Dignity: A Relevant Normative Value in 'Access to Health and Social Care' Litigation in the United Kingdom?

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Abstract

This chapter considers whether and how cognizance is given to the value of dignity in 'access to care' litigation in the United Kingdom with particular reference to the case of *McDonald v United Kingdom*. The approach taken by the Court in this case raises questions as to how 'dignity' ought to be understood in the assessment of the health and social care needs of individuals, particularly the elderly, in the context of finite resources. It is questioned whether the concept of dignity within the case is compatible with the current understanding of dignity in health and law, and in particular within a right to health approach (as defined in Article 12 of the International Covenant on Economic, Social and Cultural Rights). As stated in the first paragraph of General Comment 14 '[e]very human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity.' Dignity is not a right, rather it is a 'normative value' associated with human rights. As such it is a standard which courts ought to refer to in assessing whether the state has acted proportionately in the lawful limitation of a right, even in the context of finite resources. Given the criticism of the concept of dignity as being vague courts have been reluctant to focus on this value, except in 'hard cases'. However there is a developing body of evidence, particularly within the realm of health and

social care which can provide guidance on the meaning of the concept in particular contexts.

Introduction

Rationing of health and social care within the Kingdom (UK) is an accepted reality today.[1] As such a growing body of case law has developed giving clear guidance on the legal principles and rights that the UK Courts look to when questions of availability and access to health and social care are brought before them.[2] The case of *McDonald v UK*[3] however highlights how limited the approach to justiciability is within the courts, which further raises questions in the wider debate on rationing in the context of a growing elderly population and finite resources.[4] While the courts, in the *Mc Donald* litigation,[5] were prepared to review the procedural aspects associated with the decision making on the care provided, they were reluctant to assess in substantive terms the impact of the decision on the individual.[6] Although dignity was acknowledged as being relevant throughout the various stages of the litigation there was limited discussion of the concept. This chapter questions whether and how greater consideration could have been given to the concept of dignity as

[1] The case of *McDonald v United Kingdom* 4241/12 (2014) 60 E.H.R.R. 1 itself is evidence of this; Also see D Callahan 'Must We Ration Health Care for the Elderly' *Journal of Law Medicine and Ethics* (Spring 2012) 10 – 16 p 12 & 13 Callahan suggests that rationing in the NHS is no longer covert but is overt. He highlights the use of tools such as Quality – Adjusted Life Years in decisions on which treatments to make available as an example of this.

[2] C Newdick *Who Should we Treat? Rights, Rationing, and Resources in the NHS.* (2004) 2nd ed, Oxford University Press: Oxford

[3] *McDonald v United Kingdom* (2014) *op cit* n 1

[4] For a discussion on the limitations in current approach to litigation on rights of access to health and social care see B Clough & M Brazier 'Never too Old for Health and Human Rights' *Medical Law International* (2014) 14(3):133 – 156; L Clements 'Disability, Dignity and the Cri de Coeur' *European Human Rights Law Review* (2011) (6) 675 -685; O'Cinneide C. 'Legal Accountability and Social Justice' in Bamforth N. & Leyland P (eds) *Accountability in the Contemporary Constitution.* (2013) Oxford: Oxford University Press: Oxford 385 – 410

[5] *McDonald v United Kingdom* (2014) *op cit* n 1; R *(On the Application of McDonald) v Royal Borough of Chelsea and Kensington* [2011] UKSC 33; R *(On the Application of McDonald) v Royal Borough of Chelsea and Kensington* (2010) EWCA 1109; R *(On the Application of McDonald) v Royal Borough of Chelsea and Kensington* (2009) EWHC 1582 (admin).

[6] Ibid. Clough & Brazier p141

understood with reference to the disciplines of health and law,[7] including Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). In spite of the relationship between health and dignity being clearly acknowledged in the international right to health there is limited guidance on what dignity means within the jurisprudence on Article 12 ICESCR.[8] However empirical research on health and law has the potential to develop the concept as a standard in law. The concept has been increasingly referred to within professional guidance[9] and empirical research[10] and within a growing body of literature[11] and case law.[12] This is a body of evidence the courts could refer to in the context of access to health and social care litigation and which they can contribute to by embedding dignity as a value that ought to be considered in decision making on access to social and health care entitlements.

[7] C Foster *Human Dignity in Bioethics and Law* (2011) Hart Publishing: Oxford Chapter 5 – 7. Foster highlights examples of primary research on health care (which focused on trying to understand the meaning of dignity and the factors which impacted it) and reviews of case law looking at how the courts have approached dignity.

[8] N. Jacobson N 'Dignity and Health: A Review' *Social Science and Medicine* (2007) (64) p 292.

[9] See for example the *Values of the NHS Constitution for England and Wales* (2001) accessed at http://www.nhs.uk/NHSEngland/thenhs/about/Pages/nhscoreprinciples.aspx (18/5/2015) which includes 'respect and dignity'; the Royal College of Nurses *Dignity Campaign* (2008) accessed at http://www.rcn.org.uk/development/practice/dignity/story_of_the_rcn_dignity_campaign (18/5/2015).

[10] See for example Cairns D, Williams V, Victor C, Richards S, Le May A, Martin W & Oliver D 'The Meaning and Importance of Dignified Care: Findings From a Survey of Health and Social Care Professionals' *BMC Geriatrics* (2013)13 (28) doi:10.1186/1471-2318-13-28.

[11] Jacobson *op cit* n 8; Foster *op cit* n 7; McCrudden C 'Human Dignity and Judicial Interpretation of Human Rights' *European Journal of International Law* (2008)19(4) 655- 724; Moon G. 'From Equal Treatment to Appropriate Treatment: What Lessons can Canadian Equality Law on Dignity and on Reasonable Accommodation Teach the United Kingdom?' *European Human Rights Law Review* (2006) (6) 695 – 721; Moon G. and Allen R. 'Dignity Discourse in Discrimination Law: a Better Route to Equality?' *European Human Rights Law Review* (2006) (6) 610 – 642; O' Connell R. 'The Role of Dignity in Equality Law: Lessons from South Africa and Canada' *International Journal of Constitutional Law* (2008) 6(2) 267 – 286.

