skåne website, 'Information about Personligt Ombud in English and other languages'

< <http://po-skane.org/in-foreign-languages/> > Accessed 1st January 2018

⁹⁵ Representation Agreement Act, RSBC 1996 c405 s.7

⁹⁶ Mental Capacity Act s.9(1)

⁹⁷ Mental Capacity Act s.9(2)(c)

⁹⁸ Mental Capacity Act s.11

The decision to refuse a person to enter into an agreement does exist, but it is not taken likely by the RRA; many safeguards are to be followed before such a decision is taken.

(2) In deciding whether an adult is incapable of making a representation agreement consisting of one or more of the standard provisions authorized by section 7, or of changing or revoking any of those provisions, all relevant factors must be considered, for example:

(a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;

(b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;

(c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;

(d) whether the adult has a relationship with the representative that is characterized by trust

Thus although Andrew may have been allowed to organise an agreement of LPA under the MCA (although in the example he is deemed to have capacity for his welfare and finances, he may not be deemed to have capacity to enter into a contract), he would not have been supported by it until he was assessed as lacking capacity. Under section 15 of the RRA, on the other hand, ‘a representation agreement becomes effective on the date it is executed unless the agreement provides that it, or a provision of it, becomes effective later’.

The capacity threshold, as Herring’s example shows above, may prevent a person from being supported when their vulnerability becomes harmful to them. The main difference between the agreements made under the RRA and those of made under the Lasting Powers of Attorney is that of degree of responsiveness to vulnerability. There is no need to lack capacity in order to be supported under the RRA; the person can choose third parties to act on her behalf before incapacity is determined, and so be

more responsive to her vulnerability whilst considering her relational autonomy. Even when we have capacity, we all tend to refer to others when making important decisions, and this model formalises this natural process.⁹⁹

In order to balance the two paradigms of empowerment and vulnerability protection in a way that would be more respectful of the person's wishes and preferences, it has been suggested that the MCA could be amended to be compliant with Article 12 of the CRPD. At the moment the Committee on the Rights of Persons with Disabilities has held in its first General Comment that “best interpretation of will and preferences” must replace the “best interests” determinations’, suggesting that the MCA was not compatible with the equal recognition before the law paradigm set out under Article 12 of the CRPD.¹⁰⁰ The work of the Essex Autonomy Project highlights that

[in the MCA] the best-interests decision-maker [must] *CONSIDER* the wishes and feelings, values and beliefs of the person lacking in capacity. But Article 12(4) requires *RESPECT* for the will and preferences of disabled persons. Whatever “respect” means in this context, it must be something stronger than “consider,” even though it is less than “be absolutely bound by.” For it is possible to *consider* someone's rights, will and preferences without *respecting* them. The safeguards in the MCA's best-interests provisions must therefore be strengthened in order to achieve compliance with the CRPD.¹⁰¹

This incompatibility does not mean that I believe that the MCA ought to be replaced by other legal provisions. I believe that amending the MCA in order to comply with the ethos of the CRPD would offer the best compromise between vulnerability protection and respect for the person's wishes and make the MCA amenable to dignity. I would agree with Donnelly that the ‘MCA's potential to provide a legal framework of principled, open, and accountable decision-making should not be

⁹⁹ Series L., ‘Here's how they do it in BC’ The Small Places (9th May 2012)
< <http://thesmallplaces.blogspot.fr/2012/05/heres-how-they-do-it-in-bc.html>> Accessed 1st January 2018

¹⁰⁰ CRPD General Comment No.1 (n91) [21]

¹⁰¹ Martin W., Michalowski S, Jütten T and Burch M., ‘Achieving CRPD Compliance’ Essex Autonomy Project (22nd September 2014), 43
< <https://autonomy.essex.ac.uk/wp-content/uploads/2017/01/EAP-Position-Paper-FINAL.pdf>>
Accessed 30th December 2017

underestimated'.¹⁰² As Keene and Auckland have argued, the MCA can become compatible with the ethos of the CRPD by providing a fully supported decision making model whilst at the same time being responsive to the person's vulnerability.¹⁰³ Referring to HH Judge Hazel Marshall's reasoning in the case of *Re: S and S*,¹⁰⁴ the Essex Autonomy Project suggests that this can be achieved by the application of 'a rebuttable presumption that it is in the best interest of P to bring about the course of action that P prefers'.¹⁰⁵ Considering her approach, the Essex Autonomy Project report suggests that the person's wish shall be fulfilled in best interest determination if it meets the following conditions:

1. W is a wish which a person of full capacity might reasonably have.
2. W is physically implementable.
3. A person with full capacity having resources such as P's might reasonably consider it worth using the resources necessary to fulfil W.
4. There is no potential sufficiently detrimental effect that would provide a strong and cogent justification for overruling P's wishes.¹⁰⁶

This is just one suggestion of how to make the MCA CRPD-compliant. There is no answer in the report as to the definition of what would constitute this 'potential sufficiently detrimental effect' that could justify overruling P's wishes.¹⁰⁷ Keene and Auckland argue that going against P's wishes ought to be backed up by substantial justifications, just as those required when restricting a person's right to respect for private and family life under Article 8.¹⁰⁸ The threshold of detriment ought to be high, so as to avoid falling back into a model where the opinion of a third party can too easily override P's wishes. Such a model of decision-making, one endorsed by a CRPD-compliant MCA would give rise to conditions amenable to dignity under a

¹⁰² Donnelly (n21) 332

¹⁰³ Keene A.R. and Auckland C., 'More presumptions please? Wishes, feelings and best interests decision-making' [2015] Elder Law Journal 293

¹⁰⁴ *Re: S and S, C v V* [2008] EWHC B16 (Fam), [57] [58]

¹⁰⁵ Martin et al (n 101) 48

¹⁰⁶ *Ibid* 48-49

¹⁰⁷ *Ibid* 51

¹⁰⁸ Keene and Auckland (n104) 300

discursive model. It would do so by giving true weight to the wishes of the incapacitated person under a legal scheme aimed also at protecting her vulnerability.

4) Restraints and deprivation of liberty

Measures set out to counteract the effects of vulnerability are also found within the regulatory regime that rules care provision. Providers are under the obligation of keeping residents safe,¹⁰⁹ and free from harm.¹¹⁰ This specifically allows ‘acts that are intended to control or restrain a service user that are not necessary to prevent, or not a proportionate response to, a risk of harm posed to the service user or another individual’.¹¹¹ These particular measures reflect the difficulty carers are faced with in dealing with patients with dementia who may feel the need to wander outside of the care home, or become aggressive towards them.¹¹²

The law governing the use of restraint is also found under the Mental Capacity Act 2005. Under the Act, only those who lack capacity may be restrained without their consent, and this must be done so for their best interest.¹¹³ Restraining someone is defined under the Act as using or threatening to use force to make someone do something they are resisting doing, or restricting someone’s liberty of movement, whether the person agrees to it or not.¹¹⁴ As the report on restraint published by the Equality and Human Rights Commission concludes, ‘unless older people do not have capacity, restraint may only take place with their consent or in emergency to prevent harm. Used inappropriately, restraint can constitute abuse – which is subject to referral under the local multi-agency procedures for safeguarding adults – as well as being a criminal offence’.¹¹⁵ The unjustified use of restraint may amount to common

¹⁰⁹ Regulation 12, Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

¹¹⁰ Regulation 13, Health and Social Care Act 2008 (Regulated Activities) 2014

¹¹¹ Regulation 13(4)(b), Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

¹¹² Alzheimer Society, Caring for a person with dementia, publications

<https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2581> Accessed 16th December 2016

¹¹³ Mental Health Act 2005, s.5

¹¹⁴ Mental Capacity Act 2005, s.4(a) and s.4(b)

¹¹⁵ Commission for Social Care Inspection, ‘Rights, risks and restraints’ (November 2007)

<<https://www.equalityhumanrights.com/sites/default/files/restraint.pdf>> Accessed 7th November 2016,

assault, battery, assault occasioning actual bodily harm, or harassment.¹¹⁶

Restraints can be physical (where residents can be tied to beds or chairs), but can also be chemical (use of drugs to sedate the person), technological (keypads on doors or electronic tagging), environmental (lay out that prevents people from freely moving around), or passive (refraining from helping someone get around can be restrictive).¹¹⁷ A report compiled by the SCIE suggests that a variety of reasons are invoked for the use of such restrictions on a person's liberty.¹¹⁸ The literature review this report is based on is a compilation of studies done in the context of care homes about the use of physical restraints. These highlighted that restraints were used in a majority of cases for the person's safety (to prevent falls or injury), to manage agitation (again to prevent harm), to stop people wandering off, but also to help staff manage their workload.¹¹⁹ The latter reason could be read as a safeguarding measure, but the overriding concern should rest with the safety of the person restrained, and not the speedier delivery of care.

Restraining someone may become a deprivation of her liberty and so breach her right to liberty and security guaranteed under Article 5 of the Human Rights Act. Under the Mental Capacity Act, deprivation of liberty is defined as having the 'same meaning as in Article 5(1) of the Human Rights Convention'.¹²⁰ Article 5(1) states that '[e]veryone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law'. This includes 'the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants'.

¹¹⁶ Lyon C.M. and Pimor A., *Physical interventions and the law: legal issues arising from the use of physical interventions in supporting children, young people and adults with learning disabilities and severe challenging behavior* (British Institute of Learning Disabilities, 2004), 146

¹¹⁷ Lombard D., 'Proven Practice: Minimising the use of restraint in care homes for elderly people' (Community Care, November 26th 2009)
< <http://www.communitycare.co.uk/2009/11/26/proven-practice-minimising-the-use-of-restraint-in-care-homes-for-elderly-people/>> Accessed 1st November 2016

¹¹⁸ Qureshi H., 'Report 26: restraint in care homes for older people: a review of selected literature' (2009, SCIE)
< <http://www.scie.org.uk/publications/reports/report26.pdf>> Accessed 1st November 2016

¹¹⁹ See Chapter II

¹²⁰ Mental Capacity Act 2005 s.64(5)

The Supreme Court has clarified the meaning of deprivation of liberty in the *Cheshire West* case.¹²¹ Considering the jurisprudence of the European Court of Human Rights on the subject, Lady Hale held that an ‘acid test’ to find out whether there was a deprivation of liberty consisted in determining whether the person was subject to continuous supervision and was not free to leave.¹²² It was held that depriving a person without capacity of her liberty had little to do with the quality of her care, and that ‘a gilded cage was still a cage’.¹²³

A restraint can therefore become a deprivation of liberty and so require additional safeguards. Following this acid test, it can be envisaged that many situations within care homes could amount to deprivations of liberty. The Law Society cites the following example as one that could amount to a deprivation of liberty because of the degree of supervision and control involved, and the fact that the individual concerned is not free to leave:

Mrs Neville is eighty-five. She lives in a care home with nursing and has Alzheimer’s dementia which is now advanced. She is very confused and disorientated, and can now only manage very simple conversations. She is physically fit and mobile. She spends much of the day wandering in the corridors of the nursing home. The doors are locked and there is a sensor on the doormat at each entry to the home. On one occasion Mrs Neville found her way out of the back door of the home, which had been left open in warm weather. She was spotted walking towards the main road and immediately escorted back. Mrs Neville frequently shouts and screams and is gently escorted from the communal areas when she is making a noise, to reduce disturbance to other residents. Mrs Neville is resistant to personal care and can lash out at staff. All her personal care is delivered by two members of staff.¹²⁴

As this example illustrates, it may be very complex for care professionals to identify a case of deprivation of liberty so as to comply with the additional safeguard procedures

¹²¹ *P v Cheshire West Council; P&Q v Surrey County Council* [2014] UKSC 19

¹²² *Ibid* [48] [49]

¹²³ *Ibid* [46]

¹²⁴ Law Society, ‘Identifying a deprivation of liberty: a practical guide’ (9th April 2015)

< <http://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/> > Accessed 9th November 2016

it entails. Once the need for a deprivation of liberty has been identified, Deprivation of Liberty Safeguards (DOLS) set out under the Mental Health Act 2007, require the care home to seek authorization from the local authority when it requires depriving a person of her liberty.¹²⁵ Failing to do so will mean that the home is in breach of its obligation under Article 5. Depriving someone of their liberty can be used for the purpose of ‘giving life-sustaining treatment’ or ‘doing any vital act’ that will ‘prevent a serious deterioration’ of the condition of the person concerned.¹²⁶ The onus on the care home to keep a person safe whilst respecting their right to freedom is a difficult balancing act that is made all the more complicated by the vague definition of deprivation of liberty and the burdensome administrative safeguarding process that ensues.

Following the *West Cheshire* ruling defining the test for deprivation of liberty, it was reported that requests for DOLS soared. In the year 2015-2016, care homes requested local councils to approve 195,840 applications of DOLS, the most ever recorded since their introduction in 2009.¹²⁷ Out of all these applications, only 105,055 (or a little better than half) were completed by the local authorities, of which 73 per cent (105,055) were approved. These alarmingly high figures have resulted in delays in the application process and the commission by government of a Law Commission consultation of the DOLS process.¹²⁸ In this report, DOLS are criticised for focusing too narrowly on Article 5,¹²⁹ and failing to consider the impact that a deprivation of liberty may have on Article 8 obligations of respect for family life and home.¹³⁰

As I illustrated above, recognising a situation of deprivation of liberty on the ground can be extremely difficult, leading many healthcare professionals to ultimately ‘lack knowledge of, and confidence in, the DOLS’, seeing them as a bureaucratic process rather than a benefit to the person concerned, and so relying on their local authorities

¹²⁵ Mental Health Act 2007, s.50

¹²⁶ Ibid

¹²⁷ NHS Digital, ‘Mental Capacity Act 2005, Deprivation of Liberty Safeguards (England), Annual Report 2015-2016’ (September 2016)

< <http://content.digital.nhs.uk/catalogue/PUB21814>> Accessed 20th October 2016

¹²⁸ Law Commission, ‘Mental Capacity and Deprivation of Liberty: A Consultation Paper’ Consultation Paper No 222 (The Stationary Office, 2015)

< http://www.lawcom.gov.uk/wp-content/uploads/2015/07/cp222_mental_capacity.pdf> Accessed 9th November 2016

¹²⁹ Ibid 2.14

¹³⁰ Ibid 2.16

to set them in motion.¹³¹ Finally, the Law Commission highlights the fact that DOLS only deal with the ‘fait accompli’, once a person reaches a stage where her liberty needs to be restricted, but does not address any preventive measures.¹³²

The Law Commission suggests that DOLS should be replaced with a new system it refers to as ‘protective care’.¹³³ This new system would follow the principles espoused by the Mental Capacity Act exposed above, would be easier to follow, tailored to the individual and the setting involved, and be compliant with Convention rights and the UN Disability Convention.¹³⁴ This proposal acknowledges that depriving individuals of their liberty may be unavoidable in order to care for them safely and protect their vulnerability, but that it may be done in a way that involves the individuals as much as possible, respects their wider relationships and identity, is designed for the benefit of their overall wellbeing (and not only to comply with bureaucracy), and is as little imposing as possible on their self-determination.¹³⁵

These proposals focus far more on the person and her place within her own narrative than the previous system, largely anchored in procedures rather than the individual. Although these proposals are yet to be detailed, it seems that they would be far more aligned to the understanding of dignity put forward here than the previous DOLS regime. This is because, although they are an imposition on the person’s autonomy for the sake of the protection of their inherent vulnerability, they are more designed with the person’s relational autonomy in mind.

Others have advanced the idea that caring for the elderly ought to be done without restraint, because restraint is seldom justifiable and harms individuals more than it preserves them from harm.¹³⁶ Researchers in behavioural management have observed that conflictual tendencies in residents who suffer from dementia can be managed through appropriate responses from care professionals. For instance, Hall and Buckwalter have found out that patients with Alzheimer’s disease needed to be

¹³¹ Ibid 2.15

¹³² Ibid 2.17

¹³³ Ibid 3.2-.3.23

¹³⁴ Ibid

¹³⁵ Ibid

¹³⁶ Evans, L.K. and N. Strumpf ‘Myths about elderly restraint’ (1990) 22 Image: Journal of Nursing Scholarship 124

exposed to less stimulation in order to reduce their level of stress and prevent aggressive behaviour.¹³⁷ A change in approach from ‘custodial’ safety to ‘behavioural management’ safety could create an environment more amenable to the possibility of dignity. Williams and Finch consider this type of restraint-free care to be ‘an alternative philosophy’ in care, one that could replace the ‘task driven, staff oriented care now practiced’.¹³⁸ Reforming current laws on restraints by placing the individual at its heart may enhance the possibility of dignity, but removing restraint altogether may prove even more effective in the creation of conditions amenable to dignity.

5) Conclusion

Legal measures in place to intervene in the protection of the person in care from the effects of their vulnerability are slowly beginning to reflect a more concrete understanding of autonomy. The Care Act and the Mental Capacity Act are now built on a more universal approach to vulnerability, rejecting the old characteristics-based model of previous guidance. Although still more weight could be given to the voice of the person whose vulnerability these measures are meant to be responsive to, these legislative reforms are beginning to facilitate, in social care, the creation of conditions conducive to dignity under a discursive model.

Safeguarding is now a statutory duty of local authorities under the Care Act 2014. Safeguarding appears to embrace a universal idea of vulnerability, to take the individual’s relational autonomy into account, and to be responsive to all adults who need care and support and are at risk of harm. Nonetheless, some have argued that the duty of enquiry by local authority under section 42 is only ‘facially neutral’.¹³⁹ The duty to make enquiry is triggered when the local authority ‘has reasonable cause to suspect that an adult in its area has needs for care and support is experiencing or is at risk of abuse or neglect, and as a result of those needs is unable to protect himself or

¹³⁷ Hall G.R. and Buckwalter K.C., ‘Progressively lowered stress threshold: a conceptual model for care of adults with Alzheimer’s disease’ (1987) 1(6) *Archive of Psychiatric Nursing* 399

¹³⁸ Williams C.C. and Finch C.E., ‘Physical Restraint: Not Fit for Woman, Man or Beast’ (June 1997) 45(6) *Journal of the American Geriatric Society* 773, 774

¹³⁹ Flynn E. and Arstein-Kerslake A. ‘State intervention in the lives of people with disabilities; the case for a disability-neutral framework’ (2017) 13(1) *International Journal of Law in Context* 39, 44

herself against the abuse or neglect or the risk of it'.¹⁴⁰ They argue that as needs for care meet the eligibility criteria when they 'arise from or are related to a physical or mental impairment or illness',¹⁴¹ they create a bias for intervention directed at disabled individuals.¹⁴² It has been argued that this problem could be remedied by the use of a more neutral form of language in the Care Act that would trigger safeguarding interventions on the basis of the occurrence or risk of occurrence of 'serious adverse effects' a person may experience.¹⁴³ This form of interventionism would be more disability neutral, and encourage safeguarding measures to be rooted in the effects of vulnerability rather than its causes. Although the Care Act 2014 has moved away from defining vulnerability as attached to particular characteristics, progress could still be made to embrace an even more inherent and universal view of vulnerability.

I have argued that dignity under a discursive ethics is not capacity dependent, and that the relational situation of the individual helps give rise to it. The principles underpinning the Mental Capacity Act are promoting an ever more person-centred view of capacity and best interests determination, creating conditions more amenable to dignity. Some measures now reflect the understanding that individuals are anchored in their relational narrative, and that this fact needs to be respected when protecting a person from their vulnerability. The supported model of decision-making enshrined in the CRPD brings novel ideas to the model of capacity and best interests determination. Article 12 sets out that all individuals have legal capacity, but that some individuals need support to give rise to it. It thrives to uphold equality and self-determination, and so could further improve on the possibility of dignity. I have discussed the possibility of amending the MCA to make it compatible with the egalitarian ethos of Article 12 of the CRPD; this could be achieved by giving even more weight to the views and wishes of the incapacitated individual through reinforcing the presumption of capacity strand of the MCA.

The laws that govern restraining practices are being targeted for reform. At the moment safeguards are in place to make restraints considered to be deprivations of

¹⁴⁰ Care Act 2014 s.42(1)

¹⁴¹ The Care and Support (Eligibility Criteria) Regulations 2014, s.2(1)(a)

¹⁴² Flynn and Arstein-Kerslake (n139)

¹⁴³ Ibid 47

liberty compliant with Article 5. Unfortunately, these safeguards are adding to the weight of bureaucracy faced by councils without effectively protecting the human rights of the person being restrained. The Law Commission has therefore suggested further reforms under the label of ‘protective care’, a framework of rules that seeks to manage restraints with the person concerned and all her human rights at its heart. Once again, giving rise to dignity by striking the right balance between responsiveness to vulnerability and respect for the person’s own wishes is proving hard to achieve. Although a care environment free of restraints is a goal that may never materialise, legal reforms are moving towards the creation of conditions more amenable to dignity.

In the next chapter I will look at the environment the older people in care live in, and how the regulations controlling it - enacted because of the vulnerability of those who live there - impact on the possibility of dignity.

Chapter V

Environmental Conversion factor: the care home regulatory framework

1) Introduction

In the last two chapters, I examined the *personal* conversion factor of vulnerability. I established, as a starting point, that vulnerability should be understood as universal and inherent, according to Fineman's approach, one that demands a responsive state. I also argued that in order to be a practical basis for policy-making, vulnerability required a thicker conceptualisation. To that effect I adopted Mackenzie's definition of vulnerability as inherent, situational and pathogenic, and applied it to individuals in care. I also suggested that to be amenable to dignity, the protection of vulnerability needed to take into consideration the relational autonomy of the individual. I then proceeded to evaluate, in light of these considerations, the defensibility and effectiveness of specific legal provisions set out to protect but also manage the multi-dimensional vulnerability of the dependent elderly, (such as safeguarding, the establishment of capacity and the use of restraints).

In this chapter I will consider the regulatory framework that shapes the care home environment, making it an *environmental* conversion factor to dignity- that is, a factor which, like the *personal* conversion factor of vulnerability, mediates the ability of elderly people in care to experience dignity. Indeed, these two conversion factors are intimately connected: the extreme and multi-dimensional vulnerability of those who live in long-term care facilities means that the care home environment is heavily regulated.

The way care homes are run in England is under the scrutiny of the Care Quality Commission (CQC). The CQC is an independent regulator that was set up in 2009

under the Health and Social Care Act 2008 (HSCA),¹ to streamline costs and replace three different regulatory bodies, the Healthcare Commission, the Commission for Social Care Inspection and the Mental Health Act Commission.² My intention is to assess whether and how the current regulatory framework is conducive to the establishment of those conditions necessary for dignity as conceptualised in this paper. This means looking at the substance of the rules that shape the kind of care residents receive, the means at the disposal of the CQC and beyond to enforce those rules, but also the impact they may have on the working practices of the care professionals who work in those regulated environments.