[12] See for example McCrudden *op cit* n11 who reviews human rights treaty law and jurisprudence to question the understanding of dignity in the context of human rights law and O'Connell *op cit* n 11 who examines the concept in the context of equality law.

The *McDonald* Litigation.

McDonald v United Kingdom involved a challenge[13] against the decision (and care plan) made by a local borough council under their statutory duties.[14] The local council had a duty to assess the client's needs, make provision for those needs 'and in doing so [they] may take account of their resources.'[15] As a result of a stroke, Ms McDonald suffered from limited mobility and frequency of urination: this contributed to her being at risk of falling.[16] She needed assistance to access the toilet both during the day and the night. Her request for night –time assistance was rejected by the council, and alternative care was eventually put in place, which was the provision of incontinence pads for her to use. The use of incontinence pads was viewed as 'a practical and appropriate solution to Ms McDonald's night –time toileting needs…,'[17] in the context of available resources (and the rejection by Ms McDonald of the other care alternatives offered to her). Her needs and also wishes in the context of the care plan were considered to be 'elimination of risk of injury' and 'a desire for independence and privacy', both of which could be met with the provision of incontinence pads.[18] Lord Brown found that there was no interference with Article 8 ECHR, but stated that even if an interference with the right to family and private life

[13] The challenge at the Supreme Court R *(McDonald)* [2011] UKSC n 5 at Para 5 gave rise to four issues for appeal. These included whether the care plan reviews were a reassessment of needs, whether due regard was given to the nature of needs within the requirement of disability legislation, and whether Article 8 ECHR had been infringed and whether that interference was lawful.
[14] The relevant statutory provisions which placed duties upon the Royal Borough of Chelsea and Kensington in respect of Ms McDonald's care included the: National Health Service and Community Care Act (2009), S 47; National Assistance Act (1948) S 29(1); Chronically Sick and Disabled Persons Act (1947) S 2(1); Local Authority Social Services Act (1970) S 7(1).
[15] *R (McDonald)* [2011] n 5 at Para 8
[16] *Ibid*. Para 1.
[17] *Ibid.* Para 11 referring to the 2010 Care Plan Review for Ms McDonald.
[18] *Ibid*. Para 12 citing Rix LJ in *R (McDonald)* (2010) EWCA n 5at Para 53.

was identified, it could be justified under Article 8(2) ECHR.[19] The ECtHR did find that there was an interference with Article 8, however save in respect to a violation between November 2008 and 2009 (based on procedural aspects), that interference was lawful.[20]

The ECtHR in the case reaffirms that health and social care interests are justiciable on the basis of Article 8 ECHR, including "complaints about public funding to facilitate the mobility and quality of life of disabled applicants."[21] The ECtHR also reaffirmed its view that Article 8 in principle gives rise to positive obligations, even in the context of access to health and social care complaints.[22] However it viewed this case as giving rise to a negative obligation in respect of the right: that is the issue was not one of "a lack of action [as] the state had not refused assistance to Ms McDonald" rather it was in relation to a "decision of the local authority to reduce the care package that it had hitherto been making available to her".[23] Any interference with Ms McDonald's Article 8 ECHR right, after November 2009, was considered to be lawful and proportionate in the context of the legitimate aim of the "economic well-being of the state and the interests of other care-users".[24] The state's decision was viewed in the context of a wide margin of appreciation as it involved issues of general policy and the Court stated that the "… margin is particularly wide when the issues involve an assessment of the priorities in the context of the allocation of limited State resources."[25]

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[19] *Ibid. per* Lord Brown at Para 9. Lord Walker, Lord Kerr and Lord Dyson all agreed with Lord Brown's judgment and dismissed the appeal. Lade Hale provided the only dissenting judgment.
[20] *McDonald V UK* (2014) *op cit* n1 Para 59. A violation was found for the period 21 November 2008 to November 2009. Within that time period care was not provided in line with the assessment made. No violation was found after November 2009.
[21] *Ibid.*
[22] *Ibid.* Para 48.
[23] *Ibid.* Para 48.
[24] *Ibid.* Para 53.
[25] *Ibid.* Para 55

While the case provides evidence of the justiciability of access to health and social care claims, it also supports the view that the approach to justiciability of economic, social and cultural rights of both the UK courts and the ECtHR is limited. Clough and Brazier suggest the case provides an example of the failure of Article 8 ECHR to protect the elderly, with its narrow focus on 'procedural issues' rather than on the "impact of the decisions on the substantive rights or dignity"[26] of the individual. Clements goes further in his criticism stating that it is concerning that "parts of the judiciary do not consider that such distressing circumstances engage fundamental human rights at all".[27] Pritchard - Jones suggests that there is as much to learn from the case in respect of what is not said, as much as in terms of what is said, with the "ECtHR's disinclination to engage with substantive discussions of dignity and autonomy".[28]

The criticisms of a focus on procedure, a reluctance to consider 'normative values' or minimum standards and judicial deference in the context of resource allocation questions are part of the wider debate on the extent to which courts should be involved in challenges relevant to social justice.[29] O Cinniede suggests that even though there are times it appears that courts look to some substantive aspects (for example non-discrimination and equality) of economic, social and cultural rights, they continue to limit the review of these rights by tying these aspects to the process of

[26] Clough & Brazier *op cit* n 4 p141
[27] Clements *op cit* n 4 p 684.
[28] L Pritchard- Jones 'Night-time care, article 8 and the European Court of human Rights: A missed opportunity'. *Journal of Social Welfare and Family Law* (2015) (37) 108 p 111
[29] O'Cinneide *op cit* n 4 p 395 - 396

decision-making rather than look to the impact of the decision on the individual.[30] This is an approach which he describes as 'ethically aimless'.[31] He highlights *McDonald v UK* as an example of this, with the core issues of 'rationality' and 'dignity' being relegated to side issues while the court focused on procedural issues.[32] Whilst acknowledging the arguments for limited judicial intervention and the dangers of judicial intervention in the context of finite resources O'Cinneide suggests that there is a need for the courts to view decisions in the context of social justice. Lady Hale's approach in the *McDonald* case also seems to suggest that a standard related to the impact on the individual is necessary in the context of access to care decisions within finite resources:

> " As Lord Lloyd put it 'in every case, simple or complex, the need of the individual will be assessed against the standards of civilized society as we know them in the United Kingdom' (p598F). 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 more convenient course. We are, I still believe, a civilized society. I would have allowed the appeal"[33]

If the CESCR General Comment, which elaborates on the meaning of Article 12 ICESCR in stating '[e]very human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity'[34] is considered then the standard of a civilized society requires that individuals are treated with dignity.

In the original High Court case, the only references made to dignity (indignity) were

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[30] *Ibid.* One example of this is found in *Eisai Limited v. The National Institute for Health and Clinical Excellence (NICE), The Alzheimer's Society, Shire Pharmaceuticals Limited* [2007] EWHC 1941 (Admin) QBD (Admin). One aspect considered by the court in this case was the discriminatory effect within one aspect of the process of evaluation of the treatment.

[31] *Ibid.* p403. He identifies 'ethical aimlessness' as a term first used by Anthony Lester in association with the common law before the 'modern rule of law' and human rights.

[32] *Ibid*. p 403.

[33] *McDonald* [2011] UKSC *op cit* n 5 at Para 79 citing *R v Gloucestershire County Council ex parte Barry* [1997] AC 584 at 589F.

[34] CESCR *General Comment No 14: The Right to Health (Article 12).* (11 August 2000). E/C.12/2000/4.Para 1.

by the applicant in her claim that the withdrawal of night-time care exposed her to 'risk and indignity.'[35] In the Court of Appeal the applicant's lawyers continued to view the withdrawal of care as an 'affront to her dignity,'[36] argued that dignity was at the heart of Article 8 ECHR[37] and the impact upon 'Ms McDonald's core right of dignity' was not proportionate to the aim of 'equitable allocation of resources' or to the aim of saving money in the decision on what care to provide.[38] In contrast the council viewed the provision of incontinence sheets as a way to protect dignity and privacy, supporting this argument by highlighting the experience of others: that is 'most people were willing to accept them' and were happy with this form of care.[39] As such within the High Court and Court of Appeal no issue of dignity was associated with the nature of the care. In the context of the earlier care plan and failing to meet the needs of Ms Mc Donald, which could allow for a finding of a violation of Article 8 ECHR, the courts suggested that this "was not born out of any disrespect" for the applicants dignity but out of a concern for the council's "responsibilities to all its clients within the limited resources available to it within its budget".[40]

Within the Supreme Court Judgment Lord Brown provided some insight as to why he considered there was no disrespect for the dignity of the applicant: his view was that the council had "sought to respect as far as possible her personal feelings and desires, at the same time taking account of her safety, her independence and their own responsibilities towards all their other clients."[41] Evidence of this included offering

[35] *Ibid.* Para 1 and 4
[36] *McDonald* (2010) EWCA *op cit* n 5 Para 2
[37] *Ibid.* Para 63
[38] *Ibid.* Para 70
[39] *Ibid.* Para 24, 26 &27. The evidence appears to be anecdotal and not based on any formal evaluation.
[40] *Ibid.* Para 66
[41] *Mc Donald* [2011] UKSC *op cit* n 5 Para 19

alternative choices and aspects of support such as direct payments. In essence he viewed autonomy as being closely associated with dignity. The decision to provide 'incontinence sheets' was also considered to be an 'acceptable practice': this seems to suggest that if dignity was relevant in the case evidence of 'acceptable practice' was a sufficient measure of it being met. Lady Hale was critical of this approach, highlighting that no evidence had been submitted to support this acceptable practice: in fact she suggested that evidence would tend to disagree with that approach.[42] The range of literature and guidance on caring for individuals who suffer with incontinence would suggest that dignity is a key aspect in their care.[43] Although the applicant was continent, she was being treated as if she was not and as such it would seem that the guidance on incontinence care could be a starting point in evaluating the care. The difference between 'accepted practice' and 'expected practice' in health care is one which has been discussed in the context of negligence by Samanta.[44]

Within the ECtHR there is also limited reference to the concept of dignity. Although the Court concurred with Lady Hale and stated that dignity was engaged in this case as the applicant "was faced with the possibility of living in a manner which 'conflicted with her strongly held ideas of self and personal identity."[45] The Court associated the concept of dignity with the feelings of the applicant and not with any moral standard of conduct associated with the approach of the state. The Court went

[42] *Ibid*. Para 75 Lady Hales states 'Such Department of Health Guidance as there is, points the other way.' Although no Lady Hale does not identify the specific guidance, see Para 31 where Lord Walker identifies a Department of Health Document (2000) in support of the proposition that incontinence sheets could be provided: it stated 'incontinence sheets should not be offered prematurely."

[43] See for example Centre for Health Service Studies University of Kent & Royal College of Physicians (2009) *Privacy and Dignity in Continence Care Project* (2009) accessed at https://kar.kent.ac.uk/24800/1/Phase_1_Privacy_and_Dignity_in_Continence_Care_Report_November_2009.pdf (20/5/2015)

[44] A Samanta & S Samanta 'Legal Standard of Care: A shift from the Traditional Bolam Test' *Clinical Medicine* (2003)3(5): 443 – 446.

[45] *McDonald v UK* [2014] *op cit* n 1 Para 47 citing Pretty v United Kingdom 2346/02 (2002) 35 EHRR 1

on to conclude that the 'applicant's personal feelings and desires had properly been balanced against the local authority's concern for her safety, and independence and respect for other care users.'[46] As such dignity appears to be viewed as an interest of no greater value than safety or independence.

Throughout the *McDonald* litigation the focus was on procedural aspects of decision making within finite resources, including a broad definition of needs as safety and privacy, with the standard of care being assessed as 'acceptable practice'. Ms Mc Donald's feeling of humiliation was acknowledged but the view appeared to be that her negative feeling towards the care would be temporary, as 'acceptable practice' suggested this feeling would change once she had tried the incontinence sheets. Dignity was also associated with the efforts to involve the applicant in the decision making process. Rather than being viewed as a core value to which the courts should look it was viewed as an interest or right in the same way as autonomy and safety, and as such it seems it could be limited for the wider good in the context of finite resources. Lady Hale in her dissent does look to care standards in the context of a hospital or care home setting to identify whether the approach is acceptable, although she acknowledges that the same care is not possible in a community setting as it would be in a hospital setting.[47] The approach to both justiciability and dignity in the case is limited. It leaves questions as to what dignity ought to mean, as well as questions as to the approach that should be taken in law to dignity.