I will firstly expound the meaning, causes and aims of regulation generally, and then focus more particularly on the regulatory framework applied by the CQC to long-term aged care. I will review the relatively new care home regulation framework in place, concentrating specifically on the regulatory outcome of dignity. Drawing on the work of Braithwaite et al who have observed the regulatory system at play in care homes over many years in England and abroad,³ I will argue that in order for regulation to be effective in the upholding of dignity as understood here, the regulation framework ought to set out broad standards for quality of care instead of adopting disempowering objective rules. In order to avoid vagueness, these broad standards should be complemented by subjective criteria obtained from conversations with residents and those who care for them. In order for conditions amenable to dignity as to be fostered by regulation, this dialogical engagement ought to be used to define regulatory objectives so as to move away from set rules externally imposed on residents.

2) Purpose of Regulation

Institutional living may pose considerable dangers to the possibility of dignity:

¹ Health and Social Care Act 2008, Part One

² The Gershon Review noted that ‘front line delivery bodies often ad to deal with a plethora of bodies as funders and regulators, leading to significant additional delivery costs’ in Gershon P., ‘Releasing resources to the front line. Independent Review of Public Sector Efficiency’ July 2004, 45
<http://webarchive.nationalarchives.gov.uk/20130129110402/http://www.hm-treasury.gov.uk/d/efficiency_review120704.pdf> Accessed 31st March 2015

³ Braithwaite J., Makkai T. and Braithwaite V., *Regulating Aged Care: Ritualism and the New Pyramid* (Edward Elgar Publishing, 2007)

Nursing homes are total institutions,⁴ ... in the sense that they isolate, control, and reconstitute the daily lives of their residents. Stripping away and reconstituting the identities of their residents through rituals of initiation and degradation accomplish this.⁵

Regulations play an important part in determining the kind of environment a person in institution lives in. Regulation is deployed in two different ways: economically and socially. Regulating a particular sector of the economy has been justified in cases of 'market failures', where the market-place cannot 'produce behaviours or results in accordance with the public interest'.⁶ It has also been recognised as grounded in human rights, as a mean to promote social solidarity.⁷ Indeed, regulation has been defined as 'the sustained and focused attempt to alter the behaviour of others according to defined standards or purposes with the intention of producing a broadly identified outcome or outcomes, which may involve mechanisms of standard-setting, information-gathering and behaviour modification'.⁸ It is, according to Ogus, 'an area of public law which implements collectivist goals, that is, by which the state seeks to direct or encourage behaviour which (it is assumed) would not occur without such intervention'.⁹

In the case of healthcare, social care included, regulation can indeed come about due to market failures. For example regulation can be used to correct the monopolistic supply of healthcare, to rebalance the information asymmetry that exists in favour of providers, to avoid the scarcity of supply in certain areas, or to limit and rationalise access to a public system of healthcare that depends on finite resources.¹⁰ In the

⁴ Goffman E., 'Characteristics of total institutions' in A.S. Goldstein and J. Goldstein (Eds.), *Crime, Law and Society* (The Free Press, 1971)

⁵ Agich. G. J., *Dependence and Autonomy in Old Age: An ethical framework for long-term care* (Cambridge University Press, 2003), 5

⁶ Baldwin R., Cave M. and Lodge M., *Understanding Regulation, Theory, Strategy and Practice* (2nd Ed.) (Oxford University Press, 2013) 15

⁷ Prosser T., 'Regulations and Social Solidarity' (2006) 33 *Journal of Law and Society* 364-87

⁸ Black J., 'Critical Reflection on Regulation' (2002) LSE Centre for the Analysis of Risk and Regulation Discussion Paper 4, 20

<<https://core.ac.uk/download/pdf/219186.pdf>> Accessed 2nd February 2017

⁹ Ogus A. 'Regulation: The Public Interest and the Private Interest' In T. Kirat and B. Deffains (Eds.) *Law and Economic in Civil Law Countries* (Routledge, 2003)

¹⁰ Walshe K., *Regulating Healthcare: A Prescription for Improvement?* (Open University Press, 2003), 22-26

specific case of health and social care provision, however, it can be argued that the predominant cause for regulation is social, to promote healthcare as a public good.¹¹ The reason for regulation may then underscore certain social values. In the case of healthcare, such values have been identified as equity and fairness through a regulatory model that enables access to all regardless of means; social solidarity through regulation that sets out a system of universal contribution to cost; respect for diversity through regulation that promotes non-discriminatory services; a need for accountability, reflected in regulation that demands from providers that they achieve a certain level of performance; and paternalism in the sense of protectionism, via a regulatory scheme that monitors standards for the sake of its users.¹²

This long list of social goals shows how regulation may be used to fulfil a multitude of aims, some of them potentially contradictory in nature. These social goals also reflect a commitment to a particular ethical model. Brownsword illustrates this point in the domain of new technologies such as embryonic stem cell research, and the challenges they pose to regulators due to the multiple ethical commitments they aim to underscore simultaneously.¹³ In this case, he explains how the tripartite ethical perspectives of utilitarianism, human rights and dignity may promote conflicting aims, making regulating complicated. Whilst a utilitarian ethical commitment will stir towards progress for the greatest number regardless of the potential harm it may inflict, (in this instance the potential harm done on the embryos used), an ethical commitment to human rights will demand that all rights holders have their rights respected (embryos are not considered rights holders, but the biological source of that embryo is, and requires consent).¹⁴ A third ethical commitment, one made to dignity, can be used either as a claim to empowerment, as the enhancement of one's 'capacity for making one's own choice', or as a justification for constraint, against, for instance, 'the commercialization of the human body'.¹⁵ Whereas the potential benefits to humanity that embryonic stem cell research could generate through new cures for diseases may pose relatively little or no ethical quandary to the utilitarian or the human rights view, it certainly goes against the dignity as constraint perspective that

¹¹ Ibid 26

¹² Ibid 27

¹³ Brownsword R., *Rights, Regulation, and the Technological Revolution* (Oxford University Press, 2008)

¹⁴ Ibid 35-41

¹⁵ Ibid 42-43

upholds respect for each and every human life form.¹⁶ The juxtaposition of different ethical commitments shows the complexity faced by regulators. In this case, they need to allow the furtherance of science for the benefit of mankind, whilst at the same time restrain its development within the bounds of human dignity.

This example of regulatory complexity also demonstrates how an ethical commitment to dignity alone can promote conflicting aims. In the domain of stem cell research, dignity can be understood as a control mechanism that forbids certain actions in the name of respect for human life, but can also be used as a force for improvement for all human beings through the instrumentalisation of those living cells for curing diseases. Whereas dignity in the first instance is one that attaches to the ‘integrity’ of the human species, the other is rooted in a more individualistic perspective, one that sees dignity as concerned with, *inter alia*, the capacity for autonomy and setting one’s own ends.¹⁷ It may therefore not be surprising to come across the opinion that ‘human dignity is so vague an idea to be fit for regulatory perspective’.¹⁸ Regulating a particular activity under a dignitarian ethical commitment may indeed seem an implausible and impractical goal, one that would seek to protect and emancipate individuals at the same time. This is why, once more, it is essential to define dignity.

For the purposes of my arguments in this dissertation, the key point is that – as we have already seen in the context of vulnerability – a policy commitment to dignity may actually ‘subvert rather than enhance choice, and in some circumstances may limit rather than extend the scope of traditional “first generation” rights and fundamental freedoms’.¹⁹ In order to prevent dignity from becoming solely understood as a directive for protection, I argue here that the voice of the person under the regulated regime ought to be heard. Whereas in the example of cell stem research there is no such possibility, and so precaution and protection ought to be taken into account, in the case of the regulation of care homes, there is an argument for that kind of subjective participation.

¹⁶ Ibid

¹⁷ Feldman D., ‘Human Dignity as a legal value: Part 1’ (1999) Public Law 682

¹⁸ Brownsword (n13) 52

¹⁹ Ibid 685

Braithwaite and Braithwaite advocate for the use of standards to regulate care homes, instead of formal rules, because they allow for the beneficial input of subjectivity.²⁰

They write that:

[T]he impetus to reform subjectivity in standards through objective criteria and protocols is dangerous because quality of life, which is what nursing home care should be about, is ultimately an irreducibly subjective matter. The paradox of objectivity is that its pursuit undercuts a desideratum on which the industry, politicians, consumer groups and gerontologists (if not the lawyers) generally agree. This is that the regulatory process should be more outcome-oriented. The trouble is that inputs (the temperature of the food as it leaves the serving line; the size of the room) are usually more objective than outcomes (satisfaction of the residents with the food and the comfort of the room). Objectivity disempowers residents and empowers nursing home managements who know how to get objective inputs in a row for inspection day. (...) Subjectivity, in contrast, means that residents are empowered because (...) it is what they as residents think and want that counts.²¹

Others have also found that excluding the opinion of service users in the regulatory system of the care sector was detrimental to its effectiveness.²² It could be contended that replacing formal rules with objectives would leave regulations too vague, and so jeopardize their effectiveness.²³ The solution, Braithwaite advances, 'is to leave the words vague so [as] to specify the interpretive evidence that is privileged and to require a regulatory dialogue about this evidence'.²⁴ The evidence that is privileged here is the opinion of the service users and those in direct relation with them. Indeed, as the previous chapter established, the vulnerability of the residents must be situated within their relational autonomy, and so seeking the opinion of those who are part of the person's relational world may also help gather their input. Involving the

²⁰ Braithwaite J. and Braithwaite V., 'The Politics of Legalism: Rules versus Standards in Nursing Home Regulations' (1995) 4 *Social and Legal Studies* 307

²¹ *Ibid* 327

²² Kerrison S. and Pollock A., 'Absent voices compromise the effectiveness of nursing home regulation: a critique of regulatory reform in the UK nursing home industry' (2001) 9(6) *Health and Social Care in the Community* 490

²³ Diver C. S., 'A Theory of Regulatory Enforcement' (1980) 28 *Public Policy* 25

²⁴ Braithwaite and Braithwaite (n20) 335

individuals whose environment regulations seek to shape avoids the vagueness problem.

Dialogic accountability ought to be a feature of the regulatory model used for nursing homes, avoiding the disempowering effect of objective rules. Although some critics may argue that relying on the requirements and comments of residents who are prone to cognitive impairments is not a reliable basis for regulation, others have argued to the contrary.²⁵ I have established in Chapter II that dignity for older individuals revolved around three areas of importance: identity, self-determination and humanity. Regulation set out to uphold an environment where dignity can flourish should therefore have these areas set out as objectives, and a mechanism in place that would allow for service users to not only express what that means to them, but also whether they felt it was being achieved by the service provider. In the next part of this chapter I will therefore examine the place and meaning dignity holds in the current regulatory framework care homes are under, and assess firstly whether the outcomes of identity, self-determination and humanity are considered, and secondly whether service user participation has a place within them.

3) The Care Quality Commission

a) Care homes regulatory framework

The Care Standards Act 2000 sets out the compulsory registration of care homes.²⁶ National bodies regulate all registered care homes in the UK.²⁷ They are the Quality of Care Commission (CQC) in England, the Care Inspectorate in Scotland, the Regulation and Quality Improvement Authority (RQIA) in Northern Ireland and the Care and Social Services Inspectorate Wales (CSSIW) for Wales. I will focus my attention on the regulatory framework of the CQC. Following Orders made under

²⁵ Braithwaite J. et al, 'Raising the Standard: Resident-Centred nursing home regulation in Australia (1993, Australian Government Publishing Service)
<https://www.anu.edu.au/fellows/jbraithwaite/_documents/Reports/Raising_standards_resident_home.pdf> Accessed 22nd February 2017

²⁶ Care Standards Act 2000 s.3 and s.11

²⁷ AgeUK, 'Care Homes: Finding the right care home' (July 2014), 37
<http://www.ageuk.org.uk/Documents/ENGB/Informationguides/AgeUKIG06_Care_homes_inf.pdf?dt rk=true> Accessed 29th January 2015

section 24(2) of the Legislative and Regulatory Reform Act 2006, the CQC is under the statutory obligation to have regard to the Regulators Code when drafting its policies.²⁸ The Code establishes six principles that ought to be followed by the regulators. They include supporting regulated activities, engaging and listening to the views of those involved in regulated activities, basing regulatory activities on risk, sharing information, supporting and guiding the regulated activities through the publication of guidance, and upholding transparency.²⁹

A risk-based approach to regulation focuses on minimising harm. Risk-based regulation is based on the idea that ‘rather than preventing all possible harm, risk-based approaches promise to rationalise and manage the inevitable limits of what regulation can hope to achieve by focusing regulatory standard-setting and enforcement activity on the highest priority risks, as determined through formal assessments of their probability and consequences’.³⁰ In response to tragic incidents in the NHS in the late 1990s, including that of the abnormally high death rates in the children cardiac unit of the Bristol Royal Infirmary, risk management has developed ‘in order to avoid repeats of situations where clinical craft loses sight of patient safety and quality of care’.³¹ A loss of trust in medical expertise and the need for stronger accountability have led to a monitoring system of regulation that strives to standardise and rationalise practice.³² Risk management has been presented as a method of regulating practice able to deal with the ‘the dark side’ of the ‘craftsmanship’ of medicine,³³ where the medical work in itself becomes more important than the effect

²⁸ Department for Business Innovation & Skills, ‘Regulators’ Code: Summary of regulators and regulatory functions covered’ April 2014
<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/320713/regulators-code-summary-cover.pdf> Accessed 8th March 2017

²⁹ Department for Business Innovation & Skills, ‘Regulators’ Code’ April 2014
<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300126/14-705-regulators-code.pdf> Accessed 8th March 2017

³⁰ Beaussier A-L, Demeritt D., Griffiths A., and Rothstein H., ‘Accounting for failure: risk-based regulation and the problems of ensuring healthcare quality in the NHS’ (2016) 18(2-3) *Health, Risk & Society* 205

³¹ Brown P. and Calnan M., ‘The Risks of Managing Uncertainty: The Limitations of Governance and Choice, and the Potential of Trust’ (2009) 9(1) *Social Policy and Society* 13

³² Checkland K., Marshall M., and Harrison S., ‘Re-thinking Accountability: Trust versus confidence in medical practice’ (2004) 13(1) *Quality and Safety in Health Care* 130

³³ Sennett R., *The Craftsman* (Allen Lane, 2008)

it actually has on the patient.³⁴ The management of risk is therefore presented as a reassuring tool that appears to ‘eradicate uncertainties through reasoned calculation’.³⁵

Hillman et al have argued that the influx of risk-based governance in the provision of care has had negative effects on the possibility of dignity for older patients in NHS acute hospitals.³⁶ They explain that the practice of risk-based regulation distorts the practice of care by trying to prioritise the rational diminution of risk over the ‘irrationality of caring relationships’, to the detriment of the dignity of the patient, which necessitates opportunities for recognition through meaningful interactions.³⁷ The study they conducted shows how the pressure for accountability that ensues from risk-based management promotes defensiveness in staff, an attitude that fosters ‘a disconnection’ between them and those they care for.³⁸ Just as placing quality of care assurance solely in the hands of medical expertise can compromise it, so can the rationalisation of care through risk management by de-humanising the person cared for.³⁹ Hillman et al conclude that

risk regimes shape the conditions of possibility for acute care provision. These conditions are shown to reduce the possibilities for meaningful caring relationships between practitioners and patients in which the dignity of older people is maintained and instead promotes practices that maintain the system rather than meeting the needs of the people the system purports to serve.⁴⁰

By correlation, a risk-based approach to regulation in care homes may not be the most conducive to the development of conditions amenable to dignity. Indeed, it is more likely to embrace an idea of dignity that is protectionist in its intent, rather than one that is empowering. As I will expose in the next part of this chapter, regulatory aims fashioned under a risk based approach focus heavily on safeguard and welfare, and tend to adopt a version of dignity that fits into those objectives: dignity is considered

³⁴ Brown and Calnan (n31) 13

³⁵ Hillman A., Tadd W., Calnan S., Calnan M., Bayer A., and Read S., ‘Risk, Governance and the experience of care’ (2013) 35(6) *Sociology of Health and Illness* 939

³⁶ *Ibid*

³⁷ *Ibid* 952

³⁸ *Ibid* 949

³⁹ *Ibid* 940

⁴⁰ *Ibid* 952

as another parameter to limit harm, but it stops short of setting positive obligations beyond that aim. Section 20 of the HSCA 2008 sets out the purposes of regulating health and social care as ‘to secure that services provided in the carrying on of regulated activities cause no avoidable harm to the persons for whom the services are provided’, to ensure that any regulated service is of ‘appropriate quality’, and to secure ‘the health, safety and welfare of persons for whom any such service is provided’.⁴¹ The way in which this is achieved has recently been reformed.

The CQC regulatory regime has gone through significant changes since 1st April 2015.⁴² These changes have occurred in response to the publication of various government led inquiries such as the Mid-Staffordshire NHS Foundation Trust Public Inquiry,⁴³ and the Department of Health response to the Winterbourne View Hospital scandal,⁴⁴ into severe failures of the standards of care in the public health and social care sector. According to the Department of Health the aim of the new regulatory regime is to ‘introduce fundamental standards of safety and quality below which care should never fail, make regulations more effective and improve enforcement against them, be outcome focused, and reduce the burden on business’.⁴⁵ It could indeed be argued that the old regulatory regime established in 2010 was so lengthy and complex that complying with it was confusing and diverted energy from caring priorities.⁴⁶ It took a 278 page long guidance to explain the various outcomes service providers were supposed to generate to comply with the regulatory framework.⁴⁷

⁴¹ Health and Social Care Act 2008 s.20 (1) and (2)

⁴² CQC, ‘Guidance for providers on meeting the regulations’ (March 2015)

<http://www.cqc.org.uk/sites/default/files/20150324_guidance_providers_meeting_regulations_01.pdf> Accessed 29th March 2017

⁴³ Francis R. QC ‘Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, Executive Summary’ (The Stationary Office, February 2013)

<<http://www.midstaffpublicinquiry.com/sites/default/files/report/Executive%20summary.pdf>>

⁴⁴ Department of Health, ‘Transforming care: A national response to Winterbourne View Hospital’ (December 2012)

< https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf> Accessed 8th February 2017

⁴⁵ Department of Health, ‘Introducing Fundamental Standards, Consultation on Proposals to change CQC registration regulations’ (January 2014), 7-8

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/274715/Introducing_Fundamental_Standards_-_a_Consultation.pdf> Accessed 10th February 2015

⁴⁶ Statutory Instruments 2010 No. 781, The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 <<http://www.legislation.gov.uk/uksi/2010/781/made>> Accessed 12th March 2015

⁴⁷ CQC, ‘Guidance about compliance, Essential standards of quality and safety’ (March 2010)

< http://www.cqc.org.uk/sites/default/files/documents/gac_-_dec_2011_update.pdf> Accessed 12th March 2015

In June 2013 the CQC published a report entitled ‘A new start’, which outlined the changes that would be brought in to improve services.⁴⁸ The new regulatory regime shows a willingness to streamline burdensome regulations and ‘get to the heart of people’s experience of care’, a goal that suggests the involvement of service users. Not all concerned were reassured by this reform.⁴⁹ The Relatives and Residents Association (R&RA), who campaigns on behalf of care home residents, expressed distress at the condensation of the new regulatory regime, claiming that ‘deleting regulations’ was tantamount to ‘deleting rights’.⁵⁰ They claimed that the new regulatory system no longer directly obliged the service provider to tell residents about their complaint procedures, to plan for emergencies, or to give residents a choice of food.⁵¹ Lord Hunt brought these concerns to the fore in a House of Lord debate, holding that a general move towards deregulation had resulted in these streamlined standards, which lacked detail and could weaken the protection offered to residents.⁵²

Despite these concerns, the regulations were not amended. It was held that because the new system was outcome based, description of processes were no longer required.⁵³ As I suggested above, outcome-based regulatory models - if sufficiently focused on empowerment and participation – may avoid the inflexibility and paternalistic risk of a strict rules approach - without a trade-off in the specificity of the regulations. Therefore, the question arises whether this new lighter regulatory regime will be effective in involving those who are cared for within the regulated environment, partly on the ground of their multi-dimensional vulnerability, or whether too little participation to fill up the blanks will have the effect of lowering standards by allowing a minimum compliance mentality to develop.