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[46] *Ibid*. Para 56

[47] *Ibid.* Para 78 "The Care Quality Commission's Guidance, Essential Standards of Quality and Safety (2010), p 117 requires that people who use services have access to toilets, baths and showers that enable them to maintain privacy and dignity and are in close proximity to their living areas. The Commission's recent Review of Compliance at Ipswich Hospital NHS Trust found that dignity was not always sufficiently considered because people were not taken to a toilet away from their bed-space and commodes were used all the time: p 8."

Dignity: What does it mean?

Foster, although describing the concept of dignity as a 'slippery one,' argues that it is an important and useful concept, despite the criticism of it being vague.[48] In recent years the debate on the meaning of dignity has increased both in the context of law, and health care.[49] Often understanding of that concept begins with reference to end of life choices and palliative care. For example Jacobsen highlights that in bioethics, debates on dignity were embedded in the controversies of aspects related to care of the dying.[50] In law, Foster highlights that courts tended to look to the concept in 'hard cases', and argues that if the concept is applicable in such cases it can also have a wider relevance.[51] Foster views dignity 'as the transaction that constitutes the whole bioethical encounter.'[52] It is an approach which acknowledges that the concept arises in the interaction between individuals and groups: That is the individual is 'seen' as a person by those they are interacting with.[53]

The 'transaction' approach taken by Foster is appealing in that it allows for the recognition of both subjective and objective aspects to the concept of dignity. The subjective aspect can be described in terms of the impact on the individual including feelings of humiliation, invisibility or exclusion, while the objective aspects can be viewed in the conduct towards to the individual and the standard of conduct expected by society to all individuals. The subjective aspect of dignity appears to equate to what in health has been described as 'personal or basic dignity' and in law as dignity

[48] Foster *op cit* n 7 p 4
[49] *Ibid*. Chapter 5 – 7.
[50] See Jacobsen *op cit* n 8 p297 – 299.
[51] Foster *op cit* n 7 p 3
[52] *Ibid.* p 15
[53] S Pleschburger S 'Dignity and Dying in Nursing Homes: The Residents' Views' *Age and Dying* (2007) (36) 2 197 -202.

as 'quality'.[54] When an individual is treated without dignity, the term 'objectify' has been used to describe the approach to their care: that is the patient is not seen as an individual and is lost in the process of tasks and budgets.[55] That focus on elements of care rather looking to the individual has been one of the criticisms made in respect to the separation of social and health care, leading to calls for greater multi-disciplinary approaches to ensure the holistic needs of the individual are recognized and met.[56] The recognition of such an integrated person-centred approach has also been called for at the governance level.[57] Given this, it is interesting that limited references to health have been made in the *Mc Donald* case,[58] with no real consideration of the long term impact on maintaining and improving 'functional capacities' such as continence.[59]

The objective aspect of dignity appears to equate to a 'moral standard' or what in law has been described as a 'status' concept: In other words it appears to be associated with the value placed upon the individual by society.[60] As such it is unsurprising that dignity in law is closely associated with concepts of equality whether generally or in

[54] See Foster *op cit* n 7; Jacobsen *op cit* n 8
[55] Band-Winterstein T. 'Health Care Provision for Older Persons: Ageism and Elder Neglect' *Journal of Applied Gerontology* (2013) 1-15.
[56] Department of Health (January 2014) ' The Hard Truth: The Journey to Putting People First. Volume One of the Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry' Cm 8777- accessed at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270368/34658_Cm_8777_Vol_1_accessible.pdf (2/6/2015) Para 5.20
[57] Newdick C. 'From Hippocrates to Commodities: Three Models of NHS Governance' *Medical Law Review* (2014) 22(4) 162- 184
[58] *McDonald v UK* (2014) *op cit* n1 Para 30 – 34. The relevant international law referred to was the UN Convention on the rights of persons with disabilities and the European Union Charter of Fundamental Rights (although the relevance of this is unclear given the Charter is only binding against the Institutions of the Union).
[59] See General Comment 14 *op cit* n 34 Discussed further in the context of the International Right to Health. Although a referral was offered in relation to incontinence care for Mrs Mc Donald, this was refused as she was continent. However now consideration of how encouraging someone to be incontinent at night would impact on maintenance of long term functional capacity (continence).l
[60] M Oosterveld-Vlug, H Pasman, I van Gennip, C de Vet & B Onwuteaka-Philipsen. 'Assessing the Validity and Intra-Observer Agreement of the MIDAM-LTC; an Instrument Measuring Factors that Influence Personal Dignity in Long-Term Care Facilities' *Quality of Life and Health Outcomes* (2014) 12(17) doi:10.1186/1477-7525-12-17.

the context of human rights law. This approach of categorizing dignity into two major categories is supported by qualitative research in health care.[61]

In spite of the difficulties in defining dignity, there have been attempts by the professional regulatory bodies and unions for health and social care practitioners to define the concept. The more detailed attempts Foster suggests are found in the context of nursing.[62] Although he highlights all the definitions are subject to criticism. The need for these professions to explain the concept is telling as to the importance they place on the value in health and social care.[63] As such there is a growing body of health care research which seeks to understand what dignity means from the perspective of those receiving care, those providing care, how dignity should be measured and the factors influencing subjective and objective concepts of dignity.[64] One study, albeit based upon a small sample suggests patients recognise that quality of life and dignity are not synonymous concepts, although the likelihood of violations of dignity does increase for those requiring support from others, such as those living in care homes.[65] This emphasizes that when there is some aspect of dependence, the potential for dignity to be infringed increases.[66] The studies, much as Foster's theoretical examples in relation to dignity, highlight that dignity is not solely about autonomy or independence, or about the way we are made to feel but also about how the individual is treated: that treatment provides an indication of how society views

[61] See Foster *op cit* n 7 p 75 citing the findings of Pleschburger *op cit* n53
[62] *Ibid.* Chapter 5.
[63] *Ibid*.
[64] See for example Pleschburger op *cit* n 53; Royal College of Nursing *Defending Dignity. Challenges and Opportunities for Nursing* (2008) Royal College of Nursing accessed at http://www.rcn.org.uk/__data/assets/pdf_file/0011/166655/003257.pdf (20/5/2015). Cairns et al *op cit* n 10; Oosterveld et al *op cit* n 59
[65] Oosterveld et al *op cit* n 60 p 26
[66] Ibid. Also see Pleschburger *op cit* n 53

that individual.[67] The studies in their attempts to identify factors which 'maintain or retain dignity' give rise to a common theme of dignity as an 'evaluation of oneself in close relation to others.'[68] Arguably this still leaves a sense of vagueness associated with the concept, which requires greater clarification in the context of law.