⁴⁸ CQC, ‘A new start. Consultations on changes to the way CQC regulates, inspects and monitors care’ (June 2013)

<http://www.cqc.org.uk/sites/default/files/documents/cqc_consultation_2013_tagged_0.pdf> Accessed 12th March 2015

⁴⁹ Ibid 8

⁵⁰ R&RA, ‘New government commitment on deleted regulations’ 6th November 2014 <<http://www.relres.org/latest-news/2014-11-deleted-reg-hol-debate.html>> Accessed 10th February 2015

⁵¹ These are respectively Regulations 19(1), Regulation 9(2) and Regulation 14(1) from the Health and Social Care 2008 (Regulated Activities) 2010 which disappeared in the new regulatory regime

⁵² House of Lord, 5th November 2014, Column 1692

< <http://www.publications.parliament.uk/pa/ld201415/ldhansrd/text/141105-0002.htm>> Accessed 1st April 2015

⁵³ Ibid, Column 1698

The need to involve service users in the development of regulatory criteria is compounded by the fact that the CQC regulates an impressive and diverse array of services. Annex D of the guidance document for providers identifies a total of 28 different types of health and social service providers under the responsibility of the CQC for quality monitoring.⁵⁴ These services range from community-based services for people with mental health needs, to dental services, hospices or acute services, and so cover a multiplicity of service users ranging from new-borns to the elderly, all with a wide variety of health conditions and care needs.¹

Even groups with similar demographic profiles do not have the same conception of dignity. A study used in Chapter II compared the meaning of dignity for patients with a terminal disease and that of elderly people in care.⁵⁵ It concluded that although there were similarities in the way in which ill and elderly individuals perceived dignity, those in residential care were particularly concerned by the sense of loss they felt and they resented that their old age be assimilated to being ill.⁵⁶ Whether one regulatory regime can effectively define the meaning of dignity as an outcome for all individuals using healthcare services seems improbable, unless as I mentioned above, service users are involved not only in filling in the gaps of how outcomes can be reached, but also in the process of checking that they are being fulfilled. I will now turn my attention to how dignity is defined and understood under the new regulatory regime laid out under section 20, and assess whether it does make room for service user participation.

b) Dignity regulation and accompanying guidance

For the first time dignity is set out as a stand alone outcome under Regulation 10 entitled ‘Dignity and Respect’. The previous regulations only addressed dignity

⁵⁴ CQC, ‘Annex D: Service types’

<http://www.cqc.org.uk/sites/default/files/20150210_guidance_for_providers_service_types_annex_d.pdf> Accessed 29th March 2017

⁵⁵ Hall S., Longhurst S. and Higginson I., ‘Living and dying with dignity: a qualitative study of the view of people in nursing homes’ (2009) 38 *Age and Ageing* 411

⁵⁶ *Ibid* 412

indirectly under Regulation 17 entitled ‘Respecting and involving service users’.⁵⁷
The new regime stipulates under Regulation 10 that:

- (1) Service users must be treated with dignity and respect.
- (2) Without limiting paragraph (1), the things which a registered person is required to do to comply with paragraph (1) include in particular—
 - (a) ensuring the privacy of the service user;
 - (b) supporting the autonomy, independence and involvement in the community of the service user;
 - (c) having due regard to any relevant protected characteristics (as defined in section 149(7) of the Equality Act 2010) of the service user.⁵⁸

Under Annex C of the guidance, dignity is defined as to be ‘(...) concerned with how people feel, think and behave in relation to the worth or value they place on themselves and others. To treat someone with dignity is to treat them as being of worth and respect them as a valued person, taking into account their individual views and beliefs.’⁵⁹

The idea of ‘treating people as being of worth’ appears to imply that dignity is inherent, and so presumes that the person in care already has a sense of worth. The role of the provider is limited to respecting this worth by a particular behaviour towards the person cared for as directed under Regulation 10. Studies used in Chapter II highlighted the impact a move to a care home could have on people’s sense of dignity. A longitudinal study revealed that a person’s sense of dignity evolved with time,⁶⁰ and that accepting the changes brought on by age helped to sustain it.⁶¹ Although some residents interviewed mentioned that they possessed an unshakable

⁵⁷ CQC, Regulation 17, Health and Social Care Act 2008 (Regulated Activities) 2010
< <http://www.legislation.gov.uk/ukdsi/2010/9780111491942/regulation/17>> Accessed 1st April 2015

⁵⁸ CQC, Regulation 10, Health and Social Care Act 2008 (Regulated Activities) 2014
< <http://www.legislation.gov.uk/ukdsi/2014/9780111117613/regulation/10>> Accessed 1st April 2015

⁵⁹ CQC, ‘Guidance for providers, Annex C, Glossary of terms’, 5
< <http://www.cqc.org.uk/content/glossary-terms-used-guidance-providers-and-managers#d>> Accessed 1st April 2015

⁶⁰ Mariska G. Oosterveld-Vlug, H. Roeline, W. Pasman, Isi E. van Gennip, Martien T. Muller, Dick L. Willem and Bregie D. Onwuteaka-Philipsen, ‘Changes in the Personal Dignity of Nursing Home Residents: A Longitudinal Qualitative Interview Study’ (2013) 8(9) Plos ONE

⁶¹ Woolhead G., Calnan M., Dieppe P., Tadd W. ‘Dignity in older age: what do older people in the United Kingdom think?’ (2004) 33(2) Age and Ageing 165

inner strength,⁶² and the ability to accept their new life, others revealed the sense of loss they felt following the severance they had experienced from all that was familiar to them.⁶³ This sense of place in the world and self-worth may be jeopardized by a move into a care environment. Thus, the regulatory framework's assumption that elderly people in care already possess such sense of self-worth may narrow down the idea of dignity too much, conceiving it merely as a 'control' element acting on the behaviour of the service provider, rather than as something to be nurtured and sustained, that is, as an 'empowering' notion for the benefit of the resident.⁶⁴

Taylor explains that 'our identity is partly shaped by recognition, or its absence, often by the misrecognition of others, and so a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves'.⁶⁵ Recognition, Taylor continues, is gained through 'the dialogical in human life', the interaction we engage in with 'others who matter to us', 'through our acquisition of rich human languages of expression'.⁶⁶ Individuals questioned in the studies used in Chapter II revealed that communication, relationships, participation, and the physical and psychological changes brought on by aging and loss, were important constitutive elements of their identity. All these elements hinge on third party recognition and cannot be fulfilled by the individual alone. Rather than directing providers to respect an assumed sense of worth, the regulatory scheme should emphasise the importance of recognition through dialogical participation as an important component part of fulfilling of dignity.

According to Regulation 10, dignity, or the 'worth that people feel', demands a certain treatment, one that rests on the respect of privacy, autonomy and non-discrimination. Important aspects of dignity established in Chapter II are addressed by this regulation. The guidance breaks down the meaning of treating someone with dignity in four main components. Under component 10(1), respectful communication

⁶² Franklin L-L., Ternstedt BM., and Nordenfelt L., 'Views on Dignity of Elderly Nursing Home Residents' (2006) 13 Nursing Ethics 130

⁶³ Hall et al (n55)

⁶⁴ Brownsword (n13)

⁶⁵ Taylor C., 'The Politics of Recognition' in A. Gutmann (Ed.) *Multiculturalism: Examining the Politics of Recognition* (Princeton University Press, 1994), 25

⁶⁶ *Ibid* 32

is identified as essential to dignified care.⁶⁷ In this instance the guidance specifies that suitable means of communication must be made available to the person cared for, and that the choice of non-communication must also be respected. Respecting people's personal preferences in their care choice, but also in the way in which they wish to be addressed, are also identified as part of providing dignified care. On the other hand, offence to dignity in the form of neglect or undignified treatment is addressed via a reference to Regulation 13, which deals with 'safeguarding service users from abuse and improper treatment'. This Regulation prohibits discrimination, regulates the use of restraints, defines and forbids degrading treatment and sets minimum standards to meet people's care needs.⁶⁸

Respect for people's privacy is addressed prominently under component 10(2)(a).⁶⁹ The guidance for this issue identifies that individuals' particular idea of privacy should be followed when possible, that privacy should be respected during care and treatment (even when the person is asleep or unaware due to lack of capacity or unconsciousness), when care is discussed, when people interact with others such as friends, carers or visitors, and via the purposeful segregation of genders in sleeping accommodation and bathroom facilities. The issue of privacy was clearly identified by those interviewed in Chapter II as a component part of dignity under the heading of identity. Under this topic, those interviewed mentioned the importance of being shielded from the eyes of others when receiving intimate treatment, or the importance of being kept separated from the opposite sex in the context of mixed wards.⁷⁰ It is also true that others found that they got accustomed to the intervention of others in their daily lives and accepted it as part of their new life in an institution.⁷¹ Privacy is a subjective value, which meaning varies from person to person. The person cared for ought to be consulted in situations when privacy issues occur (such as personal treatment, future care plans, sleeping and washing arrangements etc.), and their wishes respected as far as feasibly possible.

⁶⁷ CQC (n42) 34-36

⁶⁸ CQC (n42) 50

⁶⁹ Ibid 35

⁷⁰ Chapter II, 8

⁷¹ Ibid

Component 10(2)(b) addresses autonomy, independence and involvement in the community.⁷² This guidance seeks to mitigate independence with safety concerns, but also to engage service providers to foster the independence of the service user according to their wishes. It also encourages service providers to facilitate the relationships service users wish to maintain whilst in care. The importance of relationships was clearly highlighted during the discussions of the studies used in Chapter II. Participation, on a scale suitable to the service user, is also mentioned under this sub-section. It recommends this to minimise isolation. This was found important for dignity in the studies used in Chapter II. Component 10(2)(c) specifically deals with non-discrimination towards service users.⁷³ Equality of treatment was recognized as needed for dignity in Chapter II under the theme of humanity in the provision of services in particular, and the treatment of elderly people more generally by society. The guidance reminds providers that discrimination on the ground of age is forbidden under the Equality Act 2010.

The guidance on Regulation 10 also acknowledges under component 10(2) that the areas of dignity as expressly set out in the regulatory regime do not form an exhaustive definition of dignity, and that providers should consider offering a dignified service at all times. Compared to the previous regulatory regime and guidelines, the new rules are far more in tune with the meaning of dignity expressed by elderly people in the studies used in this paper. Dignity is singled out as a standalone Regulation, which was not the case under the previous regime.⁷⁴ The guidance defining how dignity translates into the provision of services is far more comprehensive, clear and person-centred than previously where dignity was defined solely in the context of treatment and care.

It is worth noting here the effect the regulatory framework can have in case law. In the previously discussed case of *McDonald*, Lady Hale referred to Regulation 17, the regulation concerned with respect for dignity set out under the previous Social Care Act 2008 (Regulated Activities) Regulations 2010.⁷⁵ She reminded the court that this

⁷² CQC (n42) 36

⁷³ Ibid

⁷⁴ CQC (n58)

⁷⁵ *R (on the application of McDonald) v Royal Borough of Kensington and Chelsea* [2011] UKSC 33, [78]

Regulation ‘requires a registered person, so far as reasonable practicable, to make suitable arrangements to ensure the dignity, privacy and independence of service users’.⁷⁶ She then quoted the relevant CQC guidance about standards of quality with reference to toileting facilities, requiring service providers to enable service users to have access to such facilities in order to preserve their privacy and dignity.⁷⁷ This argument failed to be persuasive to the other Law Lords, but shows a willingness by Lady Hale to use social care regulations to bolster a pro-dignity argument, one that respects the person’s wishes, their privacy and self-determination.

The other Law Lords could have disputed this argument by quoting other regulations that uphold the safety of service users. Under the current regulatory system, Regulation 12 is dedicated to the safe care and treatment of service users.⁷⁸ However no other Law Lords referred to the CQC regulatory regime. Instead, they agreed with the decision of the local authority that the safety of Ms McDonald was assured by providing her with incontinence pads instead of a night time carer to help her reach the toilets, and that this solution was ‘a proportionate response to the appellant’s needs because it affords her the maximum protection from injury, greater privacy and independence, and results in substantial cost savings’.⁷⁹ This case illustrates how privileging certain outcomes (such as safety) over those favoured by the person concerned can lead to situations where the dignity of the person is not respected. Dignity defined by a third party cannot be imposed on another on the ground of their welfare; for dignity to be meaningful it ought to be conceptualised from the person’s perspective.

Although the CQC is responsible for checking the performances of care homes and home care providers in the UK, it is not responsible to assess the performance of councils in their social care commissioning functions. Nevertheless, the guidance published for the Care Act 2014 does stipulate that ‘local authorities should consider the emerging revised Care Quality Commission standards for quality and any

⁷⁶ Ibid

⁷⁷ Ibid

⁷⁸ Social Care Act 2008 (Regulated Activities) 2014

⁷⁹ McDonald (n75) [19]

emerging national frameworks for defining outcomes'.⁸⁰ The regulatory framework that sets standards for care providers ought to inform local authorities' commissioning duty of social care provisions, but there is no legal requirement for them to do so at present. At the moment, only the principle of wellbeing under the Care Act 2014, defined as including the element of dignity, legally binds the council in their social care duties.⁸¹

Despite these positive regulatory reforms about dignity, there is still little or no built-in mechanism that seeks to open a dialogue with the person cared for in order to find out what dignity is to them, and how it may be fostered for that person. Some of the outcomes expected under the regulation are in line with the main findings about dignity exposed in Chapter II, but it does not mention that the people who are using the service ought to be the ones who help shape how the outcome can be fulfilled. This is a considerable limitation of the reformed regime.

Privileging a risk-based approach to the regulatory framework that sets standards of care means that dignity has to be interpreted in the context of other standards that focus on keeping the person safe. But promoting dignity and ensuring safety are not always compatible aims, and privileging the latter in some cases could even be detrimental to dignity, as the case of *McDonald* mentioned above shows.⁸² Service user participation as to the meaning of dignity for them is not required, and although the guidance mentions the need to support the autonomy of the service users, it fails to require their engagement to achieve such goals.

c) Inspection and enforcement regime

In order to enforce the standards set out by the regulation, different models can be followed, based on deterrence, compliance or responsiveness.⁸³ A regulatory model

⁸⁰ Department of Health and Social Care, 'Care and support statutory guidance' (Updated 17 August 2017), 4.14

<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#other-areas>> Accessed 5th February 2018

⁸¹ Care Act 2014 s.1

⁸² Hillman et al (n35)

⁸³ Walshe (n10) 35-48

based on deterrence assumes that the organization regulated would naturally choose to promote its own self-advancement, and so uses inspection and sanctions to seek regulatory observance.⁸⁴ The compliance model on the other hand supposes a less confrontational relationship between the regulator and the regulated activity, and favours a more cooperative approach, based on the provision of guidance and support.⁸⁵ Most regulation adopts a mixture of these models. Responsive regulation is presented as an alternative to these two models, though it can be viewed as a particular combination of them. A responsive regulatory model seeks to escalate enforcement progressively, but starts by trying to build on the strengths of the organisation in order to ‘absorb weaknesses’.⁸⁶ This model is often represented as a pyramid, where the baseline represents cooperation and dialogue, and where the next port of call is punishment, to be escalated if needed.⁸⁷ This system works on dialogue and cooperation, with the added bite of potential sanction in cases of recurring failures to comply.

The CQC uses a mix of compliance and deterrence in its bid to improve quality of care. It follows the compliance model by publishing detailed guidance to help registered service providers comply with regulation, but also uses deterrence through inspections and enforcement tools in the form of sanctions, fines, criminal prosecution and potential de-registration.⁸⁸ Indeed, it could be argued that its enforcement methods are responsive, because they are progressive and incremental.

None of these models are fool proof in the upholding of quality of care. A report into the failings of the inspection system employed by the CQC at the Hillcroft Nursing Home is an example of how inspection can fail to spot even the worst kind of abuse.⁸⁹ A home described by an inspection as ‘compliant with all essential standards’ was

⁸⁴ Ibid

⁸⁵ Ibid

⁸⁶ Braithwaite J., ‘The Essence of Responsive Regulation’ Fasken Lecture (2011) 44 University of British Columbia Law Review 475, 480

⁸⁷ Braithwaite et al (n3) 277

⁸⁸ CQC, ‘Enforcement Policy’ (February 2015)

<http://www.cqc.org.uk/sites/default/files/20150209_enforcement_policy_v1-1.pdf> Accessed 10th March 2017

⁸⁹ Lancashire County Council, NHS, Lancashire Constabulary, ‘Learning Review of Incidents of Significant Harm at Hillcroft Slyne with Hest Care (Nursing) Home’ (June 2014)

<[Learning Review of Incidents of Significant Harm Publication-12-06-14.pdf](#)> Accessed 12th February 2015

later the subject of a police investigation which resulted in four members of staff being charged with offences of ill treatment and wilful neglect under section 44 of the Mental Capacity Act 2005. Although this is only one example of failure of the inspection system, it illustrates how abuses can go uncovered despite the inspection regime in place. In this particular instance, a series of warnings had been given to the CQC and the local authority, but protocols in place at the time and lack of inter agency coordination meant that some residents only stopped being abused when the police intervened and criminal charges were brought.⁹⁰ This tragic event is one of the triggers that have led the CQC to review its inspection and enforcement regime. Below I will examine the changes made, and apply Braithwaite's recommendations for regulatory reforms to assess the possibility of substantive improvements in quality of care in aged care.⁹¹ This in turn will have a beneficial effect on the possibility of dignity.

The CQC's new framework for inspection is currently based on five key questions to assess the safety and quality of the residential adult social care services audited.⁹² Inspectors must assess whether the home is safe, (whether 'people are protected from abuse and avoidable harm', effective (whether people's care 'achieves good outcomes, promotes quality of life and is based on the best available evidence'), caring (whether 'staff involve and treat people with compassion, kindness, dignity and respect'), responsive (whether the services meet people's needs'), and well-led (whether the 'management ... of the organisation assures the delivery of high quality person-centred care, supports learning and innovation and promotes an open and fair culture').⁹³

The inspection is not precisely linked to each Regulation but revolves around answering these five key questions. Such auditing method may encourage a more holistic inspection regime, one that focuses on the outcome of quality of care rather than forces a tick box exercise that loses sight of the bigger picture and breeds unreliability. Braithwaite explains how 'rule ritualism' can indeed frustrate the aim of

⁹⁰ Ibid 16

⁹¹ Braithwaite et al (n3)

⁹² CQC, 'How CQC regulates: Residential adults social care services. Provider handbook' April 2016 <http://www.cqc.org.uk/sites/default/files/20160422_ASC_residential_provider_handbook%20April_2016_update.pdf> Accessed 10th April 2017

⁹³ Ibid 9

regulation.⁹⁴ This practice means to ‘write a rule instead of solving a problem’; it is the consequence of politicians willing to be seen to improve quality of services, bowing to the pressure of ‘conservative ritualists’.⁹⁵ Increasing the amount of rules may indeed appear to tighten the grip of regulators on the service providers, but it may stunt the possibility of actual substantive improvements. Although increasing the abundance of regulation may reassure service users and the electorate alike, it may also jeopardize the quality of the audit performed. It can do so by forcing inspectors who are pressed for time to pick and choose the standards they actually survey, increasing rather than limiting their level of discretion, generating higher levels of unreliability in their reporting and institution rating.⁹⁶

Braithwaite argues that keeping to a few standards or outcomes (as is the CQC’s new inspection design), encourages a ‘a proper process of information-gathering and team deliberation on that standard’.⁹⁷ He believes in the proposition, also defended in this dissertation, that ‘dialogue about residents-centred outcomes conduces to more reliability than recourse to authoritative interpretations of the meaning of words in rules’.⁹⁸ This proposition can be illustrated in the case of privacy, an important element of dignity, and a notion whose meaning differs from person to person.⁹⁹ Compliance with dignity objectives ought to be made easier and clearer through the involvement of service users. Fleshing out the meaning of dignity standard as well as the monitoring of its possibility ought to be led by those who live in the regulated service.

In this respect, the CQC mentions the involvement of ‘Experts by Experience’, service users who are specifically recruited to help speaking to service users during the inspection process.¹⁰⁰ This initiative, grounded in a dialogical approach that upholds the importance of subjectivity, could be effective in improving conditions for dignity for service users. So far lack of resources has been compromising the potential

⁹⁴ Braithwaite et al (n3) 222-227

⁹⁵ Ibid 220

⁹⁶ Baldwin R. and Hawkins K., ‘Discretionary justice: Davis reconsidered’ (1984) Public Law 570

⁹⁷ Braithwaite et al (n3) 226

⁹⁸ Ibid 234

⁹⁹ Ibid

¹⁰⁰ CQC ‘Experts by Experience’

< <http://www.cqc.org.uk/content/become-an-expert-experience> > Accessed 7th March 2017

beneficial contribution of these exchanges.¹⁰¹ I would argue that in the case of nursing homes and for the outcome of dignity, service users and their relatives ought to be the prime sources of information gathering. Unfortunately, Braithwaite et al have noted the ‘the greatest weakness of English regulation is on the empowerment of residents’.¹⁰² It has been observed that very few care homes had residents’ committees, and no regulation so far insists on a meeting with that committee during inspection.¹⁰³

In order to improve compliance, the CQC has enforcement measures at its disposal under the Health and Social Care Act 2008 as amended by the Care Act 2014.¹⁰⁴ These powers are used to improve the quality and safety of healthcare services. The aims of the enforcement measures the CQC has at its disposal is two-pronged: to ‘protect the people using the service from harm, and to ensure they receive health and social care services of an appropriate standard’ by requiring and then forcing improvements, and to ‘hold providers to account for failures in how the service is provided’.¹⁰⁵ Due to the nature of my enquiry into the protection of dignity, I will concentrate here on the mechanisms in place to protect the service user.

The enforcement regime in force until the 31st March 2015 was burdensome, slow and lacking in bite.¹⁰⁶ Enforcement was previously dependent on the urgency of the situation uncovered by inspection and on whether the impact of the regulatory breach on the service user was found to be minor, moderate or major.¹⁰⁷ Formal regulatory action in the form of a compliance action could then turn into an enforcement action through a warning notice.¹⁰⁸ Only then could the CQC use criminal enforcement methods starting from a penalty notice all the way to prosecution, and/or civil

¹⁰¹ Beresford P., ‘User involvement in care inspections is jeopardized by CQC’s short-sighted thinking’, (4th February 2016) The Guardian
< <https://www.theguardian.com/social-care-network/2016/feb/04/pay-user-involvement-care-inspections-risk>> Accessed 7th March 2017

¹⁰² Braithwaite et al (n3) 152

¹⁰³ Braithwaite et al (n3) 152

¹⁰⁴ CQC, ‘Enforcement Policy’, February 2015, 4

<http://www.cqc.org.uk/sites/default/files/20150209_enforcement_policy_v1_final.pdf> Accessed 13th March 2015

¹⁰⁵ Ibid 7

¹⁰⁶ CQC, ‘Enforcement Policy’ June 2013

<http://www.cqc.org.uk/sites/default/files/documents/enforcement_policy_june_2013_0.pdf> Accessed 12th February 2015

¹⁰⁷ Ibid, Appendix A: Regulatory response escalator table, 24-26

¹⁰⁸ Ibid

enforcement tools ranging from a variation of registration conditions to the suspension of registration, their ‘most powerful sanction’.¹⁰⁹ Only 34 homes were closed in 2014 because of extensive failures to comply with the regulatory regime.¹¹⁰ This figure takes its full meaning within a context where a total of 1829 care homes failed to comply with at least one key quality standard.¹¹¹ This figure represents almost 20%, or one in five of all homes inspected by the CQC whose report was available in the first week of January 2015.¹¹² In real terms, this means that for over 70,000 elderly people, care was below standards in safety, effectiveness, caring, responsiveness to needs, or management. An alarming 96 homes out of these 1829 failed on all five key quality standards, effecting around 3500 residents.¹¹³ It is true that the effect of below standard care on residents must be mitigated against the potential trauma of moving home,¹¹⁴ and that the failure to meet a standard could be solely due to an administrative shortfall not actually affecting the residents’ quality of life. It could also unfortunately mean that extremely basic standards of care are not met. Without any or few of those basic standards in place, the sustainability of dignity appears compromised.

The new enforcement regime is designed to allow for more effective remedial means to deal with those providers who fail to comply with the fundamental standards of care. On top of the enforcement powers available to the CQC described above, the Commission now has the ability to prosecute for the breach of specific Regulations.¹¹⁵ Breaches of Regulations 11 (Need for consent), 12 (Safe care and Treatment), 13 (Safeguarding), 14 (Meeting nutritional and hydration needs), 20 (Duty of candour) and 20A (Requirement to display performance assessments), can now all be

¹⁰⁹ Ibid 18 [66]

¹¹⁰ Figures concerned homes forcibly deregistered between 09/01/2014 and 31/12/2014. Information obtained directly from the CQC Data Requests Team via email received on 13th March 2015

¹¹¹ Information obtained directly from LaingBuisson (‘Provider of information and market intelligence on the independent health, community care and childcare sectors’) on 13th February 2015 from their compiled ‘Care Compliance Monitor-Care Homes’, data for January 2015 < <http://www.laingbuisson.co.uk/Home.aspx>> Accessed 23rd March 2015

¹¹² Ibid

¹¹³ Ibid

¹¹⁴ A review of the studies conducted on this subject has shown that indeed ill prepared relocations could have a negative effect on the health of the person forcibly moved, a transfer to higher quality care establishment had good outcomes for the resident.

Holder J. and Jolly D., ‘Forced relocation between nursing homes: residents’ health outcomes and potential moderators’ (November 2012) 4(22) *Reviews in Clinical Gerontology* 301

¹¹⁵ Health and Social Act 2008 (Regulated Activities) Regulations 2014, s.22

prosecuted through the criminal justice system.¹¹⁶ Overall, the enforcement mechanism has been streamlined and considers the ‘seriousness of the concerns’ and ‘multiplicity and recurrence of breaches’ to decide on the action to take instead of the more rigid system of level of harm caused.¹¹⁷

The enforcement regime is based on a responsive model of regulation that escalates the seriousness of the punishment when faced with persistently non-compliant service providers. Braithwaite has claimed that this pyramidal model of enforcement also needs to be combined with a pyramidal model of reward (calling it the ‘Dual Pyramid Principle’) to be effective.¹¹⁸ Although there is a need for a regulatory pyramid that is designed to ‘respond to a fear about a risk’,¹¹⁹ and the regulation model endorsed by the CQC is indeed risk-based, there is also a need for a reward mechanism for service providers to build on their strengths to the detriment of their weaknesses.¹²⁰ This kind of ‘strengths-based’ pyramid does not seek to guarantee a minimum standard of care, but rather aims at ‘maximising quality by pulling standards through the ceiling’.¹²¹ Reward without the risk of punishment is not sufficient, because a system built solely on praise after compliance would incentivise service providers to find ways to obtain the reward without engaging with the regulatory process (Braithwaite names this the ‘moral hazard’ of rewards for compliance’).¹²² Only when weaknesses are addressed can the reward system be triggered, minimizing the risk of moral hazard.¹²³

Setting out a responsive model of enforcement appears to be the most efficient in pushing service providers to adhere to the regulation framework. It is clear that timing and transparency are of the essence when it comes to the efficiency of such enforcement models. Involving service users may be the key to an enforcement system that responds quicker than at the pace of the regulator’s schedule. Involving small groups of service users to regularly communicate with a dedicated team of regulatory monitors may prove more efficient in discovering inadequate practices and

¹¹⁶ CQC (n88) 12

¹¹⁷ Ibid 17

¹¹⁸ Braithwaite et al (n3) 315

¹¹⁹ Ibid 318

¹²⁰ Ibid 317

¹²¹ Ibid 318

¹²² Ibid 278

¹²³ Ibid 320

areas ripe for improvement, than waiting for the regulatory body to decide on inspections and follow-up actions. Conditions for dignity would be improved if those who receive care were in some measure able to have a stake in how well the care home they live in is following regulations.

d) Regulation and care professionals

So far, I have established that in order to create conditions necessary for dignity to flourish in care homes, it is essential to construct a regulatory scheme that is responsive to the meaning of dignity from the perspective of those who live there. I have argued that using experiential dignity as a guide to the construction and implementation of regulation rests on the relational nature of persons, and implies the need to engage in dialogical exchanges. Engaging with those who are dependent on the care of others because of their age has revealed that the realisation of dignity depends on actually experiencing identity, self-determination and respect for one's humanity. Individuals move into care homes only because they are no longer able to live independently, and so their reliance on others becomes a prominent feature of their lives. Although some residents may still have links with those who form part of their previous relational world, the role of staff becomes paramount in almost every aspect of their dignity, from their sense of identity, to their capacity for self-determination and the respect they feel for their humanity.

People's appreciation of their identity is helped by the relationships they form with those around them, and is founded in the mechanism Honneth names 'mutual recognition'.¹²⁴ In a care home, the residents' sense of identity is shaped by the relationships they have with the caring staff. Care professionals who recognise and acknowledge the person they care for help foster a sense of identity: alternatively they can obstruct this process and contribute to the depersonalisation of the individual care for. It could be said that the image residents have of themselves depends heavily on the attitudes the staff have towards them. Keeping residents looking presentable in

¹²⁴ Alex Honneth has described mutual recognition as essential to human relationships, and that without the possibility of being recognised and accepted by others, there would be no possibility of dignity in Honneth A., *The Struggle for Recognition: The Moral Grammar of Social Conflicts* (MIT Press, 1996)

¹²⁴ Ibid

order to retain self-respect is another aspect of identity important to many.¹²⁵ How staff address the residents, whether and how they communicate with them and enable them to participate in the life of the home and in the decisions that concern their care also play a part in that perception of self. Carers are in a position to help elderly people adjust to the debilitating consequences of physical changes, cope with the upsetting effects of loss, and feel part of their new surroundings. These are all important aspects that make up a person's sense of identity, a fundamental part of dignity.

Staff can also influence people's ability to self-determine, to have a stake in their lives in spite of the institutional setting they live in. Remaining independent for as long as possible could be made possible by the provision of the right equipment or the delivery of the appropriate help. Retaining some form of control over private space, allowing for the possibility of choice in a usually rigid daily routine and facilitating the acceptance of a new life chapter can also be made possible by the respectful attitude of staff. As to people's sense of humanity, the staff's role is also pivotal. Maintaining a sense of intrinsic worth may be possible through the personalisation of care staff can offer, and the acknowledgement of residents' individuality. The feeling of being treated equally to others and not seen as a sub-class of citizens can also come from the attitude of staff. Staff behaviour and treatment of the residents in their care is intrinsically linked with the possibility of dignity for those they care for.

The importance of the role of caring staff professionals in the delivery of dignity enabling conditions is not reflected in the way the care industry is, generally, treating them. Turnover in the care staff sector is high. Figures show that the yearly turnover rate for staff in the adult residential sector is 27.3%.¹²⁶ This is even higher for the 40,500 registered nurses who work within residential care settings,¹²⁷ with a turnover of 33.5%.¹²⁸ This may prevent residents from building meaningful relationships with those who care for them, an important aspect for dignity. Furthermore, 1 in 3 are non-British and there is no statutory requirement for language skills, which might be

¹²⁵ See Chapter II

¹²⁶ Davison S. and Polzin G., 'The state of the adult social care sector and workforce in England' Skills for Care (September 2016)

< <https://www.nmds-sc-online.org.uk/Get.aspx?id=980099> > Accessed 28th August 2017

¹²⁷ Ibid 19

¹²⁸ Ibid 41

another obstacle for relationships to form.¹²⁹ The Social Care Institute for Excellence recognises that low staffing levels are also a common challenge for care homes, and cites low status and pay, poor training and support, stress and sickness as some explanations for that problem.¹³⁰ Pay is on average £14,400 per year for a care worker, which is 26p above the National Living Wage compulsory since April 2016,¹³¹ and 79p below the UK Living Wage.¹³² The living wage is set by the Living Wage Foundation and is based on the cost of living in the UK.¹³³ Some care services employers have even been found trying to avoid paying the minimum wage.¹³⁴

Recent figures show that around 665,000 people work in the residential care sector regulated by the CQC.¹³⁵ ‘Quality service’ is rated by Skills for Care as one of the many advantages of professional qualifications, but 48% of people who work in the adult care sector have no relevant qualifications for social care recorded.¹³⁶ Out of those who do hold qualifications, only 21% have a level 2 qualification, 16% a level 3 and only 12% a level 4 or above (3% have other types of qualifications).¹³⁷ A chart recording the type of training care workers receive shows that the majority is in the area of ‘moving and handling’ (74%) and safeguarding adults (70%).¹³⁸ This type of training reflects an overall concern for the management of risk and safety. This may well suggest that care home providers’ priority is to protect themselves from litigation rather than create conditions for dignity. On a more positive note, the data recorded

¹²⁹ Registered Nursing Home Association ‘Nursing, A sector in crisis’ December 2014
< http://www.rnha.co.uk/web_images/pdfs/call_for_evidence_rnha.pdf> Accessed 17th March 2015

¹³⁰ Social Care Institute for Excellence, ‘Commissioning care homes: common safeguarding challenges’ February 2012
<<http://www.scie.org.uk/publications/guides/guide46/underlyingcauses/staffinglevels.asp>> Accessed 26th March 2015

¹³¹ The National Minimum Wage (Amendment) Regulations 2016
The figures cited here may be lower than the new Minimum Living Wage as they were collected prior to its enactment.

¹³² Davison and Polzin (n126) 69

¹³³ Living Wage Foundation < <http://www.livingwage.org.uk/what-living-wage>> Accessed 26th March 2015

¹³⁴ A report from the HMRC found that the most common reasons for paying below the threshold was deducting costs from pay such as uniform, unpaid working time such as travelling or training time or applying the wrong rate of pay.

HM Revenue & Customs, ‘National Minimum Wage compliance in the social care sector. An evaluation of National Minimum Wage enforcement in the social care sector over the period 1st April 2011 to 31st March 2013’, 13

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262269/131125_Social_Care_Evaluation_2013_ReportNov2013PDF.PDF> Accessed 28th August 2017

¹³⁵ Davison and Polzin (n126) 18

¹³⁶ Ibid 82

¹³⁷ Ibid

¹³⁸ Ibid 83

also shows that 83% of care home staff had received an induction and 21% had completed or were in the process of completing a Care Certificate.¹³⁹ This may be the result of the Francis enquiry into the failings of the Mid-Staffordshire Foundation Trust that led to the commissioning of an independent research into the adequacy of care staff training.¹⁴⁰ It concluded that the training standards carers received varied wildly, and that no set minimum was required. It recommended Higher Education England to develop a ‘Certificate of Fundamental Care’ for all staff to have prior to being able to work unsupervised.¹⁴¹

High staff turnover, poor pay and lack of training can have direct consequences on the attitude of caring professionals towards regulation compliance. These factors may encourage ‘motivational postures like game-playing and disengagement that conduce to ritualism’.¹⁴² Motivational postures have been defined as ‘conglomerates of beliefs, attitudes, preferences, interests, and feelings that together communicate the degree to which an individual accepts the agenda of the regulator, in principle, and endorses the way in which the regulator functions and carries out duties on a daily basis’.¹⁴³ Whereas disengagement is ‘a posture of withdrawal’ towards the authority of the regulator, game-playing ‘circumvents rules and laws while appearing to do what is expected’.¹⁴⁴

In order to avoid such behaviour, it is essential for care homes to provide a working environment that promotes a ‘motivational posture of commitment to the regulatory order’ and continuous improvement in quality of care.¹⁴⁵ Achieving this state of affairs involves that ‘inevitable webs of regulation are complemented by webs of support that increase freedom in (the) lives (of care staff) that give them more meaning, that help them build on their strengths to develop a career trajectory from

¹³⁹ Ibid 84

¹⁴⁰ The Cavendish Review, ‘An Independent Review into Healthcare Assistants and Support Workers into the NHS and social care setting’ July 2013
<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/236212/Cavendish_Review.pdf> Accessed 17th March 2015

¹⁴¹ Ibid 55

¹⁴² Braithwaite et al (n3) 248

¹⁴³ Braithwaite V., Murphy K. and Reinhart M., ‘Taxation Threat, Motivational Postures, and Responsive Regulation’ (January 2007) 29(1) Law & Policy 137, 138

¹⁴⁴ Braithwaite V., ‘Defiance and Motivational Postures’ (February 2012), 2
<<http://valerie.braithwaite.net.au/home/postures>> Accessed 27th March 2017

¹⁴⁵ Braithwaite et al (n3) 248

more decent base incomes to even higher incomes as their skills grow.’¹⁴⁶ In effect, care professionals who are valued, adequately trained and who feel part of an organisation that is able to offer them incentive for the work they do, are more likely to want to adhere to the regulatory regime and less likely to be resistant to it. As I have alluded to above, efforts have been made to implement the living wage, and encourage the development of industry-wide training standards.

4) Beyond Regulation; Complaints procedure, Ombudsman and Advocacy

Braithwaite has remarked that ‘no group is harder to empower than the institutionalized aged who are more lacking than others in both the muscle and the voice to resist’.¹⁴⁷ If the inspection system fails to spot a problem, or the operator refuses or is reluctant to make the necessary changes to improve care in order to become compliant with regulations, it should be the case that the individual harmed by sub-standard care should be able to complain and seek redress. It is made clear by the CQC that they cannot settle formal complaints.¹⁴⁸ This is the role of the provider, whether that may be a private company or a council led service. The only indirect role the CQC has in facilitating personal complaints is in the compliance of registered service providers with Regulation 16, which provides that ‘[a]ny complaint received must be investigated and necessary and proportionate action must be taken in response to any failure identified by the complaint or investigation’.¹⁴⁹

Should issues not get resolved satisfactorily, people are directed to contact the Local Government Ombudsman (hereafter LGO). Since October 2010 this applies whether the care is paid for privately or by the local council.¹⁵⁰ The service is free and either the service user or their representative can use it when reporting ‘poor quality care, fees and charges, poor complaint handling, delay, assessments of need and safety and

¹⁴⁶ Ibid

¹⁴⁷ Ibid 3

¹⁴⁸ CQC, ‘Complain about a service provider’

< <http://www.cqc.org.uk/content/complain-about-service-or-provider>> Accessed 30th March 2017

¹⁴⁹ Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, Regulations 16(1)

¹⁵⁰ Schedule 5 of the Health Care Act 2009 amends Chapter 7 of The Local Government Act 1974 to include privately arranged or funded adult social care.

<<http://www.legislation.gov.uk/ukpga/2009/21/schedule/5>> Accessed 23rd February 2015

safeguarding'.¹⁵¹ Once a complaint has been logged, the Ombudsman checks that the provider was given the opportunity to rectify the problem first and then assesses whether or not the case justifies further action.¹⁵² Once it has been established that the complaint is valid, an investigation is carried out in all anonymity. Possible outcomes, that are not legally enforceable range from an apology, the provision of a service that should have been made, changes to a demand for improvement or some form of payment.¹⁵³

In an illustrative case study about good practice in cases of capacity determination, the LGO shows how relatives of vulnerable elderly adults ought to be involved, especially when the person concerned has difficulties communicating with others.¹⁵⁴ Their example shows the traumatic effect a decision to move an elderly woman with Parkinson's disease to hospital on the ground of safeguarding concerns after a determination of lack of capacity had on her and her family.¹⁵⁵ Here the LGO argues that the council should have involved the woman's daughter prior to determining incapacity, because she was able to understand her mother's difficult speech, and would have been able to explain that her mother was safe and wished to stay home.¹⁵⁶ The LGO represents another layer of enforcement on the ground, to check that complaints handling, safeguarding policies, rules on mental capacity determination and the quality standards set by the CQC are followed by those organisations that procure adult care services.¹⁵⁷ All these aspects of care practices are important to build an environment amenable to dignity.

Another case shows how failing to engage with those who know the vulnerable adult best can have dire consequences on the dignity of the vulnerable adult:

¹⁵¹ Local Government Ombudsman, 'How to complain about a care home or care in your home' < <http://www.lgo.org.uk/adult-social-care/how-we-can-help> > Accessed 30th March 2017

¹⁵² LGO, 'How we deal with your complaint' < <http://www.lgo.org.uk/make-a-complaint/how-we-deal-with-your-complaint>> Accessed 30th March 2017

¹⁵³ LGO, 'Possible outcomes' < <http://www.lgo.org.uk/make-a-complaint/possible-outcomes>> Accessed 30th March 2017

¹⁵⁴ Local Government & Social Care Ombudsman and Parliamentary and Health Service Ombudsman 'Working together to investigate health and social care complaints' (December 2016) Focus report: learning lessons from complaints <https://www.ombudsman.org.uk/sites/default/files/Joint_working_team_focus_report_December_2016_0.pdf> Accessed 6th February 2017

¹⁵⁵ Ibid 7

¹⁵⁶ Ibid 15-16

¹⁵⁷ Ibid

A dementia sufferer had to stay in respite care, despite his son arranging a private care package that could have allowed him to stay at home, a joint investigation by the Local Government Ombudsman (LGO) and the Parliamentary and Health Service Ombudsman (PHSO) has found. The man had been living in respite care while his wife, who also suffered with dementia, was being treated in hospital. His son organised a care package to allow him to come home. But two local authorities applied for a Deprivation of Liberty Order, forcing the man to stay in care, apart from his wife, without informing his son of their plans. Before the stay in respite care, the man was admitted to hospital with acute glaucoma in April 2009. The couple's son - himself a doctor - told the authorities that he believed the injury had been caused by a blow from his mother, who was beginning to show signs of dementia. This report was not followed up, and a safeguarding plan was never implemented. Instead the father's discharge from hospital was hastily arranged and he returned home without any protection.

Then over time, the couple's needs increased. The woman's symptoms were deteriorating and in September she was admitted to hospital, and her husband went into respite care. The woman stayed in hospital for six weeks while her son arranged a care package. Despite the son telling the authorities that he was employing a registered general nurse to provide care when his father came home, the two authorities agreed that that this would be inadequate and applied for the Deprivation of Liberty Order – without involving him in the decision. In addition to this, when the Trust wrote to the son recommending that his parents be placed in separate care homes, they sent a copy to his mother – causing her a great deal of distress.¹⁵⁸

One commentator from the LGO stated that ‘as a result of actions by both the council and the Trust, the couple were denied the chance of living at home together in a settled lifestyle for longer than they did. The couple suffered a needless loss of

¹⁵⁸ LGO, Report in confidence on a joint investigation into complaint 11004229 against Kirklee Metropolitan Borough Council and South West Yorkshire Partnership NHS Foundation Trust' (20th November 2013)
<<https://www.lgo.org.uk/information-centre/news/2013/nov/south-yorkshire-family-excluded-from-care-planning-for-elderly-relatives>> Accessed 6th February 2018

dignity, while their son felt ignored, undermined and excluded from any decision about their care'.¹⁵⁹

The main problem with the LGO is its slow processing time of complaints and investigation, which impedes its effectiveness and responsiveness on the ground. In one example of complaints received, the LGO found that Regulation 17 (the predecessor of Regulation 10, the one that dealt indirectly with dignity) had been breached because the service provider had failed to involve the resident in her own care.¹⁶⁰ Participation is an important element of dignity for elderly people in care.¹⁶¹ The recommendation for redress involved an apology but no financial redress, as the care provider's fees for respite care costs had already been refunded.¹⁶² This instance illustrates that the dignity of the person involved was never truly protected effectively, and that redress only occurred after the damaging events had occurred. In this case the person concerned had died by the time the Ombudsman had reached its investigative conclusions.

It was also remarked that complaints procedures were not easily accessible and well advertised in care homes in the UK.¹⁶³ It is therefore essential that local and accessible advocacy services be at the heart of the residential care system in order for all residents to have a voice. Local authorities must, under the Care Act 2014, provide Independent advocacy to individuals who are subject of a safeguarding enquiry, if it is believed that they would fail to understand the information provided to them or be unable to communicate their views.¹⁶⁴ There is no right to advocacy when a person seeks to complain about the care they receive. Only Regulation 20, the Duty of candour, seeks service providers to be open and effective when a safety incident occurs, and so advises the use of advocacy services.¹⁶⁵ Small local advocacy groups that regularly engage with residents' committees would add another layer of dialogical exchange. This would help residents put their opinions across and allow

¹⁵⁹ Ibid

¹⁶⁰ LGO, 'Bupa Care Homes (BNH) Limited (13 015 719)' (9th April 2014) <<http://www.lgo.org.uk/decisions/adult-care-services/residential-care/13-015-719>> Accessed 23rd February 2015

¹⁶¹ Chapter II

¹⁶² LGO (n160)

¹⁶³ Kerrison and Pollock (n22)

¹⁶⁴ Care Act 2014 s.68

¹⁶⁵ CQC (n42) at 81

them to engage with the environment they live in. These measures would go a long way in fostering conditions for dignity by adding another layer of accountability.

5) Conclusion

The environment the person lives in will either facilitate or hinder the possibility of dignity, making it in the language of the capabilities, an environmental conversion factor. Working out whether an environment can promote favourable conditions to dignity understood from the perspective of the resident can be done by looking at how the CQC, the regulatory body in charge of health and social care, has designed the rules that shape that environment. Current guidelines set out that regulation for this sector must be risk-based, to ensure that all providers of health and social care deliver services that can prevent avoidable harm and respect the welfare of the service user. I have argued here that risk-based regulations may not be the best model to follow in order to implement conditions conducive to dignity as understood in this dissertation. Although the current guidance for dignity standard appears to embrace some aspects of dignity important to those concerned (i.e. respect for privacy, autonomy and non-discrimination), it does not require the participation of those who live in the regulated environment to elaborate on the meaning of dignity and on the ways in which it could be realised.

I have argued that in order to make the CQC enforcement model more efficient and dignity-compliant, it ought to engage with the various stakeholders of care homes, and be applied in conjunction with a strengths based pyramid of support. A combination of punishment and reward could improve the effectiveness of an audit based enforcement mechanism. Engaging with residents may start with the setting up of groups of representatives who meet up regularly with carers and relatives, and are to be consulted as part of the inspection routine. This would also improve those conditions needed for dignity by empowering residents to communicate and have a stake in the running of the environment they live in. I have also considered the effect of regulation on care professionals' motivational postures, and have concluded that compliance would improve with if working conditions and morale were addressed.

I have discussed how a risk-based model of regulation for elderly individuals in care could harm the creation of conditions amenable to dignity. Imposing a risk-based regulatory model to healthcare provisions may be appropriate in the delivery of medical treatment, but in institutions caring for individuals at the end of their life, there is an argument that welfare and the prevention of unavoidable harm should not be prioritized to the detriment of dignity as an empowering force. For instance, the use of restraints regulated by the CQC and adopted on the ground of safety (based on risk limitation),¹⁶⁶ causes, amongst other physical and psychological trauma, a loss of dignity.¹⁶⁷

A regulatory model underpinned by dignity rather than risk may forbid such practice altogether, preferring the use of more creative caring methods that would do without the use of restraints.¹⁶⁸ Currently, the regulatory framework in place for care homes considers dignity as one aspect of its welfare aims, understood as the limitation of preventable harm, therefore restricting the understanding of dignity to its protective functionality. If, on the contrary, safety and welfare were to be considered as an element of dignity, the claim dignity makes against harm and the instrumentalisation of individuals, the regulatory framework could also include its empowering functionality. Instead of limiting dignity to an objective rule that would fit into a regulatory system of risk-based governance, it could be adopting the subjective criteria of residents through dialogical engagement.