The concept of dignity in law has traditionally been considered in challenges related to 'end of life' decisions;[69] individual integrity and autonomy;[70] equality[71] and human rights.[72] There is also a need to consider that concept in the context of health and social care law, and in particular in respect to access to treatment cases. As with understanding of dignity in health, understanding of the concept in law seems to be have been discussed to a large extent within end of life contexts, the cases Foster describes as 'hard cases'. In the context of the *McDonald* case, the ECtHR referred to *Pretty v UK*[73] to discuss one aspect of dignity, which is 'self-identity' and the right to choose. Other aspects the Courts have recognized include 'physical integrity' and equality.[74] Mc Crudden suggests that there are three aspects to the 'minimum core' of dignity in human rights law which includes: (1) 'the intrinsic worth of the human being,' (2) respect for the intrinsic worth of the human being and (3) "…the state should be seen to exist for the sake of the individual human being, and not vice versa (the limited-state claim)".[75] He goes on to consider the nature of dignity, and questions whether it is a right, which can be enforced or a principle from which rights

[67] Foster *op cit* n 7 chapter 1 provides hypothetical examples to highlight this point.
[68] Oosterveld *op cit* n 59 p 26
[69] See for example *Airedale N.H.S. Trust v Bland* [1993] A.C. 789; *Pretty v. United Kingdom* (2002) *op cit* n 45
[70] See for example *Tyrer v United Kingdom* [1978] ECHR 2; *Pretty v. United Kingdom* (2002) *op cit* n 45
[71] See the articles by Moon *op cit* n 11in respect of Canadian law and O'Connell *op cit* n 11in respect to the European Convention on Human Rights.
[72] See McCrudden *op cit* n 11 who reviews the approach to dignity in Human Rights law.
[73] *Pretty v. United Kingdom op cit* n 44
[74] McCrudden *op cit* n 11 p 723
[75] *Ibid.* p 679

can be derived and which underpins judicial interpretation.[76] He suggests dignity is viewed as 'underpinning' rights. [77] This would suggest that it is a value within the law of this jurisdiction. This was the perspective put forward by Lord Justice Munby in *Burke v General Medical Council*[78] when he said dignity

> "is a core value of the common law, long pre- dating the Convention…the invocation of dignity of the patient in the form of declaration habitually used when the court is exercising its inherent declaratory jurisdiction in relation to the gravely ill or dying is not some meaningless incantation…it is a solemn affirmation of the law's and society's recognition of our humanity and of human dignity as something fundamental."[79]

Although the Court of Appeal was critical of Lord Justice Munby in this case his comments on dignity were 'not disapproved'.[80] One criticism of the approach of Munby J in the *Burke* case by Foster is his view that autonomy and dignity have equivalence in law. Foster suggests that 'dignity is a deeper concept than autonomy,'[81] although he describes both concepts as rights he describes 'dignity as the parent right'.[82] Arguably dignity is more than a right (if Mc Crudden's description of the minimum core is considered), it is a value which underpins rights, and is the standard by which rights implementation is assessed. It should not be subject to limitation in the way that autonomy would be when assessed against other rights. Yet despite dignity being the 'parent right', in the *McDonald* litigation it is trumped by safety in the context of finite resources. Contrast this with the approach of the ECtHR in respect of autonomy and safety in deprivation of liberty challenges and the requirement for safeguards.[83] An approach where dignity is balanced against

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[76] *Ibid.* p 680 &681
[77] *Ibid.* p 683 citing *Pretty v. United Kingdom op cit* n 45
[78] *R(On the Application of Burke) v General Medical Council* [2005] QB 424
[79] *Ibid.* Para 57
[80] Foster *op cit* n 7p 101
[81] *Ibid.* p 110, he goes on to say that autonomy is a manifestation of dignity.
[82] *Ibid.*
[83] *HL v UK* 45508/99 (2004)ECHR 471

interests or rights such as autonomy or safety contradicts the description of it as being fundamental, or as being a value which underpins rights.

If dignity is a value within the context of human rights and equality law it ought to be the context in which rights protection is considered (whether that is described as the 'standard of a civilized society', the 'expected practice' or a 'measure of humanity').[84] Such a standard would have imposed a positive obligation upon the council in *McDonald v UK* to ensure that care met that standard. It would have required the Court to question how the needs of the individual were to be met, in a way that was consistent with dignity. To date as Foster has highlighted the adoption and development of dignity as a standard, or what he has called a 'lodestone' has not been taken up by the Courts.

Fabre also suggests dignity can contribute to '…a common metric by which to judge the relative importance of conflicting interests.'[85] That common metric can be described in terms of a 'minimal decent life' and equality.[86] In the context of health care as previously argued in this chapter, there is empirical evidence to suggest that 'expected practice', with reference to dignity can be defined. In the particular facts of the *McDonald* case it would require looking to the NHS values, professional codes of conduct and the existing research in relation to incontinence (for the outcome in this case would have similar implications for the applicant as for those who are

[84] *Burke v General Medical Council* [2005] *op cit* n 78 Para 71 also citing at Para 72 Baroness Hale What can the Human Rights Act Do from My Mental Health (2004) Paul Sieghart Memorial lecture p 22 ; See also *op cit* n 33, n44, n79

[85] C Fabre *'Social Rights under the Constitution: Government and Decent Life'* (2000) Oxford University Press: Oxford. p2.