Furthermore, the regulatory framework imposed on service providers ought to have a greater bearing on the effects of service provisions commissioned by councils. As the case of McDonald shows, the mention of these standards is sparse if almost non-existent. There is a case to argue that services commissioned by public authorities ought to follow such standards more transparently, instead of following its own assessment procedures. Beyond the enforcement of regulations, individuals who feel their care providers have treated them unjustly can lodge a complaint with the Local Government Ombudsman. The process of investigation is slow and sometimes too

¹⁶⁶ CQC, 'Brief guide: restraint (physical and mechanical) October 2015 (revised April 2016)
<http://www.cqc.org.uk/sites/default/files/20170126_briefguide-Restraint_physical_mechanical.pdf>
Accessed 30th March 2017

¹⁶⁷ Evans L.K. and Strumpf N., 'Myths about elderly restraints' (1990) 22 *Journal of Nursing Scholarship* 124

¹⁶⁸ Braithwaite et al (n3) 135-136

late to bring any redress, but offers another layer of scrutiny on the performance of care services.

Regulations of care homes are applied externally but seek to influence the internal workings of the organizations they target in order to improve their performance and quality.¹⁶⁹ Walshe remarks that such external approaches to improvement have their limits because ‘they ignore the complexities and subtleties of organizational behaviour, take little or no account of organizational context and culture, and make naïve, universal assumptions about the mechanisms for organizational changes’.¹⁷⁰ This can be illustrated by the one-fit-all approach the healthcare regulatory model adopts across all services. Despite this problem, I have argued that outcomes are less restrictive and paternalistic than strict rules, but they need to be complemented by subjective criteria in order to be effective.¹⁷¹ This could be achieved through a dialogical approach, for instance at the time of admission and through periodic interviews, by a member of staff designated, as some nursing homes have already done, as a ‘Dignity Champion’.¹⁷²

On the other hand, Walshe writes that ‘the problem with this kind of internal approaches to improvement is that they often behave as if the organization exists in isolation from its environment, and ignore the powerful institutional, social and economic pressures that shape organizational objectives’.¹⁷³ It is indeed naïve to consider regulating a particular environment in a vacuum. Care homes are situated within a wider social environment they cannot be disassociated from. The macro-environment care homes function within has to be taken into account in order for regulation to be effective.

¹⁶⁹ Walshe n(10)

¹⁷⁰ Ibid 7-8

¹⁷¹ Braithwaite and Braithwaite (n20)

¹⁷² Dignity in Care < http://www.dignityincare.org.uk/Dignity-Champions/Becoming_a_Dignity_Champion/ > Accessed 7th March 2017

¹⁷³ Walshe (n10) 7

Chapter VI

Social Conversion factor: Ageism

1) Introduction

In the first two chapters I established the theoretical underpinning and conceptualisation of dignity under a discursive ethical model to be used in long-term aged care. I argued that in order to enable the possibility of dignity as defined in this way, certain conditions were needed to allow the development of identity, self-determination and respect for one's humanity. Inspired by the capability theory, I set out to examine the possibility of dignity through the lens of conversion factors, or areas prone to be obstacles to the creation of those conditions needed for its flourishing. I do so throughout this dissertation by examining how the law shapes the experience of the older individual in care by either helping, hindering or having no effect on the creation of those conditions.

In Chapter III and IV I discussed the personal conversion factor of multi-dimensional vulnerability in the possibility of dignity. I concluded that laws created to protect and safeguard individuals in care needed to keep the person's relational autonomy in mind to be compatible with the possibility of dignity. I then considered the way in which care home regulation, another legal tool, could convert the environmental factor of care homes into a setting amenable to dignity. I argued that, inter alia, dialogical engagement with those who lived in the regulated environment ought to form an intrinsic part of the construction and monitoring of the regulatory framework for dignity conditions to be possible.

I concluded that regulatory models did not exist in a vacuum: wider social forces also shape the way in which long-term aged care functions. Therefore I now turn my attention to a broader environmental conversion factor that influences the possibility of dignity, that of our society's attitude to old age. The way in which older individuals and old age are viewed and treated by society will have a repercussion on the

possibility of constructing conditions favourable to dignity. It can do so in two ways. Firstly, ageism can irrevocably and inexorably push the issue of dignity in old age away from current concerns. This is the result of a 'them and us' dichotomy between dependent elderly people and the rest of the population. Secondly, ageism can have a direct impact on the everyday lives of older individuals in care, jeopardizing their ability to sustain their identity, pursue self-determination and have their humanity respected.

In order to understand the impact ageism is having on the possibility of dignity I will firstly delve into the complex origins and causes of society's prejudiced relationship with ageing. Secondly, I will look at the consequences ageism is specifically having on dignity in care. I will then review the current equality laws in place aimed at narrowing the 'them and us' divide, and whether they are in any way effective in achieving a social context amenable to the realisation of dignity. I will finally suggest how law can play a positive, albeit limited role in trying to change the way in which we treat those in need of care at the end of their lives.

2) Definition and origins of ageism

a) Definition

Despite the pessimistic tone of this introduction about our complex relationship with ageing, many studies have focused on its positive effects. Getting older often means becoming more rational in choice making,¹ wiser about the resolution of social conflicts,² and more emotionally healthy.³ The average life span has increased by ten years over the 50 years between 1960 and 2010,⁴ and pensioners' incomes have

¹ Tentori K. et al 'Wisdom and Aging: Irrational preferences in college students but not older adults' (2001) 81 (3) Cognition B87

² Grossman I. et al, 'Reasoning about social conflicts improves into old age' (2010) 107 (16) Proceedings of the National Academy of Sciences of the United States 7426

³ Williams L. et al, 'The mellow years? Neural basis of improving emotional stability with age' (2006) 26 Journal of Neuroscience 6422

⁴ Office for National Statistics, 'Mortality in England and Wales: Average Life Span, 2010' (17th December 2012)

< http://www.ons.gov.uk/ons/dcp171776_292196.pdf> Accessed 25th September 2015

increased more than the average income since 1998/99.⁵ Despite these changes for the better, studies have also shown that prejudices against age are still very much alive.⁶ Butler was one of the first to define the term ageism as ‘a process of systematic stereotyping of, and discrimination against people because they are old, just as racism and sexism accomplish this for skin colour and gender’.⁷ Seeing elderly people as a separate entity is symptomatic of ageism and has resulted in a ‘them and us’ dichotomy harmful to our older selves.⁸

Ageism has been identified as a source of derogatory humour, lack of respect, discriminatory treatment, and the conviction that older generations are a burden to the young.⁹ It is, by definition, based on misconceived stigmas. Stigmas are built upon the perception of attributes some individuals may have that make them abhorrent to others.¹⁰ In the case of the elderly these attributes are for instance ‘frailty, forgetfulness and nearness to death’.¹¹ This negative reaction to ageing is even more curious if we think that ageing is a phase of life we will all (with any chance) experience, unlike any other types of stigma-based characteristics such as gender, disability, race, religion or sexual orientation.¹² Ageism distorts our perception of what it means to be elderly. I believe that the negative image it reflects back at us is a very important reason why we still have unresolved problems with the way in which people are treated in care homes today.

Many have tried to understand the phenomenon of ageism and have elaborated theories to explain why the process of ageing has resulted in these deep-seated

⁵ Department for Works and Pensions, ‘The Pensioners’ Income Series United Kingdom 2012/13’ (July 2014), 14

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/325315/pensioners-incomes-series-statistics-july-2014.pdf> Accessed 25th September 2015

⁶ See the study conducted by Eurage and commissioned by AgeUK, ‘Ageism in Europe, Findings from the European Social Survey’ (AgeUK, 2011)

<http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/ageism_across_europe_report_interactive.pdf?dtrk=true> Accessed 13th July 2015

⁷ Butler R. ‘Ageism’ in Maddox G. et al (Eds) *The Encyclopaedia of Aging* (Springer, 1995) 22-23

⁸ Nelson.T. D. ‘Ageism: Prejudice Against Our Feared Future Self’ (2005) 61(2) *Journal of Social Issues* 207

⁹ Palmore E.B. ‘The Ageism survey: First findings/response’ (2001) 41 *The Gerontologist* 572

¹⁰ Weiner B., Ota H., Pierson H., Gallois C., Ng S, et al. ‘An Attributional Analysis of Reaction to Stigmas’ (1988) 55 *Journal of Personality and Social Psychology* 738

¹¹ Hagestad G. and Uhlenberg P., ‘The Social Separation of Old and Young: A Root of Ageism’ (2005) 61(2) *Journal of Social Issues* 343, 350

¹² Equality Act 2010 s.4

stigmas.¹³ North and Fiske have classified these theories according to their point of origins, ranging from those borne out of our own individual psyche, to those explained by wider socio-cultural changes.¹⁴

b) Psychological theories

Individual level theories see ageism explained as emanating from the will to protect the ego.¹⁵ Terror Management Theory, set out mainly by Martens et al¹⁶ and Becker,¹⁷ is based on the idea that the knowledge of our own mortality is ‘a potent threat to the human psyche and that people defend against this threat by clinging on to cultural systems of belief to maintain a sense of self-esteem’.¹⁸ This theory shows that the vilification of old age can be explained by the various threats it poses to our ability to mitigate our thoughts about frailty, decrepitude and unavoidable mortality through the construction of cultural meaning and self-esteem.¹⁹ Martens et al identify three types of threats that may crystallise into ageism.²⁰ Firstly, ‘the threat of death’ means that humans feel threatened by the fact that older people are a vivid representation of their own fragility and that they will eventually ‘decay and die’.²¹ Secondly, the threat of ‘animality’ is linked to the deterioration of the elderly body, a more indirect reminder of the finite nature of our own flesh.²² Lastly, ‘the threat of insignificance’ is the perception that old age does not allow for the construction of self-esteem through the realization of certain cultural standards, and so opens up the potential for death anxiety. We may fear that getting older means that we have to relinquish the status we achieved through work or other means of association, or the attributes we ascribe value to, such as beauty or physical fitness that have filled our sense of worth during

¹³ North M. and Fiske S., ‘An Inconvenienced Youth? Ageism and Its Potential Intergenerational Roots’ (2012) 138(5) *Psychological Bulletin* 982

¹⁴ *Ibid*

¹⁵ *Ibid* 984

¹⁶ Martens A., Goldenberg J., Greenberg J., ‘A Terror Management Perspective on Ageism’ (2005) 61(3) *Journal of Social Issues* 223

¹⁷ Becker E. *The Denial of Death*, (Free Press, 1973)

¹⁸ Martens et al (n16) 224

¹⁹ Martens et al. (n16)

²⁰ Martens et al (n16) 227-229

²¹ Martens et al (n16) 227

²² Isaksen L. W., ‘Towards a sociology of (gendered) disgust’ (2002) 23 *Journal of Family Issues* 791

our lifetime.²³ As our culture is very much focused on valuing youth and all that it represents (beauty, productivity, strength, agility...), building self-esteem in old age may indeed be perceived as an impossible task, triggering ageism rooted in fear.

Some theories set out the premise that it is the action of interacting with older people that elicits ageism.²⁴ Research has indeed described how the physical appearance of older people may have a 'negative halo effect' on others, which means in this case that the perceived unattractiveness of the older person is automatically assimilated to negative character traits and aptitudes.²⁵ Likewise, the 'overgeneralisation effect' theory proposes that certain naturally occurring neutral facial traits are wrongly interpreted as the signal of an emotion, itself eliciting certain prejudices and behaviours.²⁶ For instance, the droopy eyes of an older person can be read as sadness and elicit responses congruent with that reading, although the person is not actually sad.²⁷

These theories argue that stigmas are influenced by first impressions. This leads on to the question of whether the current importance ascribed to physical attractiveness - often linked to youthfulness - in social contacts, is contributing to the occurrence of negative stigma building about older people.²⁸ Studies have looked at stigma building through the perception of negative character traits or physical attributes that are rejected by society.²⁹ It has been shown that older women especially try to fight ageing through the use of 'beauty work' (make up, cosmetic procedures and hair colouring), in order to remain visible in an ageist and sexist society.³⁰ 'Beauty bias', or the bias that may exist against those 'less physically attractive than the alleged ideal' has been hailed another mechanism of social stratification and exclusion.³¹ For these reasons, it is probably accurate to conclude that the physical appearance of the

²³ Martens et al (n16) 228

²⁴ North and Fiske (n13) 984

²⁵ Langlois J. H. et al, 'Maxims or myths of beauty? A meta-analytic and theoretical review' (2000) 126 *Psychological Bulletin* 390

²⁶ Zebrowitz LA. 'Physical appearance as a basis for stereotyping' in MacRae N, Hewstone M, Stangor C, (Eds). *Foundation of stereotypes and stereotyping* (Guilford Press, 1996), 79–120.

²⁷ Montepare J. M. and Zebrowitz L. A., 'A social-developmental view of ageism' in Nelson T. D. (Ed.) *Ageism: Stereotyping and prejudice against older persons* (MIT Press, 2004)

²⁸ Berrie B., *The Power of Looks, Social Stratification of Physical Appearance* (Ashgate, 2008)

²⁹ Goffman E., *Stigma: Notes on the management of spoiled identity* (Prentice-Hall, 1963)

³⁰ Clarke L. H. and Griffin M., 'Visible and invisible ageing: beauty work as a response to ageism' (2008) 28(5) *Ageing and Society* 653

³¹ Berrie (n28) 2

very old (Chapter II mentions this ‘unrecognizable body’ older individuals refer to) plays a prominent role in the construction of negative stigma.

Other theories explain ageism as indirectly rooted in the natural and instinctive Darwinian selection process of evolution that favours the survival of the species through the fit and young over the burdensome sick and aged.³² A study has shown that in a hypothetical scenario where the need to help arose, the young and healthy were chosen over the old and the sick.³³ This prioritisation of society’s strongest members over its more vulnerable has also been explained under a ‘socio-functional perspective’ as being motivated by the exclusion of those who can no longer benefit the group they belong to.³⁴ This particular view of ageism considers that once a person becomes unable, due to their age, to reciprocate the advantages they acquire from being part of a group, their inaptitude to carry on contributing to that group’s overall success will result in their exclusion.³⁵

c) Cultural theories

Ageism can also be explained as a consequence of ‘socio-cultural’ events or practices that have led to the irreversible downgrading of the place and the role of the older person in contemporary societies.³⁶ Under the theoretical framework of modernisation, as set out by Burgess,³⁷ or Cowgil,³⁸ the decline of the status of the elderly has been explained by the transition of western societies from traditional and agriculture-based to modern and industry-based.

³² North and Fiske (n13) 985

³³ Burnstein E. et al, ‘Some neo-Darwinian decision rules for altruism: Weighing cues for inclusive fitness as a function of the biological importance of the decision’ (1994) 67 *Journal of Personality and Social Psychology* 773

³⁴ Cottrell C. A. et al, ‘What do people desire in others? A socio-functional perspective on the importance of different valued characteristics’ (2007) 92 *Journal of Personality and Social Psychology* 208

³⁵ Ibid

³⁶ North and Fiske (n13) 985

³⁷ Burgess E. W. (Ed.), *Ageing in Modern Societies* (University of Chicago Press, 1960)

³⁸ Cowgil D. O. ‘A theory of aging in cross-cultural perspective’ in D. O. Owfill and L. D. Holmes (Eds) *Ageing and Modernization* (Appleton-Century-Crofts, 1972)

Modernisation theory links the demise of the elderly person's place in society to the erosion of the extended family because of urbanization and industrialization.³⁹ From the mid-nineteenth century onwards, the role of the elderly person as a productive part of the family unit was slowly eroded, and the segregation of society by age began its irreversible trend.⁴⁰ Not only did industrialization eventually enabled families to live without having to send their children and elderly relatives to work, it also forcibly weeded out from the labour market the less productive workers.⁴¹ The increased need for a mobile, flexible and adaptable labour force post-industrialisation has also been cited as a root cause of the devaluation of the role of older people, whose experience became relatively less sought after as a result.⁴² One socio-historical theory has even pinpointed the advent of the printing press as the cause of this downwards shift, triggering the loss of older people's function as storytellers and bearers of knowledge.⁴³

Advances in medicine also began the categorization of the elderly as a frail, disease-prone and incurable segment of the population, whilst at the same time enabling more and more people to live longer, enlarging the proportion of elderly in society to unprecedented proportions.⁴⁴ The family changed from a self-sufficient multi-generational unit, to a smaller entity with far fewer children and a wider gap between generations.⁴⁵ Once an active, productive and important member of the family, the elderly person was now regarded in a negative light, as a burden on resources, and the living representation of the end of life and all the ills that it entailed.⁴⁶ The 'material constraints explanation' justifies the withdrawal of family support for its elders on the ground of a lack of resources, of poverty faced by families during industrialization

³⁹ Aboderin I., 'Modernisation and ageing theory revisited: current explanations of recent developing world and historical Western shifts in material family support for older people' (2004) 24(01) *Ageing and Society* 29, 33

⁴⁰ Whitton L. S., 'Ageism: Paternalism and Prejudice' (1996-1997) 46 *DePaul Law Review* 453, 458-459

⁴¹ *Ibid* 460

⁴² Nelson (n8)

⁴³ Nelson (n8)

⁴⁴ Howard P. Chudacoff, *How Old Are You? Age Consciousness in American Culture* (Princeton University Press, 1992)

⁴⁵ Whitton (n40) 461

⁴⁶ Gratton B., 'Factories, Attitudes, and the New Deal: The History of Old Age' in Beth B. Hess & Elizabeth W. Markson (Eds.) *Growing Old in America, New Perspective on Age*, (4th Ed. Transaction Publishers, 1991)

through inadequate or insufficient employment.⁴⁷ Studies conducted in developing countries have indeed shown that a lack of resources means that support is directed at immediate relatives first, spouse and children, to the detriment of older generations.⁴⁸

Added to this economical shift in the roles of generations, youth eventually became the specific and preferred target of advertisers and filmmakers, synonymous with the promise of a better society in a new technologically advanced era,⁴⁹ changing forever the high status of the once respected older person.⁵⁰ More recently the birth of the welfare state in the period between the two World Wars has increased the degree of separation between generations, associating the idea of retirement and old age with economic dependency,⁵¹ and increasing the pressure on the young to fund increasingly burdensome pension and public health costs.⁵²

Some have criticized this theoretical approach on ageing as culturally biased towards western countries, and glossing over many social complexities.⁵³ Laslett has challenged orthodoxy by indicating that family units were not often multigenerational, questioning the idea that the breakdown of the family unit was responsible for the demise of the position of the older person in society.⁵⁴ Fisher's account disputes the timing and so the causes of the shift in attitudes towards the elderly.⁵⁵ His research traces the origins of the change back to the egalitarian spirit of the Enlightenment era of the early 1800s, which resulted in the rejection of unequal age-based hierarchical and often patriarchal authority.⁵⁶

⁴⁷ Craib I. *Classical Social Theory* (Oxford University Press, 1997)

⁴⁸ Golstein M. C., Schuler S. and Ross J. L., 'Social and economic forces affecting intergenerational relations in a third world country: a cautionary tale from South Asia' (1983) 38 *Journal of Gerontology* 716

⁴⁹ Achenbaum A., 'Images of Old Age in America, 1790-1970: A Vision and a Re-Vision' in Mike Featherstone & Andrew Wernick (Eds). *Images of Aging: Cultural Representations of Later Life* (Routledge, 1995), 19-23

⁵⁰ Laslett P., *The World We Have Lost, further explored* (4th Ed, Routledge, 2004)

⁵¹ Fineman M.A., "'Elderly' as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility' (2012-2013) 20 *Elder Law Journal* 71

⁵² The cost of pensions is the largest in the welfare budget after that of the NHS with an estimated spend of £83 billion for the year 2013-14, rising in cash terms and real terms over the last thirty years. Office for Budget Responsibility 'Welfare trends report' (October 2014)

<http://budgetresponsibility.org.uk/wordpress/docs/Welfare_trends_report_2014_dn2B.pdf> Accessed 25th September 2015

⁵³ Achenbaum (n49) 308

⁵⁴ Laslett (n50)

⁵⁵ Fisher Hackett D., *Growing Old in America* (Oxford University Press, 1977)

⁵⁶ *Ibid*

Fisher's account is echoed by those strands of modernisation theory according to which 'the decreased willingness of children to support older parents is seen as a result of the erosion of the ethics of 'familism' (of which filial obligation is assumed to be an integral part), itself a consequence of increasing secularization and the growing influence of 'modern' values of individualism'.⁵⁷ Older generations could enforce filial obligation through potential 'economic, familial and religious sanction' because of their high authoritative and powerful status in traditional societies.⁵⁸ Beside these sanctions, younger generations also benefited from useful services provided by the older generations in the shape of 'domestic help, advice, child-minding and education'.⁵⁹ Aboderin explains that once the status and role of older people is lost through the process of 'education, urbanization and new technologies', this intergenerational exchange has no longer reason to be.⁶⁰ Filial obligation therefore becomes more bound to the feelings children may have towards their parents, potentially leading to diminishing support.⁶¹ Like other theories of modernization, however, even this account has been criticized for its lack of empirical grounding, and conceptual limitations.⁶²

Modernization has also had some beneficial consequences. Until the early nineteenth century, many women were expected to give up their aspiration to a life of their own to dedicate it to the care of elderly relatives.⁶³ Although women still perform the bulk of caring duties in the UK today,⁶⁴ modernization followed by the rise of welfarism and institutional care post World War II, has had the positive consequence of opening up more opportunities for those women who would previously have been destined to a life of caregiving. It is also important to note that the current trend to reduce the

⁵⁷ Aboderin (n39) 36

⁵⁸ Ibid 37

⁵⁹ Ibid

⁶⁰ Ibid

⁶¹ Dinkel R. M. 'Attitudes of children towards supporting the old' (1944) 9 *American Sociological Review* 370

⁶² Aboderin (n39) 41

⁶³ Abel E. K., *Who Cares for the Elderly? : Public Policy and the Experience s of Adult Daughters* (Temple University, 1991)

⁶⁴ In 2011, 57.5 per cent of unpaid carers were women in England and Wales

Office for National Statistics, 'Full story: The gender gap in unpaid care provision: is there an impact on health and economic position?' Part of 2011 Census (May 2013)