[86] S Fredman . 'From Deference to Democracy: The Role of Equality under the Human Rights Act 1998' *Law Quarterly Review* (2006) 53 at p 60; Also see Moon *op cit* n 11; Moon & Allen *op cit* n 11.

incontinent) and the approach to dignity and health in those standards.[87] Foster highlights the relevance of *Bolam v Friern Hospital Management Committee*[88] and the requirement in negligence cases of a practice being 'endorsed by a responsible body of opinion in the relevant specialty' as a useful approach to look at standards of care: an approach which Samanta suggests involves looking to 'expected' and not 'accepted practice'.[89] Also a right to health approach requires that care should be based upon need, and that the care is 'scientifically and medically appropriate'.[90]

Réaume suggests a failure to respect human dignity is associated with 'prejudice, stereotyping and exclusion from benefits or opportunities.' [91] Given the acknowledgment that ageism exists in health care provision it is unsurprising that failure to respect dignity is a recurring theme in reports and inquiries on health care provision involving older people.[92] It ultimately comes back to the value society places on the individual:

> "the more important a particular benefit is to one's ability to participate fully in society, or the more it is a marker of true belonging in society, the more one should worry that exclusion from it will carry the connotation that members of the excluded group deserve less respect."[93]

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[87] In particular see the Centre for Health Service Studies University of Kent & Royal College of Physicians *op cit* n 43.
[88] [1957] 1 WLR 583; Also see Samanta & Samanta *op cit* n 44 who discuss the impact of *Bolitho v City and Hackney Health Authority* [1998] AC 232 on *Bolam.*
[89] Foster *op cit* n 7 p 7
[90] General Comment 14 *op cit* n 34 Para 12 (d)
[91] Moon *op cit* n 11 p 705. citing D Réaume 'Discrimination and Dignity' (2003) 63 Louisiana Law Review p 672
[92] See J Harris. & S Regmi. 'Ageism and Equality' *Journal of Medical Ethics* (2012) 38(5): 263 – 266; Parliamentary and Health Service Ombudsman 'Care and Compassion? Report of Health Service Ombudsman on Ten Investigations into NHS Care of Older People' (2011) accessed at http://www.ombudsman.org.uk/__data/assets/pdf_file/0016/7216/Care-and-Compassion-PHSO-0114web.pdf (28/05/2015). See also Northern Ireland Human Rights Commission 'Emergency Health Care' (2015) accessed at http://www.nihrc.org/uploads/publications/NIHRC_Emergency_Healthcare_Report.pdf (3/05/2015)
[93] Moon *op cit* n 11 citing D Réaume *op cit* n 91 p695.

Strikingly in contrast to a developing advocacy and a large body of evidence of ageism on the rights of older people there is a limited body of case law relating to older people and health and health care.[94] The reaction in the context of health care to the evidence of ageism and the issue of dignity has been an upsurge in research on the meaning of dignity in health and social care, as well as campaigns to ensure respect for individual dignity. This would suggest that in litigation on health and social care access, the courts ought to give more consideration to this normative legal value. A starting point in developing the approach to dignity in this particular context could be the international right to health.

Dignity and the International Right to Health.

The argument that Article 12 ICESCR is an important starting point in developing understanding of dignity is made despite the view of the UK that the Covenant does not give rise to justiciable rights, only principles that guide policy.[95] The UK state reports to the Committee on Economic, Social and Cultural Rights (CESCR), the Treaty monitoring body the ICESCR, suggests that policy and action on health (including for older people) is compliant with right to health requirements.[96] As such there is an acknowledgement by the UK of the right to health irrespective of their view of the right as a non-justiciable.[97] Whether the right is viewed as a set of

[94] Rodriquez- Pinzon D & Martin C 'The International Human Rights Status of Elderly Person' *American University International Law Review* (2003) (18) 4 915-1008.
[95] United Kingdom 5th Periodic Report on Implementation of the International United Nations Covenant on Economic, Social and Cultural Rights (31 January 2008) E/C.12/GBR/5 Para 51 & 74.
[96] *Ibid*. Para 296 – 325.
[97] Department of Health NHS Constitution for England (2013) accessed at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf (19/5/2015). Although the term right to health is not specifically used in the Constitution many of the rights associated with a right to health are identifiable such as non-discrimination; Also See Department of Health ,Social Services and Public Safety for Northern Ireland (June 2014) Making Life Better: A Whole System Strategic Framework for Public Health 2013 – 2023 accessed at

principles to guide policy or as a justiciable right the starting point to understanding it is General Comment 14 of the Committee on Economic, Social and Cultural Rights.[98]

General Comment 14 describes the right as a right to the freedoms and entitlements, which are necessary in order that an individual can attain 'the highest attainable standard of health conducive to a life in dignity', which is possible for them.[99] Two important caveats exist in relation to this standard; (1) there are aspects beyond the control of the state in respect to what health can be achieved by an individual[100] and (2) the individual right to the freedoms and entitlements, which are within the control of the state, can be lawfully limited. Lawful limitation of the right is allowed on the same grounds as civil and political rights, and in addition state discretion is afforded in implementation of the right within the context of available resources and the point from which progress in implementation of the right to health starts.[101] Two overlapping approaches have been developed to explain the obligations imposed upon the state which are subject to limitation, both can be identified in *General Comment 14*.[102]

The first of the frameworks to explain state obligations revolves around a traditional obligations approach to human rights and is associated with civil and political rights as much as economic, social and cultural rights. That framework is the tri-partite

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http://www.dhsspsni.gov.uk/mlb-strategic-framework-2013-2023.pdf (18/5/2015) at p 8 in which the 'right to the highest attainable standard of health' is acknowledged as an underpinning value of the strategy.

[98] General Comment 14 *op cit* n 34

[99] *Ibid*. Para 1 The definition in Article 12(1) is developed with reference to dignity.

[100] *Ibid*. Para 8 & 9

[101] *Ibid*. Para 31.