< <http://www.ons.gov.uk/ons/rel/census/2011-census/detailed-characteristics-for-local-authorities-in-england-and-wales/rpt---unpaid-care.html> > Accessed 28th September 2015

institutionalization of the elderly,⁶⁵ added to the drive to cut down social budgets as part of current austerity measures,⁶⁶ may revert the pressures back onto families and hence still impact women disproportionately.

d) Structural theory

Looking into the future rather than the past, North and Fiske suggest that ageism may be brought on by ‘socio-structural tensions’ from intergenerational resentment borne out of a growing number of older people in society.⁶⁷ They anticipate this probability based on current theories linking ageism to the sharing of scarce resources and the challenge it poses to traditional age progression.⁶⁸ It is possible that policies such as the rising of the pensionable age to address some of the pressures on limited resources an ageing population may be a cause for rising tensions between the working young and the retired old.⁶⁹ This is despite the fact that figures show that more and more people aged 65 and over are in work,⁷⁰ making contributions to the economy through tax, volunteering work, charity donations and spending.⁷¹

Nonetheless, it is currently estimated that the ‘old age dependency ratio’, or the number of people over pensionable age per 1000 people in work, is rising. Following existing working trends, the ratio, which was 280 in 1971, is likely to be 354 per 1000 by 2032, and would have been 455 without the raising of the statutory pensionable

⁶⁵ Rostgaard, T., Timonen, V. and Glendinning, C. ‘Guest editorial: Reforming home care in ageing societies’, (2012) 20 *Health & Social Care in the Community* 225

⁶⁶ Local Government Association and Association of Directors of Adult Social Services ‘Adult social care funding: 2014 state of the nation report’ (October 2014)
<<http://www.local.gov.uk/documents/10180/5854661/Adult+social+care+funding+2014+state+of+the+nation+report/e32866fa-d512-4e77-9961-8861d2d93238>> Accessed 14th October 2015

⁶⁷ North and Fiske (n13) 986

⁶⁸ North and Fiske (n13) 987-989

⁶⁹ Binstock R. H., ‘Old age policies, politics and ageism’ (2005) 29 *Generations* 73

⁷⁰ 16 per cent of people aged between 65 and 74 were working in 2011, compared to only 8.1 per cent in 2001

ONS, ‘What Does the 2011 Census Tell Us About Older People?’ (6th September 2013)
<http://www.ons.gov.uk/ons/dcp171776_325486.pdf> Accessed 29th September 2015

⁷¹ The Women’s Royal Voluntary Service (WRVS) estimates that the net contribution of people over 65 totalled £40 billion in 2010 after deduction of costs of welfare, pensions and health. WRVS, ‘Gold age Pensioners, Valuing the Socio-Economic Contribution of Older People in the UK’ (March 2011)

<http://www.royalvoluntaryservice.org.uk/Uploads/Documents/gold_age_report_2011.pdf> Accessed 29th September 2015

age.⁷² Higher numbers of elderly people in society may lead to the perception that they are diverting the bulk of scarce resources, encroaching onto the ‘traditional progression of age’ by doing so.⁷³ These figures assert the belief that the pressure exerted on welfare funds by a growing number of older people could jeopardize the expectation the young have of reaping the rewards of their social contributions in old age.⁷⁴

The recent recession has also put fuel on the intergenerational divide by highlighting how the baby boomers have lived life to the full and left their children facing a bleak and uncertain future.⁷⁵ Questions are being asked as to the long-term viability of current pension schemes in the face of this change in demographics.⁷⁶ It may be the case that the young feel they must suffer welfare cuts in order to sustain the lifestyle of the wealthier old.⁷⁷ They may also begrudge the fact that whilst they struggle to find work, the old are no longer obliged to vacate the workplace and make room for the next generation, following the abolition of the statutory retirement age.⁷⁸

Despite these gloomy predictions, some have argued that the growing ageing of our population may not inevitably trigger an increase in ageism. For instance, research findings have mitigated the strength of unequal welfare redistribution as a real cause of resentment between the young and old.⁷⁹ Instead, fluctuating market forces, the expansion of consumerism within the welfare sector, and the rise of individualism have all been held to influence the lives of the young and old far more than the arrangement of supposedly age-biased social policies.⁸⁰ The sheer number of retirees from the post war baby boom era also means that a large transfer of assets and care is

⁷² Pensions Act 2014 s.26 increases pensionable age to 67

⁷³ North and Fiske (n13) 987-989

⁷⁴ Schultz J.H. & Binstock R. H., *Ageing nation: The economics and politics of growing older in America* (Paeger/Greenwood, 2006)

⁷⁵ Willetts D, *The Pinch: How the Baby Boomers Took Their Children's Future- And Why They Should Give it Back* (Atlantic Books, 2011)

⁷⁶ Esping-Andersen G. 'Towards the good society, once again in Esping-Andersen G. (Ed.) *Why We Need a New Welfare State* (Oxford University Press, 2002)

⁷⁷ Higgs P. and Gilleard C., 'Generational Conflict, Consumption and the ageing welfare state in the United Kingdom' (2010) 30(8) *Ageing and Society* 1439

⁷⁸ The Employment Equality (Repeal of Retirement Age Provisions) Regulations 2011

⁷⁹ Higgs and Gilleard (n77)

⁸⁰ *Ibid* 1441

underway, and these elements contradict the prediction of the rise of intergenerational resentment.⁸¹

The increased presence and visibility of older people in society may also have a positive effect on their status in the eyes of the young. For instance, a higher presence of elderly people in society could mean higher levels of intergenerational contact, which has been shown to disperse stereotypes.⁸² It does so by debunking the negative traits previously held about the elderly. More elderly people in society could also translate into a wider pool from which to construct more positive stereotypical subgroups (i.e. the positive stereotype of ‘good grandparents’ as differentiated from the negative one of ‘senile old man’).⁸³ Although stereotypes are a stigmatised representation of people, the rise of their positive form could have a positive effect on the perception of the elderly generally.

Ageism is a complex phenomenon that stems from a variety of causes. It may be borne out of individual and deep-seated fears about mortality and the need to counteract them through the construction of self-esteem. It may be caused by face-to-face interactions with our future selves, and the assimilation of the physical aspects of the elderly to negative character traits. It may be the result of evolutionary instincts that favour the fittest over the weakest for the survival of the specie. It may have developed because of historical socio-cultural events that have had the effect of downgrading the status of the elderly, and may worsen because of the pressures exerted on the young by an ever-enlarging ageing population. Ageism forms an integral part of the macro environment institutionalised elderly care exists in, and for that reason must be taken into account when considering solutions to realise dignity in care. It impacts its realisation on many fronts, and the next paragraphs will explain how.

⁸¹ Ibid

⁸² Hale N. M. ‘Effects of age and interpersonal contact on stereotyping of the elderly’ (1998) 17 *Current Psychology* 28

⁸³ Hummert M. L., ‘Multiple stereotypes of elderly and young adults: A comparison of structure and evaluations’ (1990) 5 *Psychology and Aging* 182

3) Effects of ageism on dignity

a) Effects on individuals' identity

Ageism impacts on how individuals in care develop their sense of identity through the eyes of others: this is based on the need of recognition for identity formation. Taylor suggests three types of 'politics of recognition'; the first one is a 'politics of universalism' owed to all individuals on the basis of their human nature, linked to the idea of intrinsic human dignity.⁸⁴ The second, a 'politics of difference', recognizes the unique cultural features of each person.⁸⁵ The third is the recognition of the concrete individual borne out of love and friendship, emotions that belong to the private realm.⁸⁶ Honneth believes that each level of recognition provides a person with self-confidence, respect and self-esteem.⁸⁷ Being recognised as an equal to all others, but also as a unique individual, has a direct impact on a person's ability to build a sense of identity, an element of dignity.

Ageism produces stereotypes that shape the behaviour we adopt towards the elderly, perverting the recognition process. Stereotypes are by definition 'a widely held and oversimplified image or idea of a particular type of person or thing'.⁸⁸ Generalisations homogenise individuals under one group and pre-condition the behaviour of those interacting with that particular group. Social psychology studies have shown that warmth and competence are essential character traits indicators.⁸⁹ According to the creators of the Stereotype Content Model (SCM), the 'warmth' indicator is defined as the quality of those who are seen as 'good-natured, trustworthy, tolerant, friendly and sincere', whereas 'competent' suggests 'capable, skillful, intelligent and confident'.⁹⁰ Statistical surveys have shown that elderly people are a group classified as 'warm and incompetent' on the SCM, based on perceptions of

⁸⁴ Taylor C., 'The Politics of Recognition' in *Multiculturalism: Examining the Politics of Recognition* in A. Gutman (Ed.) (Princeton University Press, 1992), 37

⁸⁵ Ibid 38

⁸⁶ Ibid 37

⁸⁷ Honneth A., *The Struggle for Recognition: The Moral Grammar of Social Conflicts* (MIT Press, 1996)

⁸⁸ <<http://www.oxforddictionaries.com/definition/english/stereotype>> Accessed 1st September 2015

⁸⁹ North and Fiske (n13) 268

⁹⁰ Cuddy A., Fiske S., and Glick P 'Warmth and Competence as Universal Dimensions of Social Perception: The Stereotype Content Model and the BIAS Map' (2008) 40 *Advances in Experimental Social Psychology* 65

their low competitiveness and low status.⁹¹ This shows that stereotypes are not always negative.⁹² Nevertheless, ‘benevolent ageism – the old is considered ‘warm’– perpetuates and legitimizes policies and practices that stigmatize and limit the lives of older adults’,⁹³ by triggering certain emotional responses.⁹⁴ Pity is usually felt towards elderly people based on their stereotype profile.⁹⁵

The sentiment of pity can influence how health and social care professionals interact with older individuals. It can for example foster the misconception that residents are helpless and dependent.⁹⁶ It can surreptitiously convince the residents that they are indeed in need of assistance.⁹⁷ This in turn affects people’s sense of identity, playing an integral part in preventing the fulfilment of their dignity. Language choices used in elderly care settings can also convey pity. The use of ‘overaccommodation’⁹⁸ and ‘baby talk’⁹⁹ are two such noticeable consequences of that practice. ‘Overaccommodation’ simply means that behaviour is overly altered to accommodate perceived ageist stereotypes.¹⁰⁰ One study showed that care workers in a nursing home were talking to the residents in succinct and simple sentences, presumably in response to their perception that their interlocutor could not understand complex speech forms.¹⁰¹ ‘Baby talk’ means using a similar tone and pitch that one would use to talk to babies, a more pronounced and negative form of overaccommodation.¹⁰²

⁹¹ Fiske S., Cuddy A., Glick P., and Xu J., A model of (often mixed) stereotype content: Competence and warmth respectively follow from perceived status and competition (2002) 82 *Journal of Personality and Social Psychology* 878

⁹² Allport G., *The nature of prejudice* (1954, Addison-Wesley)

⁹³ Bugental D. and Hehman J., ‘Ageism: A Review of Research and Policy Implications’ (2007) 1 *Social Issues and Policy Review* 173, 174

⁹⁴ Cuddy A., Norton M., Fiske S., ‘This Old Stereotype: The Pervasiveness and Persistence of the Elderly Stereotype’ (2005) 61(2) *Journal of Social Issues* 267

⁹⁵ Fiske et al (n91)

⁹⁶ Nussbaum J., Pitts M., Huber F., Raup Krieger J., Ohs J. ‘Ageism and Ageist Language Across the Life Span: Intimate Relationships and Non-intimate Interactions’ (2005) 61(2) *Journal of Social Issues* 287

⁹⁷ Cohen E., ‘The elderly mystique: Impediment to advocacy and empowerment’ (1990) *Generations: Journal of the American Society on Aging* 13

⁹⁸ Giles H., Fox S., Harwood J. & Williams A., ‘Talking age and aging talk: Communicating though the lifespan’ in Hummert M. et al (Eds) *Interpersonal communication in older adulthood: Interdisciplinary theory and research* (Sage, 1994)

⁹⁹ Caporaal L. ‘The paralanguage of caregiving: Baby talk to the institutionalized aged’ (1981) 40 *Journal of Personality and Social Psychology* 876

¹⁰⁰ Giles (n98)

¹⁰¹ Kemper S. ‘Elderspeak: Speech accommodation to older adults’ (1994) 1 *Aging and Cognition* 17

¹⁰² Caporaal (n99)

Shifting perception could be beneficial to the people stigmatised because it appears that groups that are situated simultaneously on both the high competence and high warmth categories of the SCM are less likely to suffer the consequences of prejudices.¹⁰³ Unfortunately, mixed stereotypes are difficult to shift upwards concurrently, because although the warm stereotype is sensitive to change, competence is far more resistant to it.¹⁰⁴ Experiments on individual perceptions have revealed that the more incompetent an elderly person behaved, the more he gained in warmth, but it didn't mean that he gained in competence the more competently he behaved. On the contrary, he only lost in warmth.¹⁰⁵ It is as though those whose behaviour exceed expectations are rewarded by higher warmth for conforming to the stereotype model they are assumed to fit in, whilst those who challenge perception are punished with lower levels of warmth and no change in competence.¹⁰⁶ Disproving incompetence by factual evidence to the contrary is not a straightforward path to shifting negative stigmatisation.

In recent years the baby boomers generation has been hailed as powering the economy and redefining old age not as 'a fate', but as a 'lifestyle'.¹⁰⁷ The increase in the proportion of elderly people that will make up our population in the future is also bound to mean they will have even greater influence and power in society. These changes might eventually transform the 'incompetence' stigma attached to them into a labelling of 'competence', but this, as I mentioned above, could also result in diminishing the positive 'warmth' stigma they attract. This could change how elderly people are treated in health and social care settings, and may eventually have a positive impact on their sense of dignity.

¹⁰³ Ibid

¹⁰⁴ Cuddy et al (n94) 275

¹⁰⁵ Cuddy et al (n94) 275

¹⁰⁶ Ibid

¹⁰⁷ Daneshkhu S., 'The Silver Economy: Baby boomers power new age of spending' Financial Times, 14th November 2014

<<http://www.ft.com/cms/s/0/e9fc95c0-44b1-11e4-ab0c-00144feabdc0.html#axzz3e4nimJUz>>
Accessed 25th June 2015

b) Effects on individuals' self-determination

Grouping people in categories according to their age, or age categorisation, has been identified as a potential problem for self-determination.¹⁰⁸ Age categorisation is used in theoretical thinking and in practice. For instance, although research using age-based data may be useful in highlighting differences in the treatment of older people, it may also have the negative effect of homogenising people's characteristics by compartmentalising individuals within specific but arbitrary age categories.¹⁰⁹ Homogenisation is said to fuel intergenerational tensions by perpetuating the 'them and us' divide through the reinforcement of prejudices.¹¹⁰

On a practical level, age categorisation is the actual separation of people through different institutions according to their age.¹¹¹ The lifecourse can be depicted as a three-tier system of age segregation, with education, work and leisure reflecting defined institutional areas for each age groups.¹¹² Hagestad goes one step further and sees institutions as age segregationist, reinforcing the spatial separation of generations.¹¹³ In this instance nursing homes are described as an 'extreme version of residential age segregation'. This segregation may have an impact on many aspects of identity creation: it can stunt participation, alter relationships, and limit autonomy. Physical separation may also de-humanise the person by placing her within an environment where the person is objectified, no longer seen as an individual but as a task to be performed.¹¹⁴ Here, self-determination could be affected by the physical removal of the person from their usual place of residence to an institutional setting.

Despite these concerns, there are practical arguments in favour of age specific services. Grouping people with similar needs may be far more economical than catering for individuals in a multitude of settings. Some individuals also prefer the company of their contemporaries, especially in a phase of life where they feel more

¹⁰⁸ Bytheway B 'Ageism and Age Categorization' 61(2) (2005) *Journal of Social Issues* 361

¹⁰⁹ *Ibid* 366-368

¹¹⁰ Billig M., *Arguing and Thinking: A rhetorical approach to social psychology* (1987, Cambridge University Press)

¹¹¹ Hagestad G. and Uhlenberg P., 'The Social Separation of Old and Young: A Root of Ageism' (2005) 61(2) *Journal of Social Issues* 343, 346-347

¹¹² *Ibid* 360

¹¹³ *Ibid* 347

¹¹⁴ Chapter II

vulnerable and isolated.¹¹⁵ This is the difference between the appropriateness of age-differentiated services and the damaging effect of stereotype-based ageist behaviours.¹¹⁶ Offering help to an isolated elderly person who needs 24 hour care is age-appropriate, whereas delivering it in an environment that stunts individualism and fosters helplessness is not.¹¹⁷ Braithwaite reminds us that ‘stepping back to take a broader view of our institutional structures for dealing with all types of ‘isms’ may be a necessary first step for making progress on addressing ageism’.¹¹⁸ The physical segregation of age may be breeding ageism by preventing intergenerational contacts.¹¹⁹

c) Effects on individuals’ humanity

In Chapter II, I linked humanity with the idea of equal treatment. Ageism can breed inequality, affecting the humanity of the older person in care, and so have a negative effect on the possibility of dignity.¹²⁰ Elderly people are the largest users of health and social care services.¹²¹ Some have reported that they were treated less well or afforded less choice than younger service users.¹²² Nussbaum et al have highlighted the potential ageist bias of using age as an evaluating tool for the prioritization of medical treatment.¹²³ This is reflected in practice by the use of Quality Adjusted Life Years (QALY) in the determination of medical resource allocation, however old the person concerned may be.¹²⁴ The National Institute for Health and Care Excellence defines QALY as ‘a measure of the state of the health of a person or group in which the

¹¹⁵ Hess B., ‘Friendship’ In M. W. Riley, M. Johnson, & A. Foner (Eds.), *Aging and society* (Russell Sage Foundation, 1972)

¹¹⁶ Pasupathi M. & Lochenhoff C., ‘Ageist Behavior’ in Nelson T. (Ed) *Ageism; Stereotyping and prejudice against older people* (2002, MIT Press)

¹¹⁷ Avorn J. & Langer E., ‘Induced disability in nursing home patients; A controlled trial (1982) 30 Journal of American Geriatric Society 397

¹¹⁸ Braithwaite V. ‘Reducing Ageism’ in T.D. Nelson (Eds.) *Ageism: Stereotyping and prejudice against older persons* (MIT Press, 2002), 311

¹¹⁹ Allport G., *The nature of prejudice* (Addison-Wesley, 1954)

¹²⁰ Chapter II

¹²¹ In 2012, two in three social care clients were 65 and over, so were one in 5 A&E attendances, one in two inpatients bed days, and two in five inpatients day cases, whilst the population aged 65 and over only made up one in six of the total population.

Health and Social Care Information Centre, ‘Focus on the health and care of older people’ (June 2014), 41

< <http://www.hscic.gov.uk/catalogue/PUB14369/focu-on-hac-op-main-pub-doc%201.1.pdf>> Accessed 1st July 2015

¹²² Chapter II

¹²³ Nussbaum et al (n96) 299

¹²⁴ Anand P., ‘Capabilities and Health’ (2005) 31 Journal of Medical Ethics 299

benefits, in terms of length of life, are adjusted to reflect the quality of life'.¹²⁵ A whole year of full health has a value of 1, death is rated as 0, and partial health will have a value between those two numbers. These numbers are used by the NHS as a method of outcome measurement in deciding how to best use their resources.¹²⁶

Although not directly ageist, the maximisation of QALYs has a strong but natural bias on youth and has been branded by some as ageist.¹²⁷ Two arguments have been brought forward in the long-standing debate about the merits of QALYs. The first is based on the proposition that as 'older people have enjoyed more life and have less life left to enjoy', it is justified to suggest that 'age is an ethical objective, and cost effective criterion for rationing health care'.¹²⁸ This 'fair innings' argument underscores the idea that it is fairer to invest limited resources to treat a young person who has not yet reached their expected natural lifespan (or fair inning), rather than spending it to treat an older person who has already reached theirs.¹²⁹ This has been branded egalitarian ageism, where it is recognised that we ought to all be allowed to live an averagely equal amount of years, and that therefore treatment should be given to those who still have a lot of years yet to live.¹³⁰

The second argument rests on the idea that using age as a rationing tool will ultimately optimise health benefits overall. This is called utilitarian ageism and derives from the idea that young people will reap more QALYs from treatment than older people because of their longer life expectancy.¹³¹ Rivlin rebuts this justification by questioning the veracity of the principles underpinning its apparent fairness.¹³² He contends with the idea exposed above that age is an objective criterion that can be used to maximise health benefits.¹³³ According to him, this is a fallacy that cannot be applied to all, as some elderly people would benefit greatly from certain medical interventions even once older than an arbitrarily set age limit. Should the objective of

¹²⁵ <<https://www.nice.org.uk/glossary?letter=q>> Accessed 27th August 2015

¹²⁶ Soares M. O., 'Is the QALY blind, deaf and dumb to equity?' (2012) 101 (1) British Medical Bulletin 17

¹²⁷ Harris J., 'QALYfying the value of life' (1987) 13 Journal of Medical Ethics 117

¹²⁸ Shaw A.B. 'In defense of ageism', (1994) 20 Journal of Medical Ethics 188, 191

¹²⁹ Williams A., 'Rationing health care by age: The case for' (1997) 314 British Medical Journal 820

¹³⁰ Nord E. et al, 'The significance of age and duration of effect in social evaluation of health care' (1996) 4 Health Care Analysis 103

¹³¹ Ibid

¹³² Rivlin M., 'Protecting elderly people: flaws in ageist arguments' (1995) 310 BMJ, 1179

¹³³ Ibid 1180

the health system be to maximise health, the benefits a person may gain from a particular treatment should not depend on their age only, but be assessed according to their particular physiology.¹³⁴ For instance, Rivlin replies to the ‘fair innings’ argument that the use of age is far too blunt an instrument and should be replaced by other more sophisticated and individualistic considerations.¹³⁵

Rationing health expenditure according to age is complex and fraught with ethical dilemma about the intrinsic value of life.¹³⁶ The current age-based system of healthcare distribution can be read by ethics theorists as promulgating ageism on the back of economic efficiency arguments.¹³⁷ A distributive system based on age alone would affect the elderly’s sense of humanity by reinforcing the societal message that their life is now less worthy of resources than others. Although age alone may be the wrong criterion to go by, the fact that resources are scarce still remains and forces some kind of evaluative framework for their effective allocation.

In this respect, the individualisation of prognosis and choice of treatment would appear a lot fairer than the use of chronological age only as a tool for rationing resources. It would take into account lifestyles and individual preferences, and may benefit from more open discussions about the resources available and what they can contribute to a person’s own health priorities (be free of pain, being able to walk unaided etc....) for the achievement of quality of life. Treatment should be afforded for its ability to help realise a person’s idea of a good life, and be balanced against the harm it may cause to realise it.

Beyond impacting people’s dignity through unequal quantity of treatment, ageism also has a repercussion on a person’s humanity through the quality of the treatment received. Studies have reported that ageist attitudes can inhibit the recruitment of medical staff who wish to specialise in the care of older patients,¹³⁸ and this is

¹³⁴ Evans J. G., ‘The rationing debate: Rationing health care by age: The case against’ (1997) 314 *British Medical Journal* 822

¹³⁵ *Ibid* 1181

¹³⁶ For an in-depth analysis of the issue of health resources rationing Newdick C., *Who Should We Treat? : Rights, Rationing and Resources in the NHS* (2nd Ed., Oxford University Press, 2005)

¹³⁷ Rivlin (n132)

¹³⁸ Ferrario C., Freeman F., Nellett G., Scheel J. ‘Changing nursing students attitudes about aging: an argument for the successful aging paradigm’ (2008) 34(1) *Education and Gerontology* 51

promulgated and perpetuated through medical training.¹³⁹ This may impact negatively the quality of the care received by people in institutional settings, which in turn may stunt the possibility of dignity. As I argued previously when analysing the importance of the person's environment for dignity to exist, a sufficient number of appropriately trained care home staff is essential to the realisation of identity, autonomy and humanity of the people cared for.¹⁴⁰

Not only is ageism partly to blame for some staffing issues, it has been linked to the recurrence of neglect or abuse of the elderly in the institutional sphere.¹⁴¹ Ageism does not per se provoke abuse or neglect, but it is the stereotypes it is based on that perpetuate the idea that it is acceptable to treat people as if less worthy than others.¹⁴² Age driven separatism has caused for stereotypes to form and endure. Whitton reports that 'the typical negative stereotypes reported and studied by sociologists, psychologists, and gerontologists include beliefs that the old are impaired, incompetent, unproductive, depressed, disengaged, inflexible, senile, and lack sexual desire'.¹⁴³ Herring writes that these preconceived ideas held about elderly people can have dire consequences.¹⁴⁴ Ageism gives the elderly a negative image of themselves and their place in society and so shunts their willingness to speak up and demand change. Ageism seems not only to perversely give the caregiver ammunition and justification for abuse, it can also take away from the person cared for the ability and confidence to question and fight back against abuse. The devaluation of the elderly person through their stereotyping appears therefore to justify their maltreatment.¹⁴⁵ Any disregard for the physical and psychological integrity of the person stands as an evident violation of their dignity and another negative consequence of ageism for those living in care homes.

¹³⁹ Gleberon B.J., 'Combatting ageism through student education' *Topic in clinical chiropractic* 9, 41-53, Watkins, J. Waterfield, C. 'An exploration of physiotherapy students' perceptions of older adult rehabilitation' (2010) 28 (3) *Physical & Occupational Therapy in Geriatrics* 271

¹⁴⁰ Chapter IV

¹⁴¹ Quinn M. J., and Tomita S. K., *Elder Abuse and Neglect: Causes, diagnosis and intervention strategies* (Springer, 1986)

¹⁴² Nelson (n8) 213

¹⁴³ Whitton (n40) 465

¹⁴⁴ Herring J., *Older People in Law and Society*, (Oxford Scholarship Online, May 2009)

DOI:10.1093/acprof:oso/9780199229024.003.0005) 159-160

¹⁴⁵ Hudson M., 'Analyses of the Concepts of Elder Mistreatment: Abuse and Neglect' (1988) 1(1) *Journal of Elder Abuse and Neglect* 5

Whether as part of inter-subjective relationships in social care settings, or on an institutional level, a pervasive and cross-cultural message remains: old people are different, less able, more fragile, and require more welfare resources than their younger counterparts. This prejudiced discourse influences the social construct of age, which in turn will define how the elderly is treated on an individual basis and as part of a defined group.¹⁴⁶ I believe that an ageist environment not only partly defines the type of institution we assume appropriate for the delivery of long-term aged care, but also contributes to the many infractions committed against the dignity of those who use them. The fact that society can regard old age in such a stereotypical and negative way may indeed go some way to explaining the existence of institutionalised care as we know it today, and the reason behind why the treatment some residents receive can be damaging to the opportunity of dignity. Becoming aware that ageing is an intrinsic part of our human life course and not a disease we wish to avoid catching,¹⁴⁷ might make us all petition louder for an environment suitable for dignity when we come to need it most.

4) Law and ageism in long-term aged care

a) Domestic law

The law in the UK plays a role in mitigating the negative effects of ageism. It has, for instance, been tackling age discrimination, ‘the practical manifestation of ageism’,¹⁴⁸ in a very formal way, under the Equality Act 2010, based on the non-discriminatory principles of the Human Rights Act 1998. The Equality Act potentially lends itself to protecting some aspects of dignity in care home settings in three different ways. It may do so by forbidding the discriminatory treatment of individuals, by questioning the rationing of finite healthcare services on the ground of age, and by making a

¹⁴⁶ Hockey J. and James A., *Social Identities Across the Life Course* (Palgrave, 2003)

¹⁴⁷ Chapter II

¹⁴⁸ Institute for Conflict Research, ‘Strengthening Protection for All Ages against Age Discrimination outside the Workplace’ A report for the Equality Commission (March 2014)
<<http://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/Age-Discrimination-ICR-Final-Report-Final.pdf>> Accessed 7th July 2015

statutory requirement the consideration of the effect of public body decisions on those whose characteristics are protected.

Firstly, equality law can contribute to the protection of identity within the care home environment. The Equality and Human Rights Commission's guidance about the rights of social care services users under the Act¹⁴⁹ stipulates that they may expect equal treatment by staff irrespective of their particular protected characteristics. That is, elderly people in care must be free from discrimination not only on the ground of age, but also disability, gender, sexual orientation, religion and ethnicity.¹⁵⁰ This means that the actions or omissions of service providers should not cause 'unlawful discrimination, harassment or victimisation' and they should include making 'reasonable adjustments' in the case of disability.¹⁵¹ For instance, the Equality Act enhances conditions for dignity by forbidding ageist language that may damage self-esteem, a component part of identity building. Indeed, section 26(1)(b)(i) of the Equality Act 2010 that defines harassment states that the conduct must have the purpose of 'violating' the person's dignity. This could in theory include the patronizing form of language I mentioned above.

Secondly, the Equality Act can protect that component of dignity that I referred to as humanity directly through non-discriminatory provision of services under section 29 which came into force in October 2012. The government consultation about this provision states that

[O]rganisations, and individuals, working in health and social care including "commissioners" (those, such as doctors who commission services, and all providers where they are delivering public services) can continue to treat people differently because of their age. However, they will need to show, if challenged, that there is a good reason ("objective justification") for that different treatment.

¹⁴⁹ Equality and Human Rights Commission, Guidance 'Your rights to equality from healthcare and social care services, Equality Act 2010, Vol.4 of 7' Updated June 2015
<http://www.equalityhumanrights.com/sites/default/files/publication_pdf/EqualityGuidance-Healthcare-SocialCare-2015.pdf> Accessed 25th August 2015

¹⁵⁰ Ibid 27

¹⁵¹ Equality Act 2010, Chapter 2

This approach will contribute towards ensuring that high quality, dignified and compassionate care services are provided on the basis of need.¹⁵²

This caveat implies that the refusal of expensive but dignity-enhancing medical treatment may be shown to be a proportionate mean to achieving the legitimate aim of overall health benefits maximisation. The use of QALYs by the NHS has been deemed by the Department of Health to remain an appropriate tool to assess the value of certain medical treatments, and so this provision might prove ineffective to combat age discrimination when economics reasons are used to rationalise the rationing of dignity enhancing treatment.¹⁵³

Thirdly, the Equality Act also enables adult social care claimants to question, via the Public Sector Equality Duty (PSED) laid out under section 149 of the Equality Act 2010, the potentially dignity-damaging effects of public spending cuts. Having due regard in public spending decision-making ‘to the need to eliminate discrimination, advance equality and foster good relations between those who share a protected characteristic and those who do not share it’,¹⁵⁴ means to have due regard as is ‘appropriate in all the circumstances’.¹⁵⁵ Circumstances include ‘on the one hand the importance of the areas of life of the members of the disadvantaged ... group that are affected by the inequality of opportunity and the extent of the inequality; and on the other hand, such countervailing factors as are relevant to the function which the decision-maker is performing’.¹⁵⁶ The duty demands a balancing act between the needs of those with a protected characteristic, and the pressure imposed on those who distribute finite public resources.

¹⁵² Government Equalities Office, ‘Equality Act 2010: Banning age discrimination in services, public services, public functions and associations’ Government response to the consultation on exceptions.’ 2012, 1.7

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/84985/government-consultation-response.pdf> Accessed 10th October 2015

¹⁵³ Department of Health, ‘Implementing a ban on age discrimination in the NHS- making effective, appropriate decisions’ (28th September 2012), 16

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212944/ban-on-age-discrimination.pdf> Accessed 12th October 2015

¹⁵⁴ Equality Act 2010, s.149(1)(a)(b)(c)

¹⁵⁵ *R (On the application of McDonald) (Appellant) v Royal Borough of Kensington and Chelsea (Respondent)* [2011] UKSC 33 at [23]

¹⁵⁶ *R (Baker) v Secretary of State for Communities and Local Government* [2008] EWCA Civ 141 at [31]

Recent case law discussing the meaning of the PSED in cases of inequality of treatment for the elderly in care gives out mixed messages as to its efficacy to improve care quality. In a recent case, two disabled elderly claimants failed to show that cuts to the adult social care budgets had been made without the PSED duty in mind, resulting in their unfavourable treatment.¹⁵⁷ The judge ruled in this instance that ‘the duty to have due regard does not involve the taking of any prescribed step nor the achievement of a result. The regard is what is appropriate in the circumstances, namely at a point where the budget was set and a commitment to engage in an impact assessment was acknowledged’.¹⁵⁸ The judge also stated that ‘having regard to the needs of the elderly and the disabled does not exclude other considerations and the weight which is to be attached to each consideration’.¹⁵⁹ In this case the judge was cautious not to impinge on the decision making power of the local authority responsible for budgeting all services within tighter parameters.

Some care home operators have been able to demonstrate that the local authority had not followed the PSED duty when it had made the decision to reduce the fees they paid for care home places.¹⁶⁰ The court in *South West Care Homes* held that the council had failed to consider that the lower fee it was proposing to pay the care home could harm residents by deteriorating the quality of care they received, and by increasing the risk of relocation they faced due to higher risks of closure.¹⁶¹

Judicial review makes more transparent the decision-making process of local authorities by examining whether the impact on protected characteristics was taken into account. Nonetheless, it could be argued that as individuals drive the process of judicial review, it may limit the overall impact of the PSED in fighting discriminatory services. It is worth noting therefore that in a recent case the court held that ‘in a case where large numbers of vulnerable people, many of whom fall within one or more of the protected groups, are affected, the due regard necessary is very high’.¹⁶² The more

¹⁵⁷ *R (On the application of D and another) v Manchester City Council* [2012] EWHC 17 (admin)

¹⁵⁸ *Ibid* [64]

¹⁵⁹ *Ibid* [68]

¹⁶⁰ *R (On the application of South West Care Homes Ltd. and others) v Devon County Council* [2012] EWHC 2967 (Admin)

¹⁶¹ *Ibid* [53]

¹⁶² *R (Hajrula) v London Councils* [2011] 151 (QB), [69]

individuals with a protected characteristics are affected by a public body decision, the higher the level of scrutiny ought to be on the discriminatory effects it could have.

The Equality Act is obviously not able to eradicate ageism, an engrained and complex societal problem with a multitude of origins. It may be used to challenge and stamp down on discriminatory behaviour and service provision, and scrutinise whether the decisions made by those responsible for the public funding of care were taken with equality in mind. In this respect, it goes some way in helping the realisation of dignity. It does so by forbidding abusive conduct towards care home residents borne out of age discrimination, contributing to the protection of the integrity of the person's identity through self-respect. It also does so by forcing service providers and public bodies to take equality into account when making welfare decisions, preventing the systematic rationing of care services on the ground of 'fair innings'. It plays a part in sending out the message that ageism has no place in society, contributing in some way to the recognition of old age as an intrinsic part of the life course, and so facilitating identity creation.¹⁶³ The Act confronts the ageist environment we live in, by publically claiming that old age should not be a justification for poorer treatment in health and care services.

Nonetheless, the Equality Act only deals with the manifestation of ageism rather than its causes, falling short of addressing deeper ethical considerations. Although it protects dignity by forbidding the use of age as a weapon to perpetrate abuse, and by attempting to keep the effects of age discrimination in the mind of those who decide on the distribution of scarce health and care resources, it cannot stop the prioritization of spending that favours the young and certainly cannot prevent the proliferation of stigmatising prejudices about the value of the elderly person in society.

b) International law

In 1982 the international community concerned with the issues affecting older individuals including the problem of age discrimination, published the Vienna

¹⁶³ Honneth (n87)

International Plan of Action on Ageing following the first World Assembly on Ageing organised by the United Nations (UN).¹⁶⁴ In 2002, the second World Assembly on Ageing resulted in the Madrid Plan of Action and a Political Declaration which specified, under Article 5, the commitment to eliminate age discrimination.¹⁶⁵ In 2010, the UN created an Open-Ended Working Group on Ageing in order to strengthen the protection of the human rights of older people.¹⁶⁶ Ten years on from Madrid, the UN published a Resolution on the Follow-up to the Second World Assembly on Ageing, noticing that ‘in many parts of the world, the Madrid Plan of Action remains limited or non-existent’.¹⁶⁷ Despite this unsatisfactory result, some still argue that soft laws alone can be effective in influencing domestic policy, and that the current United Nations initiatives for older individuals are already very comprehensively covering all issues that concern them specifically.¹⁶⁸

It has been suggested that a Convention on the Right of Older People may be the solution to filling the gap in national protection laws against discrimination, but so far no treaty has been agreed upon.¹⁶⁹ Specific international treaties on the rights of children, women and the disabled have had positive effects throughout many member states, even though they have not completely eradicated the problems they seek to address.¹⁷⁰ It can be argued that these conventions have precipitated action from states and NGOs, and that without them change may have taken longer and gathered less momentum.¹⁷¹ It is surprising therefore that a comparable document still has to emerge for the protection of the rights of the older person.

Doron voices several concerns as to the creation of such a convention. He advances the view that ‘past experience shows that international conventions for human rights

¹⁶⁴ UN General Assembly, Resolution A/RES/36/30, 13th November 1981

¹⁶⁵ United Nations, ‘Political Declaration and Madrid International Plan of Action on Ageing, Second World Assembly on Ageing, 2002’

< http://www.un.org/en/events/pastevents/pdfs/Madrid_plan.pdf > Accessed 7th August 2017

¹⁶⁶ UN General Assembly Resolution A/RES/67/139, 13th February 2013

¹⁶⁷ UN General Assembly Resolution, ‘Follow-up to the Second World Assembly on Ageing’ 21st February 2013

¹⁶⁸ Doron I. and Apter I., ‘The Debate Around the Need for an International Convention on the Rights of Older Persons’ (October 2010) 50(5) *The Gerontologist*, 586

¹⁶⁹ Age international, ‘We need a UN Convention for Older people’

< <https://www.ageinternational.org.uk/policy-and-research/human-rights/un-convention-for-older-people/> > Accessed 7th August 2017

¹⁷⁰ Doron and Apter (n168)

¹⁷¹ Courville S. and Piper N., ‘Hope, power and governance: Section one: Building institutions of hope: Harnessing hope through NGO activism’ (2004) 592 *Annals* 39

create “superficial” legal rights rather than true social change’, because states with poor human rights records usually sign such treaties as a show of their human right commitment, without actually ever implementing them.¹⁷² More pertinent to this discussion is the fact that such conventions actually do not create ‘true’ equality because they always fail to ask those they concern to take part in their construction.¹⁷³ This can result in biased views that omit to represent certain voices within the group concerned, or fail to take into account intersectionality in the type of protection offered. As I discussed in Chapter III, elderly individuals can be vulnerable on a variety of levels beside age, be it their ethnicity, gender, sexual orientation or disability.¹⁷⁴ Once more, applying a discursive ethical model to the creation of such instrument may produce an international human right instrument more appropriate to the delivery of substantive equality.

In the same way that I doubt the Equality Act can do much more against ageism, I suspect an international human right instrument alone will not be its nemesis. As I discussed in Chapter II, older people seem to mistrust the human right discourse, associating it with issues far removed from their own concerns.¹⁷⁵ A convention on the rights of older individuals would undoubtedly add pace to the anti-discriminatory discourse, but in order for it to be implemented as a tool to uphold rights, its enforcement mechanism will have to be tailored to those whose rights it seeks to protect. Doron’s study shows that although the European Court of Human Rights hears a relatively small number of cases brought by older individuals (11.9% of cases over a ten year period were started by an older applicant, the majority of which were born between 1921-1940), a very high proportion resulted in a violation being found (91% of the sample of judgments).¹⁷⁶ These figures may suggest that older people’s access to the courts, whether regional or under international law, needs to be improved.

¹⁷² Doron and Apter (n168) 589

¹⁷³ Ibid

¹⁷⁴ Chapter III

¹⁷⁵ Chapter II

¹⁷⁶ Spanier B., Doron I. ad Milman-Sivan F., ‘Older Persons’ use of the European Court of Human Rights’ (2013) 28(4) *Journal of Cross Cultural Gerontology* 407

5) Anti-ageism Reforms

a) Legal means

Beyond equality laws, other types of interventions could improve the way in which we perceive and treat elderly individuals who rely on care. In the healthcare sector, it has been suggested that more soft laws and guidelines would reduce discriminatory treatment towards the elderly person.¹⁷⁷ This could include more guidelines for practitioners that focus on respect for older patients.¹⁷⁸ By concentrating on improving the way in which the older patient is treated, there may indeed be less chances of delivering services that are prejudiced. Such reforms sound helpful, but presume a prior commitment to fight ageism in health policies, when the problem instead is how to engender that kind of commitment in the first place

Others have argued that courts, in order to truly improve equality, should take dignity into consideration as a value in discrimination cases.¹⁷⁹ This may influence the decision making process in judicial review cases that examine the application of the PSED duty for care funding discussed above. In particular, Moon and Allen reflect on ‘dignity and the imperative for different treatment’.¹⁸⁰ They argue that respect for individuals’ dignity ought to be at the core of the equality law requirement to make reasonable adjustment where not doing so would put the disabled person at a clear disadvantage.¹⁸¹ They argue that dignity, if kept in mind as a discreet value, can help decision-makers operationalize the rule of equal treatment that dictates that similar situations are to be treated similarly but different situations are to be treated differently.¹⁸²

This rule, they suggest, falls short of explaining when two individuals are in the same situation, and is silent as to the nature of the different treatment when they are in

¹⁷⁷ De Oliveira G., ‘Health Law and Elderly Persons’ (2015) 34 Medical Law 603

¹⁷⁸ Ibid

¹⁷⁹ Moon G. and Allen R., ‘Dignity discourse in discrimination law: a better route to equality?’ (2006) European Human Rights Law Review 610

¹⁸⁰ Ibid 635

¹⁸¹ Equality Act 2010 s.20

¹⁸² Moon and Allen (n179) 633

different situations.¹⁸³ They suggest that dignity can be the answer. A person who is disabled ought to be treated differently and material adjustments made if not doing so would undermine the equality of her dignity.¹⁸⁴ In the same way, when the person's disability has no impact on the situation at hand, then equal dignity demands that treatment be equal.¹⁸⁵ I believe that the provision of care for the frail dependent elderly is akin to reasonable adjustment. Admittedly, the effectiveness of Moon and Allen's solution turns on how clearly the notion of dignity is apprehended and articulated. In this dissertation, however, I have taken pains precisely to specify the content of dignity for elderly people in care. The dignity of the person, as understood in this dissertation, offers a benchmark according which to gauge whether those adjustments are being made appropriately.

Indeed, if the concept of dignity is not rigorously specified, it can be used to rationalise rather than combat ageist practices. In the case of *Seldon*, pre Equality Act, the Supreme Court had to decide on the legitimacy of the aims pursued by a forced retirement.¹⁸⁶ Here the court held compulsory retirement had the legitimate aim to 'avoid the need to dismiss the older workers on the grounds of incapacity or underperformance, thus preserving their dignity and avoiding humiliation, and as avoiding the need for costly and divisive disputes about capacity or underperformance'.¹⁸⁷ This assumption, as Vickers points out, seems 'suspect and based on irrational prejudice and stereotypical ageist assumptions as to older workers' capabilities'.¹⁸⁸ This case highlights the importance of the meaning given to dignity. In order not to have paternalistic and ageist undertones, it must be understood from the perspective of the person concerned, and not be allocated an objective value. Ageist bias distorts the meaning of dignity. In the next section of this chapter I will suggest other means to stamp down ageism responsive to its deeper causes explored above.