[102] *Ibid*. Para 34 – 37; Also see United Nations Commission on Human Rights, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt (*11 February 2005) E/CN.4/2005/51 who discusses these frameworks at Para 46 – 50;

obligations of respect protect and fulfill.[103] The second framework has been described as a useful tool to examine state policy,[104] and involves viewing state conduct in the context of questioning what should be made available and who has access. The literature also speaks of acceptability and quality, and sometimes affordability in relation to entitlements. However this chapter focuses on availability and accessibility, viewing the facets of acceptability, affordability and quality as aspects of that broader categorization. The overlap of these characteristics with the concepts of availability and accessibility can be seen in the context of the *McDonald* case. The care she wanted, the provision of carers to assist her in accessing toilet facilities during the night was not provided instead an alternate care package was provided, which was the supply of 'incontinence sheets'. The state view and indeed, the ECtHR view was that acceptable care was provided within available resources: the alternate view would be that there was no access to the necessary care, given that the care plan gave rise to questions of acceptability on the part of Ms McDonald. In assessing the right of access to care, including the quality of care, the court looked to affordability, and viewed the acceptability of the care from the perspective of the care provider only.[105]

The framework of availability and accessibility allows questions to be asked on how decisions are made as well as in respect to the impact of those decisions. General Comment 14 provides guidance on what should be considered in looking at those decisions. Procedural aspects to be considered include that decisions are based on scientific evidence and assessed needs, while the impact of those decisions is

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[103] See M Sepulveda M '*The Nature of the obligations under the International Covenant on Economic, Social and Cultural Rights' School of Human Rights Research Series 18* (2003) Intersentia: Antwerp for an overview of the development of the recognition of these obligations.

[104] Hunt *op cit* n 102 Para 46

[105] *Op cit* n 42

considered in the context of whether they are discriminatory, provide for equality of opportunity and are 'conducive to a life in dignity'. The scope of what should be made available (freedoms and entitlements) can be considered with reference to Article 12(2), which outlines broad programmatic areas of the right to health. However given the breadth of the programmatic area, and the acknowledgement in *General Comment 14* of the broad definition of health the scope of the right is arguably determined by the impact on health. The focus of this chapter is dignity and the subsequent question is how is dignity associated with state obligations in respect of the right to health.

Three references are made to the concept of dignity in the main text of *General Comment 14*.[106] The right is described as the right to 'the highest attainable standard of health conducive to living a life in dignity'[107] suggesting that dignity is part of the definition of the right as well as a standard to be met. It also seems to be a pre-requisite for realisation of the right, when the right to health is described as being dependent upon other human rights 'as contained in the International Bill of Rights', one of which is stated as 'human dignity'.[108] The third reference to dignity is found in the context of care for older people. The concept is associated with care which should 'maintain the functional capacities' of older people through preventive care as well as curative care.[109] It is not clear given the formulation of the statement if this is a general principle to be applied in respect of the right to health or is associated with the care of the terminally ill only. The rationale for an approach, which focuses on supporting the 'maintenance of functional capacities' appears to be associated with

[106] General comment 14 *op cit* n 34 Para 1, 3 and 25. A further reference is made in footnote 13 of the General Comment in respect to 'healthy, natural and workplace environments'.
[107] *Ibid.* Para 1.
[108] *Ibid.* Para 3.
[109] *Ibid.* Para 25

resources: the argument made is that over a longer time care will be less resource intensive. [110] Reference is also made to General Comment 6 on the economic, social and cultural rights of older persons, which in turn emphasizes the importance of the United Nations Principles on Older Persons[111] and which states

> "older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse, should be treated fairly, regardless of age, gender, racial or ethnic background, disability, financial situation or any other status, and be valued independently of their economic contribution"[112]

General Comment 14 seems to suggest that dignity ought to be part of any rights approach, including a right to health approach. However, given the limited references to the concept it is difficult to identify what exactly that means within any right to health approach. One aspect is that dignity appears to be a part of the definition of a right to health ('the highest attainable standard of health conducive to living a life in dignity').[113] A second aspect raised in respect of older persons is that 'functional capacities' should be supported, although in the context it is discussed it appears to be about supporting and maintaining independence. The final three aspects to the concept in General Comment 14, are it is suggested, more in keeping with the traditional perspectives of dignity in law: (1) dignity as associated with individual integrity (freedom from inhumane and degrading treatment and torture),[114] (2) dignity

[110] *Ibid.* Also see CESCR General Day of Discussion on the Rights of the Ageing and Elderly in Respect to Rights recognized in the Covenant, 20 December 1993, E/C.12/1993/SR.12. The concept of dignity was mentioned in the context of independence and involvement with the community.
[111] United Nations Principles for Older Persons, 16 December 1991, General Assembly resolution 46/91.
[112] *Ibid.* Article 17 cited in CESCR *General Comment No 6: The Economic, Social and Cultural Rights of Older Persons*. (8 December 1995) Contained in E/1996/22. Para 5
[113] *Ibid.* Para 1.
[114] General comment 14 *op cit* n 34.

as associated with non-discrimination and equality law[115] and (3) dignity as associated with care for the terminally ill.[116]

The concluding observations of the Committee on Economic Social and Cultural Rights, responsible for monitoring the implementation of the ICESCR, appear to offer limited further guidance on the meaning of dignity in the context of the right to health. A review of the concluding observations in 2014 and a search within the Bayefsky database of concluding observations until 2005 highlight few references to the term 'dignity' in association with health.[117] As with *General Comment 14*, when dignity is explicitly used, it is referred to as a standard which legislation should be consistent with.[118] One factor of that standard is found in the concept of 'inhumane conditions',[119] although this linkage of dignity to inhuman conditions is found in a discussion report, between the Committee and the State in respect of the State report and not the concluding observations.[120] In the discussion report concerns in respect of state run nursing homes were acknowledged by the state representative, including that care 'quality was poor, and many, instead of providing active nursing care,

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[115] *Ibid.*
[116] *Ibid.* Para 25
[117] In a review of the 2014 Concluding Observations of the CESCR there are only two references to the concept of dignity. CESCR *Concluding Observations regarding El Salvador* (19 June 2014). E/C.12/SLV/CO/3-5 Para 22 CESCR; CESCR *Concluding Observations regarding China, including Hong Kong, China and Macao* (13 June 2014) E/c.12/CHN/CO/2 Para 30 (the issue forced evictions in the context of city renewal and the state is urged to ensure '…free, prior and informed consent and with full respect for their safety and dignity.' A thematic search of the Bayefsky.com site also highlights limited references to the concept, with only 6 references made to the concept up until 2001 and 3 references from 2001 – 2005.
[118] *Ibid.* Concluding Observations regarding El Salvador at Para 22 "The Committee urges the State party to revise its legislation on the total prohibition of abortion to make it compatible with other fundamental rights such as the woman's right to health and life, and consistent with the dignity of women'
[119] CESCR *Concluding Observations regarding Germany* (24 September, 2001) E/C.12/1/Add/68 Para 24 and 42. The observations refer to a grave concern about 'inhumane conditions' in nursing homes for older people.
[120] Economic and Social Council *Summary Record of the 49th Meeting Regarding Germany*. (30 August 2001).E/C.12/2001/SR.49. Para 67 (a statement by the Mr Willers, a representative of the State)

resorted to passive treatment in the form of sedation, with a resulting high incidence of incontinence, malnutrition and dehydration."[121] It was an acknowledgment of the requirement for change particularly when the state believed that "living standards were governed by a series of laws and that the aim of social welfare was to enhance human dignity".[122] However in the concluding observations it was the concerns in respect of conditions that were raised, with no mention of dignity.

In 2011 the Special Rapporteur on the Right to Health provided a 'thematic report' on the right to health of older people which expands on some aspects of dignity.[123] In that report there are eight references to the term 'dignity' in the context of older people which includes the perception of dignity as (1) part of a right to health approach,[124] (2) as an aim or standard for care in life[125] and in terminal illness,[126] (3) related to the security or integrity of the individual[127] and (4) as an aspect of autonomy. In relation to autonomy two references are interesting and include as per *General Comment 14* the need to maintain the functional capacities of older people,[128] (although again this is a very broad concept and in this instance appears to relate to contribution to society as much as physical capacity) and secondly the Special Rapporteur makes mention of 'the impact of institutionalization on the autonomy of

[121] *Ibid.*
[122] *Ibid*. Para 68 (a statement by Ms Kuck-Schneelmelcher, a representative of the State). Despite this the issue was raised again in the CESCR *Concluding Observations regarding Germany* (12 July 2011) E/C.12/DEU/CO/5. Para 27 where the CESCR observed that the state had not taken sufficient measures to deal with the difficulties in state nursing homes.
[123] Grover A. *Thematic Study on the Realization of the Right to Health of Older Persons by the Special Rapporteur on the Right to Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Arnand Grover*. (4 July 2011) A/HRC/18/37.
[124] *Ibid.* Para 10
[125] *Ibid.* Para 11 Para 11
[126] *Ibid.* Paras 21, 54, 59 & 60 par 54,
[127] *Ibid.* Para 61
[128] *Ibid*. Para 21

older persons and its often harmful effect on their dignity."[129] A further aspect of infringement of dignity was also highlighted which is the linkage to 'humiliation' in the statement "[l]oss of full independence, restricted freedom of movement and lack of access to basic functions would cause feelings of deep frustration and humiliation to any individual. Older persons are no exception to this."[130] The last comment has particular resonance in the *McDonald* litigation. A further comment by the Special Rapporteur on dignity, which is worth stating in full, is that "older persons must be treated with as much dignity during the process of dying as they should have been in the early phases of their life course."[131] The statement highlights the development of the concept in approaches to end of life care. Although dignity seems to be acknowledged as a standard within the right to health, there is a need to develop understanding of that concept further not only in relation to care of the dying but also in respect of all aspects of care to enable a standard of health which is conducive to living a life in dignity.

The centrality of the concept of dignity to the right to health is reflected in a recent 'right to health assessment' of emergency health care by the Northern Ireland Human Rights Commission.[132] Within the report the concept of dignity is frequently referred to, and is equated with a 'person-centred approach' to care[133] although the report suggests there is more to do to understand dignity when it states

> "There are, however, a number of gaps in the referencing of human rights in domestic law. The operational meaning of "dignity" is often lacking within both the Quality Standards and the PCE Standards. It is therefore difficult to ascertain how "dignity," including dignity in

[129] I*bid*. Para 49 & 61 where dignity and autonomy are also associated together.
[130] *Ibid.* Para 49
[131] A Grover *op cit* n 123 Para 60
[132] *Op Cit* n 92
[133] Ibid p 17. Within the report dignity was referred to 107 times. The inquiry found no systemic evidence of violations.

> death, can be put into effect, especially in the challenging environment of an [emergency department]"[134]

The research to develop the operationalization of the concept already exists if reference is made to existing case law and empirical research on health care practice, (although it is accepted that more needs to be done on this): Both research and case law can contribute to the understanding of dignity within 'a right to health' approach to health and social care.

Dignity: A Normative Value in Access to Health Litigation?

If "…policies in respect of the elderly reflect the ethical principles of society"[135] then there is a need to question what ethical principles have relevance in decisions on access to health and social care for the elderly. The evidence that would suggest that dignity ought to be a central value which requires greater consideration includes: (1) it is a recurring theme where failures of care have been identified, (2) there is a growing body of literature and empirical work on the concept of dignity in health and law which courts can look to, to question the application of dignity in the context of particular legal questions and (3) dignity is a central value which informs human rights protection. If the approach to access to health and social care litigation was to be considered in the context of a right to health approach then a fourth reason can be identified and that is, it is part of the core standard of the right. The central argument against using dignity as a standard lies in the criticism that it remains a vague and unclear concept, a criticism which is less true today. In recent years there has been an increase in empirical research on the concept, which provides some guidance as to what dignity means in health and social care practice (and in the context of particular

[134] Ibid p 21
[135] General Day of Discussion on the Rights of the Ageing and Elderly (1993) *op cit* n 110 Para 29

types of care), which can contribute to the development of dignity as a norm within the current narrow approach to justiciability of access to care challenges. This research provides guidance on how dignity is perceived and maintained in care settings. A consideration of empirical evidence as to what dignity means in continence care, including the requirement to 'maintain functional capacities' ought to have been a relevant discussion in *McDonald* litigation. However if dignity is to become a meaningful standard in access to health care litigation and provide what *O' Cinneide* describes as a 'normative steer'[136] in a way that would not create 'judicial overreach' [137] then greater consideration needs to be given to its meaning and application both within the international right to health jurisprudence and in the approach of the ECtHR and the domestic courts.

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[136] O' Cinneide *op cit* n 4p 403. In the context of the discussion on accountability the 'normative steer' is being suggested in relation to social justice.

[137] *Ibid.* p 408. In particular O'Cinneide suggests that judicial review should only be available in the context of a 'sufficiently grave situation' and that social justice is an important aspect of legal accountability.

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