¹⁸³ Ibid 634

¹⁸⁴ Ibid 635

¹⁸⁵ Ibid 637

¹⁸⁶ *Seldon (Appellant) v Clarkson Wright and Jakes (A Partnership) (Respondent)* [2012] UKSC 16

¹⁸⁷ Ibid [57]

¹⁸⁸ Vickers L. and Manfredi S., 'Age Equality and Retirement: Squaring the Circle' (2013) 42(1) *Industrial Law Journal* 61, 69

b) Socio-cultural means

Martens et al suggest that one of the keys to reducing ageism is to accept our own mortality.¹⁸⁹ To this effect, they suggest a better education on the subject of death (although beneficial, these classes have not been proven a direct solution to ageism).¹⁹⁰ Beliefs based on religions such as Buddhism, which focus on the acceptance of the ephemerality and passing of life, are other ways of lessening the fear of death by detaching ourselves from the value systems we build in our lives.¹⁹¹ They suggest that western existentialist philosophers such as Sartre have also argued for the liberating feelings that come with transcending our own mortality, freeing the individual to seek meaning in life elsewhere.¹⁹²

Living within a culture more accepting of death may indeed have a positive effect on how we regard ageing, but might be difficult to achieve. Another solution could be to find sources of self-esteem that do not lead to ageism.¹⁹³ Should ‘activities that are associated with death provide a culturally valued basis for self-esteem’, then mortality anxiety would diminish.¹⁹⁴ Solutions include taking a ‘limited future time perspective’.¹⁹⁵ Doing so, even when we are young, should make us seek out more meaningful and immediately rewarding relationships (rather than those sought by the young for the benefits they may them bring in the future), and invest in ‘generativity’ or the investment into future generations through the provision of knowledge, skills or goods.¹⁹⁶ This would transform the process of ageing into a source of self-esteem and so prevent it from becoming the cause of ageism. Alternatively or additionally, young people could gain comfort from the knowledge that ageing may bring self-esteem through, for instance, emotionally rewarding relationships.¹⁹⁷

¹⁸⁹ Martens et al (n16) 232

¹⁹⁰ Ibid

¹⁹¹ Ibid

¹⁹² Ibid 233

¹⁹³ Martens et al (n16) 233

¹⁹⁴ Ibid 234

¹⁹⁵ Ibid

¹⁹⁶ Ibid

¹⁹⁷ Ibid

Another way to find sources of self-esteem in ageing is the ability to change one's perspective and take that of the older person's.¹⁹⁸ This has been shown to reduce the tendency to create stereotypes about the elderly.¹⁹⁹ This could only work if the older person were to be regarded as a valued part of society. Martens suggests that one way of achieving this may come from the better integration of the elderly individual within families through better role distribution, such as that of counsellor and advisor.²⁰⁰ Aspiring to such respected status may no longer make us fear ageing but make us look forward to it as a rewarding chapter of our life.²⁰¹

In response to the problem of age segregation and the way in which it breeds ageist attitudes, Hagestad and Uhlenberg recommend 'stable lasting interactions' within an age-divers environment.²⁰² They envisage that although the creation of identity may be the result of a sense of belonging to one specific group, this emphasis on grouping neglects the potential benefits of sharing mutual interests with people from other groups (in this instance older people sharing their interests with younger ones). This interaction could blur the lines of group structures and allow for the 'them and us' categorization to fade.²⁰³ Harding et al refer to this process as 'the acceptance of other individuals in terms of their common humanity, no matter how different they may be from oneself'.²⁰⁴

The law could play a role in bringing about these cultural shifts by furthering generational integration. Planning law reforms could facilitate the construction of mixed-use care facilities that are built not only for the purpose of looking after the dependent older person, but also as a community hub for other generations to use. In the Netherlands, for instance, students can live rent-free in care homes in exchange for their help looking after the residents.²⁰⁵ Educational links could be made between

¹⁹⁸ Galinsky A.D. and Moskowitz G. B., 'Perspective-taking: Decreasing stereotype expression, stereotype accessibility, and in-group favoritism' April 2000 78(4) *Journal of Personality and Social Psychology*, 708

¹⁹⁹ Ibid

²⁰⁰ Martens et al (n16) 236

²⁰¹ Ibid

²⁰² Hagestad and Uhlenberg (n111) 355

²⁰³ Harding, J., Proshansky, H., Kutner, B., & Chein, I. Prejudice and ethnic relations. In G. Lindzey & E. Aronsen (Eds.), *Handbook of social psychology* (2nd ed., Addison-Wesley, 1968), 5

²⁰⁴ Hagestad and Uhlenberg (n111) 356

²⁰⁵ Reed C., 'Dutch nursing home offers rent-free housing to students' (5th April 2015) PBS Newshour

schools and mentors in homes, reinforcing those links already made now by schools visiting care homes.²⁰⁶ Laws could be put in place to incentivise such ventures or simplify their realisation. It is the physical rapprochement of generations that may break down the psychological barriers and stigma perpetuated by ageism. In the health care sector it has been suggested that law could play a part in achieving this aim, but it is dependent upon the will of policy makers, service providers and future service users. These legal reforms suggest the need for a deeper ethical change in the political domain, one that integrates the importance of dialogue and the recognition of the other.

c) Ethical means

The ubiquity of liberalism may be intrinsically linked to the phenomenon of ageism. Grounded in the paradigm of the fully functioning man, liberalism in its purist form hails a particular form of autonomy as the ultimate political value. It can be argued that in that respect liberalism fails to consider those individuals at the margins, who, like elderly people in care, are unable to abide by the particular model of autonomy it embraces. The discursive ethical model that I have adopted to justify the need to engage dialogically with individuals to understand dignity, arcs back to the recognition of ‘the concrete other’.²⁰⁷ It is based on a feminist perception of the individual that recognises our relational nature and the vital need we have to be linked with others to form our autonomy.

This ethical model acknowledges that we are relationally autonomous and inherently vulnerable, and so contrasts sharply with the ethics of justice’s founding pillar of autonomy understood as freedom from interference. Although it has been argued that an ethics of justice need not exclude a propensity for the virtue of benevolence, I

< <http://www.pbs.org/newshour/rundown/dutch-retirement-home-offers-rent-free-housing-students-one-condition/>> Accessed 20th April 2017

²⁰⁶ See for instance the intergenerational initiatives organised by Dry Water, a not for profit art organization in the North East of England between school children and care home residents with dementia.

< <http://www.drywater.org/intergenerational/4582812732>> Accessed 27th April 2017

²⁰⁷ Benhabib S., *Situating the Self: Gender, Community and Postmodernism in Contemporary Ethics* (Polity Press, 1992) 164

would argue that it does so inevitably with an undertone of paternalism.²⁰⁸ It suggests that there are two categories of individuals: those who function ‘properly’ and benefit from the value system liberalism espouses, and ‘the other’, such as the very old, who need assistance. It may be that an ethics of justice instils ageism by presenting the elderly person as out of the liberal loop, a stranger to its reigning value system. Instead of trying to know ‘the other’ through dialogical engagement, as a relational ethics supposes, it may be that a system based on the ethics of justice shunts ‘the other’ because of its inability to conform to the autonomous ideal. This conclusion would mean that in order to address ageism, a social conversion factor for dignity, the dominant ethical system of justice would need to embrace a more inclusive, discursive and relational stance. This is change at the deepest level of society and requires far more than legal reforms.

6) Conclusion

Treating people less well because of their advanced chronological years surreptitiously sends out the message that they are no longer full members of that society. Fear of death and disgust of our potentially ‘unrecognizable bodies’ can lead us to treat those who trigger those feelings as reassuringly unlike us. Being considered by society as a group less worthy than the rest of humanity is bound to affect the dignity of older people in care, especially at a time in life where interactions with others are essential to its achievement. Dignity as conceptualised in Chapter II rests on the possibility of identity formation, self-determination and the respect of one’s humanity. The fundamental basis of this conceptualisation is dialogical engagement between policy makers and those who live in long-term institutional aged care. In order to appreciate how these values can be fulfilled under the circumstances of institutionalised dependency, the will to interact and understand individuals in care is essential. The problem is that if stereotypes about the elderly persist, stereotypes that tell us that they are incompetent, frail and incapable, the adoption of a discursive ethical model in our understanding of dignity for the elderly in care is unlikely.

²⁰⁸ For an exposé on the similarities between ethics of justice and ethics of care see Okin S.M., ‘Reason and Feeling in Thinking about Justice’ (Jan 1989) 99(2) *Ethics* 229

Our negative attitudes towards the older person can stem from our deep-seated fear of death. The old reflects back at us our own mortality. Ageism can also be explained by the loss of the older person's place in society, and by processes that have broken down little by little the links that were binding generations together. Nowadays, by choice or by circumstances, the care of the frail elderly is often no longer considered the responsibility of the family. Older individuals have become a burden, with a lesser role to play with the younger generations they used to educate, provide for and advise. Resources have also become scarcer than at other times in recent history, directing those left to the closest kin and away from the dependent elderly. The causes of ageism are complex and intertwined, making its eradication difficult.

Equality laws currently in place to mitigate the negative effects of discrimination on the ground of age forbid certain behaviour and require public bodies to consider the effect of their decision on those whose characteristics are protected. The Equality Act forces public bodies to make their decisions with equality in mind. This is particularly important for those who have to bear the consequences of the rationing of health budgets. The process of judicial review gives individuals the possibility of examining whether the decision makers took equality into account. International efforts to bring awareness of those discriminatory issues that affect older individuals have stopped short of setting up a new Convention for the right of the older individual. But I have suggested that substantive equality required more than equality laws.

I have argued that although equality laws bring to the fore the issue of ageism and make illegal its practice, they stop short of tackling substantive inequality. Other means, such as that of soft laws in health care, or the use of dignity as a parameter to bear in mind in discrimination cases may help move equality rights in more substantive directions. I have also argued that trying to reduce ageist attitudes requires a move towards generational integration. Laws can facilitate the creation of institutions and initiatives that bring generations closer together, but this depends on the political will to do so. This type of anti-ageist approach rests on the belief that there is no 'them and us', but rather 'they are us'.

Conclusion

In this dissertation, I have argued for the use of a *subjective* understanding to dignity in elderly care – that is to say, dignity as understood by the individual cared for – as a better basis for social policies. I have argued that such a conceptualisation of dignity can guide the legal obligation of dignity in the delivery of care services for older individuals. I set out to justify this approach by rooting dignity in relational autonomy understood as a process undertaken by all individuals throughout their life course. Using qualitative social studies conducted on the topic of the meaning of dignity for the older person, I concluded that dignity covered the themes of identity, self-determination and humanity. Inspired by the capability theory,¹ I then set out what I believe to be the main conversion factors relevant to dignity defined in this way – namely the multi-dimensional vulnerability of the person in long-term aged care, the regulations controlling the institutional environment the person lives in and the treatment of the older person by society.

This dissertation has also examined the role played by law in creating conditions amenable to dignity. I have therefore looked into whether and how legal provisions and the judicial process influenced the conversion factors to dignity referred to above. The criminal, human rights and safeguarding laws protecting vulnerable individuals; the regulatory model controlling care homes: anti-discrimination laws dealing with ageism - all of these have an impact on the possibility of dignity for the individual who lives in care facilities. In each chapter, I have examined whether current legal measures dealing with those conversions factors - namely the presence of personal vulnerability, the institutional environment of the care home, and the social phenomenon of ageism - could be amenable to dignity.

I have found that several conditions were important for dignity in care to be a possibility, and that laws could, sometimes but not always, help set out these conditions. Firstly, I argued that in order to make dignity a priority in care, it ought to be defined by those concerned under a discursive ethical model. Contrary to the

¹ Robeyns I, 'The Capability Approach: a theoretical survey' (March 2005) *Journal of Human Development* 6(1) 93

Kantian idea that dignity is rooted in an idea of autonomy that is free of all human emotions and borne out of pure rationality,² I have anchored dignity in a feminist view of autonomy that relates to the embodied individual and is acquired through relationships.³ This version of autonomy is inclusive of, but not solely dependent on, a view of personhood anchored in rational agency. It embraces an idea of the individual that is vulnerable, embodied, and interconnected with others. This conceptualisation of concrete individuals connected to one another demands that to know and care for the ‘concrete other’, one has to engage in dialogue.⁴ This means that the first condition for dignity is the development of a meaning that is experiential and subjective. This way of understanding dignity respects the person in front of us, without assuming anything on their behalf.

The second condition for dignity I put forward is the way in which individuals, institutions, and the state perceive and hence treat *the person* in care. The way in which elderly individuals in care are thought of is important because it conditions the type of legislation that will shape the experience of care. It will for instance influence self-determination, an element of dignity, by legally defining the boundaries between the possibility of autonomous decision-making, and the duty of the state to protect those at the mercy of dependency. Thus I submitted that vulnerability, a personal factor to dignity, ought to be recognised as inherent and universal to all human beings, so as to avoid the homogenisation of older individuals into a group, and treat that group in a paternalistic way.⁵ In order to make policies responsive to that vulnerability, I have argued that it was important to develop this understanding of universal vulnerability further. The person in care ought to be recognised as someone with multi-dimensional vulnerability. Inherently, situationally and ‘pathogenically’ vulnerable,⁶ the person in care must be seen as more than just an old person who needs to be kept safe. For instance, an intersectional approach to vulnerability is

² Kant I., *Groundwork of the Metaphysics of Morals* (trans. Mary J. Gregor) *Practical Philosophy* (Cambridge University Press, 1997)

³ Nedelsky J., *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford University Press, 2012)

⁴ Benhabib S., ‘The Generalized and the Concrete Other: The Kohlberg-Gilligan Controversy and Feminist Theory’ in S. Benhabib and D. Cornell (Eds.) *Feminism as Critique* (Polity Press, 1987)

⁵ Fineman M.A., *Autonomy Myth: A Theory of Dependency* (The New Press, 2005)

⁶ Mackenzie C., ‘The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability’ in C. Mackenzie, W. Rogers and S. Dodd (Eds.) *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2013)

needed where the person's gender, sexual orientation and ethnic background must be taken into account. I then reviewed the current legal means available to protect that multi-dimensional vulnerability in order for dignity to be a possibility. This meant reviewing how criminal, human rights and safeguarding laws could offer the possibility of identity, self-determination and respect for humanity.

I found that criminal laws embraced a universal idea of vulnerability, were responsive to situational vulnerability, and were primarily (but not exclusively) better at protecting older individuals from physical harm. I then turned my attention to the protection against vulnerability offered by human rights laws under Article 8 and 3. I concluded that the protection offered by Article 8 was not absolute and that thresholds for triggering Article 3 were high. I also suggested that older individuals did not feel particularly concerned by the human rights discourse, diminishing its potential usefulness as a tool to protect vulnerability. I examined in more details the role of Article 8 in the context of dignity in the case of *McDonald*. This case illustrated how its use was limited by the application of a wide margin of appreciation in matters of publically funded services. The *McDonald* case also highlighted how the statutory duties local authorities were under in their social care function influenced the conceptualisation of dignity. I concluded that the new statutory duty of wellbeing created by the Care Act 2014 could in time foster the development of a more subjective understanding of dignity.

In the following chapter I continued to explore the compatibility of legal provisions set to protect individuals from the effects of vulnerability with conditions amenable to dignity. In this particular chapter I reviewed the main measures set out to protect vulnerability through intervention under safeguarding laws, capacity and best interest determination rules under the Mental Capacity Act 2005, as well as laws and safeguards regarding restraint practices. I argued that legal provisions concerned with capacity and best interest determination were taking relational autonomy into account, but that they could give even more weight to the views of the incapacitated person. I discussed the potential impact Article 12 of the Convention on the Rights of Persons with Disabilities could have in doing so.⁷ This new approach assumes capacity rather

⁷ Convention on the Rights of Persons with Disabilities Article 12(2)

than tries to establish it, and seeks to offer support to anyone who wishes to make decisions.

The third condition I suggested should be satisfied for dignity to be possible relates to the regulatory framework that controls the *care home environment*. I suggested that I submitted here that residents ought to be able to take part in the design of the regulatory outcomes that controlled the operations of care homes. I argued that imposing a regulatory framework without consulting those impacted by it could frustrate the possibility of identity, self-determination and respect for humanity because it implied that the person cared for had no part to take in the running of the institution they lived in. I suggested that the CQC also ought to engage with those who lived out their days in care homes to find out from them whether regulatory outcomes were being fulfilled. Accountability to the individuals in care ought to be a feature of the regulatory model in place. As I have quoted before, an institution that ignored the voices of those it takes care of may run the risk of becoming a ‘total institution’, one that ‘isolates, controls and reconstitutes the daily lives of their residents’.⁸ I argued that the adoption of a risk-based model of governance in care settings was not necessarily favourable to the development of dignity. I exposed that as risk-based regulations sought to rationalise the diminution of harm in the irrational world of caring relationships, they could stunt the possibility of meaningful and dignity enhancing relationships to develop between staff and those they cared for.

The fourth condition I set out was that of *anti-ageism*. The way in which society considers and so treats older people in general affects their ability to form a sense of identity, influence their daily lives in institutions, and their status in the eyes of others. This is why I consider ageism to be a social conversion factor to dignity of the older person in care. I looked into the many causes of ageism. I found out that some were embedded in our psyche and linked to our primeval instincts for survival, whilst others were likely to be cultural and the result of the way in which the family group had evolved. The fact that we now live longer, benefit from social security and work away from the home has meant that the family unit is no longer the place where care for the very old is expected to be delivered. Although many carers are still family

⁸ Agich. G. J., *Dependence and Autonomy in Old Age: An ethical framework for long-term care* (Cambridge University Press, 2003)

members,⁹ a considerable number of older individuals now rely on professional and institutional carers. I have examined the role of equality laws in the fight against age discrimination and the positive duty put on local authorities to consider the impact of their decision on those whose characteristics are protected. I have concluded that dignity realisation as understood in this dissertation ought to be an intrinsic part of equality laws, and that initiatives to interweave generations may lessen our innate fear and rejection of old age. Although equality laws play an important part in stamping down the negative effects of age discrimination on dignity, I have argued that a cultural shift in our relationship with old age also needs to happen for dignity in care to flourish.

Care homes should offer living conditions that allow us to experience dignity. Dignity is a feeling we become conscious of when it is taken away, or chipped at, when it is in the hands of others. Similarly, when all is well, ‘our body is simply the vehicle for achieving ends in the world and is transparent to our intentions’.¹⁰ When our body becomes weak and overcome by disability or illness, the usual functioning of our day-to-day life becomes dependent on others. Dialogue becomes essential, as the perception of the help we require to achieve our ends may not be the same as that of the person providing care.¹¹ A third party, regardless of how well intentioned, cannot fathom, without engaging with us directly, what makes us who we are, what decisions we would like to make about our day to day life and the way we would like to be treated. Respecting a person’s dignity ought to begin with the willingness to interact with that person so as to get to know who they are and what they want. It is only through this knowing process that we can hope to create conditions that will allow for dignity to be realised.

I believe that upholding the understanding of dignity I argue for in this dissertation turns it into a valuable concept, one that can serve as a guide to care that respects the person. It is a claim for treatment that enables us to form and hold on to a sense of identity, that allows us to make decisions about our lives, and that values the person

⁹ The Carers Trust estimates that there are currently 670,000 unpaid carers looking after people with dementia in the UK

< <https://carers.org/key-facts-about-carers-and-people-they-care>> Accessed 23rd August 2017

¹⁰ Agich (n8) 104

¹¹ Ibid 105

that we are on the ground of our humanity. A care home that manages to create conditions that allow for dignity to be experienced is a place where residents have a stake in how the environment they live in is run, are engaged with on an equal footing, where they have the possibility to discuss their past, present and future, their care, their daily lives and their preferences. It is a place where care professionals are valued, rewarded and trained adequately. A place led by individuals who understand what matters to the people they care for and takes that into account when delivering care to them in a safe manner.

The role of law in establishing such conditions is important. Throughout this dissertation I have referred to the wellbeing principle enshrined under the Care Act 2014, and the potential it represents in embracing a more person-centred idea of dignity. Its judicial interpretation, if true to a genuinely person-centred conception of care, could bolster a discursive meaning of dignity. The power of judicial interpretation to give real weight to the wishes of the person cared for can already be seen in the judicial application of the principles underpinning the Mental Capacity Act 2005.¹² Although the meaning of the wellbeing principle under the Care Act 2014 has yet to be settled by the courts, it may become another legal tool used to reinforce the importance of the views of the person in care. On an international level, the advent of the CRPD, and more particularly that of Article 12, which establishes a presumption of capacity for all, is also bringing a new perspective on the importance of the voice of those individuals who need others to thrive, and how laws can help facilitate these voices to be heard.

Clements nonetheless writes that ‘judgments must, when the usual ‘due process’ tools fail, include that most judicially ridiculed of instrument – the *cri de coeur*: the simple statement that - no matter how rational the process; no matter how pressing the need; no matter how politically charged the context - ‘this cannot be’: the ‘revulsion’ option’.¹³ This is why our understanding of dignity needs to come from the person claiming it. My suggestion is that if our - and the courts’ - understanding of dignity comes from the persons claiming it, it is less likely that the courts will abdicate their

¹² See for instance the cases of *Re: S and S, C v V* [2008] EWHC B16 (Fam) and *A London Authority v JH* [2011] EWCOP 2420 discussed in Chapter IV

¹³ Clements L., ‘Disability, dignity and *cri de coeur*’ [2011] 6 *European Human Rights Law Review* 675, 685

responsibility to denounce violations of dignity that would be permissible under other - judicially favoured - standards and arguments, such as pressing needs, rationality of the process, and deference to legislatures on matters of controversial social policy.

Finally, I would like to address the main criticisms that I think this dissertation may provoke. Asking elderly individuals to define dignity and implementing those findings in the legislative framework of social care and in judicial and extrajudicial decision-making processes care may come across as unrealistic and too expensive to achieve. I do not believe it unrealistic to finding out the meaning of dignity from a subjective point of view in order to help build a framework with which to work from. It would indeed be unrealistic to use every response given to the question of the meaning of dignity as a definition to implement in social care settings. Yet, many individuals in care appear to share the same main ideas about the meaning of dignity, as I showed in Chapter II. Individuals may find one area (identity, self-determination or humanity) to be more essential to them, and how they manage to fulfil it will again vary from person to person. Gathering and comparing the views on dignity of elderly people in care is meant to provide a framework that can help build regulations, and persuade institutions to include residents in their implementations. It is meant to guide safeguarding and capacity laws. It is supposed to engage a multi-generational dialogue. A society willing to truly listen to the voices of those it usually assumes as voiceless is a society that creates conditions fertile for dignity.

This point brings me to the second argument against the idea of using subjective dignity in order to ground social care policies, the one that sees it failing on cost. The response to this objection is that seeking the participation of those who are dependent on care to establish the meaning of dignity as a basis of social care legislation is not the same as channelling unlimited resources and deploying every means possible towards the end of realising dignity. It is clear that someone with ‘champagne tastes’, as Dworkin refers to in his argument against equality of welfare, ought not receive more resources than others, and the same principle applies in order for dignity to be realised. It is doubtful that frail individuals – individuals who are at the very end of their lives – would have extravagant requests in order to fulfil their need for their

sense of identity to thrive, their self-determination to exist, and their humanity to be respected.¹⁴

On the other hand, it is possible that an older person in care who is to have a stake in the shape of her daily life within a care institution may, for example, be privileging certain aspects of her life over health and safety concerns. A system responsive to her views would readjust its priorities accordingly. I believe that a system of care home regulation and social care laws inspired by a concept of dignity borne out of discussions with those whose lives they shape would create a care environment that would truly give precedence to the dignity of the person. The wellbeing principle enshrined in law under section 1 of the Care Act 2014, as well as the SCIE's guiding work about dignity,¹⁵ are some of the signs that the conceptualisation of dignity argued for here may one day be upheld.

¹⁴ Dworkin R., 'What is Equality? Part 1: Equality of Welfare' (Summer 1981) 10(3) *Philosophy & Public Affairs* 185, 189

¹⁵ Cass E., Robbins D. and Richardson A., 'Dignity in care' Social Care Institute for Excellence (March 2009)
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